CALIFORNIA CRYOBANK (CCB)

Note From Wendy: For those of you who used California Cryobank, and wonder why your donor hasn't yet registered on the DSR, here's a possible reason why: A former California Cryobank donor emailed me about what CCB had just told him about the DSR.

He said, "...they were quite strong in their position that I should NOT register [on the DSR] bc there are likely errors with people putting wrong donor id, or even fakes, so that if I register, CBank says there's more than a slim chance I'd be reaching out or opening up to people not really offspring of mine."

If you used CCB or are a CCB offspring, I encourage you to let CCB know how you feel about them discouraging donors from posting and connecting on the DSR.   This is from the sperm bank who has been known to delete urgent medical information from a donor's profile?   We have been operating since 2000, long before CCB ever thought about having a registry. We spend many thousands of dollars each year to maintain and protect our website and our member's privacy. We have successfully connected more than 22,000 people, with more than 75,000 members. In all that time, and through all those members, we had one single donor impostor, a couple of years ago. I caught him within the first 24 hours. Certainly not worthy of negating our 20 years of hard work and thousands of s

11/2023	Private Email and Facebook

6 Reports on California Cryobank from November 2023:

I was a donor, and I connected with CCB 25 years after donating when my bio-children started finding me on their own. They have referred a couple of them to me. But many clinics they sold to destroyed records and CCB has no idea where the donations went once they were sold to other clinics. My donations were sold to clinics all over the US and, supposedly, Canada and Europe.

My daughter was conceived using donor sperm from California Cryobank. After she turned 18 she contacted the Cryobank to see if she could find out anything about her donor (and wants to just thank him really) but the Cryobank came back to her saying they have no idea about his whereabouts so cannot help her.

Our donor died one year ago, and even though the California Cryobank knew about it, they never informed us. I wished we knew so that my son didn't keep on hoping to meet him when he will be 18! And the way we found out was pretty disgusting! Peace to his soul. The donor had informed himself the clinic about his health issues. He wanted to know his offspring before dying. The clinic didn't allow it. A family member informed the clinic after his passing! They were supposed to informe the numerous offspring.

Our donor died at the age of 28…when our son was 4 months old. California cryobank did not inform us either and when we reported his death to make sure they notified other families, their response was that we could actually face legal action for contacting donor family and finding out…and also that they had no obligation to inform the other siblings. So now, every time another sibling is found I feel a huge moral responsibility to be the bearer of bad news.

I showed up to California Cryobank about 9 years ago and asked questions in person. They were quite shocked to see donor-conceived people in real life. They did reveal some information to us, like that our donor wanted absolutely nothing to do with us.

The first of our siblings turned 18 last year and he contacted CCB and they told him the same thing.

10/2022	DSR’s Facebook Group

My two children reached out to them when they turned 18 and CCB never responds to any of their calls or requests. Terrible company.

7/2022	DSR’s Facebook Group

From Wendy Kramer, posting for a DSR mom who didn’t have Facebook: *One mom, who used California Cryobank said that her donor listed his height as 5'7". When she met him, she immediately noticed that he was less than 5'3". It is also apparent that California Cryobank was very aware of his actual height as they said that they initially turned him away because of his height but then decided to take him on because of his cute baby photo.*

A prospective parent replied*: This is very concerning; I have been looking at donors and I called to ask California Cryobank if the donors height is measured or if it's based on what the donor says. The California Cryobank phone rep said that anything that can be verified will be verified and that includes height... Clearly they're just deceptive.*

One CCB mom replied: *They lie about everything. They lied about our donor's education. One of their reps wrote in some education on the profile at the time I first inquired about him, knowing education was important to me. Then when I got a copy of the profile years later, that education was not on the form.*

Another CCB mom replied: *Everything that was provided on our donor profile was spot on. However, we learned through ancestry dna that our donor is actually deceased. When I reported this to the bank and asked if they would notify other recipients they stated they were not required to report that information.*

A donor who donated to another sperm bank (that shared some donors with California Cryobank) replied:
I have discovered this as well. When I first began interfacing with my bio kids, I asked for the profile that one of them had, that had been provided by the facility many years ago to his Mom. Turns out, they increased the height of almost all my immediate family members.
They left my height alone (5'10"), but increased my Dad by 3 inches, one brother by 4 inches, and another brother by 7 inches(!).
They also changed the professions of a couple of family members in the family profile. Ostensibly to "bump up" that there is creativity in the family. (I'm in the creative arena.)
Nobody has complained to me about this, but this is so disingenuous of the facility to have done this.
And for one of my family members, they made my Grandmother a "Painter/Sculptor." (No, she wasn't.) But then on the other hand, they listed my Mom as a "Homemaker." (No, she worked.)

6/2021	Email

Not that any of this will surprise you, but I just had an employee from CCB chuckle when I asked about limits. He then admitted they do not in any way limit how many people they sell vials.

To give background, our donor recently had a new family join the sibling registry. We are now up to 11 families. Thankfully, our donor is restricted to sibling use, but he was active on the site for over two years before that happened.

I wanted to see if they would give me an idea of how many families had confirmed pregnancies/births to them, but not registered on the site. Of course, they wouldn't do it. Knew it was a long shot, but figured worth a try as there is always someone who mistakenly provides information they shouldn't.

Anyway, he first tells me that I would have to join myself. I clarify that I am on the registry which is what led to my question. Explained that I had been told donor was limited to 10 families before my first purchase. Then was told limited to 25 families after reporting my child's birth. Explained I was nervous seeing that we were at 11 families knowing that not all people report. He actually laughed. I mean it was a chuckle, but still, laughed at the idea of limits. Told me that to be put on sibling restriction you had to have anywhere from 15-20 families report and so we were "at least" at that point since he was restricted. I was too annoyed to ask why it would vary between 15 to 20. But, he goes further and said there is actually NO LIMIT to how many people they will sell to before they hear back about pregnancies/live births.

He then went further and tried to get me to understand they were a business selling internationally. When I reminded him they were a business engaged in helping to create life, it barely registered. When I said they should require reporting and tracking, he told me it would be impossible and the company would never do that. When I said it could be made part of the contract that you had to report, he told me people from the company would not follow up with us as it was too sensitive a topic. They wouldn't want to cause further harm if they followed up only to find out we had losses.

I swear these people are unbelievable. I realize I am preaching to the choir here, but I just had to share my frustration with someone. I love my son and would not want to change having him. But, I so wish I had been more educated about the lack of regulation ahead of time. This industry needs regulation.

8/2020	DSR's Facebook Group

I was a donor at California Cryobank who was open to contact and still every time a biological child of mine has reached out they have put up roadblocks.

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My moms used CCB as well and the narrative they/we were given was also that I could reach out when I was 18 etc etc. Well I did when I was about 21/22 and played phone tag with some sort of client relations person who never ended up getting back to me. ...didn't need her to anyway because we found my donor through Ancestry DNA lol.

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<table>
<tr><td colspan="2">We used the CCB and they were very clear that the only potential for contact would be when my daughter turned 18 and then she had to contact them. Even then, when they did locate her donor, all at least initial communication had to occur through email through the CCB.</td></tr>
<tr><td>6/2020</td><td>Personal Email</td></tr>
<tr><td colspan="2">Just FYI we still have never had any communication back from CCB, even after Latrice told my son that the donor agreed to written or phone correspondence through her & he wrote a heartfelt letter to the donor, as she requested.

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<table>
<tr><td>11/2019</td><td>NBC News Story</td></tr>
<tr><td colspan="2">Scott Brown, vice president of communications for California Cryobank, said. “Family is what we are in the business of, not genetic connection.

https://www.nbcnews.com/news/us-news/modern-family-20-plus-sperm-donor-siblings-find-each-other-n1071656?fbclid=IwAR3Y8cF_Qtl6jCSCGi1qkJHWaaJRwUmeOnm9uuK8C9t-8ClvkwA-2rgwj6U</td></tr>
<tr><td></td><td></td></tr>
<tr><td colspan="2"></td></tr>
<tr><td>7/2019</td><td>DSR Facebook</td></tr>
<tr><td colspan="2">I will almost guarantee you that CCB never attempted to contact your donor. We've had several kids attempt contact through them and our donor reports that he never received any correspondence from them. And his contact info is all up to date.

Another issue I had the sperm bank wouldn't allow me to report my live births without the clinic contacting them first and still to this day 6 yrs later I can't register my live births because supposedly the sample wasn't suppose to be shipped out of country and so they can't count my children.</td></tr>
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<table>
<tr><td>7/2019</td><td>Personal Email</td></tr>
<tr><td colspan="2">I wanted to tell you about recent activity with ongoing interactions with CCB.

Today I sent an email checking to see if they had reached out to the donor as promised to see if he would have contact with my son or if they could at least ask if we may have a photo. I was told that the donor had agreed over a year ago to correspond by email, but only through CCB. We apparently fell between the cracks. So if I had not felt frustrated enough to follow up again today we would still have no support from CCB.

I can’t believe that such an important life event is treated so carelessly. When we told the CCB employee that we would like them to reach out to the donor on our behalf, the email I received back stated that the donor was willing to email my son through CCB. This was the first time we heard this information. I was also given a little lecture on how anonymous donation works & “isn’t it nice that he is willing to email at least, since he has no obligation.”

The CCB employee did not produce an email where she told us the donor’s willingness to correspond, nor did she apologize that she thought she sent it, but didn’t.</td></tr>
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<tr><td>6/2019</td><td>DSR Facebook Page</td></tr>
<tr><td colspan="2">I am in touch with my daughter’s 40 siblings. We were told there was a limit of 20. The cryobank was also notified of severe mitochondrion disease in one child, traces in others and several reports of autism and they kept selling sperm.</td></tr>
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<table>
<tr><td>4/2019</td><td>Personal email and DSR Posting</td></tr>
<tr><td colspan="2">"For anybody that was looking for health updates or genealogy information for their children, I apologize for not posting to the registry sooner. I naively assumed that CCB would have requested updates or actually informed me of any offspring that tried to reach me after turning 18." " My experience with CCB is very similar to what is reported on your website. I remember being explicit that I wanted to be available if any offspring wanted to contact me. Yet they had me listed as anonymous. And I also remember them assuring me that only 5-10 families would be sold to." – CCB Donor</td></tr>
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2/2019 Facebook Group

I did look at CCB website last night to check. They still sell Anonymous, Open and ID release. Having paid premium pricing for Open (willing to be known) I looked at their new conditions with the third category. I was horrified to discover that the first statement on Open Donors is that it specifically excludes learning the identity of the donor. Not what I had in mind at all.

ID Release gives the donor’s identifying details to the 18+ on request. However, amongst other conditions, they now require the DC person to sign a non-disclosure agreement specifically forbidding them to tell their siblings. Otherwise they will refuse to deliver the ID the parents paid for.

These conditions and unilateral changes probably would not stand up to challenge under contract law but have not been tested yet.
"For anybody that was looking for health updates or genealogy information for their children, I apologize for not posting to the registry sooner. I naively assumed that CCB would have requested updates or actually informed me of any offspring that tried to reach me after turning 18." " My experience with CCB is very similar to what is reported on your website. I remember being explicit that I wanted to be available if any offspring wanted to contact me. Yet they had me listed as anonymous. And I also remember them assuring me that only 5-10 families would be sold to."

2/2019 NY Times and CBS News

NW Cryobank and California Cryobank are partners:

CBS: Woman uses DNA test, finds sperm donor — and pays a "devastating" price

https://www.cbsnews.com/news/woman-finds-sperm-donor-after-using-dna-test-raising-questions-about-donor-anonymity/?fbclid=IwAR0Obec-XMd6mI3xjw_pX3MsLLNphCY1o-2RIiYn2rFoOhgFpHiFgM_5xyE

NY Times: *A Mother Learns the Identity of Her Child’s Grandmother. A Sperm Bank Threatens to Sue.*

https://www.nytimes.com/2019/02/16/health/sperm-donation-dna-testing.html

9/2018 Facebook Group

“I just want to point out though, that we are up to about 15 or so known half-sibs so far and I keep reading here about similar or larger groups from California Cryobank. But I distinctly remember CCB telling me that they “retired” donors after 10 live births were reported. I know for a fact that at least the four moms I am close to reported, and I see no reason why others wouldn’t. It’s in everyone’s best interest. So it’s clear that CCB (and many other banks) lied.”

“I used CCB and they told the same to one of the moms. When we reached 12 families she asked again and was told the limit is closer to 25-30. We are getting close to 25 siblings. Our donor is Hispanic and 5'6", so I don't think he is one of the most popular choices.”

<table>
<tr><td>4/2018</td><td>Personal Email</td></tr>
<tr><td colspan="2">"I was wondering if you could help with the following. Suppose a parent has a donor child, diagnosed with autism spectrum disorder. Then, one would find out the identity of a sperm donor (when the donor child is still young), only to discover that the donor has autism too, and apparently in a more serious way then the child (meaning, it should have been rather obvious for the donor bank when the donor offered his services). Can you hold a donor bank liable? Are they under any legal obligation to refuse potential donors with autism?”</td></tr>
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<table>
<tr><td>12/2017</td><td>Personal Email/Facebook</td></tr>
<tr><td colspan="2">“My sons contacted CCB when they turned 18 and CCB told them they would send a certified letter [to the donor] and they would contact them when they had any information. They waited a couple of months and contacted CCB again because they hadn't heard back. CCB said that he never responded and that they would send another certified letter. Months later my sons called them again and they said they had just received a reply. My point is that CCB didn't contact my sons.”
“I was conceived thru a donor from CCB I never got a response from them, I kept calling and they just said that the donor had not responded yet.”</td></tr>
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<table>
<tr><td>12/2017</td><td>Facebook</td></tr>
<tr><td colspan="2">"...my oldest daughter reached out to CCB last spring when she turned 18, requesting contact with the donor. After a few days, Latrice Allen emailed my daughter and told her that they "know his whereabouts" and will reach out to him, but not to expect contact because he has the right to say</td></tr>
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No. She said they would attempt to contact him 3 times. My daughter never heard back."

9/2017	Facebook Group

CCB has just changed their rules and now insists that the DC adults seeking their one facilitated connection with an Open Donor sign a non-disclosure agreement prior to the bank facilitating the contact and stating that the Open Donor will remain anonymous. A shocking change of conditions.

When I chose Open Donor with CCB it was written that Open Donor included annual medical updates for the first 6 years. I emailed after 1 year and was told no new information. I emailed after 2 years and was told the donor hadn't notified them of anything. I did not get the impression that the bank had asked. I gave up asking. The first 6 years was not necessarily the best option anyway, every 3 years to age 18 and contact might have been better.

9/2017	Facebook Group

“Same exact experience here with California Cryobank. They continued to release sperm long after they were told of autism and medical issues.   Today we know and love 36 siblings!!!”

8/2017	DSR Message

A new DSR member says this about her California Cryobank donor, "...the donor refuses to meet, talk or provide any photos, even though he was a "yes" donor. "

6/2017	FDA Citizen’s Petition

The type of regulation we are requesting is not complicated. We are not asking that the government limit the reproductive rights of the people. We are asking that the sperm industry comply with minimum requirements. At this moment a fabric mesh used for hernia surgeries and the fabrication of pills is much more regulated than sperm used to produce an unlimited number of individuals (i.e., 200 children from the same donor). If this continues without regulation the government will have in its hands a population of genetic disorders of epidemic proportions. I ask that you please, consider this an FDA priority and investigate with more urgency than a Tylenol recall or an error on an IFU which nobody reads.

My name is Lynnette Rios. I am the mother of twin boys born in 2009with the use of a sperm donor. I have a PhD in Biomedical Engineering and completed a postdoctoral program from one of the National Laboratories, I have worked in projects with the DOD, DOE, NIH and as an engineer in private medical devices and pharmaceutical industries, so I know what I am talking about.

Since my boys were 3 years old I have been contacting California Cryobank (CCB) hoping to get more detailed and updated health history from our sperm donor, since the health history provided by CCB shows zero family health concerns for this donor. My boys were speech delayed and in trying to find the cause and before moving forward with an uncertain diagnosis we visited multiple specialists (speech pathologists, hearing specialists, allergy doctors, genetic doctors, etc) all of whom asked about my boys' health history and I had to answer that I do not know half of their genes. CCB's genetic specialist originally stated they would contact the donor for an update. I stayed in touch every few days, then every few weeks and eventually every few months to ask if they had reached him, but always received a negative answer. I have to explain that I paid extra money for an Open Donor, one which would be open to contact when my children reach 18 years of age. If CCB cannot reach this donor 3 years after I initially used him, what are my hopes of them being able to reach him when my kids turn 18?
(I have come to understand that 18 is a relative number that has more to do with the sperm industry being able to discard medical documents soon after, rather than an age at which donor kids are capable of understanding their origins.

In 2015 one of my boys was diagnosed with cancer (T-cell Lymphoma/Leukemia) a rare disorder with possible genetic pre-disposition, a week after celebrating his 6th birthday. I once again reached out to CCB in tears asking them to please contact the donor or allow us to contact him. They said they will ask him for an update during his next scheduled appointment or when my boy turned 18.

My boy's biopsy was abruptly halted when the anesthesiologist realized she didn't know what type of anesthesia to use for my boy's surgery. The tumor in his chest was so large and heavy over his lungs that if she put him under general anesthesia the results would be "catastrophic" (to use her words). Since at age 3 a genetic specialist had diagnosed my boy with a metabolic disorder, she could not use lipid-based anesthesia. I remember a group of about 7 doctors arguing next to my boy's bed about how to proceed (while CCB wanted to wait until the donor's next scheduled appointment). Finally they put my boy under hallucinogens, which means he was conscious during his surgery, and then gave him meds to forget.

Fast forward to 2017.My boy has been in chemotherapies for almost 2.5 years. CCB has no updates on our donor and no scheduled visits. Luckily I am in contact with a dozen families who used the same donor (about 25 children)and I informed them of my boy's diagnosis because CCB has not contacted any one of them to provide this health update. Recently a representative denied there was a health update of cancer, even though I have written prove that I provided evidence of my son's diagnosis.

Anonymity is not an option we choose. It is imposed on donors and families to hide information such as health history. How could you possibly suggest the FDA has more important priorities?!

Obtaining health information, genetic information and genetic origins is a Human Right. Most people have come to accept that adoptees have a right to obtain their records and to know their origins. It has taken them decades of hard fight to get to this point. We are not willing to wait that long. There is no reason to. The evidence of why regulation is needed is clear. Perform an

inspection of the documents from these sperm companies (or the lack of documents) to have more evidence for the need for regulation.
http://www.9news.com/news/local/investigations/mother-worries-about-sperm-donors-medical-history/406656420

6/2017	FDA Citizen's Petition and Facebook Reply

"The cryo bank (CCB) did discover that the donor seemed to have a genetic disorder (he reported it to them). This was after my son was born. CCB did not attempt to contact me to tell me. I only found out when I called them to see if I might be able to contact my donor. Otherwise I would never have known. I also contacted CCB when my son became psychotic at age 14; they did not contact his half-sister and let her mom know. We connected with the half-sister through Donor Sibling Registry (and the donor himself) when my son and his sister were 21. These cryobanks can do anything they want without consequence. They need over sight. Thank you."

Facebook Reply: I called to order more specimens and was told I needed to sign a waiver, as there was a report of a genetic issue. Where the hell was my notification? They had all of my contact information on file. Thankfully, it was not serious.

1/2017	Personal Email (and Facebook Replies)

"They told me in 2011 it was limited to 20 family units but they are now saying it has increased to between 25 and 30 family units."

"In 2011 CCB also told me that they limit families of open id donors to 20 and anonymous donors to 25. "

"Back in 2004 I was told that each donor had 10 vials and that was it. "

"When I used CCB in 1999 they told me limited to 30 families- as of right now there are 30 kids.

"In about 1990 they told me ten. I guess it just depends on who answers the phone!"

"In 1991 they said 1 or 2 births was the limit."

"In 2005 we were told the limit per donor was ten families "

"In 2010, when we chose our CCB donor, we were told 10 families max."

Note from Wendy: When a prospective donor called CCB last summer and asked this question: "What is the maximum number of children that you allow per donor? California Cryobank told the prospective donor, "12 to 15 family units."

6/2016	Facebook Group

I called California Cryobank a few years ago [for another reason], and was told, after getting my answer, "I need to transfer you to the genetics department; your donor has been red flagged, so anyone with offspring from him has to be referred to the genetics department." He transfers me, I get a voicemail. I'm freaking out, call back and he tells me they're all in a meeting. Uh, why did you transfer me? Was -I- supposed to leave a message about I don't know what? I ended up getting a return call telling me that our donor had produced at least 10 offspring who had some type of neurological abnormality, seizure disorders, autism, ADHD, etc. I asked why we had never been contacted, as we had reported via our physician the live birth of our son. She said they don't routinely contact offspring families but if they call in, they're referred to genetics. It was such a big deal, they are doing a study in conjunction with a local university. We ended up participating, but WHAAAA?? You don't routinely call when more than TEN OFFSPRING have neurological problems? Our son, while not diagnosed with anything, definitely has neurological quirkiness, and has since early childhood. When he was little, we called it "neurological hyperstimulation syndrome" (this doesn't exist, but we are both nurses, and it was a good name for his quirkiness). He is functional, does well in school, but still has his unusual quirks. Anyway, I think it's a travesty when a bank doesn't notify families of live offspring of issues like this.

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I used ccb too, when I found d my donor I contacted them to confirm that he had a daughter, they stated that had NO record of my using their donor! We did genetic testing to prove he was the donor/father. They still deny they supplied the sperm!! How do they think I got? They need to get their records straight, one of the donor siblings has a sleep disorders and when he contacted my donor, my donor agreed to have a sleep study at his own expense, you can't depend on the cryobank to b helpful, they r out to make money, not to help people.

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This happened to me too. I also used CCB and found out that the donor I chose has a blood clotting disorder that he didn't know about. There was a child born with a severe form of the disorder and that's how the bank found out. I only found out because one of the moms of the other siblings I had been talking with received a phone call and told me. I waited a week for CCB to call and never heard from them. I ended up calling them and they very nonchalantly said that the donor did in fact have the blood clotting disorder and that if I wanted to have my child tested they could email me a letter stating what the issue was so the pediatrician understood what the issue was. Out of the 10 moms in our group only 4 were called. The rest of us found out through word of mouth.

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My child was conceived through CCB and on our donor family group out of the 30 children that we know of we have at least 5 that have some sort of neurological issues

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We used CCB, and I actually called them after our daughter was diagnosed with autism and anxiety disorder, just to ask why they did not, and maybe they should, ask these types of questions on the donor's health info. The geneticist told me that they wouldn't take a specimen from an autistic person, that the staff "would have known by meeting him" if he had ASD. Ha! People with ASD go their whole lives without being diagnosed...you cannot tell by LOOKING at someone! I was surprised and disappointed at their lack of knowledge on it.

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We also used CCB. When I called a few years ago, they told me that our donor had been flagged for cystic fibrosis. I don't know how many offspring he has, but we know a set of twin girls, a girl in England and I believe there are also triplets. I have two daughters using the same donor. Worrisome! Though my girls are doing well, I worry about their children when they have them.

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Our donor-conceived daughter was born with at least three physical birth defects and when we contacted the sperm bank (not CCB), they just dismissed us. They didn't want any details or follow-up and that just seemed so odd to me.

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We also have contacted them about our group of siblings... So far 3 have been diagnosed with Autism... Didn't get anywhere

12/2015	Facebook Group

California Cryobank, where I donated, knows of 35 successful pregnancies from me. Those were reported to them and the ONLY reason they stopped selling me was because one of the moms had a Chromosome test done on her daughter. There was unusual banding on the 15th chromosome. Turns out that comes from me. If that hadn't happened who KNOWS how many kids they would have allowed to be born. Yet, when I donated I was told 10 families was the maximum number who would be allowed to use me.

7/2015	Facebook Group

Krabbe disease (which can be fatal and has no cure). It was also discovered through connecting to other parents of #### donor offspring on the DSR that three other children had been born with the same exact disease. What would the CCB do? Nothing. For "privacy" reasons or for the sake of not wanting to be sued.

The donor we used reported a non-life threatening medical condition - but it was never passed on to me via CCB - yes they listed it on his page on their website but that was about it. My son also had a bad reaction to I don't know what. Hives everywhere (and I mean EVERYWHERE, along with difficulty breathing and a trip to the ER. We had him tested through an allergist and they came up with nothing. I contacted CCB several times to see if they could reach out to the donor so he could maybe shed some light on the situation and they said they would put a note in the file and let the donor know the next time he did an update which is supposedly every few years. I found out that our donor had also donated at another sperm bank and when I called them, I was told they could not give out any information.

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6/2015	Personal Email

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I was told last year (after exhausting attempts to get information from CCB), that my sperm donor had passed away about five years ago. I had a gut feeling that he had passed before I was even told so it wasn’t a total shock. My gut feeling thinks it is a car accident. It will be interesting if I EVER find out. However, I still wanted to know how he died and CCB said they couldn’t tell me that information. If the man is dead, what damage could be done? I only wanted to know for curiosity sake and for health reasons. Also, if he is really dead I want to know if I have any half siblings who also might have reported a pregnancy with his sperm. I feel everyone’s frustrations and whirlwind of emotions in dealing with the legalities of the industry. I hope that laws will be changed in the future allowing easier access to this information. I know very little about him, but what I do know is posted on the DSR in hopes that a half sibling or someone will come across it.

6/2015	Personal Email And Facebook Group

My worst nightmare as a SMC was losing my job (which happened), but what we are going through is worse. Since I can remember I have always waved off most of life's difficulties saying, "This is not a problem. A child with cancer, now, that would be a real problem." When I first heard the bad news from our doctor, one week after celebrating my twins' 6th birthday, I was so devastated that I wanted to disappear. I don't mean suicide, I am well aware that I am fully responsible for the two children I brought to life, I mean that I wanted to curl up into a cocoon and vanish, so I would not have to see my child go through all that was coming. People kept saying, "Be strong," and I thought that was ridiculous. I chose to be a SMC and gave birth to twin boys at age 33, got a PhD, lost a job and a career and built it up again, lost my house in the process and have always found the way to keep on going. I have been strong my entire life but I could not be strong for this. No one could!

My son's biopsy surgery was halted because the swollen node on his neck had spread all over his chest, his trachea, his heart and pretty much through every lymph node in his body. The anesthesiologist was concerned because he had a metabolic disorder so he could not have lipid-based anesthesia and the chest mass made it dangerous for her to use general anesthesia because his lungs could collapse. To use her own words, "a simple biopsy could be catastrophic," for my son.

Not for the first time I wished I had more information about my twins' genes. The biopsy was finally performed under a strange type of anesthesia that causes hallucinations. Then the Oncologist called me and my family to a private room. I knew.

"Precursor T-cell Lymphoma/Leukemia," and it was all over his little body, including his blood and bone marrow.
After the initial shock some of my first concerns were, "Is his twin at risk?" and "Will my son ever get to meet his genetic dad?"

My son Ricky had been asking to meet his genetic dad since he was three. At that point I had two reasons for contacting CCB. In addition to providing more information to my child, I also wanted to know if there were cases of metabolic conditions or autism in his family, since there were none in mine. I found out about my sons' metabolic condition because by age 2yrs it was obvious they had speech delay. One therapist recommended me to a doctor, a doctor to another specialist and so on, and all those times I had to repeat over and over, "I don't know half of my children's health history, but I will try to find out more."

I contacted CCB and they were adamant about not contacting the donor or providing me with information about him, going as far as saying that they discouraged contact among donor families and refusing to recommend the Donor Sibling Registry (DSR) to a donor because there was no way to prove that the donor was whom he claimed to be, and their anonymity had to be protected as promised above all things until the child turned 18. It made me feel as if I was seeking something forbidden, sinful and illegal, which I know very well is not the case. My children have an innate right to learn about their origins. Even if they are under 18 they feel a connection to this stranger and so do I.

So I continued to argue my point with the CCB representative, until my insistence let him to transfer me to a genetic specialist. Initially the genetic specialist tried to be nice, but as our conversation

kept going in circles my A-type temper escalated. Eventually it became time for both to give in and meet each other half way. I accepted that I could not contact the donor and they agreed that they could contact him themselves, to inquire further about his health and bring him in for more testing. So I let them contact him and I waited for a response. And I waited. I spoke and emailed the genetic specialist again a few days later, then a few weeks later, then every few months. I knew it could take some time, that the ball was now on the donor's court, and that I had to accept his choice, that he might not be ready, but I had no idea how long it could take. The genetic specialist at CCB kept saying the donor had not contacted them back.
When my boys were 3yrs old a speech therapist and an ENT recommended they get ear tubes. That was their first surgery, the first time an anesthesiologist needed genetic information to choose the correct anesthesia. My educational background includes enough Physiology and medicine that I know the dangers related to anesthesia, and some of those dangers are very much genetic. I emailed CCB with more urgency, but obtained the same reply, "the donor has not contacted us."

