

NEW ENGLAND CRYOGENIC CENTER (NECC)

10/20	Email to Wendy Kramer
<p>Dear Wendy,</p> <p>I have told my kids from age 3 that they could meet their father when they were 18. I realize that I was not told the truth by the cryogenic center and they are NOT going to try to make the initial contact so the twins can connect with him. I worked very closely with the owner Cathy Rizza and her deceased husband John 20 years ago. I thought this was so honest and never imagined I would be lost and not know how to finish the job and do what I promised to my kids.</p>	

6/20	Email to Wendy Kramer
<p>I turned 18 about 6 months ago and immediately called New England Cryogenic Center to see if I could begin the process of contacting my donor, who opted into the open ID program. After calling them an initial time in early January, I never heard back so I would call periodically from month to month, just trying to find someone to answer a few questions about even beginning the process of contacting my donor. There were even several occasions when the personnel who answered the phone was able to verify that my mother's record was in the system from when she obtained the sample, but told me that someone else would call me within minutes to answer my questions. Time and time again I have never received a call back, even after explaining what has happened to me. About a month ago, I received an email saying that they had received my call from January and that they had no record of my mother in the system. I am absolutely frustrated and devastated with this process so far, as it seems that they want to avoid beginning the process with me. I have heard from others that this particular cryobank tries to avoid aiding those who participate in the open ID program. I am confused about what steps to take next. I am going off to college in a few months and at least want to begin the process of finding my donor, even though I know this may not be possible.</p>	

1/20	Email to Wendy Kramer
<p>Dear Wendy,</p> <p>I hope this will be useful to other users of your site.</p> <p>I used NECC to conceive my daughter. I chose an open ID donor whom I tracked down via DNA testing and contacted when my daughter was nine.</p> <p>The donor was very receptive and he and I are now in regular contact. However, it turns out he did not know what an ID release donor was - let alone that he was one. He remembers ticking a box on the donor info form (weight/hobbies/personal message etc) indicating that he was interested in having contact with offspring when they turned eighteen but, crucially, he thought he was expressing an inclination, not making a commitment.</p> <p>The donor received no information or advice on open ID donation from NECC. He had no idea parents</p>	

would be raising their children in the certainty that he was willing to share his identity in the future. He can't remember if he was given more money by ticking this box or if this was an incentive. He is an intelligent and thoughtful person so if he missed this about open ID, it must have been very well hidden.

6/17 | Email to Wendy Kramer

As for the NECC: I emailed Caryn Levy, Sales Manager of the NECC, back in February of 2013, and here was her reply:

New England Cryogenic Center did not overtake the client records of Rocky Mountain Cryobank. We did purchase their inventory and equipment. Regrettably, we do not have any records prior to the purchase date. The original owners of Rocky Mountain Cryobank retained the client records. Please feel free to call me at [617-244-4447](tel:617-244-4447) if you have any questions.

Regards,
Caryn

Caryn Levy
Sales Manager
New England Cryogenic Center, Inc.

10/2016 | Email to Wendy Kramer

We have been trying to work with NECC to contact our identity release donor for months now and are not having any luck hearing back from them as to the status of our request except that they have the paperwork needed to move forward. Phone calls and emails are not returned. Last I heard our case had been bumped up to Kathy who I assume is Kathy Rizza. I read that other people are having similar problems. By chance, do you have any advice for us?

9/2016 | DSR Facebook Group (A reply to the posted message below this one)

I am going through this with NECC now! It is dragging out to months and I can't get any info from them as to what is taking so long. They acted like this was the first request for donor contact they had gotten.....

9/2016 | Email to Wendy Kramer

I chose a "yes" donor/donor release option, have paperwork saying the info will be released to my daughter once she's of age, yet the owner of the bank is not honoring the agreement, and wouldn't even return a phone call for months, then after one okay/civil conversation, in which she agreed to call me back with no information...completely disappeared and never called back.

8/2016	Email to Wendy Kramer
<p>A former NECC donor just called them for his donor number and was told "we don't do that". This is a deliberate attempt to keep donors from (sharing medical information with) offspring and their families.</p>	

7/12	Email to Wendy Kramer
<p>Sperm: The vials I received were low count. Not sure if this issue is from Rocky Mountain Cryobank (sold sperm to NECC), NECC, or just this particular donor.</p> <p>Customer Service: Friendly but seem uninformed. I asked them where Rocky Mountain Cryobank was and they said Colorado. Wasn't it in Wyoming? Overall they are okay. My emails for receipts and donor questions are responded to promptly.</p> <p>Billing: I was charged a \$200.00 fee that was nowhere declared on any paperwork or website. I disputed it with no resolution. No response to voice mail messages I left about this issue. I called my credit card company and reported it as fraudulent. They took it off, yet it was recharged by them because NECC had provided paperwork stating I was indeed a real client of theirs. Of course I was a real client, but the FEE was not real! I finally gave up on the issue and moved on.</p> <p>Only a year after I had my child, all the Rocky Mountain Cryo donors that had been sold to NECC were taken off the market due to various problems, including lack of genetic testing for cystic fibrosis.</p> <p>Do I wish I had spent more time and money looking at different donor profiles and banks?...yes. I got slightly biased when I saw this donor was 100% of my nationality. I feel that I chose this donor too quickly, without really knowing anything about NECC's issues, and without considering the long-term advantages of open-ID donors or checking to see if there were sibling groups already on DSR.</p> <p>My advice to anyone choosing a donor: Take your time. Don't be afraid to spend money to compare different donor profiles at different banks. It's worth it. Think long-term. Look beyond what the donor looks like on paper - consider your long-term plan about raising a donor-conceived child. If you're all about open communication with paternal relatives, then choose a donor with open-ID or one with siblings already known on DSR.</p> <p>- NECC MOM</p>	

2/18/12	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14936
<p>I am a CF carrier and especially asked the NECC if they had tested all donors for CF. They said "yes" and then recommended me a donor who had not been tested for CF. Luckily my kids do not have CF. I took court proceedings against the NECC including this matter, well before poor little Jaxson was conceived. The NECC are really evil!!!!</p>	

2/18/12	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14935
<p>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. NECC - Released cystic fibrosis positive sperm.</p>	

11/9/11	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14721
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I'm not sure obtaining non-screened free sperm via the internet is less safe than buying from some sperm banks. I bought sperm from NECC having been told it was screened for cystic fibrosis, which was important to me being a carrier, but then I found out my donor had never been screened. NECC has had at least one kid born recently with CF.