By the time my boys were 6 yrs old I had stopped contacting CCB on a regular basis. I had probably contacted them months or even a year before my son was diagnosed with cancer.

I have been in touch with a group of about 12 families of siblings (a total of 21 children) since my boys were 1yr old. On facebook we exchange pictures, health information and watch the children as they grow. The children meet through Skype and the families that live close by meet in person. We are an extended family. I kept them in touch of Ricky's condition as it progressed, from the time I thought it was a simple throat infection to the moment his biopsy results came back. They were devastated, as if it had happened to their child, as if their children had the same probability of having the same diagnosis as mine. I once again contacted CCB, this time in tears.

> *One of my twins was diagnosed with cancer yesterday. I wanted to report this as part of the medical conditions and ask that now more than ever please, look to contact the donor. I would like him to know that my boys exist, that they are wonderful and beautiful and to give him the chance of getting to know them NOW.*
> *I know he was probably a student and has now moved and the only email in record might be his student email. Please, do EVERYTHING in your power to contact him.*
> *We are in the hospital right now and will be for at least four weeks, but as soon as I can get to a printer or pen and paper, I will send that letter to the person you mentioned before. What I ask meanwhile is to get an accurate contact information from him. I want to give both my son and the donor a chance at knowing about each other.*
>
> *We are still dealing with the metabolic disorder and speech delay (educational autism for one of my boys) but none of those things were life threatening. This new condition is.*
>
> *Please, do everything in your power to make sure he is contacted, in person.*

Their response was that the donor could only be contacted by the child when he turned 18, and that he would be informed about the medical condition during his next routine update.
Frustrated, sad, and overwhelmed with the demands of my son's new condition, I stopped inquiring.

3/2015	DSR Facebook Group

As an ID Release Donor my adult offspring should be able to contact California Cryobank, say "Hey, # XYZW was my donor. Please give me his contact information." Every time I have moved or changed phone numbers or email addresses I have dutifully updated California Cryobank. So I asked one of my 20 year old kids (who I met through the DSR 7 years ago) to test sperm bank.

He called them yesterday and was transferred to a voicemail. I figured nobody would call him back, but lo and behold they did call him today. They asked him a bunch of questions to prove his and his mother's identity, then told him I was an anonymous donor (Lie) and they didn't have my contact information (Lie) but they would try to get in touch with me.

Thankfully nobody is reliant on these liars in order to get in touch with me. Offspring need only to Google Search "How do I find my sperm donor" and they will get to your site toot sweet, but goodness their dishonesty makes me furious.

And a response from another CCB Donor:

Sadly, I have reached the same conclusions as T regarding CA Cryo Bank's active discouragement of donor-offspring contact. The geneticist at CA Cryo Bank claimed that all offspring were told the donor was anonymous until the donor could be contacted and it could be confirmed that the donor still wished offspring contact. Yet CA Cryo Bank never contacted T nor, I assume, did they contact the offspring of T's who had initiated contact. This is telling and, for me, is confirmation that CA Cryo Bank is saying one thing and doing another. In our conversation, Ms. Ray also confirmed that until very recently all CA Cryo Bank donors were considered anonymous--even if the donor had placed in his file a clear desire for open contact with offspring, as I had with CA Cryo Bank staff years ago. From T's test, it appears that CA Cryo Bank has been misleading us, it's open donors, for many years now and that it continues to actively discourage donor-offspring contact. If you have a relationship with CA Cryo Bank, I encourage you to register your disapproval to CA Cryo Bank management regarding the apparent discrepancy between it's stated policy vs. it's actions regarding donor-offspring contact.

My conversation with the co-owner of California Cryo Bank (CCB), Dr. Sims, convinces me without a doubt that CCB has committed FRAUD and continues to commit FRAUD. I believe the owners of CCB should be held criminally and civilly liable for this FRAUD.

Today it was confirmed by CCB that--when I was asked back to the donor program in 1993 after initially donating in the 80's--the statement they lured me back with ("you'll be providing a bio-sibling for a family with an existing offspring from your sperm") was not necessarily true. They never bothered to confirm it. In fact, it is their policy NOT to confirm it. The client could have been a cousin. Or an old girlfriend.

Yet CCB let me believe the family-with-an-existing-offspring-from-your-sperm story just the same. In fact, I would not have returned to the bank if it wasn't for the story I was told. The bank was out of my sperm and so CCB could not have made the sale if I refused. So CCB trafficked in lies to make the sale. I didn't think at the time to question them. Why would I?

There's is a racket and a rigged game. CCB goes out of their way not to confirms births and then they do so much confirming and foot-dragging with regards to donor-offspring and offspring-offspring contact (all in the name of privacy protection--right!) that it will make you sick.

I no longer believe a word out of the mouth of Dr. Sims or anybody affiliated with CA Cryo Bank. I do not trust the CCB sibling registry one iota. It's a non-functional joke. I believe the owners of CCB are criminals and liars and that this slimy industry is in need of a massive clean up and some serious regulation.

I invite anyone whose been lied to by CCB to contact me with your story as I will be creating a website shortly that will feature information and evidence regarding CCB's FRAUD.

P.S. The co-owner of CCB, Dr. Sims, had this to say about group member and former CCB donor T, whose recent test exposed CCB lies:

"I don't know who this fellow is--he's not a donor--some kind of a ranter I'm guessing."

Dr. Sims has known about T’s test since last week and had his full name and donor number. Dr. Sims refused to comment with regards to the specifics of T's test, other than to discredit T and cast doubts on his authenticity.

Another March Facebook Comment:

Just want to add that I also reported my son's birth almost immediately to CCB (in 1995), and when I called years later, it hadn't been documented...

2/2015	Personal Email

My oldest donor child just turned 21. As an ID Release Donor my adult offspring should be able to contact California Cryobank, say "Hey, # *** was my donor. Please give me his contact information." Every time I have moved or changed phone numbers or email addresses I have dutifully updated California Cryobank. So I asked my donor son to test them.

He called them yesterday and was transferred to a voicemail. I figured nobody would call him back, but lo and behold they did call him today. They asked him a bunch of questions to prove his and his mother's identity, then told him I was an anonymous donor (Lie) and they didn't have my contact information (Lie) but they would try to get in touch with me.

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5/2014	DSR Facebook Page

☐ CMD: Has anyone had any issues with CCB's version of a sibling registry? I've gotten error messages and database errors going on eight months, I've heard from others in my group they never got notifications when I added my listing. I've sent emails to CCB but I just get a "we're working on it email" and they say they can update something for me manually. It bums me out that something so important can be treated so haphazardly. We have a mother and son who were the first to register to find nobody online yet and didn't leave any contact info, and it's seems a shame they might not know that we have the whole gang now because of issues with the system. It makes the work DSR does so much more important, in my eyes. It's appreciated.

☐ DW: Yes, it's been like that for a long long time. If you update your information, it won't update it. One mother in our group listed her kids 3 times by mistake and now it won't delete. And it never let's you know when people join in. They obviously aren't concerned about it as I contacted them too and they promised me it would work soon… that was 2 years ago. Thank god for the DSR or else families wouldn't be able to connect

CMD: That's so infuriating to hear. I mean, it's a one thing they try and make it, be it from external pressures or a noble cause, but it's a little shameful to keep it in such a state of disarray for long. How many people have tried to update contact info with no luck, or waiting for an email that won't come? I concur about DSR.

LN: I've also been having problems with the CCB sibling registry.

5/2014	DSR Facebook Page
After the birth of my daughter last year I sent the letter to report her birth to sperm bank and then did a follow up email a month later. They apparently had no record of my pregnancy or birth report. I'm glad I did a follow up with them. I'm still concerned whether or not anything was filed after my email.	

4/2014	DSR Facebook Page
My son's donor found out he had a blood clotting disorder after a child was born with a severe version of it. CCB contacted some of the other mothers in my group but I didn't hear from them and had to call them personally even though they have all my updated information.	

2/23/13	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/15578
All I know is that this is what I was told on the phone, and made sure that I also got it in a direct email quote that I could share. It came from one of their higher-ups, someone who should be very clear about their policy.	

It is possible that they have changed their policy, but how would we know for sure?

Here are a couple of donor family experiences:

"The CCB told me they had actually contacted my donor and he was coming in to update his files and never showed up for the appointment. I later met my donor and he said that never happened."

And another- A DSR member emailed me to tell me that she and her teen aged son contacted CCB several years ago and told them they wanted to meet the donor. During this same time period, their donor also contacted CCB and told them that he would be open to meeting any interested offspring.

Not only did CCB never connect them (they met up on the DSR) but the donor recently went into CCB to ask them if he had any offspring open to contact.....and they still said "no"! The mom had reported the meeting to CCB and also posted the fact that she met up with the donor on CCB's website.

So, even if you have told them that you are open to meeting, and they say they have put that information in your file, don't assume that they will connect you with your willing donors.

2/23/13	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/15575

Families who used California Cryobank should know about their open donor policy:

A couple of years ago I asked CCB about their open donor policy, and was told that when a child of 18 requested contact, the donors were sent a letter only asking them to "update" their information, not mentioning anything about a child desiring contact. So, if a donor read the letter and thought "I have nothing to update" he'd likely just toss the letter. He would never know a child desired to meet him, and the child would think that the donor refused contact. So I asked CCB:

"Your rep said that when there is a request, donors are sent a letter to ‘update’ their file. They are not actually notified that a child actually wants to meet them. Is this true? This could explain the low response rate, as the
donors are not made aware that a child is actually wanting to meet them."

The reply I received back from CCB:

"Our system is set up to protect the interests of all parties. We contact the donors via mail and/or email. If he chooses to respond, we explain the situation and ask if he is interested in moving forward with the contact. To send a letter with information about an offspring out of the blue could be very jarring, irresponsible, and could ultimately illicit an even lower response rate from the donors who do not understand the specifics of the interaction. We don't phone them until they give us the ok, because if they have a wife or children who could answer the phone, it could put them in an awkward position."

9/24/12	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/15345

[Nordisk bought this donor sperm from California Cryobank.]

Full article: http://cphpost.dk/news/national/sperm-donor-passed-disease-nine-children

A sperm bank is facing criticism for not acting quickly enough after suspicions were first raised that one of their donors had passed on the disease NF-1

A sperm donor passed on an inheritable disease to at least nine of the 43 children conceived using his sperm in 14 different fertility clinics.

And at least two children were conceived using his sperm in the six months between when the sperm bank Nordisk Cryobank, which has offices in Frederiksberg and Aarhus, was first warned and when the sperm was withdrawn. One of those children was born with the disease.

The revelations, made last night on the TV news programme '21 Søndag' on public broadcaster DR, have lead to the health authority, Sundhedsstyrelsen, tightening sperm-bank regulation.

The move is little consolation to Lone Søndergaard, mother of one of the affected children, however.

"I thought the system was designed to protect against inheritable illnesses," Søndergaard told DR. "It's just unacceptable that there is no oversight."

The nine children were born with Neurofibromatosis type 1 (NF-1), which creates non-cancerous lumps on the bodies of affected individuals. The severity of the illness can vary widely, but in its most severe form it can lead to learning difficulties, blindness and epilepsy.

According Anne Marie Vangsted from Sundhedsstyrelsen, some of the illnesses could have been prevented if Nordisk Cryobank had withdrawn the sperm immediately after receiving the first warning.

“We know that children were conceived during that period and that could have been prevented if the sperm bank had acted correctly and stopped using the donor sooner,” Vangsted told DR.

In June 2009, Nordisk Cryobank received the first warning that a child conceived using the sperm had been born with NF-1. According to Sundhedsstyrelsen's rules, the sperm bank should have immediately stopped using the sperm and contacted the clinics that had bought it.

But according to Nordisk Cryobank's CEO, Peter Bower, the sperm bank didn't act immediately because they thought the donor was not responsible for passing on the disease.

6/17/12	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/15207

To celebrate Father's Day, my daughter and I listened to the audio tape we have of her donor speaking about life and choices, etc. that was provided by CCB.

2/26/12	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14997

I too had a daughter with a genetic (recessive) condition that had never shown up in my family before. I received my donation from the California Cryobank and after she was born, the donor sperm was removed from the market. I had heard later on there was another sibling with a similar condition. As much as I
adored my daughter (she was a twin - whom was completely healthy), she led a life of tremendous pain - so much so - it was discussed with her doctors that at some point we would have to put her in an indefinite induced coma to relieve her pain. As it was, she had to be kept on heavy narcotics

to provide relief. Her genetic disorder caused multiple disorders which continued to worsen as she aged. She passed at 9 years old and I am thankful she died peacefully. The alternative was very much a real possibility and threat.

2/18/12	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14935

My partner and I will be trying to have a child soon, and the hardest part of the process is trying to find the "perfect" bank. It seems that every bank we liked we were able to find some damaging information which made us scared to use that bank. California Cryo - very secretive and too many kids.

9/29/11	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14586

I was conceived at the Tyler Medical Clinic (1983) in Los Angeles, Ca, however- When doing some research into clinic policies/procedures, I contacted the CCB.

The receptionist was really nice (even after I told her why I was calling) she even transferred me to the voice mail of a CCB employee who used to work at Tyler Medical Clinic in the 80's/90's. I went ahead and left a message.

A month passed, with no reply, and then I got a call from a man. He was under the impression that I was conceived at the CCB, and said he wanted to help me find my donor. I explained the mix up to him, and asked him some general questions.

It was nice of him to take the time to call me back, but the weird part about this whole thing, is the message I originally left was for a female employee on maternity leave.

9/28/11	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14585

My family has also dealt with CCB and possible genetic issues while I was pregnant and after. One of our donor siblings was born with spina bifida. Our donor was made no longer available except to families that had previously used him. The problem that I had was that CCB never called me to tell me this. I knew only because I knew the family with the child. I called CCB and asked when/if they were going to notify families. They stated that because spina bifida is not a KNOWN genetic issue (apparently the research is mixed) they didn't feel the need to notify families. However, when we went to purchase the same donor for our second child (after much thought and consideration) we were required to go through genetic counseling.

9/28/11	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14576

One element that I have not mentioned that will hopefully be heartening amidst all the other topics of concern... is that I too have had a very good experience with the CCB with regard to health/genetic issues.

When I was 5 months pregnant, I received a letter from the CCB asking me to phone their genetic counselor, as new information had arisen with regard to the donor or one of his offspring and all families that had purchased his sperm were being informed.

It turned out that a woman had given birth to a baby (conceived with my donor's sperm) and that baby had an extremely rare (90 cases known in the world) genetic condition that meant the baby's digestive system did not develop at all and within a year, the baby would die.

Naturally, being pregnant and on my way, I was very alarmed, but spoke at length with the CCB genetic counselor, who answered all my questions and told me exactly what I needed to tell my medical practioners to look for during ultrasounds... and in my case, thankfully, everything turned out fine.

The CCB counselor also told me that they had notified the donor too, as they didn't know if this had to do with the mother, the genetic mix of the donor and the mother, or the solely the donor. She also told me that the donor sperm would no longer be available to the public, and would hitherto only be available to families who had already had a child from this donor .

I found the whole approach and process very professional and compassionate. It was exactly what I would have hoped for in circumstances such as these.

9/28/11	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14571

When an 18 year old child contacts CCB asking to make contact with their donor, CCB sends a generic letter to the donor asking him to "update his file", with no mention that a child wishes to make contact with him. So if the donor thinks he has nothing to update, he might toss the letter- never knowing that there was a child wishing to make contact. And the child may think that the donor made the decision to refuse contact. Not a perfect system.

9/28/11	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14570

My experience with CCB has been quite good. We have found a number of siblings on their registry and just received - when asked for - donor updates though pretty basic. In fact, we just found another half sib - so that makes 8 moms, 10 kids, and one on the way.

A few of us our quite close, see each other regularly and our kids are essentially like extended family.

CCB does now say on their site that they will reach out to donors upon request of 18+ DC folks.

9/28/11	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14515

California Cryobank

From a DSR member:

"You were curious to know why there seems to be few takers when it comes to the sperm banks telling donors about the DSR, despite all your efforts. I can't say I find her reasoning hugely compelling, but here's what I was told by the CCB:

I was told that the CCB does not tell donors about the DSR because they don't feel there is regulation or a way on the DSR for families to verify that the donor is in fact their actual donor. She stated to me that someone could come forward on the DSR saying he is donor # x and in fact, it could be anyone saying this. The CCB told me that we should always check with them first to ensure that we cross check the legitimacy of someone claiming to be our donor on the DSR."

In 11 years, and through almost 33,000 people and more than 8,600 matches I have never heard of a case where anyone found out that a donor that they had connected with on the DSR turned out to be an imposter. And this doesn't even make any sense as far as a reason for not telling the DONORS about the DSR. It is an excuse. And a lame one at that.

And....the CCB has continually promised me over the years that they do indeed hand out our brochures (they had me mail them a large batch). No one I know has ever seen them in any CCB office. So what's the truth CCB? Who exactly are you protecting? Why did you commend the brochures (see below), but then never hand them out? And why are you now telling families that you won't hand them out to donors because of fears of people posing as donors. Makes no sense to me.

"Wendy,

I would like to inform you that the CCB marketing department has approved placing the DSR brochures, Guide to the World of Donor Conception, in our front office for our clients. It is very well done and tasteful. I support the message in the brochure; I am asking Scott Brown to contact you for an initial supply and to be in charge maintaining the supply for our clients.

Charles Sims {CCB}"

7/21/11 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14373

Currently, there are only 18 donors of African American descent at three of the major banks (Fairfax, California Cryobank, and Xytex) in the U.S. It is much worse for other ethnic groups.

5/13/11 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14167

I've just learned that my '88 donor from Fairfax also has an off spring from California Cryobank; in '88 I was on a waiting list for fresh sperm, 2 days before my insemination cycle they switched to frozen (re AIDS). I called Fairfax and asked the lab tech about my soon to be donor, she said he was "really cute and nice to his girlfriend". I wonder if they told that to ALL donor recipients who called about ALL donors; was my donor originally at Fairfax or California Cryobank?

5/13/11 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14166

Re: Does California Cryobank have more than one location in California?
They took over a fertility center in NYC so there's NYU, Columbia, and probably the suburban colleges in Westchester, etc.

5/13/11 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14166

Re: Does California Cryobank have more than one location in California?

They recruit from advertising on buses, etc., not just from universities.

They say, "California Cryobank serves Los Angeles, Ventura and Orange Counties from the Westwood Village office. The San Francisco Bay area is served by our Palo Alto office. Boston and greater Massachusetts is served by our Cambridge office. New York is served by our mid-town

Manhattan office and the greater Indianapolis and Marion County area is served by our Indianapolis office."

They also place ads on Craigslist, e.g. Boston, Los Angeles and S.F Bay.

<table>
<tr><td>3/11/11</td><td>http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14060</td></tr>
<tr><td colspan="2">In reading the opinion in Johnson V. California Cryobank, it appears that the sperm bank was aware that the donor had a family history of kidney disease and they did not test him for the presence of the disease. These facts were not revealed to the recipient family whose child contracted the disease.</td></tr>
</table>

<table>
<tr><td>3/9/11</td><td>http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14054</td></tr>
<tr><td colspan="2">I can say for sure that we were not called when a donor sibling was born with Spina Bifida. We called the bank and asked them why they had not notified us (we call them yearly to update our records) and they said "We do not call patients in the event that the disability is not genetic. Since medical research is unclear about if SB is genetic we did not call you." We used California Cryobank from 2007-2009.</td></tr>
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<table>
<tr><td>3/9/11</td><td>Full article:
http://donorsiblingregistry.com/The%20Truth%20About%20Donor%201084.pdf</td></tr>
<tr><td colspan="2">The Truth About Donor 1084
For more than a decade, she has also been the poster child for sperm gone wrong, having inherited a life-threatening kidney disease from California Cryobank Donor ###.</td></tr>
</table>

<table>
<tr><td>3/9/11</td><td>http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14051</td></tr>
<tr><td colspan="2">Have you seen the Johnson vs. California Cryobank case? They actually deleted Polycystic Kidney Disease from a donor's medical profile. A young girl came down with the disease: "Polycystic kidney disease (PKD) is passed down through families (inherited), usually as an autosomal dominant trait. If one parent carries the gene, the children have a 50% chance of developing the disorder."

The scary part of this story is that CCB only knows of approx. 20% of the births that occur from any one donor. How many others are out there who haven't come down with the disease yet. It usually strikes adults.</td></tr>
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<tr><td>2/18/11</td><td>http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14006</td></tr>
<tr><td colspan="2">I learned of the sperm bank and donor number when Ryan was three and I called the clinic. They said" you never received the long form?" Nope, no one ever told me that I could know anything about the donor and
certainly no one ever offered me a long form!</td></tr>
</table>

<table>
<tr><td>2/18/11</td><td>http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14004</td></tr>
</table>

In my case, it remains an uncertainty whether the donor will agree to meet my daughter (14) or not. I have tried to find out who he is but was told by CCB who bought Procreative Technologies in Los Angeles, that it was not possible until my daughter would be 18 to even inquire about his identity.

9/10/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13619

I'm suspicious that their policy is in place to make them look good, just like the embellished profiles that they send out. I'm aware of too many past lies and deceptions on the part of CCB to trust them.

9/9/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13615

The CCB told me they had actually contacted my donor and he was coming in to update his files and never showed up for the appointment. I later met my donor and he said that never happened. My daughter is not 18 yet so maybe they were just telling me something to get me off their backs because I had contacted them regarding some of the children having disabilities. CCB told me only one report had been made to them regarding a child with a metabolic disorder. I know for a fact that that was not true because 2 of the moms in my group had contacted the bank regarding birth defects. My donor was actually pulled of the shelf due to birth defects. Somewhere along the way I thought that if three birth defects were reported than the donor was pulled.

I guess I should just be happy I got the information I did.

9/9/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13605

A woman just posted to the DSR's Facebook page last week:

"Has anyone had any luck getting info from CCB about contacting their donor? A few years ago I contacted them and they said they would contact my anonymous sperm donor, but I never heard back from them... Any help in trying to get further in this would be greatly appreciated, since I've been told the people at this bank are somewhat difficult!"

CCB has told me (in writing) that they send snail mail letters asking donors to "update their files"- with no mention of a child's desire to meet them. Many donors simply toss the letters, never knowing that there was a child desiring to know them.

9/9/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13604

This was posted by California Cryobank on their Facebook page today:

"Now, and even before we instituted the Open Donor Program, our policy is/has been that when they reach the age of eighteen, any CCB child has the right to request additional information about his/her genetic father. We make all reasonable efforts to supply that information either from our records or by attempting to contact the donor on the child's behalf.

The child also has the right to request contact with his/her genetic father. Again, we make all reasonable efforts to contact the donor on the child's behalf. If the donor is willing, CCB will help facilitate the initial contact.

If you'd like to find out more, please check out our Anonymous Donor Contact Policy here: http://www.cryobank.com/Services/Post-Conception-Services/Openness-Policy"

7/29/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13461

California Cryobank commented on your wall post:

"Lorraine is correct; they are judged to be the best of our subjective abilities. Whenever possible, more than one celebrity is listed to give you a better general sense of what the donor looks like.

No celebrity is meant as an exact match for any donor, nor should you assume that your future children will look like any celebrity listed.

At times, two or more celebrities listed for a single donor may not necessarily resemble each other. In these cases, consider the fact that many people look like both their parents, without their parents actually looking like each other.

It could be that the donor's eyes resemble one look-a-like, his chin resembles the other and his mouth is shaped like the third's.

7/29/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13459

> What if they find their donor like I did and he is not a
> movie star twin?

Which I think is bound to be the case!

We've got contact with our donor, including pictures, and he has "celebrity matches" on the CCB site. He's a good-looking guy, but not a movie star (neither am I - heck, movie stars don't look as good as movie stars when you look at their "before peak stardom" pictures!), and it made me angry, too, to see that they're using professional beautiful people to sell "normal" people.

At first, I didn't really see any resemblance, but then I sat down with pictures side by side, and after looking for a bit, I could say "Oh, they chose this celebrity for a match on this specific feature." So I don't think that the comparison is 100% misleading if you have all the information (which the people picking the celebrity matches do). But if you don't have all the information (recipients and kids), you'd never figure out which features from which celebrities were a match to the donor's.

Call me not a fan, either.

7/28/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13457

http://www.cryobank.com/Donor-Search/Look-A-Likes/

Just take a look at the advertisement that the bank is displaying. I used a donor from California Cryobank and I think this is absolutely ridiculous. Under the ad it even says that the photo in the ad is not actually a donor.
In my opinion this is just too much! The banks have already falsified heights and SAT scores. The banks have hidden birth defects. I am so happy to have my daughter and so happy to have met her half siblings. What will the mothers think when their children don't look like a movie star? What if they find their donor like I

did and he is not a movie star twin? I am angry with this and I am usually easy going. Your thoughts appreciated.

7/28/10	Full article: http://donorsiblingregistry.com/washingtontimes710.pdf

Sperm bank peddles celebrity look-alike donors
By Hillary May - The Washington Times

Is it custom-designing a baby in the image of your favorite celebrity? The next logical step of the evolutionary desire for attractiveness? A silly result of sperm-donor anonymity rules? Or all that and more?

The Los Angeles sperm bank that began a celebrity-inspired Donor Look-a-Like service has raised eyebrows and hackles among champions and critics of artificial insemination.

California Cryobank launched the service in late July to allow clients to search for donors who best resemble certain actors, artists and athletes.
…
Scott Brown, a spokesman for Cryobank, said the service may appear to be "something that it's not" and insisted that it is not a "designer baby factory."

He said Cryobank's clients truly understand the reason behind the service and are not caught up with the idea of what the baby will look like.

"People's primary concern is having a healthy, happy baby, and the safety of the mother," he said.

Because donors remain anonymous, the service provides an easy and creative way to make the parents' difficult selection a more "humane process." Staff members carefully choose two or three celebrities who resemble a donor most closely, which Mr. Brown calls more of an "art than science."

Because of anonymity, he said, "this was the best way we came up with to show what the donor actually looks like."

7/28/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13452

You can still report. And it is worth it, esp. if your donor is still available b/c some banks limit the # of vials to a certain number of families. If they do not know that another family has been created, then the vials will be
distributed even more. Again w/ no federal regulation, this is a small step to keep things in check.

I, too, used CCB, and that was what was explained to me 8 years ago. So, to any families out there who have yet to report pregnancies and/or live births, this is very important information to give to the banks. It's more than a courtesy, it's our responsibility.

7/28/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13451

Re: reporting a child’s birth to a sperm bank:

I didn't. It just didn't occur to me in the hectic life of a new mom. And the bank (CCB) never asked.

7/22/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13427

Are you aware that the CCB has a Facebook page that anyone could view? It has been mentioned on their homepage so I'm sure that parents and donors alike can view. It's puzzling that such a forum would exist in a "world" based on anonymity.

3/1/10	Full article: http://www.slate.com/id/2243743/pagenum/all/#add-comment

Are Sperm Donors Really Anonymous Anymore?
DNA testing makes them easy to trace.
By Rachel Lehmann-Haupt

…

Donor 3066 was being sought out by Michelle Jorgenson, a 39-year-old waitress from Nederland, Colo., whose daughter, Cheyenne, was born in 1998. When her daughter turned 5, Jorgenson joined the Donor Sibling Registry and began searching for other mothers and donor offspring who used Donor 3066. She was concerned because her daughter was sensitive to sounds and walked on her toes, and she wanted to know if other half-siblings were displaying similar behavior.

Through the registry, she met a number of other mothers and half-siblings. She discovered that two had autism and two other showed similar signs of sensory disorder. Over the years, the group, which grew to 13 families, formed a bond around this anonymous man who was their biological link. They had unions and reunions and exchanged holiday cards, but none of this socializing answered any of Michelle's questions about the donor's identity. Because he signed a waiver, the California Cryobank would not release his identity. And because genetic testing is not part of their protocol or an FDA requirement, they could not offer any clues to his genetic history that might have caused these traits.

11/12/09	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/12305

Recently I had a very good experience with California Cryobank and I feel obliged to let people know.

I ordered sperm samples online, but they were having computer problems. I tried again the next day and the order went through. A week later I got a call from my doctor, informing me that two separate shipments arrived.