9/21/11 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14537>

Re: finding number of offspring

I have not dealt with Biogenetics. But, I have asked the same question of the New England Cryogenic Center (NECC) via phone conversation. They refused to tell me if any other children had been conceived using the same donor. I even requested this info from the Director of the bank via email and again ran into a brick wall. My daughter has been listed on the DSR for years now with no matches so, I figured I would request the info from the bank. I find that NECC is very resistant to solicitations for basic information.

9/15/11 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14497>

Since last week's NY Times article about a donor sibling group of 150, many concerned families, and some sperm banks have contacted me to find out which sperm banks produced the largest number of large half sibling groups on the DSR.

Although the DSR does have open records, that is, anyone can search through any of the sperm bank's listings on our site, here are the sperm banks that do have the most large numbers of half sibling groups that we know about on the DSR:

Fairfax, Xytex, New England Cryogenic Center (NECC), Midwest, Cryogenic Labs (CLI), and Pacific Reproductive Services (PRS). Some of these sperm banks ship sperm to small clinics and facilities around the world, so half siblings can also be in Canada, Mexico, Australia, etc.

7/25/11 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14386>

I know for a fact that three parents reported health problems with my children's donor to the NECC over a seven year period and the sperm was still sold with no information about the health issues supplied to prospective purchasers, and the sperm was not withdrawn from sale until litigation started.

6/21/11 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14243>

I'm 19 and although the clinic that my mother went to does not release names of donors I think it's reasonable to try and see if this is the guy.

4/25/11 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14115>

Donor info is often inaccurate.

Our experience with an NECC donor is that it stated on the profile that our donor had studied at Harvard, but after years of tracing (very exciting story) we found out that the donor had actually attended BU and had never been to Harvard.

Obviously the NECC thought it could get away with claiming Harvard for an anonymous donor. It's probable the NECC and other sperm banks do this on a regular basis, claiming all sorts of fantastic attributes for anonymous donors in the belief no one would catch them out.

So to enhance your probability of getting accurate info on your donor I would opt for the willing to be known.

4/8/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13125
<p>Just a warning about using an NECC sperm donor.</p> <p>Besides the fact that the NECC have been caught out several times in the past couple of years for failing to karyotype their donors and failing to screen for obvious genetic disorders, now it seems that they actively lie about their donors academics claiming falsely that their donors are Harvard educated etc.</p> <p>I used what I was told by the NECC was a Harvard donor and they told me that they had his Harvard transcript in the file, but it turns out now that my donor has been ID'd, that he never attended Harvard at all, and in fact was a student at a much less prestigious institution.</p> <p>Also, I found out that my donor is totally bald and was at the time of donating, however John Rizza at the NECC claimed he had a good head of hair and told another recipient that he had really thick hair.</p> <p>So if you don't mind having a non-screened donor healthwise, and don't mind the surprise of finding out that your donor just attended community college rather than Harvard or MIT, then go for the NECC.</p> <p>But if you want a healthy, smart and good looking donor - my best advice is to look elsewhere!</p>	

10/16/09	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/12224
<p>I believe from what I have read also that Jane Doe is taking this route because it is the only way to make necc respond. It is scary that there are no laws or agency regulating sperm banks. If there is a serious health issue that can be proven is from the donor than there should be some sort of way to make the bank report it to anyone who purchased the donors sperm and the donor. I personally have been trying to get necc to notify all parties involved with the donor I use for 1 and 1/2 years and have been put off or ignored. I have 2 children from the donor and they both have the exact same chromosomes affected. I have been tested and mine are normal. One of my children is very severely disabled due to it. Since mine are normal it is definitely from the donor. necc has all the reports etc but will do nothing. And all I want them to do is notify the people who used that donor. I don't want to know who the donor is or money or anything. I just want to prevent anyone from having to go thru what I have been through and more importantly prevent another innocent child to be born in that condition. It's heart breaking. And for the life of me I don't know what their reasoning is for not doing it. And that's where there should be something in place whether a law or an agency to regulate it. And I am always amazed about how unethical humans can be.</p>	

10/5/09	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/12175
<p>Over the years, I have heard many stories from donors, recipients and adult donor conceived people that just can't get their donor numbers from banks like Fairfax, CLI, Idant and NECC. Sometimes they just refuse, sometimes they say that they can't find the records, and sometimes they say that the records have been destroyed. I just do not understand how they can deliberately keep people from making mutual consent contact. It is incomprehensible to me that they deliberately keep people from sharing medical information.</p>	

4/25/09	Email to Wendy Kramer
<p>As a legal reproductive expert in Massachusetts law I'm writing you to warn your members about the New England Cryogenic Center's (NECC) recipient legal agreement.</p> <p>This agreement seeks to deprive recipients of every legal recourse they may have against the NECC for even the most negligent screening of a donor/sperm, or the deliberate provision of falsified information and even the intentional supply of sperm with serious genetic disorders.</p> <p>NECC is a spermbank with a horrible track record of extremely poor donor screening, procreating babies with extremely serious genetic disorders, lying about donors academics and accomplishments and flagrantly lying about their donors looks. Unfortunately, now since they've been hit with several law suits, rather than the NECC making efforts to clean up their rotten show and remove their poor quality donors, they are instead trying to wiggle out of the liability they legally have to their recipients.</p>	

In a situation where a recipient has to put absolute faith in a spermbank an trust that they will very carefully vet the donor for disease and do appropriate due diligence to make sure the donor's claims about qualifications/attainments etc are accurate (eg - ask for transcripts) a sensible recipient should make sure that she chooses only a very reliable spermbank. Because the NECC is arguably much less reliable than most other US spermbanks and in addition to that is seeking to avoid all its legal liability for the job it does, I strongly advise your members against using an NECC donor. Obviously not all NECC donors are problematic but it is frankly impossible to know from the information provided by the NECC which are healthy good looking donors with academic or other aptitudes and which are not.

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

2/10/09 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11611>

Re: Anyone Receive DSR Handout/Info from Sperm Bank?

I wanted to let you know that, when I called NECC to report my pregnancy, I asked for all of the information they had about my donor (there were one or two snippets that weren't in the profile).

Unsolicited, they referred me to the Donor Sibling Registry. I thought that was nice! I don't know if it was the result of some promotional material you sent out.

I know some people here have had negative experiences with NECC, but I have had a very good experience with them so far (and it's no longer true that there are no NECC donors represented on the registry).

10/6/08 <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.

9/28/08 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11192>

We have the exact situation you describe. NECC donor, undisclosed genetic disorder (possibly kearns sayre, we are scheduling some tests). We'd be interested in seeing what this program is about and how we could be a part of it.