When I called California Cryobank, they looked into it and told me to have the second sent back and they would reverse the charges. I didn't have to argue. They did the right thing, immediately. In a world where there is little corporate responsibility, their behavior was refreshing.

8/5/09	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/12078

A DSR member just emailed me to tell me that she and her teen aged son contacted CCB several years ago and told them they wanted to meet the donor. During this same time period, their donor also contacted CCB and told them that he would be open to meeting any interested offspring.

Not only did CCB never connect them (they met up on the DSR) but the donor recently went into CCB to ask them if he had any offspring open to contact.....and they still said "no"! The mom had reported the meeting to CCB and also posted the fact that she met up with the donor on CCB's website.

So, even if you have told them that you are open to meeting, and they say they have put that information in your file, don't assume that they will connect you with your willing donors.

8/5/09	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/12077

One CCB representative recently told a DSR mom:
CCB receives 3-5 requests per week for contact with their donor from donor conceived people.
CCB has a 99% success rate of locating donors.
Donors are sent a letter asking for an "update" (No mention that the real reason is because a child is curious or a family might be looking for updated medical information.)
1% of donors actually respond to these "update" letters.

Another CCB representative then told me:
There have been 21 requests from offspring to meet donors in the past three years. 8 of these donors responded positively.
He confirmed the first rep's report that a letter asking for an "update" is sent. He indicated that the donors have lives and families and that they had to respect that.
When I was at CCB offices in 2007, another person told me, "we have never had a donor say no to contact when we've contacted them on behalf of an offspring". At the time I knew this was not the truth, because of our own personal experience.

Has anyone else out there been told any other conflicting information?
So those of you who think your donor has been (or will be) given the opportunity to connect, think again. How many of these donors throw away the letters completely unaware that there is a child wanting to know them? How many of them, if adequately educated on the reasons why kids are curious, or why updating and sharing medical information with families is important, would be willing to share and update information with their offspring?

4/20/09	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11840

Sperm Banks- Most to Least Progressive
Here are current numbers for anonymous vs. open donors that the each sperm bank has in their current catalog. PRS, TSBC and Xytex being the most progressive. Fairfax, CCB and NECC unfortunately still promoting anonymous donors as the bulk of their catalog.

PRS
95 id release 88%
13 anon 12%
108 total

TSBC
49 id release 64%
27 anon 36%
76 total

xytex
81 id release 61%
51 anon 39%
132 total

Fairfax
39 id release 21%
144 anon 79%
183 total

CCB
56 id release 20%
228 anon 80%
284 total

NECC
35 id release 20%
139 anon 80%
174 total

355 id release (37%)
602 anon (63%)
957 total available donors on 4/19/09

2/16/09 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11629

Hi, all. Has anyone noticed that CCB's website now requires users to agree to a number of points before they can log in?

10/19/08 Email to Wendy Kramer

For what it's worth. We live in CT and used CCB, although we have only had limited interactions with them all the interactions we have had have been positive. We are a lesbian family with two donor conceived children. We know of about 4 other couples who have also used CCB without any negative interactions to speak of. We'd all use them again. My health care provider (a large well known university based practice which has its own embryo lab) recommends only 3 banks and they have CCB 1st on their list.

10/06/08 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11228

Re: Message from Representative from GIVF
Update:
I would like to update the GIFV (Fairfax) Director's "corrections" to our list:
His item #2: "2. CLI is not able to confirm the statement that the same donor had previously donated at Zygen Laboratories and California Cryobank."

This is accurate. We have confirmed.

His item #10: "10. CLI has NEVER distributed California Cryobank (CCB) donors and likewise CCB has not distributed CLI donors."

We have also heard from a parent who purchased her sperm from California Cryobank, but her donor list has a CLI heading, and she now matches with other moms who actually purchased their sperm from CLI.

His Item #9: "9. CLI has NEVER had any donors listed on the Biogenetics donor catalogue."

We have a donor who is indeed on both Fairfax and Biogenetics lists. We also have a donor on both Fairfax and NECC lists.

10/1/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11216

The Director from GIVF Cryobanks (Fairfax Cryobank and Cryogenic Laboratories, Inc.) has different information than we show on our clinic list (which was compiled from former clients). It's easy to see why there is so much confusion!
I have agreed to post his information, as follows:
1. The Genetics & IVF Institute's (GIVF) main office is in Fairfax, VA. GIVF no longer has offices in Ashburn, VA and Gaithersburg, MD., where clients seeking infertility treatment were seen. GIVF is made up of Divisions, that specialize in infertility, genetics, sperm sorting, cryobanking, infectious disease testing, and pre-implantation genetic testing. Certain divisions have locations in various states (TX, CA, MN, PA) and internationally (China and Mexico) however not all divisions and services are represented in those locations. Please refer to our web site for additional information regarding our products and services: www.givf.com
2. CLI is not able to confirm the statement that the same donor had previously donated at Zygen Laboratories and California Cryobank. However, if the donor number from the CLI donor in question is forwarded to CLI management they will follow up with the donor.
3. CLI has NEVER changed any donor numbers. It cannot be done. Donor numbers are written on the vials that contain the semen. Once frozen, the numbers cannot be changed without thawing the vials and then refreezing them. Such a process would render the semen unacceptable for distribution. CLI is also AATB accredited and this practice would be in direct violation of the AATB standards which require that a unique identifier be assigned to each donor.
4. CLI was acquired by GIVF from John Olson in 2002. The 2000 numbers were from donors that were recruited following the acquisition and were not from other banks. Some donors with pregnancies listed are b/c they have children of their own and have created pregnancies as their samples were used.
5. CLI, IC and Follas have NEVER used ReproTech Ltd. as a freezing facility. In fact, ReproTech Ltd. an independently owned company does not operate a freezing facility they are a storage facility only.
6. ReproTech Ltd. was located in the same building as CLI in Roseville, MN until 2007. In 2007, they moved to a new location in Minneapolis/St. Paul.
7. CLI and ReproMed Ltd. were both started by John Olson. CLI donors and ReproMed donors were shared with distribution in the US and Canada. The first ReproMed donor was donor #3000. The CLI affiliation with ReproMed Ltd. was discontinued in 1999. ReproMed Ltd. is currently independently owned and operated. There are currently no shared donors between CLI and ReproMed Ltd. ReproMed and CLI have one donor (# 3040) in common on both catalogs currently. All other donors that CLI and ReproMed had in common are sold with ReproMed.
8. CLI has and continues to distribute semen produced by some of the following banks. Supplies of these donors are limited and once they are gone, there will be no additional units available from CLI. Clients interested in future specimens on these donors will have to contact the original bank to check availability. InternationalCryogenics , Inc. (ICI), Follas Laboratories, and Park Avenue Fertility (PAF), Reproductive Resources, University of Nebraska (currently out of business), Washington Fertility Study Center (currently out of business). (NOTE: The sperm banking division of Follas Laboratories was sold to General BioTechnology LLC and is currently doing business as Genome Resources). Donors from the other banks, were/are distributed with the same donor number as the originating bank. The CLI profiles on the donors were created with information supplied by the originating banks.
9. CLI has NEVER had any donors listed on the Biogenetics donor catalogue.
10. CLI has NEVER distributed California Cryobank (CCB) donors and likewise CCB has not distributed CLI donors.
11. Fairfax Cryobank DID NOT purchase Follas Laboratories or any other bank (see above) . GIVF of which Fairfax Cryobank is a division, owns CLI. GIVF has not purchased any other cryobanks.
12. Each cryobank has its own donor numbering system. Therefore, several banks can have the

same donor number on a past or current catalogue, however, they are not the same person.
13. Can Am Cryoservices, Inc. in Hamilton, ON distributes donor semen throughout Canada produced by Fairfax Cryobank and Cryogenic Laboratories, Inc. The samples are produced in the US and imported into Canada. All donors and their samples must meet strict Health Canada regulations regarding screening and infectious disease testing. Some donors are distributed both in the US and Canada at the same time. They would have the same donor number in both the US and Canada.
14. GIVF egg donor program is separate from Fairfax Cryobank sperm donor program. In addition, Fairfax Cryobank sperm donor program is separate from the CLI sperm donor program. Likewise, egg donor screening is different than sperm donor screening. All three programs are FDA registered and FDA inspected.
15. CLI NEVER had an affiliation with the University of Utah for donor sperm.

9/26/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11184

Re: [DonorSiblingRegistry] Does Fairfax Allow Letters to Donors?
California Cryobank told me I could send a letter and they even said the donor was coming in for an update. Later I was told he never showed up. What do you think?
-------Original Message-------
>> I just heard that another bank allows letters/photos of DI kids to be
>> sent to the bank, who passes them on to the donor, if the donor wants.
>> Does anyone know if Fairfax does this? (They're already closed for
>> the day or I'd call them and ask.)
>>
>I would guess NOT... because this leans towards openness and they are for closed-tight-ness.

8/22/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11041

California Cryobank uses "Donor Sibling Registry" name as their advertising slogan.
California Cryobank has been using the copyrighted "Donor Sibling Registry" name in their Yahoo advertising. We have been notified by people who have seen this advertising on at least two Yahoo groups (including this one, our own!). Their advertising box simply says "Donor Sibling Registry", and then "The Leading Semen Donor Bank" and when you click on it, you are taken to the California Cryobank website- an organization and website that we have no affiliation with.
Although we are flattered….it is extremely disappointing that they could not come up with their own advertising slogan and resorted to using our name, without permission, to attract clients to their sperm bank.
This is the best they could do? Shame on you California Cryobank. Try advertising using your own merits, not the Donor Sibling Registry's.

8/22/08	http://www.bionews.org.uk/new.lasso?storyid=3949

US BAN ON EUROPEAN SPERM
Health officials in the US have placed a ban on imports of sperm from European men to protect Americans from the human form of mad cow disease. Stores of European sperm are now running out, causing problems for women wishing to use them.
Before the ban, the use of sperm from Nordic donors in particular had grown in popularity. Companies such as California Cryobank in Los Angeles and Cryos International in New York City imported sperm from Denmark for which there was a huge demand, largely due to the donors' blue eyes, blond hair, and their tendency to be tall and well educated.

Since the ban, put in place in May 2005 by the Food and Drug Administration (FDA), sperm banks are no longer allowed to import sperm from Europe for fear it might spread the fatal and incurable human form of mad cow disease, Creutzfeldt-Jaokb disease (CJD). The ban was one of a number of restrictions the US government put in place after the spread of mad cow disease in Europe in the late 1990s. Other measures included banning people who lived in the UK for more than three months between 1980 and 1996 from giving blood. The disease, in rare cases, is spread from cow to human by eating meat from infected animals, and has also been known to spread from using contaminated surgical equipment and transplanted tissue, such as corneas. There are, however, no known cases of infection from sperm and scientists say that, although it is theoretically possible, the risk is insignificant.

Soon, the last few vials of European sperm imported before the embargo will be gone. Many women, who used this sperm before and now wish to have another baby using the same donor, are having to pay thousands of pounds to travel to Europe for insemination. Other women are travelling to Canada or Mexico, or even haggling with other women who have leftover vials. In response to the uproar, Nordic Cryobank has filed a petition asking the FDA to lift the restrictions.

8/8/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10985

I also reported my birth to CCB when R was three years old (when my clinic told me the cryobank and donor number) and then two years later got a letter from CCB asking if I had had any children, because they had no record of any.

8/4/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10954

A member recently wrote to ask about Fairfax Cryobank and which other clinics they have bought up or sold sperm for. Here is the information that we've collected about who shares/sells/buys sperm:

-CCB of CA sells CLI sperm (same numbers), donor profile actually says CLI. Recipient pays CCB.

-CCB affiliates are Procreative Technologies (St. Louis, MO), Palo Alto, CA, Los Angeles, CA, and Cambridge, MA.

-Kaiser Permanente in San Francisco used to use Procreative Technologies, which later was sold to CCB. The Denver Kaiser used CCB.

7/19/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10822

In message 10318 was written:

"I wouldn't swear to it, but I am 99% certain that California Cryobank told me that my sperm would be made available to 10 families maximum. Each family could have as many children as they liked, but no more families than the 10 would have access to my donations."

Response to the above:

A few years ago (in Feb '05) I asked California Cryobank if they limit the number of offspring per donor. Here is the response I got: (btw, this response was not signed by anyone and the email address it came from was askccb@cryobank.com)

We do limit the number of vials that each donor can donate. This limit is based on our calculation which factors in the average number of attempts to achieve a pregnancy, the type of inseminations used and the number of vials clients purchase and store for sibling pregnancies. Our goal is to limit each donor to approximately 10-30 family units worldwide. Please review the answer below for more background information:

Do we limit the number of pregnancies allowed per donor?

This question is commonly posed to us because people have concerns that their child might encounter a half-brother or half-sister later in life, and then unknowingly enter a relationship and have children. Population geneticists have calculated that 25 children per donor would be safe (meaning that it would be highly unlikely for half-siblings to mate) in a population of 800,000.

1. A second study indicated that approximately 300 children per donor per state in the United States would be a statistically safe number.
2. With our current vial limit policy, we do not even remotely approach 300 live born children per donor worldwide. Our goal is to limit each donor to approximately 10-30 family units worldwide. A family unit may consist of more than one child from the same donor per recipient.

We actively pursue and strongly encourage our clients to share with us the outcome of their inseminations, but not all of our clients do so. In order to limit the number of offspring per donor, California Cryobank limits the total number of specimen vials that we collect and distribute per donor, and we routinely monitor and review the number of offspring per donor. Although we cannot directly control the number of pregnancies per donor, by limiting the number of vials we distribute, we ultimately limit the number of offspring. Our company ships to all 50 states and approximately 30 countries. Therefore, the likelihood that a child of one of our donors would inadvertently meet and mate with another offspring of the same donor is extraordinarily low.

You can minimize the risk that your child might partner with, or have children with a half-sibling. One way is to share with your child that you used a donor to build your family, and make sure that you keep records indicating the donor number and sperm bank that you used. Therefore, your child will have that information available upon reaching childbearing age. DNA testing is also available to determine the degree of relationship between two people. Companies that specialize in paternity testing may offer this type of testing, which can be used to determine if two individuals are half-brother and half-sister.

1 de Boer, A., Oosterwijk, J.C., Rigters-Aris, C.A.E. (1995)
Determination of a maximum number of artificial inseminations by donor children per sperm donor. Fertility and Sterility 63(2): 419-421.
2 Curie-Cohen, M. (1980) The frequency of consanguineous matings due to multiple use of donors in artificial insemination. American Journal of Human Genetics 32: 589-600.

7/19/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10820

There are fourteen matches for the donor I used on the DSR. Most of the families listed for this donor have been in contact for quite some time. There are also two additional children registered on California Cryobank's registry. My daughters are 5 and 7 and I recently discovered that one of the other offspring listed on CCB's registry was the related to a friend of mine, and the children actually attend preschool together. This was a shocking at best! While I am very thankful to have established contact with the other families, I was not prepared for day in day out contact with another family. My daughters have age appropriate understanding about their conception and their relationships to these other children, but there is a big difference between seeing pictures and and hearing bits and pieces about other children and daily contact. I have always been able to answer my girl's questions about our family honestly, but I don't think they are ready to process on this level. Although this situation is a huge coincidence, I don't believe we will be the only family who encounters this. What if my daughters were of dating age and this child was in their classes??? I understand that each family has to make decisions about whether and when they disclose information, but this illustrates why it is so important for people to be truthful with their children.

I called CCB a few months ago to ask them how they limit the number of families or people in a geographic area they sell to. The woman I spoke with told me she thought 25 families all together. I asked her how they could do that if not everyone reports pregnancies. She said she would have to call me back and actually did. According to her, CCB limits to 25 families by retiring a donor after they have sold vials to 25 different family units. Then, the only people who can purchase that donor are people who have already reported pregnancies to them. This does not take into account the fact that some families may not be buying directly from CCB and may be getting sperm through a fertility clinic....

7/18/08 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10813

I wouldn't swear to it, but I am 99% certain that California Cryobank told me that my sperm would be made available to 10 families maximum. Each family could have as many children as they liked, but no more families than the 10 would have access to my donations.
The last time I spoke with a geneticist there I was told they had 35 confirmed births from me.
Wendy Kramer has told me that typically only about 40% of births are ever reported to the sperm banks. That means there could well be 80 or 90 kids out there. That is mind blowing, and way more than I signed up for.
So I share the concern of the parents who worry that their children may not have access to a numerically overwhelmed donor. There's nothing I can do about it now but it would be great to impose some regulation on the banks, or at least disclosure laws.

6/08 Email to Wendy Kramer

A couple of years ago, I gave some baby photos to the California Cryobank. I also filled out a questionnaire as well. I believe that they gave me a $25 or $50 gift card to Best Buy (electronics store) as compensation. I don't really remember signing anything at the time, but I certainly would not have signed anything forbidding contact with offspring.

5/9/08 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10593

Re: Limiting number of children born per donor...Why again?
None of this matters if a single donor is donating at several different labs. Each and every lab can impose their own rules about limiting the number of offspring per donor, but like in our case, where our donor donated at 3 different major labs (CCB, ZYGEN, CLI), then there is absolutely no way of tracking how many 1/2 sibs there actually are. (We are still unsure if these labs shared our donor's samples with one another or if he actually donated at them--the labs all say he was THERE in person!) And that goes without saying how many parents are not reporting their pg's and live births to their labs. I think that there is no way to track 1/2 sibs at this point without serious change and process!!!! I am sure the actual numbers of 1/2 sibs with certain donors is ASTONISHING!!!

4/18/08 http://health.groups.yahoo.com/group/DSR_Discussion/message/4564

Now even if most donors are honest, even just a few dishonest donors and sperm banks can procreate very many offspring with a lot of health problems. Take for example donor ### of the California Cryobank. Donor ### divulged some health issues that indicated that he had hereditary polycystic disease. But Dr. Cappy Rothman and Dr. Charles Sims decided - probably with a view to the fact that polycystic kidney disease doesn't usually manifest until the sufferer hits the thirties - not to disclose the health information. Drs. Rothman and Sims let donor ### donate some 320 times and sold around 3000 vials of his sperm, which in turn has produced an estimated 75 offspring who will be hit with polycystic disease in due course. Drs. Rothman and Sims still head up the CCB. Is it any wonder that I have no confidence at all in sperm banks or donors????

4/4/08 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10342

From the CCB..What a sperm donor had to say.
"I was a donor for the California Cryobank for two years during college. I was told about it through a friend. The experience was great. The staff is very accommodating and the monetary incentive is ample. I was able to supplement my income by being a donor because it did nit interfere with school or my job. I recommend this program to anyone who is unsure about becoming a donor."
- Cambridge Donor

4/2/08	http://www.cnn.com/2008/HEALTH/conditions/04/02/autism.sperm.donor/index.html

Article about California Cryobank siblings and autism.

3/21/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10295

We are a lesbian couple and have 4 year old son through California CryoBank. We were impressed with their experience, knowledge, selection (yes, like a catalog!) and professionalism.

2/16/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10058

Just wanted to let everyone know that my experience with the CCB in changing from anonymous donor to open donor was seamlessly easy. I emailed them first. They called me back. We spoke for a few minutes. And they updated my information with current address, phone number, etc. Simple. Anyone needing help with this issue, email me and I can give you direct phone numbers which may be helpful.

2/12/08	http://health.groups.yahoo.com/group/DSR_Discussion/message/4432

I remember this donor -- was it the man who was living in the trailer with all the dogs? I think it's possible for someone to have advanced degrees, and then decide to reject a material lifestyle. Or possibly he developed mental illness after he donated, and is on social security disability. Or maybe he has a big trust fund. Who knows. But he seemed like a really nice, sincere man, so I imagine his children are really nice people.
--- In DSR_Discussion:
> This might be unfair, but I'm haunted by a strange little CA. donor
> profiled on 60 Min. last yr., who fathered scads of kids w/ a great
> sounding bio, but didn't seem to resemble his donor profile AT ALL!

2/12/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9965

...my experience at Fairfax about 2000-03, was that they tried to prevent donors from discovering their donor # as well. I happened to see some of my paperwork when I was hanging out in the lab with the techs, which is how I learned mine. (And subsequently, they put the donor info online for customers, so any donor could theoretically search for his characteristics and find his donor #.) I have heard from other people who have donated (CCB and NECC, and some tiny place in carolina) that they too were not "allowed" to receive donor #s either. Perhaps things have changed as of late... don't know.

2/12/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9952

CLI and Repromed refuse to give donors their numbers. (Some donors forget or never received their numbers). This makes it extremely hard to make themselves available for contact. I spoke with

a CCB donor over the weekend who said he has tried several times to call California Cryobank to update his medical history, and no one will return his phone calls. I have many parents-to-be writing me to ask my opinions of sperm banks (more than 50 this past weekend). Issues like these are very important to pass along.

2/10/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9894
I mailed out more than 400 letters a few weeks ago to sperm banks, clinics, Reproductive Endocrinologists, and infertility doctors asking them if the would include a DSR information sheet in their "new client" packets. I only have ONE respondent- Xytex, who asked for 500 of the info sheets, to include in every new patient packet that they hand out or mail out. This information sheet tells people about the DSR and a child's possible curiosities in a very non-threatening and friendly manner. What does this tell you about the infertility industry? That they just do not want to acknowledge the needs of families post pregnancy. There is an industry meeting on March 28th, in Chicago, for further discussion on the "Feasibility of a National Donor Registry". There is not one donor conceived person that has been asked to speak or participate in any manner at this event. I am the only mother of a sperm donor conceived person asked to speak. (One egg donor mother as well) I hope that some of you will be able to attend this meeting so that the industry can hear your voices. It makes you wonder who's needs they are looking to serve in "self-regulating". Certainly not the donor families....	

2/8/08	http://health.groups.yahoo.com/group/DSR_Discussion/message/4415
I was a donor w/CCB around 1999. CCB sent me a 1099 for donor compensation. As with other businesses, they are required to send 1099's if compensation to a non-employee exceeds $600 in a given year, though I think this was a change in IRS policy in the 90's. It is my understanding that the IRS then requires the contractor (me, in this case) to pay Self-Employment taxes (normally the 'employer' half of FICA/Medicare taxes), regular FICA/Medicare taxes (the 'employee' half), and income tax on this income. The income is taxable in this fashion whether or not a 1099 is actually issued (i.e. <$600 total compensation), though of course without the IRS being notified of the income, compliance is probably relatively low. The payer is not required to tell you anything about tax liability up front, though CCB did with me. In order to issue a 1099 (and the 1096 transmittal form which goes to the IRS), the payer needs the payee's SS# or an EIN. CCB requested my SS#, and I gave it to them. Payers are supposed to have contractors fill out a W-9 form (I believe I did fill one out), and keep it on file. However, they are not required to obtain positive ID's to satisfy the IRS; unlike the I-9 that W2 employers must have on file for each employee, where they are required to obtain identifying documents. If a contractor were to supply false info (or refuse to supply a SS# or EIN), that person would be subject to penalties from the IRS (possibly including perjury, as stipulated on the W-9), assuming the IRS were to find out. That said, to address your implicit question, I did supply them with my state-issued ID during the application process, and they did require a biometric hand scan to verify identity prior to each donation.	

2/8/08	http://health.groups.yahoo.com/group/DSR_Discussion/message/4414
California Cryobank also whited out a couple of things on our donor profile.	

2/8/08	http://health.groups.yahoo.com/group/DSR_Discussion/message/4413

Not only do they "not check", but California Cryobank actually falsified my donor's education in order to make him more appealing to me. He in fact had no college, but they (not he) wrote in 1 year. They also changed the check box from curly to wavy hair because they knew that was what I was looking for. Those are only the things I've been able to verify, so who knows what else they lied about. Yes, getting rid of the screen of anonymity they've been able to hide behind can only be a good thing for the consumers and for our kids.

2/7/08 http://health.groups.yahoo.com/group/DSR_Discussion/message/4408

They never even asked for ID such as a driver’s license or anything of the sort? Now that is hard to believe. If that is true you could walk into that bank and donate as Jon Doe and never have to be tested for anything because how would they keep track. I know the ccb uses hand recognition. Well at least that is what I was told.

2/7/08 http://health.groups.yahoo.com/group/DSR_Discussion/message/4406

I was told a year or more back that the CCB would be starting a new program and updating all their donor files. I was also told that my donor would be coming into the bank to update his file and he even had an appointment. I highly doubt that was true. If you have used ccb please contact them and ask them about the program as I have not seen it happen at all.

2/6/08 http://health.groups.yahoo.com/group/DSR_Discussion/message/4402

This might be unfair, but I'm haunted by a strange little CA. donor profiled on 60 Min. last yr., who fathered scads of kids w/ a great sounding bio, but didn't seem to resemble his donor profile AT ALL!

2/6/08 http://health.groups.yahoo.com/group/DSR_Discussion/message/4401

I just want to correct one thing that I said. We do know that the CCB actually commit fraud since litigation uncovered evidence of their fraud regarding cover-up of donor ### kidney disease in the Johnson case. We also know that International Cryogenics (the Michigan Spermbank) could not succeed in contacting their donor who transmitted the very serious blood disorder to half his known offspring. Such inability to trace a donor who stopped donating merely year before (when I can find anyone via Google in thirty seconds) indicates a probable fake identity. Sure enough after exposure of this very serious incident (last year) International Cryogenics stated that it would start collecting identity information from its donors.
Please ask yourself the question - how much risk is this incompetence placing us in? We should be pushing the FDA for much more rigorous record keeping and vetting. Surely if anything crops us with our kids we need our sperm banks to be able to trace the donor.

> Although I'm really only privy to the NECC's drastic shortcomings I
> have no reason to believe other spermbanks operate more competently.

1/28/08 http://health.groups.yahoo.com/group/DSR_Discussion/message/4373

Just my 2 cents, but my partner and I chose to go with a much smaller bank. We chose PRS and were very happy with them. We chose a smaller bank for many reasons; the biggest reason was that we felt a smaller bank would produce fewer offspring per donor. PRS was licensed in NY [where we live] and though all the RE's we met with and asked did have more experience dealing with the larger banks (Fairfax & CCB), their previous experiences with PRS had always been positive. I can also tell you that when a question arose regarding my daughter's health, they were not only incredibly supportive- but they were also more than willing to contact the donor [who had retired 2 years prior] and ask him a whole host of questions. [BTW, it was just a reflux/allergy issue and at the time that I contacted them it was obvious that it was in no way life-threating and most likely it had nothing to do with the donor. So based on that, I thought it was especially nice of them to contact him.]

Again, just my opinion, but I do think there's something to be said for dealing with a smaller bank. I imagine that because so many people use (example) Fairfax and CCB they would be hard pressed to provide the type of customer service that a place like PRS and TCSB does. Remember, most of us have never stepped foot into these banks- all of our dealings with them are via the phone. What I liked about PRS was that every time I called- regardless of whom I spoke with, I got the sense that they knew exactly who they were speaking with.

Given all I know now, if I had to do it all over again, I would still choose PRS (actually, after being on this site, I personally feel like I kind of dodged a bullet by not using Fairfax or CCB—but that's just my opinion). You should also know that TCSB does have a 10 family limit on each donor (meaning, there's no limit on how many children they can create- but they can only create up to 10 families each). And as I see it, I don't imagine each of these ten families are having a van full of kids, so it seems to me that their number of offspring per donor would be less than most. I'm sure others can tell you how other banks restrict the use of a donor-- it's something horrifying like 25 offspring per population of 800,000 (which, when I did the math, meant that one donor could technically create something like 650 offspring in NYC alone!).

1/26/08 http://health.groups.yahoo.com/group/DSR_Discussion/message/4362

I used California Cryobank. They were always helpful. I have quite a bit of information on the donor. They always shipped the samples on a moment's notice - on time, to the correct place. The sample had great viability as per my doctor and I conceived twins. They also have a sibling registry. I will strongly recommend them.

1/26/08 http://health.groups.yahoo.com/group/DSR_Discussion/message/4361

I used California Cryobank and had an absolutely wonderful experience with them. It was nice and easy and we were treated with the utmost respect. I am not sure if you can find out any further information on defects and stuff, but when I used them, we did not really inquire about it. I know they have made changes most recently and do have a donor sibling registry you can join. I wish I had a little more info for you, but things went really smooth with us.

1/26/08 http://health.groups.yahoo.com/group/DSR_Discussion/message/4360

We have been looking on 2 donor banks web sites recommended by my doctor: (California Cryobank & Fairfax in Virginia)... Does anyone have any experiences that they would like to share regarding either one of these?