9/26/08 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11175>

If you have a child with an undisclosed genetic disorder from an NECC donor, then a Harvard affiliate institution wants to hear from you. Here in Boston, a number of Harvard affiliated doctors and geneticists are so concerned about the genetic disorders reported about offspring from NECC donors, that they are putting together a program to deal with it. They are concerned to help both the children already suffering and to prevent more children being unnecessarily conceived with disease.

If you have an NECC donor child with hereditary disorders then you can respond to me directly and I'll put you in contact.

9/11/08 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11129>

RE: [DonorSiblingRegistry] Re: One NECC Parent's Story

Yes, and let us not forget that both physician and cryobank left this woman on her own--meaning that they have both evaded dealing with her and her baby. The cryobank is to blame, but also so is the dr for not being more proactive. There

should be laws that force drs to advocate on behalf of their pts instead of being allowed to ditch them. My Dr at a major teaching hospital in Boston basically said it was not his problem when NECC sold us samples that were mostly dead for both an IVF and Clomid cycle. The Dr at that clinic eventually got NECC to refund our money and told us that because of me they would no longer recommend NECC to their pts. But somehow, I don't believe them. I had to really push for this and in the process I really felt pushed out and away from both institutions. Just because the IVF clinic was able to get us a refund does not make up for the fact that

they turned us over to Pt Family Relations--a dept that deals with their "problem pts". We felt completely and utterly blown off.

9/10/08 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11114>

This is my story and I just wanted to say a few things too. To warn people not to use necc I have found out other stories and it makes me nauseous. I hope that through the work Wendy is doing and others that like someone else posted that if a problem is found all stock is pulled and everyone who ever bought is notified. I very well could be the first one it happened to but their sorry about your luck attitude is unacceptable. Naive me thought when I called them they would be like oh my god how horrible we will notify everyone right away. The sperm donor should know as well he has a sister and they are both still of childbearing age. I have to agree that trying to make sperm donors pay child support is ridiculous and just not right. However if it's ever found out that a case was reported before my daughter hell yes necc should have to pay for her medical care. And I think private insurance may be interested in that as well not just fed/state. Of course when my sons blood test came back I thought gosh he'll never be able to have kids. but a CVS can be done on each pregnancy around 7-8 wks (also on the fertilized eggs in IVF before they are put in) and since they know they are looking at chromosome 10 and 22 they can tell you if the preg is a balanced translocation or an unbalanced translocation and if it is unbalanced you can terminate very early on. I've tried to point that out to necc as well that even the healthy children need to know they have this and how it affects their life. I think if I found this out through the DSR and not them I would be calling to have a few words w/them.

9/5/08 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11099>

I am posting with the permission of this parent. Better genetic testing of donors would keep stories like this from happening. If you had a child from this donor wouldn't you want to know about this situation?
"My daughter was born in 2008 has an unbalanced translocation of chromosome 10 and 22. Specifically she has a deletion of 10 and an extra 22. It did not show up on my amnio because an amnio only tells you if your child has the rt # of chromosomes my amnio came back normal because the extra 22 was where the deletion of 10 was. She has little to no sight. Her pupils are very small and do not dilate. She has very little hearing. She cannot eat by mouth and is having a g-tube put in. she will be severely mentally retarded and probably will never walk. I never brought her home as it was too much for me to handle. Even if I was married and could stay home 24/7 it is more than I could face emotionally everyday and in the long term just too much care. I am in the process of getting her in a long term care facility for severely retarded children. And I won't even go into the hell that has been. Anyway when they finally had a diagnosis for my daughter which took about 3 weeks my son and I had our blood drawn. I came back negative and my son came back as having a balanced translocation of 10 and 22. He is totally healthy. Because his piece of 22 is on his 10 and his 10 on his 22 so nothing is missing. The geneticist said the father definitely has the balanced translocation. I called NECC to tell them this and they totally did not care because he was "sold out" I said I know I had bought the last for my daughter but I still had some left. That people could still have some left and should not have to go thru this hell. Also anyone who has healthy children need to know cause they would have the balanced translocation and their children will pass it on. It is a 50/50 chance w/each pregnancy. They were like, "Have your Dr. write us and we will contact people." I told them they needed to do it now they did not seem to think so. I called NECC a month later to see if my Dr. wrote a letter they said no and they still had not done anything. I have contacted the dr 3 times and he apparently doesn't care either. So NECC has done nothing. They did not reimburse me for sperm or anything. I have not had the time or energy to go much further than posting it on the registry. I just hope and pray that people will see it. I can't tell you the hell I have been through. It is worse than your child dying in my opinion. and I know there was over 70 vials of sperm when I bought some for my son. I just have a hard time believing my daughter was the first. Oh well I can't go there. Sorry I wrote a book. If you need anymore details or anything please let me know. Thanks for what you are doing."

9/3/08 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11087>

Re: Questions about NECC and Rocky Mtn Cryobank
You can try talking to Maureen Burke at the NECC. She will need your donor #, and she can help see what is available.

She also suggested having our treating physician write a letter to the Medical Director, Dr. Robert Newton, explaining the situation and what information they would need.

Their address is:

New England Cryogenic Center, Inc.

153 Needham St, Bldg #1

Newton, MA 02464

Maureen's e-mail is: mburke@necryogenic.com

Can I ask what issues your children have? My daughter, born using sperm from NECC, has very poor eyesight, sever sensorineural hearing loss, and very low muscle tone. The first thing we ever noticed was nystagmus at about 4 months.

If you want, you can send me a private e-mail with your donor#. If they happen to be the same, I think that could be important.

--- In DonorSiblingRegistry@yahoogroups.com, t wrote:

- > My children's donor came from Rocky Mtn Cryobank but was purchased by
- > me from NECC. My children's stem cells are also stored at NECC
- > currently. However, I saw in some recent posts that NECC is being
- > sued and lost licensing however on their website it shows that they
- > are licensed. How do I know for sure what is real and what isn't on
- > their site?
- > Also, the reason that I have begun to research this further is b/c my
- > children are starting to show signs of some neurological issues. Our
- > donor profile doesn't show any indication that this condition comes
- > from the donor's side but we know that could be in error especially
- > since NECC purchased my donor from another clinic (which we didn't
- > know until after our children were born).
- > Can anyone give me information on how to begin the process of finding
- > out more information on my donor from NECC? Who should I ask to speak
- > with and what specific questions should I ask?

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:

-NECC confirmed that donors do in fact come from Rocky Mountian Cryobank. They also said that one donor's remaining inventory was sold to Fletcher Allen (FAHC) in Vermont. Fletcher Allen used to be University Health Center.

7/08

DSR website post

Major chromosomal defect definitely from donor. Do not use sperm. Healthy children are definitely carrying it, and will pass it on. Medical needs are so great you will not be able to care for the child. Please contact me for more info. Even if you have healthy children they do have it and will pass it on. Each preg has a 50/50 chance of it happening. NECC is not doing their job of getting the info out.