I noticed that they list in the donor profile if there were any successful pregnancies...is there a way to find out if anyone had a pregnancy where the child had any congenital defects or Autism or mental retardation? Is there a way to see how many offspring this donor has from the program? Is there a limit to the number of offspring before they pull the donor and how would I contact the other people who might have used the same donor if at all possible? Do people do this or not anyway? Are the banks following regs? Any other tips would be greatly appreciated!

[from moderator ML: You can read details of a court case against CCB here:
http://caselaw.lp.findlaw.com/data2/californiastatecases/b155896.doc
They ignored important medical information given to them by a donor, THEN falsified his records

when it appeared to have caused a problem, THEN lied about it in court. You have to read the details to find out just how despicable their behaviour was. If this had been a UK clinic, I'm fairly sure they would have lost their license over this.
There is an article about one of Fairfax's donors here:
http://www.donorsiblingregistry.com/The%20Truth%20About%20Donor%201084.pdf
There is generally no way to find out if there are any children from a given donor who have problems. These may not be related to the donor anyway. The only way to get in touch with parents who've used the same donor is through the DSR. Some people have done this. There aren't really any "offspring" limits at most of the banks, and some donors seem to have hundreds of genetic children. Most of the regulation that applies to US sperm banks is either voluntary, or designed to prevent disease transmission to the mother rather than to ensure the health of any children.]

12/19/07 | http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9319

My husband and I used a donor from CCB and we were referred to them by my doctor. Maybe it was just specifically the sperm bank. I had nothing but a good experience with CCB.

12/9/07 | Email to Wendy Kramer

The California Cryobank is supposed to be very reputable and known nationally, but the sperm sample quantity we received after being washed was very low at only <5 million.

11/18/07 | http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9236

The response from Fairfax is more notable for what it doesn't say than for what it does say. None of the specific allegations in the article are addressed, and it looks as if the procedures described in the response simply weren't followed in the case of donor 1084.
(http://www.self.com/magazine/articles/2006/10/23/1006donor_single_page or
http://www.donorsiblingregistry.com/The%20Truth%20About%20Donor%201084.pdf)
It's probably true that donor-conceived people as a whole are healthier than the general population, but then that is to be expected, since the donors are chosen specifically for their genes. I don't think it's realistic for sperm banks to run every possible test on every possible donor, and there can be no guarantee of children with no health issues whatsoever. However, when there are children with problems that appear to be related to the donor, it is not acceptable for these to be ignored or covered up. That seems to be what has happened in at least three cases that we know of. In one case, we know that CCB ignored medical information given by a donor, then lied about it, then falsified evidence given in court. I'm fairly sure that had this happened in the UK, the HFEA would have taken away their license. I find it hard to believe that there aren't other cases we don't know about where sperm banks have been able to cover up problems.
It just seems as if at least some sperm banks in the past were quite happy to ignore medical problems in the donor children, since they assumed that the parents would never be able to contact each other. It's the donor sibling registry that has changed that.
I agree with you that it makes sense for a new donor's samples to be released slowly, so that if there are problems that are immediately apparent, fewer families will be affected. In the article, it says that Ethan's problems were evident in April 2001, when he was 1 week old, but that in 2006, Fairfax were "still telling hopeful mothers that there are no adverse health reports linked to Donor 1084".
The director of Fairfax said in his response
(http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9228) that "We ask physicians and clients to notify us whenever they believe a child born by donor sperm has any medical condition. In the rare cases when we receive such notice, we immediately remove that

donor from sale and investigate the report. "
Is he saying that the article is wrong? If so, then has legal action been taken against the magazine that printed it?

11/15/07	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9222

Re: New File Uploaded for European Sperm Bank Donors
AND take an extra look if you have used donor; ####, ####, #### because at CCB:s website it says that baby photos are not available BUT at European Sperm Banks website it is.

11/11/07	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9197

Remember the case of the five small babies last year in Michigan who were all being treated by the same doctor for an extremely rare blood disorder that normally occurs once in 5 million births. Well, the sperm bank International Cryogenics said that they could not trace the donor because he had moved and they did not have his current telephone number (funny how it takes me only ten seconds on Google to find anyone I want) and then they said that they could not test any of his samples because he hadn't given consent for genetic testing only to make babies with them. Then they claimed that the genetic disorders in the kids were caused either by a chimerism or gonodal mosaicism.
I've been doing research and I think that the chances of him being a chimera are around 5,000,000/1 and the chances of five babies being born all with the same genetic mutation out of the billions of sperm that he creates are less than 1,000,000,000/1. I think the more likely probability is that he had the disorder of severe congenital neutropenia and passed it down to his offspring and that he just chose not to disclose his illness.
Then add in the case of CCB's deceit in the case of the Johnson's when they edited out the donor's kidney disease and Fairfax's dishonesty about the health of donor 1084 as well as many other cases about different sperm banks.
These cases raise the issue of the sperm banks disregard of their duty to properly screen for health and the issue of a sperm donors right to safeguard his medical confidentiality when he chooses to donate.
NECC, the sperm bank that I used to conceive my children seem to strongly believe that their sperm donors do not have a duty of full medical disclosure and they are defending my sperm donor's right to medical privacy to the extent of fighting protracted and expensive litigation in the courts.
With the big sperm banks putting at risk our children's health there is absolutely dire and urgent need for FDA regulation. The sperm banks have demonstrated conclusively that they are incapable of self-regulating themselves in a way that protects the health of the children they are helping to create and ultimately the health of the nation.
We must put pressure on our legislators to urgently address this terrible problem and put in place tough and mandatory regulation.

11/7/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/4202

Did you use an anonymous donor from the European Sperm Bank (also known as the Nordic cryo bank, some of the donors are used at the California Cryo Bank)? I myself got an audio interview - directed to the American customers (I'm from Sweden)- where my daughter's donor said that he might be open to future contact. He's an anonymous donor. And the audio interview is apparently for an American customer. Not for me. What should I do when my daughter asks for more information about the donor? And what about the answer from the cryo bank?

10/30/07 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9167

If you are a California Cryobank user with a donor number listed below, please cross check the ESB listing as it appears that the two banks have shared donors. On this home page, click on "Files". Here are some of the donor numbers that would be listed at both banks. (CCB listings are by number, ESB listings are given names.)
You might want to post under both sperm banks over on the actual DSR.
####, ####, ####, ####, ####, ####, ####, ####, ####, ####, ####, ####, ####, ####

10/29/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/4101

My husband and I had a good experience with CCB - they now have an open donor program and a sibling registry program which they did not have when we started out. Everything went pretty smooth for us, but I have heard other experiences that were not as smooth as ours.

10/27/07 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9144

I thought of few ramifications- I just wanted a baby. But now that my daughter is here (she's 14 months) I find myself thinking a lot about half- siblings and her donor [much to the dismay of my partner]. Perhaps the recipients of donor sperm should be counseled much like egg donors. I don't know. All I know is this, I live in NYC, and I'm involved in the LGBT community and my cousin is involved in SMBC groups, and I cannot tell you how many women I've met [from both worlds] that have used donor sperm from CCB and Fairfax. I used to laugh when people would make comments like, "well what if they marry each other?" Now I'm beginning to wonder.
I was under the impression that there were national guidelines restricting the use of one donor to 20 families [as far as I know, TCSB is the ONLY bank that limits it to 10 families]-- but who's really keeping track of these things? How many women out there are not reporting pregnancies, and how many banks aren't counting pregnancies that happen at home without the aid of an RE's office?
[from moderator ML:]
1) ASRM guidelines limit one donor to 25 live births per population area of 850,000. It's not clear what this actually means in practice, or how it can be enforced, especially as it's estimated that only 40% of births are reported, and we know that some donors have donated at two or more sperm banks.
2) The Rainbow Flag sperm bank limits a donor to children by 4-6 different women. Other countries typically have limits of 5-10 families.
3) The "rationale" for the "secrecy" of most sperm banks about limits seems to be that they are aware that many people are uncomfortable with the fact that some donors seem to have hundreds of genetic children.

10/22/07 Email to Wendy Kramer

I used the Cal Cryobank to have my daughter in Feb 2004. I had no problems with them (I purchased 8 vials, an audio CD, and had a consultation with a counselor), until I entered a "reactivation request" to try to reactivate my "retired" donor to have a second child. I put in the reactivation request with them, and they never called me back (as they said they would, regardless of what he decided) to let me know that he declined. I had to call them to find out what was going on, after a month or so of not hearing back from them. This lack of a response really made me lose respect for them and question their professionalism. I felt like they must have felt it wasn't worth it for them to waste 5 minutes of their time calling me back to let me know he declined, because they weren't going to make any money off me. Of course, they could have looked at it as an opportunity to counsel me about using another one of their donors, but they did neither.

10/22/07	Email to Wendy Kramer

Our experiences:
1) The donor appears to have been honest in providing info, although we really have no way to know this right now other than DD is healthy.
2) CCB has been helpful in contacting the donor for additional testing due to a blood disorder I developed during my pregnancy. The donor was no longer active, and he was responsive.
3) CCB is getting better about providing info re: # of pregnancies, reported issues, etc. Much better than they were several years ago.
4) DD was diagnosed at 6 months with a VUR (or something like that re: urinary tract not fully developed). She grew out of it without surgery. It has a strong heredity component for females. My half aunt on my father's side had a severe case of it. Neither my cousin nor I had it (I have only brothers and only 1 female cousin), so it's impossible to really tell if it came solely from me or the donor. I will say neither CCB nor the other moms I contacted via DSR seemed too interested, and I'm sure CCB did not put it in the files.
The upshot: we need to consider a different donor to have a second child. We are happy with CCB and the amount of info they provide on donors, but will also consider other banks as well given the limited pool of donors that are available to me (have to be O-, CMV- at a minimum).
I am surprised at the number of donors the banks offer who have health issues (rheumatoid arthritis, breast cancer, etc.) with a distinct genetic bias.

10/19/07	Email to Wendy Kramer

I know this isn't true for everyone, but my experiences with CCB have all been positive and exactly as they represented. The purchases and backorders were timely delivered and all the customer service representatives were professional, courteous and extremely helpful. They assisted with the photo matching, sending extra audio interviews and attempted to re-activate the donor when I was considering a second child. When my daughter had some stuttering issues (since outgrown), their genetic counselor was very forthcoming and helpful and seemed to record everything, even asking for my medical reports. My child has always been very healthy, and we have avoided almost all childhood health issues. Her little issues are few and far between. She has hereditary high cholesterol, but she could easily have arrived at this maternally since I don't have all my family history. I have nothing to gain by saying good things about CCB, but it's the truth and I'm hoping that we get a good representation of what the actual ratio is of good v. bad experiences, so I feel obligated to send this to you--anonymously, of course. This isn't to minimize the seriousness of the bad experiences, but I suspect that they are not a large percentage of people's experiences at large. Or, at least I will be surprised if that's the case. I kind of worry about only focusing on the bad experiences because if that's all that is publicized, it has the potential to eventually stigmatize our little ones.

10/7/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/4036

I also and very fortunately have had an excellent experience with CCB in terms of the outcome (e.g., my DD). According to the donor's profile, I found a reasonably intelligent, tall, good-looking guy from a family with a history of longevity and general good health, and this seems to be reflected in my DD. BUT, to have a second child, I will need to use a different donor, and I have extremely limited options according to my doctors (needs to be CMV-, Rh-, O-...the list seemingly goes on!). Frankly, choosing another donor terrifies me after reading this and the other DSR-related board. It seems like there are a fair number of people who have had problems with various sperm banks, but this information is imbedded in lots of different posts, etc.

10/3/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/4012

My donor donated at two banks and the profiles differ in dates, siblings, height and weight. Among other things. I think the donor was honest because on the typed profile things were more peachy. On the one in his hand writing it sounds more truthful. Has anyone else experienced something like this. The banks are Procreative Tech (typed profile) CCB (handwritten profile).

10/3/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/4008

I have to say that I am a bit disheartened by all this negativity about the sperm banks. I have an amazing 2 year old daughter thanks to CCB and our donor. Also thanks to CCB and this list, I have had contact with six other moms and 8 siblings for my daughter.

Sperm Banks are no more or less perfect that other human based organizations. I have had some issues myself with CCB but at the end of the day if it was not for them I would not be a mother .... which is the best thing I have ever done in my life and my greatest source of happiness. Maybe those searching for a donor might ask woman like myself who had happy, healthy children with lots of happy, health half-siblings if they have additional vials. This is one of the features of Wendy and Ryan's service.

I know there are more CCB vials out there and based on the results – the children I have met personally and the photos and stories I have received over the internet - I would say this guy is a star donor. He is an open donor and I hope one day- through my daughter - I will have the opportunely to communicate to him what a gift he gave me.

10/3/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/4006

In my case, I found that CCB deliberately falsified information in order to make the man seem more attractive to me. The man himself did not falsify the information. I trust nothing else in the profile or anything that CCB says.

10/3/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/4005

The CCB and Cappy Rothman certainly didn't do an excellent job here:
http://groups.yahoo.com/group/DonorSiblingRegistry/message/4881 and
http://caselaw.findlaw.com/data2/californiastatecases/B155896.DOC
They ignored important medical information given to them by a donor, THEN falsified his records when it appeared to have caused a problem, THEN lied about it in court. You have to read the details to find out just how despicable their behaviour was.
If this had been a UK clinic, I'm fairly sure they would have lost their license over this.
Remember, this is just one case that came to light quite by chance. How many other times did they decide to ignore bad news? How many other children have been born with disabilities because other banks didn't screen their donors properly?
--- f wrote:

> I used California Cryobank and I thought it did an excellent job. The
> head of this bank, Cappy Rothman, is often a spokesman for the
> industry. It seems to me that this bank has located in areas that
> attract intelligent donors. When I looked at the lengthy donor
> profiles, I found ten donors that met my qualifications. So, there

> was a very good selection. If you look on the DSR web site, you
> will see that quite a few people have used CCB.
> I don't know what the current status of the bank is in terms of
> identity release which many people here feel is the most important
> criteria. Ten years ago when I was looking, there was another
> California bank that was a leader when it came to identity release. I
> think it had maybe five identity-release donors at the time.
> I also agree with the person below about looking throughout the
> country. The shipping services are excellent and there is no
> problem shipping from anywhere within the country.

10/2/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3999

Given that the bottom line is king in a capitalist society, for the most part, the companies that would respond to you would be ones who thought there existed a possibility for future sales. These banks are acting like the capitalistic entities that they are and they are not operating out of a sense of duty or compassion. There have been a number of past customers who have been disappointed in the behavior of these banks. I can't say that I'm one of them because I never expect good behavior from corporations. It's hard to realize that we are dealing with cold corporations when embarking on such a warm emotional endeavor.

A few people have pointed out that there are large errors in the information they have been given. I don't know whether the donors wanted to improve their income or whether the banks encouraged them to improve upon reality. For those currently seeking services, it may be a good idea to ask about verification of the data. Does the bank check the facts? If not, can someone at the bank be paid as a consultant to review report cards, SAT data, sports involvement etc.? One of the benefits of DSR is that it is altering the anonymity factor, so that donors and banks must realize by now that there could be consequences for lying. On the other hand, if donors lied on the forms, it seems less likely they will come forward in the future, which may be disappointing to some offspring. I did notice on the DSR that something like 50% of the donors with adult offspring have come forward, so I would think that these fellows are truthful people without anything to hide. The doctors who run the industry have a history of seeking donors with similar credentials to themselves and CCB fits that mold. Though, considering your post and others like it, new customers should be wary.

10/2/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3998

I used California Cryobank (CCB) also. 13 years later, I've found outright lies on their "long profile", so you cannot rely on those for accurate information in making a decision. Also, now that I am no longer a paying customer, they are not helpful at all. They do not return phone calls or emails requesting information. I believe that a lot of people use them because they are a large organization that does its marketing well. Also, they keep themselves safe by never allowing anyone to find out the real information about the sperm selling men they call donors. If they can keep them anonymous, then no one can verify what they falsify in order to sell their products.

10/1/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3993

I used California Cryobank and I thought it did an excellent job. The head of this bank, Cappy Rothman, is often a spokesman for the industry. It seems to me that this bank has located in areas that attract intelligent donors. When I looked at the lengthy donor profiles, I found ten donors that met my qualifications. So, there was a very good selection. If you look on the DSR web site, you will see that quite a few people have used CCB.

I don't know what the current status of the bank is in terms of identity release which many people

here feel is the most important criteria. Ten years ago when I was looking, there was another California bank that was a leader when it came to identity release. I think it had maybe five identity-release donors at the time.
I also agree with the person below about looking throughout the country. The shipping services are excellent and there is no problem shipping from anywhere within the country.
--- In DSR_Discussion, t wrote:
> I think that you are very wise to be seeking feedback prior to making
> a decision about which spermbank to use. The choice of spermbank is
> critical since their competency in screening donors is crucial as is
> their accurate description of donors so that you are making an
> informed choice.
> I would really not be too concerned about choosing locally as choosing
> right!
> I could never under any circumstances recommend the spermbank I used
> (the NECC) since they did not properly screen my donor or if they did
> they didn't divulge his very significant medical issues. They also
> lied very substantially about his education and personality. They
> also told me he was identity release when he was not. If I was the
> only one reporting these NECC problems then maybe I would think it was
> a one-off case but I know of several other women reporting the same
> problems.
> So my best recommendation is to try to look through the old DSR
> messages an use the search facility to check out the names of
> spermbanks you might want to use. Note carefully the negative
> feedback. In general you can pretty much ignore positive feedback
> since all spermbanks have great customer service upfront and 96% of
> children are born normal. So even if the spermbanks didn't screen at
> all, then nineteen out of every twenty kids from their sperm would be
> born just fine. Spermbanks should be screening their donors at a
> level to significantly reduce the incidence of hereditary disorders.
> A very important factor you should condider is if the spermbank take
> affected donor sperm out of circulation when congenital abnormalitlies
> or disorders are reported. In my case an offspring was reported with
> problems prior to my children's birth, yet I was not informed about
> the issue despite being in good contact with the NECC. They ever gave
> me the option of considering an abortion. Then when I and another
> mother reported problems with later offspring, nothing was noted upon
> the medical file and the sperm was still sold for several years until
> I began legal proceedings.
> Spermbanks are definitely not all equal and since you are buying a
> product sight unseen and will have a child as an outcome, you owe it
> to yourself to be very, very careful and heed the warnings of the
> people who actually make the effort of posting to this site.
> It is certainly worth while spending the effort to do your due
> diligence in order to reap the benefits and fun of raising a healthy
> child.

9/14/07	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8915

Regarding availability of open/willing to be known vs. anonymous donors: My experience is very recent. I began working with a fertility clinic in February and am now eight weeks pregnant. The fertility clinic is large and reputable, and I trusted their choice of sperm banks. They work with four, including California Cryobank (CCB), Cryobiology, Cryogenic Labs, and Pacific Reproductive Services. Of these, CCB had a substantial number of open donors - maybe 25% of their large inventory. Even so, I had to get permission from the clinic to waive a medical concern - CMV status - to allow me to find a donor who was open and of the race that I wanted. Had my clinic not been willing to allow me to use a CMV-positive donor (I am negative), I would have been forced to choose between the donor's race and whether he was willing to be known. Race and openness are both choices that have a potentially huge impact on a child's life. It would have been very difficult to choose between the two. And CCB is one of the largest sperm banks around, with one of the largest inventories.

As for the other three banks, Cryobiology had just eight open donors. This was not indicated in their catalogue; I had to e-mail them to find out. Cryogenic, like CCB, had a substantial number of open donors, as did Pacific Reproductive Services, and I imagine that my selection at those banks would have been similar to my options at CCB. About 80% of the population is CMV positive, so if my fertility clinic had been unwilling to allow me to use a CMV+ donor, I would probably have been similarly limited in my donor options at those banks, as I would have been at CCB.

I was lucky enough to have a fair selection of open donors, though there were significant constraints within that selection. In addition, open donor programs appeared to be new, and one bank didn't have much of a program to speak of. I live in a large, liberal metropolitan area and had my choice of several fertility clinics, two of which are quite large. The clinic that I did work with used four sperm banks, so I had a range of options there as well. However, if I lived in a smaller, more conservative city, my options for fertility clinics, and thus sperm banks, might have been much more limited. And if I were doing this five or 10 years ago, my options might have been more limited still.

9/3/07	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8862

That is funny because CCB told me basically the same thing about 2 yrs ago. I think they just wanted me off their backs. I have not seen in action in that direction from them. (Referring to following two poster’s messages):

> Good news though, Fairfax has been trying to contact all their past
> and present donors to get an updated medical, background, education,
> career, etc., information. They have plans to update their website
> so we can access this information

Fairfax also told me this the other day. But, the woman I spoke with also added that they would only be posting updates on still active donors or donors who are still listed on the site, NOT donors who are restricted, terminated, etc. So, to get these updates (assuming they actually happen and i hope they do), you will need to call. I asked how would I even know when to call and was told to call about once a year (not exactly a good communication plan in my opinion).

8/23/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3832

> It says that they won't divulge the names of
> the donors. That seems like a pretty obvious distinction.
> { Note from Wendy: It says " ....expect CCB to obtain or divulge
> to client the name of any donor.... "obtain"???}

My contract with CCB says the same thing. I interpreted "obtain" to mean "go look in the file for," with an implied "so that if you had a specific name you were asking about, we might let something slip."

From my discussions with CCB specifically, I'm under the impression that staff that speak to recipients have no access to identifying information of the donors, and staff that speak to donors

have no access to identifying information of recipients. So the recipient- contact people shouldn't be expected to obtain that information, even if they don't divulge it.
Which is good from a maintaining-anonymity standpoint, because IME there are a lot of slips. CCB is currently (as of ~3 months ago, but not as of ~9 months ago) releasing reported-birth counts to recipients (but not donors - I asked); the response I got was "Five - oh, no, wait; that's something else. Two." I suspect the five was total purchasers.

8/23/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3828

Where in that statement does it say that they don't check out the names of the donors? It says that they won't divulge the names of the donors. That seems like a pretty obvious distinction. Let's not misinterpret the plain meaning of what they are saying and then create a straw man on which to vent our anger.
{Note from Wendy: It says " ....expect CCB to obtain or divulge to client the name of any donor.... "obtain"???}
They clearly know who the donors are (Name and SSN) because they pay by check and report donor income on a 1099 to the IRS.

8/22/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3824

> On the other topic, I used CCB a few years ago, and I signed an
> agreement that said (among other things):
> "Client agrees that CCB does not warrant or guarantee the
> qualifications of any donor, and that in determining whether any
> donor has certain characteristics or qualifications, CCB shall be
> required to make only such investigations of any donor as CCB shall
> deem reasonably necessary.
> Client agrees that client shall not now, or at anytime, require nor
> expect CCB to obtain or divulge to client the name of any donor, nor
> any other identifying information contained in the files of CCB.
> Client also agrees not to seek this information from any other source."

Hmm, what is really interesting is the statement where it says that the client doesn't expect CCB to obtain the name of any donor. From this statement it seems that CCB does not even check out the name of donors and allows them to use a pseudonym. What the hell are recipients paying sperm banks for???? It is ten times cheaper to just conduct a range of STD tests on a guy and get him to jerk off in a cup for you.

8/22/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3820

On the other topic, I used CCB a few years ago, and I signed an agreement that said (among other things):
"Client agrees that CCB does not warrant or guarantee the qualifications of any donor, and that in determining whether any donor has certain characteristics or qualifications, CCB shall be required to make only such investigations of any donor as CCB shall deem reasonably necessary. Client agrees that client shall not now, or at anytime, require nor expect CCB to obtain or divulge to client the name of any donor, nor any other identifying information contained in the files of CCB. Client also agrees not to seek this information from any other source."

7/29/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3712

I am truly grateful for the sperm I received and for my wonderful daughter. I have had a lot of experience with CCB. Things change quite a bit from when you are purchasing sperm and then later asking questions. I registered my daughter on the CCB site and have had lots of problems logging in etc. I believe she is still the only one registered under my donor’s number although I know there are at least 10 children thus far. I am sure there are more. The banks have a business to do and that is what they do. I think the CCB has revised its policies somewhat. Or at least they say they have. I am sure they read this site and get perturbed by people that "ask too many questions. I wonder what their profit margin is? I know that I have dealt with the same two people for at least the last few years and they are usually very nice but not very helpful.

7/28/07	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8728

California Cryobank has a new registry which you can access from its website. It is versatile but I don't think many people know about it. My daughter has three matches on Wendy's site and I haven't received notification of any on the CCB site.

7/28/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3707

CCB is a bank known to solicit donors from the very best universities and it appears that 90% of its donors range from gifted to profoundly gifted. I wonder how the decision was made to create this sort of donor catalog. It may have been Dr. Rothman's preference or perhaps the clients of his bank kept on requesting donors of high intelligence.
I was a gifted student and I imagine that many of us were because we are so self-sufficient. I ordered perhaps ten profiles from CCB and most of the donors were more intelligent than me. The gap between my daughter and me is noticeable as she thinks on a whole different level but I hope I am bright enough to perceive and meet her academic needs. Taking into consideration the entire picture, there must be some donor children who are way out of sync with the intelligence level of their parents and this raises some concern as to whether their needs can be met.

7/27/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3703

Even when births are reported to sperm banks they might not take note. When R was three and I first learned that my clinic used a California Cryobank donor, I contacted CCB to ask for a profile. I received the profile from them, after confirming with them that I actually had a child by that donor. Two years later, when R was 5, I received a letter from them stating that they had no record of any children born from me and would I please inform them if I did have a child born via a CCB donor.
I do believe that one of the changes that needs to happen in the sperm banking industry is for some sort of mandatory reporting system to be implemented. Perhaps to an agency separate from the banks themselves. I can see how this would be difficult though as each woman leaves their fertility clinic to go back to her regular ob/gyn, neither doctor would be able to report. (First doctor doesn't know about child being born, second doctor may not know the woman used DI and where the sperm came from). If she is interested in keeping a secret, no one would ever know.
All the more reason for open families using open donors...

7/25/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3677

My ultimate intention in being prepared to put myself through highly publicized litigation, is to draw the public's attention to the fact that this is a completely unregulated industry (with the exception of some mandatory STI testing in a few states).
I want to use my case to press for regulation. All sperm banks should be required to perform a full

physical. They should be required to do genetic testing for cheap available tests such as Huntington's, BRCA 1+2, fragile X. Donors should be required to supply their profile information upon pain of perjury. Donors' records should be centrally collated. A donor should be limited to live births to ten families, but initial release for attempts at pregnancy should be to no more than five families in the first year. A donor with even one congenitally disabled offspring should be pulled immediately. Autism should be incorporated into the list of congenital disability. All donors would need to be identity release.

I am personally not happy about paying donors since I believe that it is inconsistent with the dignity of the donor conceived, but if the above measures were in place then payment of donors would be something that I could still tolerate since the main thing is to ensure honesty and openness.

However, any donor who lied about his medical information that he knew or ought reasonably to have known about (eg. grandma acts completely loopy all the time - should mention that fact even if he is not aware that she has Alzheimers) should be subject to criminal sanction including fine and imprisonment.

There should be no room for lies and deceit in this industry, and that goes also to the behaviour of the sperm banks. The sperm bank and their directors should be liable for criminal penalties if they act in the way the CCB did in the Johnson case.

7/22/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3648

That is negligent on the banks part. If they had been told that more than once it should have been investigated at the least. I believe CCB pulls the sperm after 3 birth defects. That use to be the case. I heard that now they pull it if anyone complains until it is investigated.

7/16/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3567

Before deciding, I think you should check out California Cryobank's donor list. Of all the banks I examined, I was most favorably impressed by this one. This bank's list is extensive, so I was able to find a donor that had a lot going for him.

I don't think a center's preference for a certain bank is a key criteria in deciding which bank to choose. Why does the center prefer this bank? If there is a valid reason for selecting this bank, that reason should have been explained to you. The reason could be as simple as the center and the bank refer patients to each other.

Since this is such an important decision, I would think that it would be best to access catalogs from several banks. Also I would think that it would be best to prioritize exactly what you are looking for, whether it be donor health, intelligence or looks; the ability to contact the donor when your child is 18 or the cost of doing business with that particular bank.

7/11/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3546

I'm pretty sure I have seen NECC adds on Craigslist Boston. I just checked and there are only CCB adds running up there now. There are a few free magazines geared towards college aged kids that you can pick up at coffee houses, sandwich shops etc. I picked one up on the T (Boston subway system) and to my surprise saw an ad there too.

7/10/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3529

When I heard that the DSR existed I was very excited and found my old donor list and posted our information........ Then I heard that we could leave a request that, should he ever wish to be known, our information could be passed on to our donor and that CCB had its own message board for this purpose and others. So I contacted CCB. Before I could be approved for the message board CCB had to verify that I used one of their donors. They didn't have our donor records. The CCB assistant suggested that I must not have reported my pregnancy or my daughter's birth. They suggested that I had the wrong donor number, which I didn't. They sent me two different donor numbers with a query as to whether either was actually our donor. I responded and repeated that I had the correct donor number. They responded and stated that I did not have a correct donor number and couldn't the donor have actually been -----?? This is when the correspondence took on a testy note. They suggested that I didn't even know donor details!! I had sent them the exact donor number and characteristics that are in my donor list. Then they suggested that I must have actually used a different donor from the list because the donor that they had, with a very similar donor number assigned to him, was anglo! I replied that my donor number was right and they had probably reassigned the donor number, at least partially (which is in fact what happened). The communications got testier. Someone new was assigned to locate our donor from their files. She was very pleasant. It took a few weeks, as I recall. She located our donor's information from an archive storage. I was approved for the CCB donorsibling message board. But our donor profile now included characteristics from the combined information of our actual donor AND the more recent donor who had been assigned our donor's partial number.

Number one, they didn't listen. I had to clarify and clarify and when they couldn't get it they blamed me! I was treated like someone who just dropped in for a little something and couldn't even remember why some years later. Believe me, my daughter's donor characteristics were very important to me!

Number two, the completely professional and friendly contacts that I remembered from years previous seemed to have been replaced with immature or poorly selected and trained newbies. By the time my correspondence was passed up the chain to someone that I had actually had contact with in the past the exasperation (with me!) of the newbies was apparent in all of their correspondence. This person, who I had truly enjoyed speaking with in the past and by whose kind words I felt reassured when I selected this wonderful donor, now wrote to me in a testy tone as well. The tone of the letter suggested that I had confused the staff earlier when 'I didn't give them the correct donor number'............ I replied that, in fact I had the original donor information sheet with our donor's correct number and that I had expected the same wonderful interaction that I had enjoyed while ordering my samples but I was now very disappointed in how I had been treated.

I had to write to DSR because when they added CCB information to the clinic registry they received the donor 'compilation' information which included the characteristics of two men, not one. Yes, sperm banks are in the business for the money. But times change and now they need to be very meticulous with information registry and storage because consumers have spoken and they not only want donor genetic materials they also want information and possibilities. When I purchased our donor samples there was no question, all donors were anonymous. Perhaps that is why donor numbers could apparently be partially or wholly reassigned. When consumer demands changed CCB, apparently, was not prepared to manage information well. I hope that that has changed for the better.

7/10/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3526

I bought 8 vials of one donor from CCB. 4 vials were from one day's donation (each donation is divided into several vials), 4 vials from another. As it turned out, 4 of the samples (all from one donation) had low sperm counts, the other 4 were fine. I worked with CCB and they refunded me for 3 of those vials and were responsive to a letter that I wrote to them requesting to trade out the rest of the vials so I could change donors at no additional cost to me. This is not in their policy (accepting returns on vials), but with a little pressure, they agreed. As it turned out, I got pregnant during a cycle where I had my RE double up (one good vial, one "bad" vial), so I never ended up returning the vials. But this is all to say that they were willing to work with me and they never hesitated to refund my money. If I recall correctly, the RE's office needs to fill out a form saying the numbers were such-and-such and then they will process the refund.

7/10/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3524

I've posted this info before, but in light of the recent discussions on sperm bank accountability I'll go into it again. CCB did not act in a morally responsible manner regarding my donor. When a genetic link was discovered in a disease that was in the donor's family, the donor disclosed this info to the sperm bank. (Several of his great- aunts had been affected, and CCB did not ask anything about them in the original health history.) I only found out about this when I went to order more sperm and was told that the donor was no longer available. CCB did not contact me, or the one other donor parent that I'm in contact with. When I asked why they didn't contact me, I was told that they didn't know who had conceived with the sperm. It would have been responsible to notify all purchasers of the sperm-- had they not yet conceived they could decide whether to go forward. And for those of us who have conceived, it's an important piece of our children's health history.
I have asked CCB to forward a letter to the donor, which they refuse to do. Now that they have no financial interest in any of the donor's disclosures I don't trust that they would pass along pertinent health info should he contact them again.
The donor is a real mensch, and I thank him daily. Too bad CCB only cares about their own bottom line.

7/9/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3516

For me, CCB had very low sperm counts, and I never got a refund. Xytex had extremely high sperm counts, and once when there was a problem, they came in on the weekend and shipped something on the next plane so I wouldn't waste a cycle.
My best friend has two lovely kids via CCB, and she didn't have this problem, but that was 12 years ago. Also, I've had emails from people who didn't like Xytex, but I loved them. And I especially love my new bouncing baby boy, born healthy as can be at 8 pounds 8 ounces!
I got on the DSR about six months before I started using donor sperm, because I needed to check in and see what it was all about, before I took such a giant step. My bias was to use a known donor. But I was tired of waiting and running out of fertility. I contacted several donor families before choosing the sperm number/bank to use, and I found that worked well.

7/9/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3515

Make sure you read the "refund" part....We used Fairfax for 3 donors and all 3 had LOW sperm count. Not even our doctor told us there was a process to get a refund if there is no pregnancy and low sperm count. Once we switched to CCB (Cal cryo) we had high sperm numbers. Just because we got low numbers at Fairfax doesn't mean you will. I have heard other women have the exact opposite experience. We lost thousands not knowing about the refund...it doesn't help the lost months, but at least the pocket feels better.

7/7/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3487

I used California Cryobank and was very satisfied with them. I know others did have some issues with them, but just food for thought.

7/6/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3476

Yes - they do let you know (CCB) if the donor is yes/no for pregnancies. Ours was yes and we consistently got about 20 mill....even with that it took 3 tries with that donor.
{Note from Wendy: Not consistently. Many of us who used CCB were not told if there were prior pregnancies.}

7/6/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3473

I had a miscarriage in 1989 using a CCB donor, then I learned that CCB would verify which donors had "proven fertility," as in a live birth. I picked a donor who I was told had sired a boy through the program. I conceived using this donor in 1990 and gave birth in 1991. In 2005, when my son was 14, CCB denied ever telling me about the live birth and wouldn't verify the existence of an older half-brother.

7/6/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3469

We had the opposite experience with using 8 vials from California Cryobank. A few had awesome counts, but several were very low. One was only 3 million. I too felt like my entire cycle was wasted those months. We switched to a donor at Fairfax and so far his counts are pretty good, but not excellent.
They do have a guarantee so you can get your money or at least part back from the sperm bank, but if it doesn't work you still waste all the money on the process, medications, etc. There should be a way for them to increase the counts. I'm sure they use as little as possible in each vial to make the most money from it.

7/6/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3467

Just an additional note - I had just contacted my doctor's office this morning. The donor I chose (from CCB) is no longer providing vials and I wanted to make sure that I still had a current list. When I got a call back, I was told that they would no longer accept vials from Fairfax for this very reason.

7/6/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3464

There were multiple facets to my use of CCB -- just in GENERAL categories, and quickly off the top of my head, here are SOME:
(a) delivery system between the sperm bank and the doctors
(b) choosing a donor
(c) donor profiles
(d) reporting of pregnancy, miscarriage, birth from the consumer
(e) policies regarding divulging info supplied by one consumer to other consumers or potential consumers
(f) anonymity of the donor -- I was threatened with legal action if I identified the donor on my own
(g) inaccurate and inconsistent reporting of donor half-siblings
(h) follow-up on donor health-related issues
(i) dissemination of updated services, such as their own donor-sibling registry

6/26/07 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8615

You mentioned that your bank has reported ten births. Which bank is that? The bank that I used is CCB and it never has given me a concrete number. Quite the contrary! After a miscarriage in 1989, I found out that I could choose a CCB with 'proven fertility,' and I wanted to change to one of those donors. I chose one who had a baby boy through donorship, a half-brother to my potential child. I had a son in 1991 using that donor. During my latest contacts with CCB about two years ago, a CCB representative refused to confirm anything about an older half-brother and vaguely indicated there were several younger half-siblings. She refused to give details as to how many or their genders.

I registered for one year on the CCB sibling registry with no results. Fortunately, earlier this year, just before my son turned 16, he matched through the DSR to a girl who is eight months older than he. Two years ago, I identified, located and contacted the donor. He has a daughter by a conventional relationship who is several years younger.

6/18/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3241

At least the CCB acknowledged to M that they wanted the donor to answer more questions about his and his family's health history. With the NECC they initially just didn't respond for literally years to our requests for elucidating information. Now their stance is that the donor has a constitutional right to his medical privacy.

We are not at all happy with that response. If that donor had wanted to conserve his medical privacy he should have never voluntarily put himself forward as a donor. He also should not have answered one question in the whole profile without acknowledging that he was choosing not to answer the other questions. When we paid $15 for our full health profile there was no caveat that it contained only answers to questions that the donor ad chosen to respond to. It was touted as a "full health profile". Sadly it was merely a work of fiction!

We are very angry with the NECC since they have demonstrated zero concern about our kids' problems and only want to protect their donor from being required to divulge health information.

We really suspect that the NECC themselves edited out undesirable medical info - the CCB have done it in the past! The NECC have demonstrated such callousness when talking about our donor's obligations to our children stating that they are merely 'waste ejaculate' to him.

6/17/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3236

I was told a couple of years ago by CCB when I was questioning them incessantly about problems my donor or siblings may have and they assured me they were going to contact and update all the donors files. I was told my donor in particular even had an appointment to come in during the next month or so. Low and behold he never made it in and they can't find him. I find that one hard to swallow.

5/28/07	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8549

To the woman asking about CCB. I caught them in a lie about my donor's education. The form sent to me at the time I used the bank said he had been in college for 2 years. When I requested the same form 12 years later, the information about education was missing. It was the same exact form that had been photocopied. So when it was sent the first time, someone had filled that part in and copied it to send to me, since I emphasized the importance of education. But the information was apparently never on his original form. Who knows what else they lied about?

Also, there is no criteria for a donor's appearance at any of the banks. My daughter inherited excessively protruding gums from this man. She is very embarrassed about them and has been teased. I guess it's the risk you have to take.

5/11/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/3119

Take a look at the CCB's matches on the DSR. Um I think some of them have way over ten or even twenty. I am sure lots of moms don't report. I did not report till my daughter was about six months I think.

5/11/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3118

The CCB website indicates they limit offspring to 20-30 worldwide and that the average number of offspring is 10-30 "reported" per donor. I imagine though there are likely a lot of women who don't report pregnancies or births.

5/11/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3117

When I first started inquiring about the number of children allowed by a donor, CCB told me that they limited the number of children per donor to 10 – unless the children were from the same family. They said that they did not limit a family's ability to have more children by that same donor. Of course, all of this would have to be contingent upon people reporting the births (which I did, but I am sure many people did not - as we now have more than 11 families with children).

4/6/07 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8473

There is a genetic defect issue and a donor birth fatality associated with our donor from CCB and the genetics dept. seemed very aware and responsive to the issues at-hand. It is slow, disorganized and opinion-based, but in my experience, the best available.

4/6/07 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8472

I'll give you some feedback re: CCB, and I see no reason to fear them or any other sperm bank if you are discussing what you know or believe to be true. And as Wendy said, you can post here anonymously.

In CCB's case, we chose a wonderful donor for our daughter. It cost a lot to purchase all the info. Our process was to evaluate based on the free info they give you, then purchase long forms. For the few left, we purchased the audio and baby pics. I feel like you get the most info from CCB. Having said that, for medical reasons, we had to consider different donors recently in order to have a second child and found that we really couldn't find a comparable donor. Of course, I have a lot of restrictions related to Rh, CMV, etc., so my pool was more limited than it was originally. Or maybe we just got lucky with the original donor we chose.

My suggestion: decide your criteria (and you might want to review some of the issues raised on this and the other DSR web site to add to the complexity!), go by the staff impression and yours after listening to the audio and the donor's essay. Think carefully about what health issues within the donor/his family you are willing to accept. Beware of donors who don't have any health issues. I have found that a lot of potential donors I considered had breast cancer and other diseases I felt were serious and have a genetic basis. Breast cancer and other major diseases don't seem to bother any sperm bank in the slightest, but keep in mind most of these guys are too young to know if their parents have any of the diseases that grandparents may suffer from.

Other suggestions: go with a pregnancy proven donor, especially if you're older (as I am). Also, they have an attractiveness "rating" they will give you if you call and ask for it, although you can usually figure this out from the staff impressions. Don't be afraid to switch donors if one or two don't work for you. Be sure to purchase enough vials, including for additional children, since they often sell out.

Do I think you can completely trust any sperm bank? No, but larger ones like CCB do have more at stake. Should you expect all the information provided to you to be completely accurate - unfortunately, no! You can call the CCB genetics department and ask if any issues have been reported, although I have no idea if they provide accurate responses for every donor. In our donor's case, they seem to have. Also know that sperm banks don't seem to accept that conditions such as Down's, autism, etc., can come from the donor, so I wonder if they actually track these.

3/12/07 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8413

I can't tell you if the NECC are worse than other sperm banks. However, I can confirm that despite myself and another mother from this donor sending regular reports about our children's medical issues to the NECC, the NECC carried on selling our donor's sperm for a further five years.

As of February last year when I called pretending that I had just been offered this donor's sperm and specifically asked about any medical updates, I was told that there were "no notations on the file" which was clarified to me to be that there had been no reports of medical issues.

If the NECC didn't disclose any of the medical information that I and the other mother had reported to them, they might very likely have been deceitful about the donor's self-reported medical issues.

By their demonstration of dishonesty to me, I am concerned that they might well have just edited out many of the health issues that our donor reported. This was a practice at the CCB and was divulged in the case of Johnson.

Maybe this is not a practice confined just to the NECC but I have no experience with other sperm banks.

Personally, I never trust people who lie to me particularly about as big a thing as my children's genetic inheritance. Now that I know the NECC to be liars I would never risk selecting a donor from them when there are so many thousands of other donors available from much more honest open places. Why risk your child's future prospects!

2/20/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/2932

Also, for the past 18 months, I have been trying to get CCB to provide follow-on information on my daughter's donor as promised on the website as one of the advantages/features of using an "open donor". I purchased the sperm in Sept 2004 and have not received any information. They state they provide annual updates for 6 years. Has anyone tried to obtain this sort of info from CCB either successfully or unsuccessfully. At this point I am seriously considering getting the Better Business Bureau involved and the apparatus federal agency that enforces truth in advertising. My feeling is as this is clearly posted on their website it is part of the contractual relationship I have with them which they have failed to uphold. I don't really like to go the "threat" route but I am not sure what else to do.

2/14/07 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8362

I cannot speak for all sperm banks, but I can for California Cryobank. My daughter sent CCB an e-mail when she turned eighteen; which they kindly forwarded to her donor.

2/13/07 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8357

CCB staff told me in 2005 that they will forward letters; however, that doesn't mean to me that they actually will. They admitted they have made no effort to keep track of donors and are under the presumption that finding them is easy because they have the donors' SSNs. As a licensed PI, I find their position on this quite remiss and very naive.

1/19/07	http://health.groups.yahoo.com/group/DSR_Discussion/message/2828

CCB is supposed to be "updating all their donors profiles" That is what I was told in an email from someone from the CCB that I have spoken with on several occasions. I was then told that MY donor was told there would be media coverage on his offspring and they asked him to come in to the bank and update his information. To this date and to my knowledge he has not come back to the bank and they do not know where he is. I don't know what to believe in this situation. Did the bank lie and say they contacted him.. Did he really never update. I guess only time will tell. My daughter is eight now. I have been told there is a child at least 13. I guess when the first child finds out they will all find out. I have a beautiful daughter with lots of beautiful siblings. I could not wish any more than that!!!!!!

1/16/07	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8283

I, too, registered at CCB's sibling registry without any luck. My donor number is 714 and there were 3 other "reported" births besides my daughter, but none have registered. I think the big problem with the site is that you cannot look at it without registering. So if someone is hesitant, but curious, they won't ever register. I have also had no luck getting any information from CCB at all and in fact have also caught them in a lie regarding my donor (wrote on his profile {as if by him} that he was in his second year of college--knowing that was important to me, but when I got a copy of the same profile years later, that info was not written in there)--so it had to be CCB's lie and not his.
Although I have not found a match on DSR, I feel much more confident with its integrity. I will not be renewing with the CCB registry.

1/15/07	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8282

I had my information on the CCB sibling register as well as the DSR for one year. I decided to renew the DSR only. CCB was not very forthcoming with information. I don't know if it was because my daughter was conceived in 1987 when there was less information available or they were just reluctant to help. I feel the chances of any match (donor or sibling) are better on the DSR.

12/19/06	http://health.groups.yahoo.com/group/DSR_Discussion/message/2783

{Note from Wendy: WOW- NONE of the donors even mention that they are helping to create a human being that may someday want to know who they are!}
These are testimonials from donors at CCB. Just thought I would share them..
.....
My donor experience thus far has been amazing. The staff is receptive to my needs (as far as scheduling is concerned) and I always leave feeling that my participation is appreciated. "-
- Los Angeles Donor

"Being a donor is a convenient way to add some extra money to your bank account. It requires very little time making the pay to time commitment extremely high. The only drawbacks are that you have to adhere to the rules on celibacy before donating, blood draws every 3 months, and a physical every 6 months, but the positives simply outweigh. It's even better for college students who are in such a low income bracket anyways that they are able to keep nearly all of the income they get from donating."
- Palo Alto Donor

"I was a donor for the California Cryobank for two years during college. I was told about it through a friend. The experience was great. The staff is very accommodating and the monetary incentive is

ample. I was able to supplement my income by being a donor because it didn’t interfere with school or my job. I recommend this program to anyone who is unsure about becoming a donor."
- Cambridge Donor

"The CCB donor program offers a flexible, low-commitment supplemental income perfectly suited for the busy young professional or student. An understanding and helpful staff makes things run smoothly and without hassle Overall, this program has been a great experience and perfect fit for my demanding schedule."
- Palo Alto Donor

"It sounded alien and intimidating at first but the Cryobank put my fears at rest. A very warm and friendly place, very supportive and helpful staff and a really cool donor coordinator. Plus lots of perks!!!- free movie tickets, a massage chair, and free snacks. "
- Los Angeles Donor

"I've had a great experience being a donor. The staff at the bank is super-friendly and the facility is nice. The benefits are also great; free movie tickets and promos during the application process, full physicals twice a year, and great compensation for donations. More importantly for me though, is the idea of helping couples have children who have tried to conceive on their own and were unable. I am planning on having a family one day and it is really important for people to be able to realize this dream.
- Palo Alto Donor

"I was a donor for the California Cryobank for two years during college. I was told about it through a friend. The experience was great. The staff is very accommodating and the monetary incentive is ample. I was able to supplement my income by being a donor because it didn't interfere with school or my job. I recommend this program to anyone who is unsure about becoming a donor."
-Cambridge Donor

"To be completely honest I've had a great experience so far with CCB. The staff is extremely friendly and really makes a potentially uncomfortable situation smooth and easy. Besides that, the program is very flexible when it comes to donation availability and are always on time with payments and bonuses. I really can't say anything bad about the program as it stands right now. "
- Los Angeles Donor

"As probably anyone would be, I was a bit apprehensive about becoming a donor, knowing that of college life but unsure of how I'd feel about the process as it ran its course. As it turns out, my initial justifications for becoming a donor - that it was basically a helpful thing, allowing loving couples of whatever persuasion or single women to realize their desires to raise children and start or continue their families - has stayed with me. Of course, there's just something inherently odd about the whole thing, and I get almost endless entertainment out of joking about the process with my friends and even my parents, who took my decision in stride and are pleased to have me paying my own rent checks with the money. But the process is smoother, more natural and more comfortable than I could of thought, despite that essential oddness. While I can understand that anybody might have a gut instinct against this kind of donation, I'd encourage anyone who feels open to the idea to pursue it. Personally, I'm glad to help and even happier to get paid well for it."
- Palo Alto Donor

"In hopes of relating the cordial relationships, the high level of professionalism and discreetness, and, above all, the sense of respect which the staff will treat you, I can claim quite adamantly that the California Cryobank is a place where you will open your heart and mind to a great experience"

- Los Angeles Donor

"I can say that the California Cryobank has provided both myself and their clientele with the opportunity to succeed at our respective goals. The friendly, knowledgeable staff is always helpful."
- Los Angeles Donor

"Being a donor thus far has been a great experience for me. It has added a great supplemental income which has helped me immensely financially. They have great hours& and the staff is always very nice to everyone. There are snacks and drinks provided for every visit, and many other perks that come with this gig such as donor referrals, movie tickets for certain things, and extra money for pictures and others."
- Palo Alto Donor

"I definitely recommend this for anyone who needs the extra money (who doesn't) and has a few hours a week to dedicate to having some fun"
- Palo Alto Donor

"Although it was a lengthy application process, being a donor thus far has been a very pleasant experience. The staff is very friendly and conscious of making everything as comfortable as possible. The compensation is very good, and I love all the extras along the way."
- Palo Alto Donor

10/30/06	http://health.groups.yahoo.com/group/DSR_Discussion/message/2699

That is funny. They took out the part about doing something you would be doing anyway!!
(referring to CCB’s website ad for sperm donors, saying, “why not get paid for something you would be doing anyway”)
-------Original Message-------
Date: 10/30/2006
Subject: [SpermDonors] Re: Take a look at this page please!
I think it is interesting that this ad is now different than it was when M originally posted this. CCb has now taken out the offensive parts (after the MTV show aired and Wendy made mention of it there). At least the sperm banks are listening somewhat.
http://www.cryobankdonors.com/newdonors/index.cfm?ID=52

10/19/06	http://health.groups.yahoo.com/group/DSR_Discussion/message/2690

I just wanted to share that I had a very lengthy conversation with one of the genetic counselors at CCB a few days ago, about this very issue. Someone mentioned having a conversation with Xytex that reassured them. My conversation with CCB made me feel a lot better, too. That said, clearly there ARE issues with CCB, so I don't know whether or not I can rely on what I heard.
I was thinking "out loud" (well, on paper) about this and have copied my thoughts below. I got kinda long-winded, sorry :). The upshot is that I agree with a lot of what has been said about legislation. In some cases we need new and/or clearer laws. In all cases we need monitoring and enforcement of existing laws. And in the meantime, until there's a better system, I think we need to be asking LOTS of questions - of the sperm banks, of each other, of anybody we can think of, to give ourselves the best chance of getting whatever information actually is available.

The thing about this whole issue is that it actually includes several distinct problem areas. I think an effective solution will have to recognize this and address all of them.
1. Reporting

At this point the banks are dependent on parents to report births and any issues their children are having. Given only a 40% reporting rate for births, it's probably safe to assume that the reporting rate for problematic births is lower, and for problems that arise in childhood or later it would be much lower still. New York State law, from what I understand, *requires* physicians to provide the sperm bank with a report on insemination outcome. I don't know if any other state does, but if a bank says it is in compliance with NY State regulations, then at least in principle they should have better information on outcomes. It seems like there ought to be a federal requirement that all clinics must report - and all banks track - the outcomes of ALL inseminations. It seems like a no-brainer to me, but maybe I am missing something.

2. Disclosure

According to the person I spoke to, CCB's procedure is to record ANY report of an abnormality or problem, large or small, in the donor's file. This information is available upon request. When I asked, I was told that one of the donors I was interested in had a report of an early miscarriage due to "missing X." This, of course, is generally an egg issue rather than a sperm issue, but still the information was disclosed immediately and with no hesitation. I felt the person I spoke to was being truthful and upfront. However, to S's point, without oversight and enforcement there's no way to ensure that all banks are consistently recording reported issues, or that they're providing complete and accurate information.

3. Spotting "Problems" and Notifying Affected Parents/Recipients

I was told that, at CCB, any report of a "major" problem results in a donor being immediately made unavailable until further investigations can be made. Also, in this case, parents and anyone who has ordered sperm from this donor are notified. Congenital heart problems, neutropenia, anything of that level would be considered "major" under this definition.

Autism, early puberty, behavioral disorders, etc., would be considered "lesser" - especially since there is a lot of doubt in the medical community about exactly what role genetics play in these problems. "Lesser" problems also include those that are less likely to be caused by the donor's genes (as in Down's, or the "missing X" situation mentioned above). Supposedly, "lesser" problems are noted in the donor's file whenever they are reported to CCB. This information, as I said, is available upon request. Also, the geneticists supposedly monitor all files with one or more "lesser" problems, to see if a pattern seems to be emerging. If they begin to suspect a pattern, they go into "major" problem mode - they suspend the donor's availability, notify the parents and recipients, and investigate what's going on.

Now, clearly, the first issue here is one of definitions. What, exactly, is "major" and what is "lesser"? The line is very fuzzy, and seems to be left to the judgment of whatever geneticist might be monitoring a particular file. And what, exactly, constitutes a pattern? At what point does someone decide to raise the alarm? Again, it seems fuzzy and inconsistent.

The second issue is, once again, monitoring and enforcement. There is currently no way to know whether reports (major or lesser) are actually being recorded, whether files are being monitored, whether monitoring is consistent, whether the donor is suspended, or whether parents and recipients are notified.

10/18/06 http://health.groups.yahoo.com/group/DSR_Discussion/message/2684

I have no idea how thoroughly potential donors are vetted (I know there's a big hoopla about how few donors are accepted, but believe that's due more the sperm quality), but I do have experience in how completely the sperm banks presume it's always due to the mother if there is a problem. I pressed CCB and Fairfax quite rigorously re: whether different donors had had any reported issues, and they steadfastly maintained "no" and if there were problems, they wouldn't necessarily trace it to the donor. For example, sperm banks attribute Down's Syndrome only to the mother, but the fact of the matter is that it can result from both male and female factors. I've also been shocked at the health issues that different donors have within their families, from breast cancer to other serious diseases that can be inherited. I know the sperm banks say that just because a guy's grandmother has breast cancer in her 40s, it's not hereditary, but the fact is that most of these guys and their parents are too young to truly see if the donor and/or his parents or their siblings will also suffer from the same disease. I consider ourselves fortunate that the donor we selected was in his 30s and his father was in his 40s when he was born, so we have some sense of what diseases have been in his family. That's if you can trust the information - I know I'd have a hard time knowing the exact health of all my brothers, aunts, uncles, cousins and grandparents even though we all are healthy and tend to live a long time. And I doubt most donors are that open w/their families so they can really gather detailed info. My mother or father would be all over one of my brothers if they started asking detailed questions like that.

From my experience, I do believe the sperm banks purposefully do not maintain adequate records for donors - for CCB and Fairfax at least, if you call to find out how many pregnancies have resulted from a donor (important information in many respects), they say they don't know other than at least 1 pregnancy was/wasn't reported. That's complete BS. I also remember my fertility doctor telling us to avoid a sperm bank in Atlanta (or somewhere in the Southeast) because she had heard of or actually seen problems with their donors.

So after reading the Self article and hearing about the CCB lawsuit, both of which are horrifying, it seems obvious to me that:

1) sperm banks need to increase their self-regulation, otherwise outside regulation will be needed. This includes, at a minimum, screening and verifying donor-provided information more thoroughly, counseling donors re: long-term consequences and outcomes, maintaining more complete information re: pregnancies and the concerns raised by "purchasers," and paying donors for updated medical information and perhaps personal details/pictures/etc., which they can then sell to those of us with kids. Yes, it will result in a higher cost for the sperm, but well worth it.

2) these type of issues need to be broadcast beyond the donor sibling chat boards, since the vast majority of people doing DS have no idea these issues even exist. I'm a perfect example - I had no idea about any of this - the registry, concerns, etc. - and I was all over the internet searching for donors.

9/14/06	http://health.groups.yahoo.com/group/DSR_Discussion/message/2582

From CCB's website:

Donors must be between the ages of 19 and 39. According to the Cryobank's medical director, Cappy Rothman, MD, "While a man's fertility does not automatically decline after the age of 39, men under that age are more likely to consistently produce superior quality of sperm necessary for successful freezing and thawing." The American Association of Tissue Banks sets age 39 as the maximum age for donors.

9/8/06	http://health.groups.yahoo.com/group/DSR_Discussion/message/2531

Based upon what the CCB told me in the Spring of 2005, the answer to your question is "yes," it is possible that the CCB might assist your daughter with contact when she reaches 18, despite its prior policies about this. Given your history with the CCB, I apparently don't need to caution you not to get up your hopes though.