3/27/08

<http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10313>

I used a donor from NECC before joining the DSR. I chose a release of identity donor. From reading some of the messages it occurred to me that I may not have all the info I need from NECC. Sure enough, when I look on the NECC website there is a consent form to fill in for release of identity. They never sent this to me. It also says on the form that you need to send certified copy of birth certificate before 6 months. My twins are 7.5 months.

3/7/08

Email to Wendy Kramer

I also had four vials of low counts - 8,000 - 13,000 I think, IUI - from NECC. the paperwork says they guarantee 10,000 -but refused me a refund for the 8,000 for reasons I did not fully understand (because they did not fully make sense). Had to chase them for several months even to get that refusal. I would not recommend NECC because they are murky - even though they have given me lovely children and I do not believe they lied about my donor characteristics.

3/6/08 | Email to Wendy Kramer

I wondered if you had heard anything about NECC in particular that would relate to me signing or not signing a document.

The whole situation is so bizarre. NECC sell the sperm as open ID without making recipients sign a contract. And then don't tell the recipients that they need to sign an agreement if they want to receive identifying information about the donor when the children turn 18.

In my case (and I tell you this in case you haven't heard of it before) I notified the sperm bank of my babies birth when they were a few months old, and received an e-mail saying 'thank you'. A few weeks later I wrote back and asked what my children should do when they turned 18 if they wanted identifying information. I was told: 'oh you have to sign this paperwork saying you are part of the open ID programme, and we have to receive it before the babies are six months old. It seemed pretty odd that they hadn't told me this earlier - and only volunteered it when I asked.

I downloaded the forms from the internet which included clauses like you waive the right to receive information about the donor etc. But it was clear the contract was intended for recipients to sign BEFORE they even receive the sperm from NECC - indeed, it reads as if signing it is a condition of receiving the sperm.

What are NECC up to? Did they only recently introduce this contract? Are they trying to make it come into effect retrospectively? Can they do this?

I have met three other new NECC mothers who specifically chose an open ID donor and yet did not know that they were meant to have signed a contract. Does that mean that they are not part of the open identity programme, even though they were specifically sold the sperm as open identity? And can NECC legally sell the sperm as open ID and then afterwards say that as a condition of receiving identifying information it is necessary to sign a form that should clearly have been signed before the sperm was even sent out.. and in addition make no effort whatsoever to make sure that the recipients even know that an agreement even exists?

NECC do seem both dodgy and incompetent.

3/6/08 | Email to Wendy Kramer

The issues of NECC as I have heard from other Moms are:

- 1) John Rizza and staff will cut off contact with you as soon as you raise a concern. No return calls, No response to letters etc. A half sibling has a profile and his states that the donor is a NO donor. My profile states he is a YES donor.
- 2) Many women are noticing discrepancies on profiles given to women using the same donor/also the same women who ask for a profile of the same donor (request made years apart) are given profiles with differing info on it..big stuff such as where they went to college, hobbies, grades etc.
- 3) The open release issue has been very shady with many women...some get contracts, some don't, some are told their donor is identity release, some aren't (same donor)a few women noticed that online donor catalog lists their donor as a NO donor, they think they got a YES donor. One woman called NECC and was told it was a typo, then the donor was mysteriously no longer on the catalog online??(kind of a serious typo don't you think??)
- 4) Two women were promised a phone call from the same donor to be handled thru John Rizza...they both got a separate call from the same donor and exchanged notes...both felt very strongly that it was two separate men they talked to. They felt it was an imposter acting like a donor.
- 5) One woman knew she didn't get the correct donor as promised on the profile based on genetics...eye color was impossible based on her eyes and the donor eye color listed on the profile....resulting in a child who had eye color only possible from a donor with different eye color than stated on the profile.
- 6) one woman picked a donor who agreed to a phone call..she later tried to get that phone call ad then was told "we don't do that anymore" even though it was promised to her prior.

7) the list of donors I was told were YES donors were all later listed in the online catalog as NO donors many years later. A little too coincidental??

8) Not one donor is listed on the NECC DSR site. Why??

Also someone heard finally from a NECC donor himself who had been posted on another site...she wrote to him and asked some questions...he also felt something was wrong over there as he was often told his sperm count was too low and they couldn't pay him for his sperm, he got a look at his chart and all the numbers were very high, later he went to CCB and never ever had a low sperm count. He assumed they were ripping him off and lying to get out of paying him. He has been encouraged to join the DSR, but is reluctant, not sure why.

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.

2/8/08 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9841>

Did you use the NECC and have you experienced any problems?

Did you receive poor quality sperm, with a low sperm count and poor motility and did they refuse you refund?

Did they reverse your donor's status from willing to be known to anonymous?

Did they tell you a donor was willing to be known when he was not?

Did they lie to you about donor attributes? Did they claim height, fantastic looks, Havard/MIT, brilliant health but the reality is very different?

Did you feel pressured and pushed into selecting a particular donor?

Were you dissuaded from using your preferred donor by seriously negative comment about him only to find out that other women were given a rave review of the same guy?

Does your child have any hereditary disorder from the donor not mentioned on the profile?

Is your child autistic?

If you experienced any of the above (or something else stemming from deceit, misdescription, negligence or outrageous behaviour) you may be eligible to join in litigation against the NECC and receive compensation. Most importantly, through taking action you might get them to change their ways so that fewer people have to suffer as you have done!

2/8/08 http://health.groups.yahoo.com/group/DSR_Discussion/message/4412

Re: NECC - the donor perspective

I was horrified to find out that in fact to make his donations he just walked in and wrote on a label his ID and date of birth and jerked off into the cup without even seeing anyone. Under such a system a man could send in friends to donate for him when he can't make his contractual commitment of ten times a month. That could account for the fact that CaBRI has found out that not all donor offspring from the same donor are genetically related.

- > They never even asked for ID such as a drivers 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.

2/8/08 http://health.groups.yahoo.com/group/DSR_Discussion/message/4411

> are you sure this donor is for real, and not an
> imposter playing a prank on you?

I am 100% this donor is for real since I had his profile and he had been off the list for several years, so I could verify he was the donor, plus knew a lot about the procedure which only someone acquainted with the system could know.

2/7/08 | http://health.groups.yahoo.com/group/DSR_Discussion/message/4404

Are you sure this donor is for real, and not an imposter playing a prank on you?

If there is fraud involved, I think it will come to light soon, because the DNA genealogical databases make it easy to track down donors ... and then we can just research our donors and find out if we were lied to. If the sperm banks did in fact use donor anonymity to defraud the public, I imagine there will be a flood of litigation. If I ever find out that our donor did not go to MIT, I might sue for consumer fraud.