I haven't perused the CCB's website in quite some time. I seem to recall seeing a statement to this effect there, without the caveat that it doesn't apply to children conceived before this policy was enacted. You might want to have a look at their website to see if my recollection is correct. If so, PRINT IT OUT, and keep it ready to hand over when your daughter reaches 18, if you need it.

9/8/06	http://health.groups.yahoo.com/group/DSR_Discussion/message/2526

I have also had the same inconsistent behavior from CCB. I can't even get them to answer simple questions, such as the date and reason he discontinued donating, to help determine if he could be the same donor at another clinic.
I'm curious about them saying they will provide assistance in contacting a donor when the child is 18 even though it was a while back when they didn't have an "open" option/policy in place. Does that mean that I could potentially have them assist my daughter with contact when she's 18 even though 12 years ago they did not have that option at all???

9/7/06	http://health.groups.yahoo.com/group/DSR_Discussion/message/2512

Re: Here is a link to an incentive meeting for donors to join CCB
They also omit the fact that a good percentage of sperm goes to single women and lesbian couples. Instead, they say "you will be helping infertile couples..."
--- In DSR_Discussion@yahoogroups.com, Patsay wrote:
>
> Icky. They specifically state that they only use heterosexual men as
> donors. For that discriminatory policy alone, I would not work with them.

9/7/06	http://health.groups.yahoo.com/group/DSR_Discussion/message/2509

My son's CCB donor (identified, located and contacted independently of the sperm bank) donated in 1987-1989. He said it's left him, all these years later, with the impression it was a very unprofessional organization. He never has recontacted CCB. He never had any significant curiosity about how many children he sired or anything about them. He did figure that he would be contacted by one of his donor children someday. That has occurred by only one child, mine, when T was fourteen. That was a year ago. The donor said he was "glad" to be found, but does not want to encourage anyone else to find him. To honor his wishes, I have maintained his anonymity and have been careful not to expose any particulars about him, other than those provided by the sperm bank to me. Those were sufficient for me to identify him. He provided that information himself to the sperm bank in his hand-written profile, although he has stated that he really didn't think it through that the profile would be available for anyone's inspection outside of sperm bank personnel. According to him, CCB certainly didn't make this clear to him either. If anyone else used this donor and wishes to make contact with him, he has agreed to let them use me as an intermediary. My son and I both would love to hear from other families created with 'input' (I have a hard time calling it a donation) from our donor.
I have had no success in pulling any meaningful info out of CCB, and loathe how they have treated every contact from me. When I reported my son's birth, I had little sense that they would record it. There was no form. There was no encouragement for me to report by phone. I wanted a donor with proven fertility before I made my final choice of this donor, as I had miscarried before with another donor. I was told he had one live birth, a boy, through their program. When I called in the Spring of 2005, CCB denied ever telling me that and implied there were younger offspring, but they were unbelievably evasive and vague about how many, their ages, etc.
Discrepancies and evasiveness are the norm in my dealings with CCB. When my son was young, CCB offered to forward a letter to the donor, but admitted they had no idea of his location and kept no tabs on him whatsoever. When I said I wanted to find the donor and send him a thank-you letter myself, they listened politely and non-confrontationally, and then sent me a very threatening cease and desist letter in the mail! In the spring of 2005, they said they were willing to facilitate contact when my son reaches 18, and possibly sooner. When I asked how they planned to do that, I was told that they were entirely confident they could, since they had his name and apparently also his social security number. I asked why they were pursuing that policy which was not in place when he donated, and they gave me a flimsy reason about retroactively providing this service to parents of

children conceived before the policy was in place. The answers I have received from CCB not only vary in time, some of which is understandable and reasonable, but they also vary with different personnel on the same day, which I find appalling, to say the least.

9/5/06 | http://health.groups.yahoo.com/group/DSR_Discussion/message/2454

What is of particular concern to me is the section under "Your Confidentiality" that states:

"To balance the concerns for privacy and confidentiality with a child's need to know about his or her biological parents, we have developed a policy called "The Openness Policy". This policy states that we do not believe that the donor or the mother should be asked today how they or a child would feel about the subject sometime in the future."

WHY NOT? Because donors and parent may reconsider using a donor sperm --- and donors may reconsider giving up their potential offspring??????

http://www.cryobankdonors.com/newdonors/index.cfm?ID=5

9/4/06 | http://health.groups.yahoo.com/group/DSR_Discussion/message/2452

Currently the California Cryobank allows 52 live births per donor and only so many in each city. I know most people do not even report to the bank until the child is older or even not at all. I would be interested to know about moms and dads on the DSR and when they reported the birth of their AI child and what bank they used.

{Note from Wendy: HOW can CCB claim that when they have NO IDEA of how many kids are born from each donor? Why then are they on the DSR collecting information about which kids were born from which donors?}

5/24/06 | http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/7328

California Cryobank notified me when an offspring of the donor I used had a life-threatening genetic disorder. I will have to track down the notification, but it pretty much was saying that in the future, the donor's sperm would only be available to women who had already had children and were seeking additional sperm in order to have a full sibling. Maybe it was a marketing ploy :-)

Anyway, I was able to call CCB and talk with a genetic counselor to get more information on the disorder, etc....

4/5/06 | http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6926

I have recently found out that CCB gave a newspaper reporter some VERY confidential and unconfirmed information about my son Ryan. Thank goodness this reporter came to me first before reporting on it. Ironically, this is their on-site confidentiality policy. I now can wonder, who else will CCB tell this information to?

3/25/06 | http://health.groups.yahoo.com/group/DSR_Discussion/message/1721

I haven't spoken to CCB about their donor numbers. I had the CCB donor catalogs from over the course of a year back in 1999-2000. (Since I lived in LA I was able to visit the bank in persons I had the actual catalogs.) There were donors numbered in the 900s and 3000s and 5000s available at the same time (as well as other numbers). Some of the 5000s had started donating BEFORE some of the 900s. You can tell when they signed up by the date they began donating, which is clearly listed on the profile. I think you can still see this with the short profiles which are available online. Anyway, my donor retired in 2000, not long after my child was born. They do not re-assign numbers

<table>
<tr><td>so his will not be used again. BUT when I went to look for a donor for child number 2 there were newer donors with numbers also in the 900s and low 3000s that weren't available when I was first looking. So some new donors had numbers that were lower than older donors. That leads me to believe they do not issue donor numbers in order. Perhaps they group them according to some fact or characteristic.</td></tr>
</table>

<table>
<tr><td>3/24/06</td><td>http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6592</td></tr>
<tr><td colspan="2">CCB bought Procreative Technologies in the mid nineties. Certain donor numbers were changed. The donors were college people from Procreative. The donors from CCB came from all over the US.</td></tr>
</table>

<table>
<tr><td>3/23/06</td><td>http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6542</td></tr>
<tr><td colspan="2">You posted on another website that you used Zygen ###. This is also CCB ####, which I used, and CLI ####.</td></tr>
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<tr><td>3/23/06</td><td>http://health.groups.yahoo.com/group/DSR_Discussion/message/1699</td></tr>
<tr><td colspan="2">I have also caught CCB making fraudulent claims about my donor's education. When I was "shopping" for sperm 12 years ago, the long form they sent to me had him as currently a college student with 2 years of college in Theater Arts. I wasn't looking for a medical student or scientist, and figured that at least he was motivated and "smart enough" to get into a college. Then, recently, I asked that they resend his long form to me. They sent only the first page (which has education on it) and low and behold, college was blank! Everything else is still there in his hand writing, so I know it's the same form. Now, I'm wondering what would be different about his medical history if I could get my hands on the rest of the "original" form!! As a result of these discrepancies, when I'm searching through the registry for possible matches, I look for donors who are close to mine, but don't expect that they have to be exactly the same to be the same guy. I don't trust the clinics at all in what they report anymore. I think this is the kind of info that needs to be passed on to the media in terms of refocusing their attention on the issues begging for the industry to become regulated. If it were all open and above board, they couldn't lie or mislead us about donor characteristics and history. I imagine the sperm banks never dreamed that someday we would all be coming together and comparing notes like this!</td></tr>
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<table>
<tr><td>3/20/06</td><td>http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6483</td></tr>
<tr><td colspan="2">Thank you for sharing - I find that very interesting because I recently called CCB to find out if my donor was ever sold to any other bank and they assured me that not only do they do that but they make the donor sign something saying he won't donate to any other bank. Do they just tell everyone what they want to hear? There has been no consistency at all with the things they tell people. It is quite infuriating!</td></tr>
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<table>
<tr><td>3/20/06</td><td>http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6482</td></tr>
<tr><td colspan="2">I was a donor at both CCB (California Cryobank) and TSBC in Berkeley, CA. Both were very thorough regarding my background but TSBC did a follow up 5 years after I stopped donating to update their records. They also told me how many children were conceived at that time. CBC never contacted me after I took my final blood test (6 months after I finished donating). If I was looking for a donor, I would choose TSBC over CCB.</td></tr>
</table>

3/20/06	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6464

I think you will find that there will be many *most important* decisions that take place over the course of TTC, childbirth and raising an infant. Choosing a donor is important but you will find much more important things to worry about...

Even with some issues I have with Fairfax, I still would use them again. Why? Because I'm very certain that each negative thing that could be said about Fairfax could also be said about EVERY sperm bank. If you queried every customer of every sperm bank, I'm confident you'd find a multitude of reasons for and against using any one bank. And I'm sure there are many dark secrets that have been swept under the rug at MOST Of the sperm banks.

If it a very tiny sampling to get a handful of people on this one message board and make this type of decision. There are so many factors to consider. I admit I was disappointed when someone posted that NECC was awful when there are so many people who have been happy with them. I have no affiliation with them but it just seemed like an unfair thing to say.

For example, the 2 main reasons I chose Fairfax Cryobank were:

#1 after CCB sent me less than adequate specimens and left me discouraged. I then spoke with Fairfax's lab manager for at least 30 minutes on the phone who was able to tell me potential donor's average sperm count and post thaw counts PRIOR to purchasing. Also they were willing to do a hand pick of the highest motility for me. Our donor's average post thaw motility was between 70-80% and I conceived on my 3rd try with this donor. Apparently, they were right about his quality as we've found 20 half sibs now.

#2 They do extensive STD testing including a better method of doing the HIV test and a host of other tests that I don't believe are standard everywhere else (or at least not at the time i was purchasing). This was important to me too as I had myself tested for every disease possible-all negative- and wanted reassurance that the highest possible standards of testing were in place to protect my health.

So, to recap, there are reasons for AND against using every bank. I think what it comes down to is finding a donor that you feel good about, ensuring that the testing is sufficient for your concerns, and whether they will give you information about a donor's sperm count before purchasing. If i walked into a car dealership, I wouldn't buy a used car without knowing the mileage... why would I buy sperm without knowing the count?

3/19/06	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6456

Through the years, the CCB has made conflicting comments to me about donor-identity release, to put it mildly.

When my son was a baby, I mentioned to a CCB staffer that someday I hoped to locate the donor so I could at least say "thank-you." I ended up receiving a cease and desist letter.

Last year, two weeks after my son's 14th birthday on March 31, he announced that all he wanted for his next birthday was "to know who my donor is." I recontacted the CCB shortly thereafter. A staffer told me that it is the CCB's policy to try to help kids like my son make contact with their donors, and that they might be willing to do so even before he reaches 18. When I asked if they'd made attempts to keep a current address on the donor, who donated in 1987-1989, I was told they had not, but that since they had particulars such as the donor's name and SSN, they expected no trouble in locating and contacting him. As a licensed private investigator, I found that statement to be naive, impractical or just a rude attempt to avoid implementing their so-called policy.

3/19/06	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6439

In an effort to discover if there was more I could find out about our donor, I recently asked California Cryobank to send me a copy of the long history form. They sent me only the first page. I compared it to the one I received from them 12 years ago and found that they had lied about his education! The form from 12 years ago had college education listed and the one now has college education blank. I can only assume that someone in their office had checked off college on my copy of his form, but that it didn't actually exist on the original. It makes me wonder what else they lie about!

3/9/06 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6339

I know that Zygen, CCB and CLI are all linked somehow. Our donor donated (in person) at Zygen in 1994 and CCB in 1994 and 1998. Now CLI reports he is a "newer" donor, meaning that they just received his vials. I very much doubt he also donated at CLI, as he is in CA, as the other 2 labs are. I am guessing CLI "bought" the extra vials from one of these banks.

3/9/06 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6338

CCB donor #### (he is retired now, but you can do a search for him) CLI donor #### (active). Zygen donor ### (also retired now, but his profile is still on their homepage as a "sample" donor profile). All of the info is the same and the baby pics at CCB and CLI are the same--Zygen didn't offer pics at the time!

3/8/08 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6326

I hope every one of you who has had a child via a donor will report the birth, if you have not already done so. I do not believe you can or should rely upon a doctor or facility to do the reporting. Furthermore, I would not rely upon a sperm bank to record and properly annotate records that you have reported a live birth. I encourage all of you who have reported to check back to see if your child's birth report remains a part of the donor's record.
In my own case, there are a number of causes for concern. Here are just two of them:
(1) After I miscarried, I found out that I could choose a donor with "proven fertility." That meant a history of live births, according to California Cryobank. I chose a new donor, and was told that CCB had a report of one birth, a boy. You would think, therefore, that my son has at least one older donor-conceived half-brother. When I checked with CCB last Spring, when my son was 14, CCB would not confirm the existence of the older child and tried to suggest I imagined that I was told about him. When I asked how many half-siblings had been reported, I received a vague response but it was suggestive of younger half-siblings only. Since my son's donor donated in 1987-1989 only, I found that possible but unlikely.
(2) There was a sequence of donors over a span of about three years. At first, with the University of California at Davis, I didn't even get to choose. There was no associated donor number. When I did have a choice, I was required to list two backups. Waiting to be inseminated at a private clinic in Sacramento, I happened to check the vial before the procedure and noticed it had a number on it I didn't even recognize. When I asked the staff about this, it turned out to be my second or third choice donor, and it was admitted that nobody had planned to tell me that my first choice was not being used. As to why that was occurring, I eventually got the admission that the clinic had screwed up and hadn't ordered my first choice from the sperm bank in time. It snottily was suggested that I had the option to back out of that cycle, after all the hormone therapy, the time off work, the drive out of town to the clinic, etc. I decided to go with the second choice, but had a lot of conflict and angst about that decision. Had I become pregnant that cycle, I can only imagine how I would have felt about it. And, had I become pregnant and NOT caught the change in donors, I would have been left with the impression that my #1 Choice was the biological father. I would not have had reason to

check back with the doctor/clinic to confirm that. The clinic would have seen no reason to inform me. The clinic never inquired whether I became pregnant. The staff was content just to have me make repeated appointments; those in and of themselves confirmed I was NOT pregnant. BTW, I eventually found an ethical and exceedingly competent doctor and became pregnant via IVF in my first cycle utilizing his services.

3/8/06 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6307

It seems so many banks are related to one another. When I initially joined the DSR I searched through donor descriptions and that is how I found my first match. Donor #### CCB was formerly Donor ### of Procreative Technologies of Los Angeles. Before that the bank where my donor actually donated was located in Missouri. I checked the archives and it helped me quite a bit to figure this out. http://www.archive.org/ Wendy posted this site a while back and it is awesome!!!

3/8/06 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6306

Funny, I reported the birth of my triplets to CCB shortly after they were born and was never sent a form to fill out. They are very inconsistent - one of our sibling moms called them and they have no record of it!

3/8/06 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6305

I used CCB too and I called and told them of the pregnancy, they said congratulations and such, but that was it. I only reported the live birth when I happened to be dropping off forms to discard of my last samples because I couldn't afford to store them anymore. By this time my son was almost 1. I sure wish I had found this site before I discarded the samples because I would have offered them to anyone needing them....but it's too late now. My point is that I was never asked to fill out any forms to report the live birth. I would imagine if I so how got ahold of my file from CCB, that a birth would not be reported as I just told them verbally and I imagine it went no further. I was dealing with a branch of CCB in Palo Alto, CA.

3/8/06 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6300

When I spoke to the geneticist at CCB the other day she stressed the importance of people reporting live births. In the case where new and important medical information may arise about the donor, the bank will only contact families who reported live births. It is also important to give them up to date contact information.

3/6/06 http://health.groups.yahoo.com/group/DSR_Discussion/message/1488

So an interesting development occurred today. I received a call from a geneticist at CCB in response to the message I left. One of the first things she said was how surprised she was that "all these children have problems and no one ever called the" - she was saying it in kind of an accusatory tone which I did not appreciate.

I explained that two of the children are currently being evaluated and we didn't know about the common thread until just this week. When we realized it we called. It turns out that one of the moms DID call CCB because she had a lot of problems with the pregnancy at gave birth at 27 weeks. Her son also has developmental issues that are related to complications after he was born. So we will never really know if his issues are related. She said when she called CCB didn't seem the least bit interested.

Anyway, the woman from CCB said how they are very interested in hearing from all of the mothers and will look into this extensively. She said they may possibly contact the donor or other parents who reported live births if they find that the incidents are above the national average and there is some genetic component. She said they do extensive evaluations that include questions about development. I asked if it were possible that he had some disorder that went undiagnosed, therefore he did not disclose (I used Aspergers as an example because I know an adult with Aspergers and he is highly intelligent and successful. She pretty much said they it is her job to kind of diagnose the donors and she assured me they would never accept a donor with Aspergers. She was insulted that I suggested something like this would get past them but I still think it is highly possible if the person learned to compensate.
Anyway, I've read it is unknown whether there is a genetic component to developmental disorders so the bank will more than likely conclude that it is not necessary to contact anyone else. They are supposed to follow up with me in a few weeks with a report so I will keep you all posted. I am not trying to blame anyone - I just thought that 4 out of 7 (now 8 we made another match today) was a bit high and worth mentioning (BTW of the other three two are girls and one is an infant). At the very least it has piqued my curiosity. I love my son and wouldn't change anything about him - but I shouldn't have to qualify that.

3/6/06 | http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6284

I just found our donor's profile at a 3rd cryobank! All the information is the same, age, weight-a few pounds off at each, however, the health, occupation, ancestory, religon, fav animal, location raised, siblings, etc....all the same! His audio is the same too! How can this be? Are cryolabs sharing samples? Two of the labs are in Ca, and this one is on the East coast....so i am absolutely stumped and stunned! The 3 banks he is at are CCB, Zygen and now CLI!

2/22/06 | http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6091

My donor #### CCB was donor #### at Procreative Technologies before that. When I look at the two profiles I see conflicting information… He filled out these profiles. One says his mom has brown hair and the other says she has blonde hair. One says he has a degree in dramatic teaching. The other says he has a degree in theatre and one in singing... I am working with CCB to find out as much as I can about this donor. I just want to be sure when the day comes that my daughter wants this information it is as correct as I can get...

2/22/06 | http://health.groups.yahoo.com/group/DSR_Discussion/message/1428

There was a procreative Tech in MO. It is very close to Illinois. I think the donor donated there first. Then his sperm was moved to CCB. He had already saved up money to move as said in his audio tape I have. I think he then moved to California to finish his singing degree. You will have to listen to the tape. He wanted to move to California and finish his second degree. I think that is what happened. Even CCB said that he may have donated at one bank then moved across the country to donate at another. She could not give details but said that does happen. It sounded like she was giving me a hint without saying.....

2/18/06 | http://health.groups.yahoo.com/group/DSR_Discussion/message/1425

You know, I actually assumed it was California Cryobank --- I happen to believe that they are particularly bad, and have known many SMCs who have been mislead by them --- they are masters at playing at language on their website and so many women use them under the mistaken impression that they do offer willing to be known, which they do not! If you read their fine print, they only promise essentially that when the child turns 18, they agree to ask the donor if he can be contacted, but if the donor says no, their responsibility ends there. This is NOT then a true willing to be known program it is a fake promise, because if anyone has ever seen Cappy Rothman or read him in the media you know that he is adamantly opposed to any form of donation but anonymous. True willing to be known wd be where the sperm banks have both recipients and donor sign promises that give the child this right at 18 to have the donor's personal identifying info and that this info will be turned over no matter what recipient or donor may feel 18 yrs down the road.

2/17/06 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6041

When I had my son, I called CCB to tell them that he had been born. During that same call, the woman made some sort of comment to me that my son was my only child with this donor! So, I reported (AGAIN) the birth of my daughter - who was 3-1/2 at the time! I don't know how they can make any reasonable guestimate when they are completely incompetent!

2/7/06 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/5984

I had something like that happen to my donor. Also, at CCB. It occurred after he was asked to reactive for a couple. He obliged but then he changed to no. Ironically, that's when I discovered this registry and recently discovered that there are 3 half siblings. I've made limited contact with one parent of a sibling at Christmas time. However, it’s made me aware that my decision to use ADI is always evolving. I hope that in the end my child will benefit from me trying to attain the information about her siblings and donor.

2/7/06 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/5982

My donor at CCB was also a yes donor and now is a no. I am happy to say that we have four beautiful matches on the DSR. 2 girls and 2 boys. I don't know what the future has in store for us but I am happy to have the siblings we have now.

2/4/06 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/5970

I have the same issue with CCB. When we were first looking at donors, we decided that we would like to use someone who was, at least, open to the idea of possibly being identified when Isabella turns 18. All of the information that I originally downloaded/printed said the donor was willing to be id'd when the children are 18...NOW, when I look at the information - even though the donor is retired - it shows him as a NO!

1/26/06 http://health.groups.yahoo.com/group/DSR_Discussion/message/1353

I found out that my donor was/is a carrier for Tay Sacs. He's Jewish, but I'm not, so it wasn't a problem. But the only reason I found out was when I called CCB when my son was 6 mos. old. His birth had not been reported by the RE, and no one from CCB called the RE to ask about who might have used the samples. It seems like a typical sperm bank way to operate...if you call they MIGHT tell you about something.

I can see why cryobanks don't try to contact people, though: since most male-female married couples in the US still lie to their DI- conceived kids about using a donor, well, the parents will be very upset if a sperm bank calls their house. These kinds of parents are busy trying to produce amnesia in themselves, so they can forget that a stranger's swimmers helped produce their kids. If people could be open and honest, just with their offspring, it wouldn't be such a losing situation.

12/23/05 http://health.groups.yahoo.com/group/DSR_Discussion/message/1259

CCB rates donors for attractiveness. If someone had, say, pitted skin from acne or actually had a bad case of acne, he would not be chosen. That's what I was told anyway.

12/2/05 http://health.groups.yahoo.com/group/DSR_Discussion/message/1198

I would like further info on this due to the fact that my 4 yr old son is also autistic. (we used CCB).

12/1/05 http://health.groups.yahoo.com/group/DSR_Discussion/message/1194

In response to message 1185, below:
I think it has to do with the active misleading that sperm banks and particularly CCB has done. And who knows, all the healthy children out there may be the exceptions, the point is no one knows because the banks are not keeping records at all which is totally irresponsible. And that CCB has or has been alleged to have removed material information is something so serious that perhaps criminal authorities ought to be looking into it, because if they would do that, who's to say they won’t do worse? After watching the CCB guy "live" on CNN, frankly, I cannot see how anyone seeing him and his attitude would now use his services. There seems something almost sinister, definitely patronizing in his view that anonymous is best.

12/1/05 http://health.groups.yahoo.com/group/DSR_Discussion/message/1190

If god forbid my child ended up sick, I would tend to my child rather than try to blame someone for her illness. People who conceive “normally” often choose to have a child even if they know they have some genetic problem. This happens all the time, people do not want to not have kids because they may pass something along. The bank is not here to provide us with perfect genetic shopping.
When I decided to use a bank, I KNEW that the donor may have lied, I knew that he may have had health issues arise after the fact, I knew that maybe all pregnancies wouldn’t be reported. If anyone went into this thinking that they were buying “perfect, designer sperm” and didn’t contemplate the many, many things that could go wrong, the onus is really on them, and trying to put the responsibility of something that should have been carefully researched and thought out on the bank seems patently wrong to me.
Perhaps using a known donor would be a better option, of course that is a whole other can of worms. Life is messy, things aren’t perfect. I am not rushing to the defense of banks, but I very much believe that we as parents who made this choice shoulder more of the responsibility than the bank should.
I defiantly agree that banks should not lie, should not throw away or alter information, of course I agree with that. I agree that banks should be more carefully regulated, but that will need to be dealt with at a legislative level, not by yapping at banks to change when they have no reason to.
I am sorry, I am a complete realist, and many businesses are corrupt, people often lie, I took these things into account, so that is where I am coming from. In terms of defending the banks, I am not, and in terms of being grateful, I am, w/o CCB, I would not have my beautiful daughter, she would not have 7 great half-sibs, and I would be worse for not having had the choice to use them.

12/1/05 http://health.groups.yahoo.com/group/DSR_Discussion/message/1187

I am still grateful to CCB, the sperm bank I used. If we're talking about minor health issues, that's one thing. These could easily be environmental or from the biological parent who is raising the child. I think the major concern is serious life-threatening illnesses or recessive traits that maybe a donor really wasn't aware of. The only way other parents would know, before or after conception, is if other parents reported the health issues. And one would hope that the sperm banks would be open to receiving that information.
I don't think I'd like to report every health issue that affects my children though. Certainly, they have some right to privacy.
Part of me also feels badly that the sperm banks (although profit- driven here in the U.S.) are the target if so much anger about health conditions. I'm angry about untracked pregnancies and not limiting donor offspring or purposely hiding known health problems; but, having children involves risks no matter how they enter are lives. There is no way to absolutely control their health and be guaranteed 100% life-long vitality. It almost makes children sound like "products" in the marketing/business sense of the word.

12/1/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/1185

Let's not lose sight of the great service these banks have provided and by which many of us have wonderful, beautiful children. The banks are really in a "damned if you do, damned if you don't" situation. Without CCB, despite any wrongdoing they have done, I would not have my daughter. I do agree w/ full disclosure though, but still can't understand why people are so negative about the banks, the very people who helped us conceive.

12/1/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/1183

How long is it going to be before we have a Sperm Bank ratings site giving those searching for the right sperm bank the information that they need and should know about the sperm banks that they are using. For goodness sake - it's the most important decision we ever make but what do we base it on - fancy websites and sales pitches. I would have wanted to know that California Cryobank deliberately deleted negative medical information about its donors. That an east coast sperm bank failed to return phone calls made by a donor who found out that he was a carrier for Huntingtons and kept selling his sperm. That Cryos had a double murderer as a donor. That certain sperm banks routinely lie about looks, qualifications and SAT scores.

11/23/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/1162

The piece was so well done that even CA Cryo founder Cappy Rothman's backhand comment that he used to be able to promise anonymity but the technology is being "misused" was trumped by all else.

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The most revealing thing about this program, if I heard what I thought I heard, was the estimate by Rothman that three-quarters of a million children had been born as a result of his sperm bank's operations alone. I was speaking on the phone while also trying to listen to the program, so surely I must have misunderstood and he was speaking about all sperm bank births. I hope that someone will correct my error if I misunderstood this, because even if CA Cryo had 10,000 donors -- and they would never have gone to the expense to qualify this many donors (almost one a day for all 30 years of operation) -- this would imply that the average number of children born to each of the 10,000 donors was 75. This is an incredibly large average number and would grow even larger if there were fewer donors. This makes me think that Rothman must believe that the number of children born to his more successful donors must have run into the several hundreds. I am not sure that he would really have wanted to reveal this interesting information.

11/22/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/1160

Paula Zahn Interview
Wendy! Blessings, blessings! The story was great --- I'll admit I was very, no VERY worried because Paula Zahn is one of the salacious journalists who, well, you know. But I forget who actually interviewed you and Ryan (you both looked great BTW), but the story was well done. I think I may even see if I can purchase transcripts of it for my and my son's files.
The piece was so well done that even CA Cryo founder Cappy Rothman's backhand comment that he used to be able to promise anonymity but the technology is being "misused" was trumped by all else. Still, I hope that others who do interviews try their darndest to make sure that it is professionally done.

10/30/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/1135

I wrote in to tell her about this site, and also the very serious concerns people had had with certain sperm banks (CA Cryo, Xytex . . . I did not give details). I told her to join this site, make sure she read the fine print which CA Cryo at least tries to bury people in.