I remember calling a California sperm bank when I was shopping around for a sperm bank ... and I asked them if they verified the academic credentials of their donors And they said "no, we just take their word for it." this alarmed me, so I looked elsewhere for a sperm bank, and eventually chose NECC. I picked NECC because John Rizza told me he personally checked the academic transcripts of every donor!

I intend to find out if he told the truth!

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 276 kidney disease in the Johnson case. We also know that International Cryogenics (the Michigan Sperm bank) 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 up 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 sperm banks operate more competently.

2/6/08 | http://health.groups.yahoo.com/group/DSR_Discussion/message/4400

After all my various postings regarding my concerns about the NECC screening of donors I have finally been in contact with a former NECC donor who has told me about how the whole screening process went for him. Some of my worst fears have been confirmed. Apparently, absolutely nothing is verified by the NECC, and donors can just randomly claim academic credentials /school attendance without the NECC ever bothering to check. However, when I had inquired about how the NECC verifies academic claims John Rizza had explicitly told me that the NECC required the production of transcripts. Yet this donor told me that in his two years of donating he was never asked for transcripts or even any ID at all. He could have claimed to be anyone and the NECC would never be the wiser.

I say as I have said so often, such poor screening is not good at all and this market must be regulated.

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

1/28/08 | http://health.groups.yahoo.com/group/DSR_Discussion/message/4374

If you are interested in using a willing to be known donor then I would strongly caution you against using the NECC since they allow their donors to opt out of ID release at will.

The NECC are also TERRIBLE at screening. Their profiles are strongly fictitious. Their oral advice is also highly manipulative and deceitful. For example they told three of us who chose the same donor completely

different info on our donor's occupational activities. Also they have no discernment about looks at all. They do not disqualify a donor even if he has really odd features.

1/6/08 | http://health.groups.yahoo.com/group/DSR_Discussion/message/4297

No, I've got no gag order on me but I'm not involved in this issue at all. All I know is that I'm desperate to find out the true health status of my donor (on his profile all members of his huge extended family had flawless health) but the NECC has over the course of two years hired no less than five (5) partners of terribly expensive law firms to oppose my attempts at gaining insight into my daughters health problem. All of you buying sperm from the NECC should be aware that they regard the health privacy of their donors as much more important than their offsprings' health. You should also be aware that the NECC allow their donors to opt out of willing to be known status. The NECC are total scoundrels!

--- In DSR_Discussion:

- > why hasn't t chimed in about this? i wonder if
- > NECC slapped a gag order on her.

1/2/08 | http://health.groups.yahoo.com/group/DSR_Discussion/message/4289

I thought I better post the entire article, because www.boston.com has already taken the link down for the article (it was only up for a few hours early this morning).

http://www.boston.com/business/globe/articles/2008/01/02/cord_blood_bank_sued_by_former_employee/ [or <http://tinyurl.com/2upthm>]

Cord blood bank sued by former employee

Firm denies lab chief was fired for blowing whistle on quality.

By Todd Wallack

Globe Staff / January 2, 2008

The former lab director for a Newton company that stores newborns' umbilical cord blood claims he was fired after blowing the whistle on problems with the company's quality controls.

Peter Mecenias, the former laboratory director of New England Cord Blood Bank Inc., says he called federal and state regulators to complain about issues with the company's quality checks on Sept. 12. The next day, Mecenias says, he was fired and escorted out the door, according to a lawsuit he filed against the company on Dec. 18.

But John Rizza, president and owner of the blood bank, says he was unaware Mecenias had called regulators at the time. He said Mecenias was let go after the blood bank lost its accreditation with the American Association of Blood Banks, an industry trade group. Since replacing Mecenias, Rizza said, the organization is on track to regaining its AABB accreditation as early as this month. The AABB declined to discuss why it pulled the blood bank's accreditation in August or to say when it might be restored.

The suit, filed in Middlesex Superior Court, comes at a time when the business of storing babies' cord blood is gaining steam. Last month, PerkinElmer Inc. in Waltham completed a \$300 million deal to buy ViaCell Inc. of Cambridge, largely for its cord blood banking business, called ViaCord, which generated \$70 million in business last year.

Though it is still a niche business, a growing number of affluent families are paying thousands of dollars to store their newborn's cord blood in case the child needs it later in life. Umbilical stem cells are used to help treat more than 40 diseases, including blood cancers and genetic diseases, raising hope that cord blood could one day become an alternative to bone marrow transplants or other treatments for serious diseases.

PerkinElmer officials estimated that 85 percent of the market is shared by three companies, PerkinElmer's ViaCord, Cryo-Cell International, and Cord Blood Registry Inc. But there also are numerous smaller players scattered around the country, such as New England Cord Blood Bank.

In his lawsuit, Mecenias said he called the AABB, the Food and Drug Administration, and New York State licensing authorities in September to alert them about ongoing problems with the company's quality control system. In addition, he said he was concerned that the blood bank was continuing to claim it was accredited by the AABB, after it lost certification.

In the lawsuit, Mecenias said he feared he could face civil or criminal penalties because the organization wasn't in compliance with federal and state regulations. Still, the suit doesn't allege that he thought any blood was contaminated or mishandled. Rather, Mecenias was concerned the company didn't have the quality controls needed to ensure employees always followed the proper procedures for handling the blood,

his attorney said.

"It's a verification issue," said Jo Ann Jorge, an attorney with Gleason & Gleason in Ashland.

Rizza downplayed the safety concerns. "There's never been a question about the actual procedures," Rizza said. The problem was "we didn't have enough documentation."

Mecenas, who was paid \$90,000 a year, is seeking lost wages, money for emotional distress, and other damages. He is also suing for damage to his reputation, saying Rizza falsely blamed him for the company's loss of accreditation.

In addition to suing the cord blood bank, he is also suing Rizza and a related company, the new England Cryogenic Center Inc. Last year, Mecenas also oversaw the lab operations at the Cryogenic Center, which is run by Rizza's wife, Catherine Rizza, and also based in Newton.

Rizza called the lawsuit "frivolous." And a judge has not yet ruled whether any of the allegations have merit. It is unclear whether any regulators are looking into Mecenas's allegations.

A spokesman for the New York Department of Health said the state hasn't received any written complaints about the company and will not investigate nonwritten allegations.

An FDA spokeswoman said she couldn't comment on whether the agency is looking into any complaints.

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1/2/08

http://health.groups.yahoo.com/group/DSR_Discussion/message/4286

Maybe t has been right about NECC all along!

This article was on www.boston.com this morning. NECC's cord blood bank lost its accreditation after a whistle blower in the company (their own lab director!) called regulators to report violations. NECC promptly fired the guy, and now he's suing. Sounds like he has a nice whistle-blower lawsuit too.

[http://www.boston.com/business/globe/articles/2008/01/02/cord blood bank sued by former employee/](http://www.boston.com/business/globe/articles/2008/01/02/cord%20blood%20bank%20sued%20by%20former%20employee/) [or <http://tinyurl.com/2upthm>]

1/2/08

<http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9490>

This article was on www.boston.com this morning. NECC's cord blood bank lost its accreditation after a whistle blower in the company (their own lab director!) called regulators to report violations. NECC promptly fired the guy, and now he's suing. Sounds like he has a nice whistle-blower lawsuit too.

[http://www.boston.com/business/globe/articles/2008/01/02/cord blood bank sued by former employee/](http://www.boston.com/business/globe/articles/2008/01/02/cord%20blood%20bank%20sued%20by%20former%20employee/)
[or <http://tinyurl.com/2upthm>]

12/19/07

<http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9315>

It is the greatest sadness of my life that I conceived children through using a donor. I spent three years in making the decision and especially sought out a willing to be known donor and searched for the healthiest donor that I could find. Unfortunately I entrusted an extremely dishonest sperm bank (the NECC) with helping me select a donor and despite their assurances that the donor wanted to have contact with future children, it appears that it was little more than a ploy to get me to select him. My kids also have very significant lifelong and hereditary problems which were not divulged at all in the profile. They are only in the 1st and 3rd percentiles for height and never stop being teased about being so small. Since I especially chose an above average height donor I also believe that they lied to me about his height.

I honestly believe that having my children this way was the very worst decision that I ever made. Putting my trust in a sperm bank was so irresponsible that I feel that I can never forgive myself for giving my children the very worst start in life!

I would urge anyone considering using a sperm donor to think about the consequences of relying upon strangers to help you select a father for your future children. I and many other women I have spoken to you have immense regret for having founded a family this way. Sperm banks are businesses first and foremost and will lie at the drop of a hat just to make money, even if they destroy your life and create children with significant problems in the process.

12/7/07

Email to Wendy Kramer

I am responding to your request of reporting sperm bank experiences but would like to remain anonymous to the public.

We used an ID release donor from NECC to conceive our 10 months old healthy daughter.

We first bought sperm from NECC in February of 2005. The sales manager was very responsive to our few questions (like many folks we didn't really have a deeper understanding of what's important to ask) and it took surprisingly few paper work to get the sperm shipped to Germany. What took forever was the refund of our tank deposit (\$850), nearly 6 months although the tank was send back the week after delivery. For this I had to call repeatedly, sent emails and got few -responses. I reported a miscarried pregnancy and bought more sperm in November of 2005. Again, when purchasing sperm we were treated in a personal and nice manner. The tank deposit of the November 2005 delivery was reimbursed partially only after endless phone calls to sales managers, billing directors and whom not. In the end they always say they depend on Fedex bills to refund tank deposits apart from the fact that there already is an international shipping fee of \$450. I don't get it. I waited forever for the remaining money to learn about a year and a half later that after the Fedex bill there wasn't any money left to refund but NECC never bothered to inform me!

I bought sperm for a sibling in July of 2006 which I had shipped to Germany in March of 2007 and have not received the tank deposit back... During my last attempts to contact NECC it was obvious I was bounced at the front desk, I never succeeded in talking to someone responsible in person, they were always away from their desks, up to the point that the receptionist asked back whether I was calling about a tank deposit... I had questions about their ID release program and other things related to the birth of our daughter and was able to receive a prompt response via email. They don't tell the number of life births of the donor (as you know).

For ID release donors there are specific forms to fill out, to report the birth of the child, send documentation etc. They only tell if asked, they don't send the papers with the sperm or upon report of the pregnancy or birth. I didn't receive a confirmation of having used and ID release donor or of having reported the birth of our daughter correctly, respectively. I am suspicious but have no facts. We asked for an affidavit for adoption purposes to state that we used a specific ID release donor and reported the birth of our daughter but only received a general statement that we bought anonymous! donor sperm and couldn't learn the identity of the donor (which is partly true because only our daughter supposedly can...). However, the affidavit was in the mail within days of requesting it.

About the sperm quality, it seems that they are ok. For the second pregnancy I had samples prepared for IUI by an RE and they said sperm had enough motility to use just one vial and I got pregnant using just one vial with one insemination per cycle. (The first pregnancy was conceived after four at home ICI inseminations which I think is ok and also means the sperm was ok.)

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 case raises the issue of the spermbanks 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 spermbank 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 spermbanks putting at risk our children's health there is absolutely dire and urgent need for FDA regulation. The spermbanks 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.

10/29/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/4103

I would suggest that with an open donor the sperm banks would be less likely to fabricate information since you will almost certainly uncover the truth. I would certainly avoid the NECC. I used them and was told that my donor was willing to have contact but they later reneged on that. They also withdrew "willing to be known" status from at least one other donor. My kids and their cohort have also got lots of health problems and John Rizza a director told me that he was one of their top five ever donors - so go figure! The NECC also do not appear to disclose adverse issues being reported about offspring - I pretended to be making inquiries about my donor years after I and other mothers had reported problems and was told that "there were no notations on the file". I would recommend PRS since all the reports I have heard about them suggest openness and honesty. I would also consider purchasing excess sperm from someone who has healthy kids already. Just join the DSR and make a search for extra vials. It's easy and a side benefit is getting to peruse the profile for free.

- > Reading messages about people that have felt/know that have been
- > lied to about their donor is making me so nervous. I know there is
- > no way to gurantae anything even if my husband and i were able to
- > conceive, but i would expect some assurance that all the info
- > provided i truthful.

10/21/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/4072

...This is a continuation of a thread that was removed from the DSR board, because it didn't belong there. We used a sperm donor from NECC. In his profile, his height was listed as 5'-11". I am 5'-6" (and there are no short people in our family -- my sister is 6'-0, and my brother is 6'-2"). My son is turning out to be short (not that I am complaining -- I prefer men of average height over tall men). But I don't like the idea of possibly being lied to! Online, there are a few height-growth calculators that predict a child's adult height based on either genetics, or growth history. I used both. The "genetics" calculator says my son should be 5-11" as an adult. But the "growth history" calculator says my son will only be 5'-8" as an adult. I believe the later one, because my son has always been in the 25-40%ile for height at his annual physicals. However, I looked at our donor's profile last night, and I saw that one of his grandfathers was only 5'-6". I didn't notice this when I purchased his sperm. Regardless, I am thrilled with the child I have, and I don't care if he turns out to be short. And I am so grateful to our donor for donating, even if he might have had traits of Asperger's.