10/27/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/1124

I've been thinking about this, and it occurs to me that so many sperm banks are getting away with all kinds of nonsense (changing at a whim the number of clients who can buy particular sperm; not following their own procedures; misleading parents, etc.). This may be because they constantly have new customers, and those customers have no other way to really check a particular banks ethics. But what if there were a list that rated sperm banks, a website where people cd post their experiences with sperm banks, how they lie and mislead (or even how they keep the spirit of the bargains they make), so that those who use ART can get a better sense of how these sperm banks really are. Sounds like Xytex and California Cryobank are huge offenders, I know with my bank, had I known that they played fast and loose with definitions of what constituted family and on their own would increase the number of clients who could use a particular donor I may have looked somewhere else.

9/21/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/1044

---- wrote:
> I had no idea (nor recollection) that the CCB had a lab in Boston

A friend of mine whose brother was in college in the Boston area told her that CCB actively recruited on his campus. The donor we used was from another school in the area.

> reproductive tissue banking. I'm not even sure what that term
> means.

Reproductive tissue = sperm and/or eggs

9/15/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/1020

I thank J for the compliment above; however, I would like to make a correction. I had CCB ###'s basic profile from many years ago when I used his sperm, unsuccessfully, before creating my son with CCB ###'s sperm. The basic profile I received and, fortunately for J, saved, has his DOB on it.

J recently faxed the profile she received from CCB on ###. Re DOB, it includes the donor's birth month and year but not the day of the month.
For the sake of others who have a child via a CCB donor, I'd like to provide further specifics.
What I received on ###, and initially on ###, was a one-page, two sided document.
Side 1: DONOR PROFILE.
"DATE OF BIRTH" is in the upper right hand corner, followed by a line for its insertion.
Side 2: In Your Own Words...
Why do you want to be a donor?
In your own words, describe your personality and character.
What are your hobbies, interests and talents?

After I became pregnant with my son and informed the CCB of the pregnancy, they told me of what they referred to as an "expanded profile" or "the ten-page profile." I previously was unaware of its existence, or that I was entitled to receive it. I was stunned to learn that I was entitled to receive additional information from them.
On ###, the expanded profile I received is comprised of the following parts:
Page 1: ABOUT THE DONOR
Interviewer + Today's Date
Physical Characteristics (including "Month/Year of Birth"
Personal Characteristics
Fertility History
Page 2:
Fertility History continued
Personal Health History
Page 3:
Personal Health History continued
Page 4:
Personal Health: Work History/Exposures
Page 5:
Family Health History
Page 6:
Family Health History continued
Page 7:
Cont: Grid #1-4
Page 8
Cont: Grid #5-9
Page 9
Cont: Grid #10-13
Page 10
Side 2 of the two-page basic form

What J faxed me on ### is his expanded profile, which includes Side 2 but not Side 1 of the basic profile. Unless there was an error in the fax transmittal, she did not receive Side 1, which includes the Donor's DOB and possibly other helpful, useful information.
It concerns me deeply that CCB's policies and procedures seem to vary from one recipient to the next, and, in my case, from one phone call to the next, spanning a period of time dating back to 1988 and continuing with my most recent contacts with them a few months ago.

9/15/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/1019

My DI son is also 13, but he's CCB ###. His profile says 6/62. But (a member of this group) found his full DOB for me on the CCB website! My donor didn't used to have a baby picture, but recently my son was over at CCB site and saw that there was one added, so we bought that. (It's B&W and not the best quality. CCB blew it up to make it bigger, and it's too dark. But better than nothing! We were still happy to get anything.) He was offered a chance to do an audio tape when that feature was introduced with new donors, but he declined to do one.

9/10/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/1016

Yes, they do. In fact, I believe that my donor was from the East Coast and donated there to the Boston branch. My suspicion is that any college that has the ability to handle sperm samples or cryopreserve can ship to CCB. I'm not sure that I buy that all donors actually visit the CCB branch itself to donate. I could be wrong about this. Just my suspicion since their donor application asks what college, city, and state you are currently residing at.

9/10/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/1015

I just stumbled on this (see below) while doing an Internet search. I had no idea (nor recollection) that the CCB had a lab in Boston nor that it was doing reproductive tissue banking. I'm not even sure what that term means.
Job Information
Job Title: Lab Supervisor
Employer: California Cryobank
(http://jobs.boston.com/js.php?view=2&qcompid=3a429c162&qlookidu=&qComp=)
Source: Boston Globe Sunday Ads
Location: Boston, MA
Date: 08-16-2005
Job Description
Description: Laboratory Laboratory Supervisor California Cryobank Inc., a leader in reproductive tissue banking, has opening for a Laboratory Supervisor in our Cambridge Branch. $3000 sign-on bonus! This position will be responsible for the overall daily operations of the lab and office and offers advancement potential. Requirements: Medical Technologist (ASCP), supervisory exper. (min. 4 yrs), extreme attn. to detail, strong org'l skills, & ability to multitask. We offer competitive benefits, compensation and parking and are located near the T. Send cover letter and resume to: Fax (617) 497-6531, Email: cam
labsupervisor@yahoo.com
(http://jobs.boston.com/texis/apply?id=4300cc4849d40&lookid=boston&to=labsupervi\sor@yahoo.com) or mail to: Attn. K. Fitzgerald, 950
Massachusetts Ave., Cambridge, MA 02139. EOE

8/31/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/991

I have been reading all of these posts and not posting until now - I used CCB in Los Angeles and now they claim there is no paperwork for the donor I ended up getting pregnant from and their files did not indicate I became pregnant (?). I am certain that they do know, since I called after I got pregnant and told them, and then when my beautiful daughter was born, I called again. They were not very interested, and I never filled out any paperwork.

8/30/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/987

Yes, this was the infamous UC Irvine scandal. Here is a link to the Orange County reports that led to the 1996 Pulitzer Prize:
{http://www.pulitzer.org/year/1996/investigative-reporting/works/1104.html}
[or http://tinyurl.com/cp5xg]
You don't hear much anymore about misdeeds in the infertility business recently but there were a rash of them around ten years ago, including several Manhattan clinics shut down by the NY Board of Health after raids for not testing sperm, the temporary license revocation of Idant's president Feldschuh, the AIDS cases surrounding Dr. Korn's practice in Vancouver, the deceptive responses of CCB's denial of responsibility for a DI child's kidney disease, and several individual suits against clinics for replacing a husband's treated semen with an anonymous donor's (in the US, the UK, and the Netherlands). In such an unregulated business, the possibility for such mistakes and coverups is high. However, the Cecil Jacobsen case in Virginia seems to have been the worst of all.
--- In DSR_Discussion, n wrote:
> There was a NY doc who did this as well (a Law and Order episode about it), and I think a doctor/fertility clinic in Orange County, CA.
> -----Original Message-----
> From: m
> UK Channel 4 22:00, Tuesday 30th August
> "The story of a doctor supplying fertility treatment in Virginia, who
> concealed a dark secret. While he claimed to be able to match his
> patients with donors from backgrounds of their choosing, in reality he
> provided all the sperm produced by the clinic personally - and is
> believed to have fathered 75 children."

8/29/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/970

I understand people are confused at parents' change of hearts on wishing they had more donor info. But, no sperm bank or doctor ever emphatically told me what I couldn't know about the doctor or that privacy was such an issue. It was very nonchalantly put by the customer service rep at CCB that they "couldn't force a donor to make a decision today that would impact them 18 years from now"-- they were "open" to the donor's feelings. And this was only stated when I asked about the "openness policy" after I gave birth to my son. And I only asked, because other SMCs were questioning it.
I never had any conversations that people claim to have with their doctor or any conversations regarding donor's rights or what the Donor Agreement form really meant. It was simply a form necessary for me to complete so that the doctor could receive and store the sperm in his office. And most importantly, it contained my credit card information so that CCB would get their money upfront. All of this..."you were told, blah, blah, blah, emphatically" simply didn't occur with anyone I've ever met. Maybe this was a bigger issue for married couples worried about privacy issues and maintaining secrecy and in their own medical records. I was more concerned that there wasn't a clear understanding that I was single. In fact, I questioned the CCB regarding this to make sure that I wasn't going to be in the middle of a treatment cycle and have them change their mind about shipping.
I did treat at an infertility clinic whose staff tried to discourage me from pursuing motherhood. I listened to a lot of crap from a nurse who was a single mother by divorce; and, the doctor was nowhere in treatment. I saw him 4 times during one whole year of treatment, testing, surgery, etc. Frankly, I read the Donor Agreement from again a few days ago and noticed for the first time that the CCB reserves the right to destroy records whenever they chose. I never dreamed that this actually happened unless parents requested it. Here now I'm hearing that clinics and banks claim they've destroyed records all the time to dissuade people from trying to gain info.
Actually, I would never try to call CCB for information and am not surprised they don't provide more

prior to the child reaching age 18. What surprises me is that I'm figuring out that there was never an intent to keep in touch with donors or locate them later on by any sperm bank it seems--at least in the U.S.

I think when you are undergoing infertility treatment and are very afraid you may never have a child, it is very easy for someone to play on your fears and make you feel safe by saying anonymous donor insem is the way to go to avoid any custody battles. As for ID release, I never heard of such a thing until 2003, and by then, my son was 3 and I wanted a second child with the same donor--I didn't want to have 2 different donors and therefore 2 different stories to tell my children. Now I know ID release is the law elsewhere, but here in the U.S., ID release donors are in the serious minority and there is very little choice in them--temperament, background, physical characteristics, etc.

Although we are talking of someone's privacy, I still believe that since we are paying huge dollars in the U.S. for sperm, we are entitled to have some opinion on whether we are happy with the service or not--and that includes the flow of information, not just the resulting children. And it includes the total lack of counseling on this choice. I was required to go through psychiatric counseling to become a single mom by choice, and there was never any discussion of identity issues--just whether or not I was cut out for the pressure of single-parenting.

Not to be argumentative here: but I participated in ivillage forums prior to conceiving, I attended many SMC meetings, and was on yahoo and read voraciously on single parenting; and I treated at 3 different clinics: Midwest Infertility, Center for Human Reproduction, and Fertility Centers of Illinois; and, I'm just not seeing where all of this emphatically, explicitly given information was given to me?

Please, have you read any infertility/donor insem books in the U.S.? They are fertility clinic advertisements for all they're worth in terms of discussing issues on donor conception.

P.S. Reading more and ordering more Donor Conception books from Canada since the U.S. couldn't give a rat's !@#ss on this topic!

8/29/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/966

Can someone help me out here. How do sperm banks calculate pregnancies per region when they are shipping all over the country? Are you counted by where the doctor's office is who does the insemination? Also, how the heck can they count when they don't have a clue as to how many births happen from their shipments? CCB did not know that I had a child until he was three. I did not know that my doctor used CCB until that time as well. In theory, having these cutoff numbers makes sense, in reality it seems like they are blowing smoke.

Wendy

[from moderator ML: I don't know how CCB used to do it, but their website now says this:

"All clients should receive an Outcome of Insemination Report six to nine months after their last specimen order. Clients should complete this report and mail it back to us" Some people don't want to admit they used a donor though, not even to themselves, so a lot of pregnancies and births will go unreported. I've seen estimates that only 40% of births are reported.

I can't help wondering what they do when they approach their limit. Do they limit the number of recipients, or do they try with as many people as possible until they get enough reports back to know that the limit was reached 6-9 months earlier?]

8/28/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/963

Sperm banks usually define 'region' as an area having a population of 100,000. This means that, in Metro Toronto (where I am) which has a population of 3,000,000, 1 donor could have as many as 3,000,000/100,000*10 = 300 offspring.

[from moderator ML: I don't know what definition CCB use, but the ASRM now recommends a

cutoff of 25 pregnancies per region defining "region" as a population of 800,000.
Every sperm bank seems to handle this differently. The Rainbow Flag sperm bank says "We limit our donors to have children by only 4-6 different women." The Sperm Bank of California says: "Our limit is ten families worldwide for each donor."
It is possible for US donors to donate at more than one sperm bank since there is no central register.]
----- wrote:
> CCB apparently permits 10 live births from a particular donor.
> However - and this is the catch - that is 10 live births "per
> region", with region being defined in some proprietary manner - I'm
> assuming that for CCB's purposes, 'region' is defined as a state.
> So... I am hoping that there will be at most 500 (10 x 50 states)
> possible half sibs for my son :-)

8/28/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/960

1) Maybe the CCB did the right thing in your case, but in the other case I mentioned, they falsified their records and lied about it in court. You have to read the details to see just how disgraceful their behaviour was:
http://groups.yahoo.com/group/DonorSiblingRegistry/message/4881 and
http://caselaw.findlaw.com/data2/californiastatecases/B155896.DOC
Remember, this is just one case that came to light quite by chance. How many other times did they decide to ignore bad news? If the CCB had been a UK clinic, I'm fairly sure they would have lost their license over this and they would probably have gone out of business. I suspect they've had to clean up their act partly as a result of being caught red-handed, but also because DNA testing and the Donor Sibling Registry make it much more likely they would get caught if they tried anything like that again.
2) It's been mentioned before, but often parents and doctors don't report back to the clinic. Sometimes it's because no-one gets around to it, but some parents want to think that maybe it worked with the husband's sperm not with the donors.
All donor births in the UK are recorded on a national register, but I'm not sure how this actually works in practice. The UK allows births to a maximum of ten mothers per donor in a country with about 60 million people.

8/28/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/957

A few things have been said about CCB that I wanted to address.
1. When CCB learned that there was a serious medical problem with a child born as a result of using the same donor as I did, they immediately contacted me - in writing - and provided as much information as they could. Turned out to be a genetic problem that the donor was totally unaware of until well past the time that he made his donation. This trait was not passed to my son - it's something that would have shown up before age 2. CCB immediately took his sperm off the market, although they continued to make it available to women who might wish to have full sibs with the knowledge that there was a possible genetic defect.
2. CCB apparently permits 10 live births from a particular donor. However - and this is the catch - that is 10 live births "per region", with region being defined in some proprietary manner - I'm assuming that for CCB's purposes, 'region' is defined as a state. So... I am hoping that there will be at most 500 (10 x 50 states) possible half sibs for my son :-)
This last area is where I believe both donors and parents of DI children should be concerned about regulation - in addition, of course, to genetic screening, proper storage and testing standards. I believe the sperm bank should be responsible for following up and ascertaining whether there has

been a live birth as the result of the purchase of a particular vial of sperm. If not the sperm bank, then the fertility clinic or doctor performing the insemination should be required to follow the case and ascertain whether a live birth resulted - then report this info back to the sperm bank. How else can they possibly have any clue as to the number of possible sibs.

8/25/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/919

The California Cryobank donor agreement signed by recipients states that we agree not to try to identify the anonymous donor through either the California Cryobank or any other source. Now if CCB was willing to contact this donor when my son is 18 or truly relay a message to him, maybe I could understand. But I feel a bit betrayed in agreeing to this now understanding that there may be very little effort made, the donor may not stay in touch, and that there maybe 25 offspring all clamouring for the same contact!

8/19/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/893

18 years ago, CCB was one of the major sperm banks (likewise Idant) that raised loud objections to the idea that The Sperm Bank of California had the courage to buck the century-old system of total anonymity with its Identity Release Donors. Cappy Rothman was the biggest critic of it at that time. Like so many banks at that time, any potential donor that mentioned an interest in these future children, or even saw them as "their" genetic children were automatically screened out of the programs. Remember in those days not so long ago, only married couples were allowed access to donor insemination and banks actively promoted secrecy within families. Single women and lesbians resorted to other methods not sanctioned by infertility clinics. When CCB and Xytex began losing recipients who went over to TSBC, they started to realize that their clients were not going to put up with their intimidation, strict rules, and arrogance. It began known that there was another bank that actually listened to infertile people and offered them CHOICES. It wasn't until TSBC grew in popularity because of their willingness to be covered in the media, that other sperm banks began to offer some choices, although never on the level of openness that TSBC's "Yes Donors" program offers.

I would imagine that CCB is not contacting the donors from the earlier programs before they instituted their "Willing to be Known" donor program, which is a very weak version of Identity Release. Xytex appeared to have a growing level of openness and willingness to help DI children, but it looks like they are now regressing to the norm.

I am not pushing TSBC here. I don't like the fact that they still carry some "No Donors." Although I advocate choice, I don't believe that choice means ID Release versus anonymous donors. The choice should be up to the DI person conceived to make decisions about whether or not to contact his/her genetic donor.

For TSBC to offer the choice of anonymous donors is to deny the person conceived any right to choose to make connections to his/her genealogical heritage. It's not the same as someone having no choice because they were born through a private affair. In DI, society is directly involved with the conception and it is controlled by professionals who swear an oath to "Do No Harm." The assumption of harm must be taken since there is no proof that secrecy doesn't do harm. It is not up to us to prove that secrecy does harm. We DI adults know that it does. Rather it is up to the profession to prove that it doesn't, which they can't because secrecy prevents the openness necessary to make any legitimate study. In any other medical procedure, there is an explicit obligation to examine the outcome to ensure that there is no harm, or that the good of the procedure outweighs the harm. With DI we can't know that without first eliminating secrecy and especially anonymity. The answers must come from the donor conceived person himself, not as interpreted by his parents or his parents' fertility doctor. The medical profession washes its hands of responsibility for creating life in this manner by claiming that the birth of a baby is a sign of DI success. We all know that this is an extremely narrow view that dismisses the importance of the sociological and psychological impact of DI on parents, donors, DI children, DI adults as well as the spouses of DI adults and their children.

8/12/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/862

I particularly like the suggestion to limit the number of offspring from each donor. I wonder if more donors would be willing to meet children in the future if there was a more manageable number of them. With some banks allowing up to 20 pregnancies; how on earth could one person handle all of that emotionally while living with their existing nuclear family and its own needs?
If donors were required to agree with ID release, I would imagine they would prefer not to take on the responsibility of connecting with such a huge number of adult children in the future. Maybe some could go as far as meeting children periodically during the growing years much like an open adoption agreement if the number of kids were limited.
It would be especially useful for all sperm banks to have to follow the same guidelines. I see some people criticizing certain banks for their financials, number of pregnancies, lack of ID release programs, etc. And really to some extent I agree. However, as a woman with endometriosis, PCOS and luteal phase defect, part of my decision to use the bank that I did (CCB) was doctor recommendation and the reputation for providing high quality/high sperm count samples. I think most people here are assuming a male infertility problem as a reason for using sperm alone or a lesbian or SMC mother without fertility issues to be overcome.

8/10/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/804

I was going to say, when we used CCB three years ago, I found something on their website that had us calculating payments and figuring out that a guy could live on what he made by "donating." Not live well, mind you, especially in California, but he could subsist. It would make a very nice supplement to anyone's income.

8/10/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/798

In response to message 796, below:
Whoa! You know, every time I read something about CCB, I am more convinced that place should be shut down. PRS and NECC uses mature men for this. This is just too amazing. Though I remember in college ran ads for this and egg donors, I was going to be an egg donor but actually wound up meeting a prospective couple and that encounter changed my thoughts on a host of things, including even my views on abortion. I can't get over the fact that another woman would be raising my child out there. It was powerful.

8/10/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/796

Yes, often these men ARE 20 year olds. I am aware of many men who were 19 or 20 when they donated, including our own donor. These men were from the "best" and most reputable sperm banks, ours was CCB. The fee was nowhere near $200/donation. More like $35.00.

7/28/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/779

I think the Johnsons case against the California Cryobank (CC) is the best caselaw that there is on "good cause".
In the Johnsons case the CC sold the couple sperm of a donor with a family history of a very

serious genetic based kidney disease. The CC deliberately and fraudulently substituted the medical records of the donor to delete all mention of the kidney disease. The CC also assured the Johnsons that their donor was free from any identifiable genetic diseases. (Sorry to discomfort but those who perpetrated the fraud are still at the CC). However, it took years for the Johnsons to obtain a court order to get access to the file held by the CC on the donor, in order to find out about the fraud. Even though the Johnsons could show indisputable genetic evidence that the kidney disease must have been inherited from the donor, the court was extremely reluctant to allow the file to be disclosed. I believe that the Johnsons case might be the only case where the CA courts have allowed disclosure of the file and even then the donor's identity was not disclosed.

I posted a huge chunk of the court report on the Johnsons case on the other forum about 6 weeks ago.

It is my view that it is precisely the fraud which can be perpetrated by Sperm Banks because they can shelter behind sealed records which should be our rallying call to CA politicians to ask them to change the legislation on donor records. I think that if a lot of parents spoke out about their concern that Sperm Banks could be encouraged to lie about their donors because no one would find out, then it gives a sensible rational reason why disclosure of records is a reasonable thing.

6/26/05	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4881

I'm responding to a posting about her concern regarding donor's honesty. Unfortunately, I've got really bad news for her. She possibly doesn't have to be concerned so much about the donor - as about the Sperm Bank.

I recently uncovered an absolutely horrendous account of the gross dishonesty of the CCB. In case you don't believe what I am about to tell you, I am including an excerpt from the published court report of the Superior Court of California. Very brief details are this: A couple called the Johnsons purchased sperm from the CCB. They selected donor ###. They had a little girl born in 1989. Unfortunately, the little girl was sickly and in 1995 she was diagnosed with a severe hereditary kidney disease called ADPKD. As neither of the Johnsons had ADPKD or a family history of the disease, it was Donor No. ### who had genetically transmitted ADPKD to their daughter. In December 1986, Donor No. ### completed his Donor Profile. Sims and Rothman (still at the CCB), on behalf of the CCB, interviewed him and learned facts that signaled the presence of ADPKD in Donor No. ###'s family. Even though the CCB knew of Donor No. ###'s family history of kidney disease, none of this information was provided to the Johnsons at or prior to the time they purchased the sperm specimens. Specifically, on the original page 9 of his donor profile donor ### marked an X in the boxes concerning the presence of kidney disease in his mother and his aunt and uncle. On the original page 9 these answers were circled, a question mark was written next to each "X," and the notation "at risk for kidney disease" was written directly above the "X" denoting his mother's kidney disease. However, despite this the CCB, Sims and Rothman failed to examine or test donor ### to ascertain whether he was suffering from kidney disease or was a potential carrier of the ADPKD gene, they failed to properly investigate Donor ###'s family history of kidney disease. What the CCB did instead was beyond belief. They substituted a new page 9 not showing the kidney disease in the mother, aunt or uncle and falsely represented to the Johnsons that the sperm they were purchasing had been tested and screened for infectious and "reasonably detectable genetically transferred" diseases and medical abnormalities, and therefore could safely be used for pregnancy.

In January 1996 Mrs Johnson contacted the CCB and requested a copy of the Donor Profile. Although a copy of the document was provided, the Johnsons did not know, and the CCB did not disclose to them, that page 9 had been rewritten.

The long and short of it is that the Johnsons sued Sims and Rothman without at that time knowing that they had fraudulently replaced the donor's honest answers. In 1998, Sims and Rothman moved for summary adjudication as to the fraud part of the claim. In July 1999, the trial court

granted the motions, finding that there was no evidence to support the Johnsons fraud claim. The court also denied any compensation to the little girl or her parents for her hereditary illness.
On April 25, 2001, during further proceedings the trial court issued an order directing the donor's deposition. At the first session of the deposition, held on May 29, 2001, the CCB produced a redacted copy of its file on Donor No. ###. Petitioners' counsel briefly reviewed the contents of the file, and in so doing, learned for the first time that the copy of the Donor Profile the Johnsons had received from Cryobank on January 30, 1996, differed from the copy found in Donor No. ###'s file. Specifically, on the original page 9, Donor No. ###'s affirmative answers to the questions concerning the presence of kidney disease in his mother and his aunt/uncle were circled, a question mark was written next to each "X," and the notation "at risk for kidney disease" was written directly above the "X" denoting his mother's kidney disease. The document contained three different colors of ink. The Johnsons amended their claim to reinclude fraud and also requested punitive damages. The claim was thrown out on a technicality. The Johnsons never received any compensation and were hit with a huge legal costs bill.

The court report excerpt:
Petitioners Diane L. Johnson (Diane) and Ronald G. Johnson (Ronald) (the Johnsons), along with their minor daughter Brittany L. Johnson (Brittany), filed an action against real party in interest, California Cryobank, Inc. (Cryobank), and its employees, officers and directors, real parties in interest Charles A. Sims, M.D. and Cappy M. Rothman, M.D., alleging real parties failed to disclose that the sperm they sold to the Johnsons came from a donor with a history of kidney disease called autosomal dominant polycystic kidney disease (ADPKD). That sperm was used to conceive Brittany, who has been diagnosed to have this serious kidney disease. In 1999, the trial court ruled in connection with a summary adjudication motion brought by Cryobank that Brittany is not entitled to recover general damages and damages for lost earnings. In that same year, the court granted motions brought by Sims and Rothman for summary adjudication as to the fraud causes of action set forth in petitioners' second amended complaint. n1 In 2001, petitioners filed motions to reconsider or vacate the 1999 rulings and to amend their complaint to add a claim for punitive damages. In November 2001, the trial court denied the motion to set aside the 1999 rulings. The following month, the court denied the motion for leave to amend petitioners' second amended complaint to add a claim for punitive damages without prejudice to the filing of a motion pursuant to Code of Civil Procedure section 425.13, subdivision (a). The issues presented in connection with this writ proceeding are whether (1) sperm banks such as Cryobank are "health care providers" as that term is used in section 425.13, subdivision (b), (2) doctors such as Sims and Rothman and sperm banks such as Cryobank act as health care providers when they perform genetic screening of potential sperm donors, (3) an individual complaining that negligent screening of a donor's sperm caused her genetic disability is entitled to recover damages for lost earnings and general damages, and (4) the trial court erred in denying petitioners' motion to set aside the 1999 orders summarily adjudicating the fraud causes of action asserted against Sims and Rothman.

We conclude that Cryobank is a health care provider as that term is used in section 425.13, subdivision (b); Sims, Rothman and Cryobank were acting as health care providers at the time they performed the professional services alleged within the second amended complaint; and Brittany is not entitled to recover general damages or damages for lost earnings.

II. FACTUAL AND PROCEDURAL BACKGROUND

Second Amended Complaint.

Petitioners sued Cryobank, Sims and Rothman for professional negligence, fraud and breach of contract. In their second amended complaint petitioners allege that in 1986 Cryobank, a corporation in the business of providing sperm from donors to health care providers and their clients, approved an individual designated as Donor No. ### as a sperm donor. In 1988, the Johnsons' infertility physician directed them to Cryobank's sperm bank facility, and Diane selected Donor No. ###. After a successful implant procedure with sperm from Donor No. ###, Brittany was born in April 1989. In May 1995, Brittany was positively diagnosed with ADPKD. As neither Ronald nor Diane has ADPKD or a family history of the disease, it was Donor No. ### who genetically transmitted ADPKD to Brittany.

Cryobank's responses to interrogatories indicated that Donor No. ### sold 320 deposits of his semen to Cryobank. The donor's agreement with Cryobank showed that he earned about $ 35 per semen specimen. He thus received a total of $ 11,200 for his sperm. (Johnson v. Superior Court (2000) 80 Cal. App. 4th 1050, 1058 [95 Cal. Rptr. 2d 864] (Johnson).)

At the time Donor No. ### approached Cryobank in December 1986, Sims and Rothman, on behalf of Cryobank, interviewed him and learned facts that signaled the presence of ADPKD in Donor No. ###'s family. Even though Cryobank, Sims and Rothman knew of Donor No. ###'s family history of kidney disease, none of this information was provided to the Johnsons at or prior to the time they purchased the sperm specimens.

Cryobank, Sims and Rothman failed to examine or test Donor No. ### to ascertain whether he was suffering from kidney disease or was a potential carrier of the ADPKD gene, failed to properly investigate Donor No. ###'s family history of kidney disease, and falsely represented to the Johnsons that the sperm they were purchasing had been tested and screened for infectious and "reasonably detectable genetically transferred" diseases and medical abnormalities, and therefore could safely be used to effectuate the Johnsons' pregnancy.

1999 Trial Court Rulings.

The fraud causes of action set forth in petitioners' second amended complaint were based on the theory that Sims and Rothman either negligently or intentionally misrepresented, suppressed and/or concealed facts from the Johnsons regarding Donor No. ###'s medical history. In 1998, Sims and Rothman moved for summary adjudication as to these claims. In July 1999, the trial court granted the motions, finding that there was no evidence to support petitioners' fraud claims. At about the same time, the court held, in connection with a motion for summary adjudication brought by Cryobank, that Brittany is not entitled to recover general damages or damages for lost earnings.

Donor Profile.

In 1986, Donor No. ### completed a document entitled "About The Donor" (hereafter Donor Profile). In January 1996, prior to filing suit, Diane contacted Cryobank and requested a copy of the Donor Profile. Although a copy of the document was provided, the Johnsons did not know, and real parties did not disclose to them, that page 9 had been rewritten, and that certain notations contained on the original page 9 had been deleted.