10/19/07 | Email to Wendy Kramer

My son (from a NECC donor) was diagnosed with Asperger's syndrome in kindergarten. However, he got a lot better in the first grade, so the diagnosis was taken away. Anyway, I must tell you about the way NECC acted, once I called them to report health problems with my son. NECC kept selling our donor's sperm. And they did not record anything I said, because I would call back later, and pretend to be a new customer interested in purchasing our donor's sperm... and they would tell me that all his reported offspring were healthy! NOT! Since then, I have talked to 2 other NECC mothers over the phone who I met on the DSR site, and they had stories similar to mine. My son is doing great today, and I am feeling a lot better about using a sperm donor. But he was a really difficult child to raise until he was about 5 or 6 years old, and I often wondered if our donor had good mental health.

I would never choose an unknown donor if I had it to do over again, because it's impossible to vet out a person's mental health by using a donor catalog, and I don't trust the sperm banks to do a thorough investigation.

10/17/07 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9105>

I've written before about the medical problems that I and another mother have had with our NECC conceived children and the absolute non-response by the NECC. Now we've found out that our little girls (four of them) are only estimated to attain an adult height of between 4'10" and 5'. Our donor was allegedly 5'10" - 5'11" and we are 5'2" and 5'3". Going on our heights and his alleged height our daughters should statistically be around 5'4" in height, give or take two inches either way. Growth hormone treatment (costing \$40,000 a year and requiring twice daily injections into the stomach) might be possible but only if certain guidelines are met. Firstly, there is only treatment given if there is growth hormone deficit since if there is no lack of growth hormone being produced then there is no deficit of that and the reason for the shortness is not lack of growth hormone. However, growth hormone which is generally only produced in deep sleep is extremely hard to test for since its production is fleeting. Hence, doctors tend to rule out growth hormone deficit more than ruling it in, in their analysis. As a result there is no treatment for children with idiopathic short stature which is translatable to familial short stature. The reason for that is because if the parents are very short then it is not a lack of growth hormone causing the problem but just short genes. Because of my height and my donor's alleged height my children would not normally be considered to have idiopathic short stature but the fact that there are actually four girls all with such extreme short stature is statistically highly improbable and the doctor is thus extremely suspicious that in fact our donor was of extremely short stature himself, possibly only 5' or slightly taller. As a consequence I've been trying to obtain confirmation of our donor's actual height from the NECC but they have not been forthcoming with the information. In fact, for almost two years I have been trying to find out accurate height information along with other personal and health information which I am pretty certain was grossly misrepresented on the profile. I have even pursued litigation to try and obtain that information but the NECC have fought such litigation with a big highly paid legal team saying that the information is private and confidential to the donor.

10/11/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/4057

I chose a donor basing great weight upon the health history. I chose a donor who had six siblings, parents and three grandparents who were all in allegedly perfect health. Only his grandfather had ever suffered any type of medical problem and that was a heart attack at age 84. The whole family also allegedly had perfect vision and teeth. So the outcome, two of the offspring (girls are autistic) one is legally blind, several have features of ectodermal dysplasia (missing, weak and mis-shapen teeth, sparse slow growing hair, fragile negligibly growing nails, discolored skin) voice disorders, and now one girl has been diagnosed with extreme short stature (adult height expected of only 4'9") and will have to spend the next ten years having to be injected twice a day in the stomach with growth hormone. So one can only rely on the profile information if the supplier is reliable, and the spermbanks have no incentive to be reliable until they are made accountable! I'm sure the NECC feel that all mine and the other mothers' grief was worth the couple of thousand dollars that they screwed us for in selling us their completely defectively screened sperm. Of course profit has to be put on the highest priority for them! The fact that five girls have no real quality of life or future prospects is probably of meaningless concern for them. I have never received any apology from them. They have behaved at all times with the highest level of arrogance, contempt and utter and absolute disregard of the grief, despair, unhappiness and utter distress that they have put me and other women through.

10/1/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3992

I think that you are very wise to be seeking feedback prior to making a decision about which sperm bank to use. The choice of sperm bank 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 sperm bank 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 and use the search facility to check out the names of sperm banks you might want to use. Note carefully the negative feedback. In general you can pretty much ignore positive feedback since all sperm banks have great customer service upfront and 96% of children are born normal. So even if the sperm banks didn't screen at all, then nineteen out of every twenty kids from their sperm would be born just fine. Sperm banks should be screening their donors at a level to significantly reduce the incidence of hereditary disorders.

A very important factor you should consider is if the sperm bank take affected donor sperm out of circulation when congenital abnormalities 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.

Sperm banks 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.

- > Right now I'm still trying to decide on a sperm bank. I know this
- > site is mainly for the purpose of contacting other possible siblings
- > and families, so I'm hoping no one minds, but is there any chance
- > anyone on here has had recent experience with either Northwest
- > Andrology and Cryobank (Spokane, WA) or Zygen Laboratories and
- > Cryobank?

9/7/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3919

As far as I see it, sperm banks have absolute obligations that are not dependent upon their customers conduct.

Those obligations are honesty and full disclosure. The sperm banks must represent their donors' health, family background, attributes and negative aspects honestly and fully. The sperm banks also should not switch a willing to be known donor to an anonymous one.

My gripe against the NECC is for their dishonesty and deception. Let the NECC sell ugly, unhealthy, sexually perverted donors' sperm as much as much as they want. However, they should represent those donors honestly and not pretend that they are handsome, healthy men of excellent character. Real lives and real families are created by the sperm banks! They should realize that their responsibility extends further than just turning a profit!

- > > ---c wrote:
- > > > Actually the problem as I see it is related to all the talk on
- > > > this list about the Sperm Banks not living up to their
- > > > agreements/commitments. It is not reasonable for individuals to
- > > > expect the Sperm Banks to do so if they are not willing to.

7/27/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3701

The fundamental aspect of my case against the NECC and donor is not my daughters' medical issues - it is the lying.

The minimum someone should expect when they are selecting a donor on the basis of what amounts to

pretty scanty information on a profile, is that the info supplied to them is accurate. If the profile is inaccurate, incomplete and fabricated from start to finish - then that is not only dishonest of the donor/spermbank but highly disrespectful to the unwitting recipient who considers each profile very carefully and makes her selection with such careful fine balancing of all the factors. Obviously, if all goes well the recipient when she finds out might choose to forgive and forget (some do - some don't!) but if like me one finds out that the agonizing decision made in the torment of selection was based upon utter fiction - it's really upsetting! It is in my view entirely unconscionable to take advantage of anonymity by lying to an innocent trusting woman who has made the already seriously difficult and often painful decision to conceive through a man unknown to her!