During the course of the action, petitioners propounded discovery to Cryobank in an effort to obtain a copy of Donor No. ###'s files and records maintained by Cryobank. Cryobank objected to providing any information regarding Donor No. ###, claiming the donor's right to privacy and his physician-patient privilege. (Johnson, supra, 80 Cal. App. 4th at p. 1057.)

In 1998, petitioners served Donor No. ### with a subpoena to attend his deposition and produce his medical records and certain documents showing his involvement with Cryobank. (Johnson, supra, 80 Cal. App. 4th at pp. 1059-1060.) When he failed to appear, petitioners moved to compel his attendance and production of the requested records. (Id. at p. 1060.) When the trial court denied the motion, petitioners filed a petition for writ of mandate, which we granted. (Id. at pp. 1060, 1073.)

In May 2000, this court ruled that petitioners could take Donor No. ###'s deposition, and "delve into his and his family's health and medical history, and his communications with Cryobank." (Johnson, supra, 80 Cal. App. 4th at p. 1073.)

On April 25, 2001, the trial court issued an order directing the donor's deposition. At the first session of the deposition, held on May 29, 2001, Cryobank produced a redacted copy of its file on

Donor No. ###. Petitioners' counsel briefly reviewed the contents of the file, and in so doing, learned for the first time that the copy of the Donor Profile Diane received from Cryobank on January 30, 1996, differed from the copy found in Donor No. ###'s file. Specifically, on the original page 9, Donor No. ###'s affirmative answers to the questions concerning the presence of kidney disease in his mother and his aunt/uncle were circled, a question mark was written next to each "X," and the notation "at risk for kidney disease" was written directly above the "X" denoting his mother's kidney disease. The document contained three different colors of ink. On October 2, 2001, after a number of requests to Cryobank's counsel, petitioners were provided with a color-copy of the original Donor Profile. The color-copy of page 9 revealed that the donor's responses were written in blue ink, the question marks next to the donor's X's for his family's kidney disease were written in black ink, the notation "at risk for kidney disease" was written in black ink, and the circles around the X's were written in red ink.

Petitioners' Motions.

In October 2001, petitioners filed two motions. The first sought an order allowing petitioners to amend the second amended complaint to add a claim for punitive damages. The second, based on sections 473 and 1008 and the trial court's inherent equitable power, sought reconsideration of the 1999 ruling that Brittany is not entitled to recover damages for loss of earnings and general damages, and of the 1999 orders summarily adjudicating the fraud causes of action in favor of Sims and Rothman.

Trial Court Rulings.

The trial court denied petitioners' motion to amend the second amended complaint to add a punitive damages claim without prejudice to the filing of a section 425.13, subdivision (a) motion. The trial court also denied petitioners' motion to vacate or reconsider the 1999 summary adjudication orders in favor of Sims and Rothman, and the 1999 ruling prohibiting Brittany's recovery of general damages and damages for loss of earnings. The court found that the motions were untimely under section 1008, subdivision (a), and that petitioners had failed to produce evidence establishing extrinsic fraud as required by section 473. This petition for writ of mandate followed.

III. DISCUSSION

A. Petitioners were required to comply with section 425.13, subdivision (a) prior to amending their complaint to add a claim for punitive damages.

Petitioners' motion for leave to amend the operative complaint to add a claim for punitive damages was denied without prejudice to the filing of a motion pursuant to section 425.13, subdivision (a). n5 Petitioners contend this was error because Cryobank is not a health care provider as that term is used in section 425.13, subdivision (b), and Sims, Rothman and Cryobank were not acting as health care providers at the time they rendered the services described in the second amended complaint.

1. Section 425.13.

(1) Section 425.13, enacted in 1987 as a part of the Brown-Lockyer Civil Liability Reform Act, imposes procedural requirements on a party claiming punitive damages in a medical malpractice action. (Central Pathology Service Medical Clinic, Inc. v. Superior Court (1992) 3 Cal. 4th 181, 188 [832 P.2d 924, 10 Cal. Rptr. 2d 208] (Central Pathology).) Subdivision (a) of the statute provides that "[i]n any action for damages arising out of the professional negligence of a health care provider, no claim for punitive damages shall be included in a complaint or other pleading unless the court enters an order allowing an amended pleading that includes a claim for punitive damages to be filed. The court may allow the filing of an amended pleading claiming punitive damages on a motion by the party seeking the amended pleading and on the basis of the supporting and opposing affidavits presented that the plaintiff has established that there is a substantial probability

that the plaintiff will prevail on the claim pursuant to Section 3294 of the Civil Code. The court shall not grant a motion allowing the filing of an amended pleading that such an order is not filed within two years after the complaint or initial pleading is filed or not less than nine months before the date the matter is first set for trial, whichever is earlier."

Subdivision (b), added in 1988, provides that "[f]or the purposes of this section, 'health care provider' means any person licensed or certified pursuant to Division 2 (commencing with Section 500) of the Business and Professions Code, or licensed pursuant to the Osteopathic Initiative Act, or the Chiropractic Initiative Act, or licensed pursuant to Chapter 2.5 (commencing with section 1440) of Division 2 of the Health and Safety Code; and any clinic, health dispensary, or health facility, licensed pursuant to Division 2 (commencing with Section 1200) of the Health and Safety Code. 'Health care provider' includes the legal representatives of a health care provider." (Italics added.)

Although section 425.13 is not part of the Medical Injury Compensation Reform Act (MICRA) (Perry v. Shaw (2001) 88 Cal. App. 4th 658, 666, fn. 3 [106 Cal. Rptr. 2d 70]), the language of section 425.13, subdivision (b) is virtually identical to the language of Civil Code section 3333.2, subdivision (c)(1), n6 a MICRA provision enacted in 1975

(2). Where, as here, the same phrase appears in different statutory schemes, we can assume the Legislature intended the phrases to be accorded the same meaning only if the statutes involved have the same or similar designs and objectives. We therefore look to the legislative history underlying each of the statutes. (Delaney v. Baker (1999) 20 Cal. 4th 23, 32-40 [82 Cal. Rptr. 2d 610, 971 P.2d 986].)

(3) Civil Code section 3333.2, which limits the size of any award of noneconomic damages in an action for injury against a health care provider based on professional negligence, is an integral part of MICRA. (Western Steamship Lines, Inc. v. San Pedro Peninsula Hospital (1994) 8 Cal. 4th 100, 104 [32 Cal. Rptr. 2d 263, 876 P.2d 1062].) MICRA, which includes "a variety of provisions all of which are calculated to reduce the cost of insurance by limiting the amount and timing of recovery in cases of professional negligence," was enacted "in response to a medical malpractice insurance 'crisis,' which [the Legislature] perceived threatened the quality of the state's health care. [Citation.]" (Id. at p. 111.) The Legislature's goal " 'was to bring down premiums so that doctors could continue to practice medicine in California, and charge reasonable prices.' "

(Perry v. Shaw, supra, 88 Cal. App. 4th at p. 668.)

(4))We recognize that medical malpractice insurance does not cover punitive damages (Peterson v. Superior Court (1982) 31 Cal. 3d 147, 157, fn. 4 [181 Cal. Rptr. 784, 642 P.2d 1305]), and that the Legislature's goal in enacting section 425.13 was not to reduce the cost of malpractice insurance. Rather, it was to require "greater certainty of the propriety of imposing punitive damages by requiring clear and convincing evidence of fraud, malice, or oppression," and to provide health care providers with "additional protection by establishing a pretrial hearing mechanism by which the court would determine whether an action for punitive damages could proceed."

6/4/05	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4658

I used California Cryobank and when I asked them how many pregnancy my donor had, they refused to give me any numbers. I have 4 year old twins, but I have 34 embryos… imagine if I donate those embryos and 25 of them become babies? I informed CCB about this and they didn't seem to care.

6/4/05	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4653

I too used California Cryobank. I have a 4 yr old and 3 yr old triplets. So far we only have made 1 DSR match (which went extremely well might I add and just 2 weeks ago). I was told by the bank that our donor was allowed to impregnate 10- 15 families (not 10-15 children). Just think I am considered 1 family (I currently have 17 more vials in storage) and we know that not everyone registers their positive births with their banks. There truly could be A LOT of babies out there by this one donor. CCB told me that once he reached his limit of positive pregnancies they would "retire" the donor.

I am just wondering if this is what the rest of you were told too or is this a bunch of hogwash and I was just gullible? I thought CCB was one of the more highly recommended banks around. What is your take on this? I also know they have been featured on 60 minutes a number of times always (from what I have seen) in a positive light.

6/4/05	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4655

I used California Cryobank and have a fourteen YO son by Donor ###. Prior to conceiving him I had a miscarriage using their Donor ###.

Neg #1: I've called them several times through the years and they show no interest in logging any input from me about my results. I called them this week to find out my account number so I could register on their Sibling Registry, which it somehow escaped me they have. The last entry they had showing contact with me was in December 1990, which was before my son was born. They couldn't even tell me to what it pertained. I think it pertained to when I called to find out my options with regard to the remaining vials I'd had to purchase in advance of Donor ### and did not wish to use. I do recall that I was very displeased with the options presented to me. Two I remember for sure were that they simply flush the vials down the drain or donate them to research. I opted for the latter, although I had the distinct impression that they intended to flush the vials or resell them. I could get no specifics on the "research." I also think I recall that they said they could make the vials available to someone who couldn't to pay full price. I wish I knew where my notes are of that conversation, but I have many years of paperwork under archeological preservation in the recesses of my home and home-office. I know this was discussed at some point, or I wouldn't have any recall of it. I do recall that I found it absolutely abhorrent that there was no interest in finding out if there were some medical reasons relating to the Donor and/or his specific vials that may have contributed to the miscarriage. And, abominable that this Donor would be used for other women without further looking into the situation.

Neg #2: I contacted the Bank while pregnant or shortly after my son was born in an attempt to at least get a message to Donor ### to thank him. The end result of that contact was that I was threatened with a lawsuit, in writing! That letter exists someone in my archives. Let's see -- I've already used the words "abhorrent" and "abominable." For this one, "appalling" comes to mind. And, I'm only on the A's.

My son has been told the story of his conception since the 'cradle' but never really showed any serious, sustained interest in his biodad until recently. I registered on the DSR in 2003 and have had no real matches to date, although there has been contact between me and a mom who successfully has a boy with Donor ###. I haven't been able to check the CCB's Sibling Registry yet because it hasn't yet approved my registration. I knew I had to renew my efforts with regard to his biodad when, two weeks after he turned 14 on March 31st, he told me that the only thing he wants for his next birthday is to meet "my donor." That seemed to come out of the blue, but hit me like a ton of bricks. Maybe part of me realized that that load of bricks was hanging over my head all this time, waiting to fall at any time. As my son has gotten older, and his behavior more like the stereotypical teenager who's difficult to live with, I often have wondered how much of his behavior is linked to the absence of a father and/or the absence of knowledge of who his biodad is.

5/30/05	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4644

In theory, that "regulation" makes sense. In reality, the sperm banks have no idea how many children have been born from each donor. California Cryobank had no idea that I had a child until he was 5 years old. I had no idea that my doctor even used California Cryobank until that time either, so could not have reported the birth. It has been estimated by California Cryobank that only 40% of women report their live births back to the sperm banks. They have no idea then of potentially 60% of births from any given donor. For those of us who do not directly buy from the sperm bank itself, we could feasibly never tell about the birth (our doctors may not either)and it would never be a part of the supposed "record keeping". As far as the rules for different states go- that's ridiculous. California Cryobank sold sperm all over the country. How could they (or the other sperm banks) possibly know which states the offspring lived in?

3/23/05	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4383

I also wanted to share with you that California Cryobank also has an "open" donor program for those of you having this down as one of your criteria. They are highly respected and have been on 60 minutes numerous times. They have some really neat programs including their own Donor Sibling Registry.

2/16/05	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4160

I was at a Infertility Network Conference in Toronto a few years ago and met David Towles from Xytex in Georgia. We were staying in the same B&B and I watched him unload tanks from his van that he was delivering to ReproMed. During the quarantine of Canadian donor sperm a while ago, clinics were regularly receiving sperm from Xytex and other places like CCB and the Sperm Bank of California. Cryos in Denmark is shipping worldwide and setting up clinics in the US. It's like the second Viking invasion. When the directors of the UC Irvine clinic fled the country out of fear of fraud charges for using embryos contrary to their owners' wishes, most of their unclaimed embryos were delivered to Cappy Rothman at CCB, who apparently is just storing them in limbo.

Donor Michael Beany wrote, in a semi-autobiographical novel "Children of Eden," about donating at three different clinics at the same time in London during the sixties. These clinics compete with each other so I doubt they share their databases about their donors. Since the counts and quality drop with too frequent donations, I doubt this happens much or the donors would not be acceptable. Nothing theoretically stops a retired donor from donating under another ID number at another clinic after he reaches his first clinic's limit (those that have such limits). I remember an interview several years ago with a Canadian RE who said that he didn't have the resources to check out a donor's background or medical history. As he said, he was not "the morality police."

All this demonstrates the need for consistent regulation of this business/profession on an international level.

1/14/05	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3946

When I chose my son's donor CCB didn't have a baby picture available. Well low and behold they now have one, so I just purchased it. When they emailed the confirmation for the purchase the email indicated they had vials available-I totally flipped as I tried to order more right after I conceived M and they didn't have any--donor retired.

So I call CCB and they're like-yes--we have 8 vials available, but you'll need to speak to a geneticist before you can purchase them...oh no.... Well as it turns out the donor's uncle had cleft lip & palate (knew this, it was in the profile) and one of the donor children was born with it also. So since there is a possible genetic link anyone who wants to purchase the remaining vials has to sign a release form with their doctor...

Question---I really had hoped for full siblings for my son, but now I'm a little nervous about the cleft lip etc. The geneticist made it sound like they thought it was a fluke--that the chances were extremely slim it would happen again... I'm also not sure I want more children or when that will be, so this will mean storing all these vials indefinitely.

1/9/05 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3914

My CCB donor referred to himself by his donor # in his audio interview, and the CCB donor website says this: http://www.cryobankdonors.com/newdonors/index.cfm?ID=5
After becoming a qualified donor, you will be issued a donor number and you will only be identified by this number to anyone outside of the donor department. When you retire from the program, it is important that you do not forget your donor number in case you should have questions or any other reason to contact us in the future.

10/29/04 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3651

I found that CCB acted horribly irresponsibly when the donor contacted them to inform them that 2 of his grandmother's sisters had early breast cancer. They never contacted me--I only found out when I went to order more sperm and was told that he was "retired." When I pressed I was able to order more after I signed something acknowledging the information. What kind of legal requirement is there? I asked why they didn't contact all the women who purchased sperm from this donor and was told that they didn't know who had actually conceived so they weren't contacting anyone. I was impressed by the integrity of the donor but disappointed by CCB.

10/24/04 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3642

If I were you I would absolutely contact the clinic - particularly since it has been so long since you conceived your son. Laws have changed. Clinic record keeping has changed. All in the direction of releasing more medical information - and avoiding law suits. CCB didn't even know that I had delivered a healthy baby as a result of using their sperm until I contacted them - I don't remember now why I contacted them - perhaps it was to see if there was any more sperm from my donor available. Turns out he had been retired because of a genetic medical problem that was discovered some years after his donation - at least 2 children conceived with his sperm had been afflicted with this genetic disorder (fortunately not my son). The clinic (CCB) was required by law to contact the parent(s) of any children they knew had been conceived via this donor and get them specific medical information. I think you will find the clinic to be more helpful than adversarial - also, if it turns out that your son's issue is genetic in origin, the clinic has a vested interest in finding this out so that they can notify any half-sibs.

8/3/04 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3447

That's correct. Last year I had contacted CCB and they had said that they weren't taking any new clients for the program (I believed they maintained a waiting list after that). As of May, they discontinued the program altogether, although I don't believe their website reflects this. The donor coordinator told me that they had had legal actions from some clients over the program. Apparently after paying thousands of $$ to locate and reactivate the donor, and waiting many months after the donor donated for the vials to come out of quarantine, the donors weren't coming back for the follow-up testing and they weren't able to release the vials to the parents. I believe they refunded the money lost but the parents were livid because between locating the donor, testing him, having him donate and waiting 6 months to test him again, some had been waiting for a year or more for vials that they never got. You should check with them to see if there are any vials in the "sibling warehouse". Periodically someone who has a storage account may release the vials back to the bank and then they are available for purchase only by parents who already have a child with that donor. I very shockingly lucked into 6 vials from my son's donor this way in June. And even if there are none available currently, you should keep calling back periodically since you never know when vials might be released from a storage account.

8/2/04	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3446

I just got off the phone w/someone at CCB and they told me that they no longer do donor reactivations. Has anyone else heard this? The fees, etc. are still posted on their website.

7/8/04	http://health.groups.yahoo.com/group/DSR_Discussion/message/643

For any of you who used the Calif. Cryo Bank, they now offer a new service to register under your donor number to possibly get to know siblings. Not that I'm a big fan of theirs, however it may be a way to find siblings who have not yet found Wendy's site. I have to say it is very limited in scope (they have rules!!!) and there is an up-front fee of $25.00.

4/2/04	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3128

My donor is CCB. On his long form it asks if he donated at any other banks, and if so, where. He said "yes, Boston, MA." With us, he donated in Los Angeles, CA at the CCB headquarters. They also take donors out in MA, and he went to college in Boston, so I ASSUME he was with CCB in Boston, too. But I really don't know that for sure since the form doesn't say.

4/2/04	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3126

Because Kristi's questions regarding donors going to more than one cryobank is directly related to me (we seem to have used the same donor, different banks) I contacted California Cryobank. I was told that CCB does not accept donors from other banks, and they request that their donors do not go to other banks. Of course, there is no regulation of this, so CCB can't really do anything to prevent it. Also, CCB never trades/shares donors with other cryobanks to "increase their selection". CCB did buy out another cryobank in the past, however, the samples were never sold by CCB because the other cryobank they bought did not meet CCB's donor criteria. I do not represent CCB, but this is only what I was told by the person I spoke to.

3/31/04	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3119

I came across another crylabs donor's profile (CCB), and it is EXACTLY THE SAME info as our donor, used at a different lab (Zygen Labs), but in the same city/region (Southern Ca). The donor was the same age, height, weight, education/major, features, birth city and birth year and blood type. Is this strange? I thought it was weird that I had no matches under the lab I used, and now see that there are 5 other siblings with the other lab, if this is indeed our donor. I am upset that no one ever told me that donors can donate anywhere. I guess there is no way to track them! =(

3/9/04	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3065

Our CCB donor does know his number -- he introduces himself as donor ### on his audiotape. I've heard, though, that some banks either don't tell the donors their numbers or they may tell them a false number...???

2/21/04 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3019

We used a donor from the CCB and I was just curious, what else did they told you about contacting the donor? When we initially "interviewed" them, they also told us they would contact our donor when our child turns 18 but that it would be up to him if he wanted any info to be released. Recently I've been back in contact with the CCB asking if there were any plans to have our donor "come out of retirement". Not only did they say no but they said that it was not likely they could even contact him to ask for more sperm. Apparently they keep poor track of donors when they leave the program. That leaves me wondering, what's the chance they'll find him in 14 years when our daughter reaches 18.

2/21/04 http://health.groups.yahoo.com/group/DSR_Discussion/message/594

I found the information about the openness policy at the CCB website. At the site click on sperm banking on the bottom left, then click on brochures on the left. You will then see Donor Program Brochure; click on this and you will find it.

2/21/04 http://health.groups.yahoo.com/group/DSR_Discussion/message/592

I just spoke with a representative from CCB last week, and I have been told that they have an openness policy, which does allow for mutual consent contact when the child reaches the age of eighteen.

2/21/04 http://health.groups.yahoo.com/group/DSR_Discussion/message/591

My understanding is that CCB's policy has been, and still is that they will attempt contact with the donor if the child requests (when they are 18).

2/20/04 http://health.groups.yahoo.com/group/DSR_Discussion/message/590

It was my understanding, too, when I got interested in CA Cryobank that there could be contact made if both parties agreed. I now believe (and I could be wrong so correct me if I am) that they will 'attempt' to contact the donor if the child at age 18 requests it but that there is no obligation to reply on the donor's part. I've been looking at other sperm banks in case I don't get pg with those I already purchased from CA Cryobank because I'm not liking what I think I know about their policy.

2/20/04 http://health.groups.yahoo.com/group/DSR_Discussion/message/589

The one thing I would add with the Men's Health article is that, just as donors don't consider the anonymity part, as DI parents, had we known the ramifications of the anonymity aspect, we would have chosen an ID Release donor. We were very much led to believe by a representative at California Cryobank that their policy was if both parties agreed to be known, then they'd tell the child (after age 18) who the donor is. I even copied this information off of their website at the time, although the website has changed and I'm not sure if they still have anything to this effect in print any longer. We were led to believe that the policy actually meant that if our child sent a letter to the donor, then they would contact him to say there was a letter for him, and vice versa. From what I understand now, there is really no policy like this in effect at all with California Cryobank.

1/22/04 http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/2803

I used CCB and they were definitely interested in my information. I called them after I gave birth to my daughter. They asked me how many cycles it took for me to get pregnant & how many inseminations I had each cycle. I asked them whether any other births had been reported by my donor. They told me they couldn't tell me an exact number but they did tell me there were more than 2 and less than 10.

1/21/04	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/2775

FYI, California Cryobank says that they "try" and limit each donor to 15 offspring, yet only 40% of recipients report back their live births. Hmm, do the math. Those don't sound like "reasonable limits" to me. Also, no matter how well you know someone, if their parents never told them the truth about their biological origins, they'd never have a clue.

12/2/03	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/2462

CCB was updating their records from it (DSR) last summer. It's been months and I STILL think that was odd. :-o But I think mainly they live in their own self-regulated world and could care less. It hasn't affected their "bottom line" so as a business unit they have no reason to even notice. (it's easiest to understand them when you view them purely as a for profit entity, interested only in their own survival/success)

----- Original Message -----
To: DonorSiblingRegistry@yahoogroups.com
Subject: [DonorSiblingRegistry] does anyone know if any of the sperm banks know about this registry and have opinions about it? Just wondering if it impacts their policy making in any way?

8/22/03	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/1962

I have a son born 4/26/1997 with donor ### from Procreative Technologies. When I went back to try to have a sibling for him, they had moved the donor's sperm to California Cryobank and changed his number to ####. At the time (1999) they said that they had sperm available only for people who already had children with the donor. I would love to find out if my son has any half siblings.

8/16/03	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/1872

This is exactly the reason why I would never even consider CCB. A certain bank with the open i.d. policy told me that their open i.d. donors have waiting lists (I was #9 for my donor!). CCB should open their eyes and realize how much business they are losing. I just lost a baby from an ectopic pregnancy and am now forced to change banks because the bank I've been using (who shall remain nameless since they have threatened legal action against me for posting my truths/story on public forums) refuses to sell to me (they call me a dissatisfied customer). My only other options now are TSBC or PRS.

(the above is response to this message from earlier):
In a message dated 8/15/2003 2:56:55 PM Eastern Daylight Time (http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/1841), ----- writes:

> The entire purpose (focus) of this list is "to assist individuals seeking to
> make mutual consent contact with their biological relatives conceived as a
> result of sperm donation".....The EXACT thing that CCB is currently against (as
> in does not offer or advocate)........
> The only "choice" a CCB donor had was to be an anonymous donor or not be a

> donor at all. CCB guaranteed anonymity to the donor. However, they never even
> asked the donor if he DIDN'T want anonymity (as in agreeing to mutual consent
> contact when the child is 18 or similar) ....
> IMHO, offering former and current donors the *choice* to have mutual consent
> contact with their offspring is something CCB can and should do, and perhaps
> require it of future donors. Since CCB is one of the oldest and largest
> cryobanks in the world, they should be leading the pack in evolving, thereby setting
> an example for other banks to follow - not the other way
> around, as seems to
> be happening.

8/16/03	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/1870

I absolutely agree that everyone should report the birth of their child to their cryobanks but that is not all that was said in the email. Elizabeth Kim from CCB stated that through the DSR she is updating people's files. She has only email addresses to go by. That method of data collecting to me sounds preposterous. I won't find the reported live birth category very helpful now that I see how they get their info. Since she is using the data collected on the registry in a company that is definitely a for profit company, it would seem fair that they could contribute to the site.

8/16/03	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/1863

I noticed that CCB has two other locations listed on their web site other than the one I purchased from in Century City (LA area) in 1988. They have offices in Palo Alto, CA and Cambridge, MA? I seem to remember being told at the time I purchased my specimens that they only sold so many specimens in a particularly geographic area, and then shipped remaining samples across the country in an attempt to reduce the possibility or sibling marriages. From what I have been reading here about the self interest for CCB in particular I am not sure what to believe.
If this is true or partly true, it brings me to another question...
Have sperm banks been known to sell specimens to each other and then assign their own / new numbers to the vials?

8/15/03	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/1844

I loved Fairfax Cryobank and love the SIX! children (quads and twins) they gave me, BUT the policies of CCB, Fairfax, etc. are why this board is necessary. I'd much rather list my name with Fairfax using real information and have a bulletin board exclusive to legitimate, verified donors, di parents, and di siblings. Only the cryobanks themselves have enough information to separate their customers from the crazies out there. I don't mind using my real name and address on this board, but I have no guarantee that anyone posting or contacting me is the real McCoy. That said, this board is more than I had ever hoped of getting with the cryobank. And I'm very thankful for those who took the initiative to make it happen. Wish the sperm banks would provide this service. I called Fairfax today to make sure they had all my info, and they told me it was the doctor's responsibility to report births. I insisted they take my info just in case. Sorry about discussing on this loop but the subject is very pertinent to this particular group. I've never asked Fairfax for any info about donor or siblings so have no idea if they are helpful in that regard or not.

8/15/03	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/1836

I think my biggest concern is how they know that they haven't counted my child once already. How do they know by looking at my email address that I am or am not the same person in their files? They didn't ask me for my email address when I bought the vial. Even if they had, email addresses change often.

7/9/03	http://health.groups.yahoo.com/group/DSR_Discussion/message/122

It appears to me one of the line items in the CCB openness policy is in direct conflict with their client contract.
The Client agreement states:
"Client agrees that client shall not now, or at anytime, require nor expect CCB to obtain or divulge to Client the name of any donor, nor any other identifying information contained in the files of CCB. Client also agrees not to seek this information from any other source. Client agrees that following insemination and/or assisted reproductive procedures, CCB will retain all information and records which CCB may have as to the identity of the donor and the Client for a reasonable period of time, after which CCB may destroy said information and records. It is the intention of all parties that the identity of the donor and Client shall be and forever remain anonymous. CCB has an Openness Policy which allows requests for additional donor information from the adult child. Information, other than updated medical information, is provided only if there is mutual consent between the donor and adult child."
Openness policy states:
"We have never destroyed patient or donor files and plan to keep the information indefinitely."
The client agreement seems to plainly state they can destroy records at their discretion. And the client agreement is what I signed. Yet the openness policy states they keep info indefinitely (or plan to should I say). I'm guessing their openness policy resulted from pressure from the industry headed toward more openness, but their client agreement hasn't caught up with the times?? I honestly haven't been impressed with CCB's record keeping as far as accounting for pregnancy outcomes. So I guess I'm skeptical about their record-keeping in general.

5/29/03	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/1024

For those who went through California Cryobank, thought you'd be interested in the following: I called them a few days ago, and they said that they never reveal how many live births there are to anyone for a particular donor :(....they also said, that even though they too "try" to limit the number to 15, that an astonishing 60% of people who use their services fail to report back to them on pregnancies/births, so, most likely, there are more live births than 15 for each donor (possibly FAR more).....i imagine this would have to be true for any other bank as well, as no one can force someone to report a birth to a cryobank.

3/14/03	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/459

Last month I sent an email to California Cryobank, asking if they could send anyone inquiring about offspring or half siblings to our website, being that they don't facilitate a meeting process themselves. I never received a reply.

5/4/01	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/21

For those who went through California Cryobank, thought you'd be interested in the following: I called them a few days ago, and they said that they never reveal how many live births there are to anyone for a particular donor :(....they also said, that even though they too "try" to limit the number to 15, that an astonishing **60%** of people who use their services fail to report back to them on pregnancies/births, so, *most likely*, there are more live births than 15 for each donor (possibly *FAR* more).....I imagine this would have to be true for any other bank as well, as no one can *force* someone to report a birth to a cryobank.