7/25/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3683

One of the most shocking things for me is the fact that when I found out that my donor had not provided an accurate medical profile, I spent years requesting the real medical facts from the NECC only to have them ignore me. Then when I went to court to ask for medical info, the NECC assembled a big team of lawyers to argue that a donor's medical information is privileged and that he has/had no obligation to disclose it. **THEY DID NOT CARE ABOUT MY KIDS AT ALL ONLY THE DONOR'S RIGHT TO LIE!** Obviously, the fact that they are defending the donor's right not to have made accurate disclosure is scandalous. It also makes me wonder what further medical problems have not been disclosed and whether it is actually the donor or the NECC that have not disclosed the info.

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.

7/24/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3667

> It seems to me the NECC gross negligence does warrant a lawsuit. I
> also think some discretion is in the best interest of these children.
> This is a horrible situation for both the mom and the children. The
> sense of outrage is a reasonable response to such irresponsibility on
> the part of an individual and a business. But I would be very careful
> not to let the anger cloud judgment on how best to respond to this
> situation.
The NECC have essentially forced me into suing them before the camera lenses. I previously initiated litigation against them that I agreed to have embargoed by the court (ie. no one has access to the file except

the parties) but that was just carte blanche for the NECC to assemble a huge team of expensive lawyers to delay having my claim heard or any progress by putting in loads of irrelevant motions and eventually I tripped up in responding to a motion and my claim got dismissed on procedural grounds. This time around if they want to pursue those tactics the camera will record it.

7/24/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3663

>You have not addressed the question of how you are going to prevent the litigation and the media coverage from having a negative impact on your children. Suing the bank and the donor has a very clear implication that you are not delighted to have the children whom you have. Furthermore, your statements make it clear that you have an extremely negative attitude toward their biological father.

Well, if the donor had shown even the remotest slightest interest in the welfare of my children then I might have hesitated to sue him. But he has shown complete disregard for their welfare and through lawyers has stated that he is ashamed and embarrassed of their existence and that he is not prepared to supply any accurate medical information and that he considers his medical privacy as paramount.

This was a donor that the NECC told me was willing to be known!

My suing the donor is intended partly as a demonstration to my daughters that I take my responsibilities as a mother very seriously and that I tried to choose the person with the very best characteristics, health, family background and known status.

7/23/07 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8718>

Anyone who used NECC may want to get the DNA test via CABRI labs. As many women have had serious questions about the validity of what is on the donor profile, it is smart to begin a cross referencing data base. NECC donor profiles sound quite similar with just a few minor changes here and there. Your child may be related to siblings who have different donor numbers. I know some of us have strong feelings about some of the posts that are written by someone who sounds angry, but she is not the only one who is really disturbed by behavior of NECC. Some of us are equally upset, but are keeping a lower profile. The more info out there (DNA) the better we will be able to clarify some of the questions we have about NECC. Of course, if NECC ever decided to return a call or a letter they could end the mystery that exists. So for all you NECC lurkers, the numbers are growing, you may want to rethink your avoidance tactics.

7/23/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3659

Obviously if I was having sex with someone then even if he was a pathological liar etc I would be with him because I liked being with him and found him attractive. However, in the case of a sperm donor that I never met, I could only select him by considering things that he told me about in his profile, and my sperm donor lied throughout his profile and about many things that made me choose him above others.

Let me point out that I very reluctantly declined other donors whose ethnicity, height, interests etc were more appealing because of the exceptional matters that my donor lied about.

The very fact that the sperm donor is not a legal father makes it right and appropriate for me to sue him. I'm suing him because by his deliberate lies he fraudulently stole my reproductive opportunity by getting me to use his seed rather than someone who really had the characteristics, health and family background that he fabricated.

I spent years considering using donors - in the end I chose to do so in order to get the very best start in life for my children! I did not do it to subsidise a lying bastard's masturbatory activity!

(The above is in reply to this message):

> Using a sperm donor was the risk you took when you decided to have a child in that fashion. How could you have guaranteed that a male partner you were married to or even someone you picked up in a bar (a la 'Knocked Up') did not have genetic issues and was a pathological liar? Suing the sperm bank is one matter if they deliberately lied to you, but the donor... And the sperm donor is not a father. If you wanted a "father" and not someone who was giving you "wasted ejaculate", you could have found 1) another husband/partner 2) adoption, 3) embryo donation. Blaming faulty genes and trying to turn this "donor" into a father is pretty reprehensible.

7/22/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3642

There are definitely risks when you decide to use a sperm donor - agreed. That said we don't expect to be deliberately lied to by sperm banks.
I was going to use an NECC donor. He was a Berkley grad and KD. For a number of reasons, I never went forward with the donor. Four years later I again was looking for a donor. I decided to look into the same donor again. By that time we had moved and it was easier to have NECC fax over another long form than to wade through paperwork in the basement.
Surprise Surprise! That donor had mysteriously become an Anonymous donor who attended Boston University. Other characteristics had remained constant.
I cannot speak to whether or not S's donor lied on his profile, but there is little doubt in my mind that NECC would fudge paperwork to make him a more attractive donor.
I seriously considered three donors from NECC - they all had the exact same SAT scores. Exact. Coincidence? I don't know.

7/20/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3621

I posted a while ago about litigation that I was involved in against the NECC, and invited others with their own issues against the NECC to be in contact and possibly to join forces. As an outcome, I've spoken to around a half-dozen women with a range of legal issues against the NECC. Common themes are inaccurate information, withdrawal of open donor status, and no response to communications sent to the NECC.
Well, I'm set to proceed on possibly the first type of litigation of its kind in the USA. Without letting up on the NECC whom I regard as dishonest cowboys, I'm also going to be suing the donor together with another recipient. After all, the donor was basically a pathological liar in the information he gave about himself and his family. I'm in the position to do so because I have succeeded in identifying the donor.
I'll be embarking on this litigation with a documentary camera crew shadowing me. The director who'll be producing has won major accolades for his previous productions including two movies which have been shown in mainstream cinemas. My story will be a docu-story, and is intended to be produced for cinematic release as well as later showings on TV/cable.
I'm hoping to make the viewing compelling so as to drive home the message to the American public that this is an unregulated industry with very serious consequences. Donors who are liars are causing massive harm and distress, and sperm banks that put profit before standards are creating enormous liabilities for the health of the American population. Ultimately I will show how the American taxpayer has to fund the cost of a donor disseminating hereditary disease since disabled children need very expensive medical care, state funded special care, disability benefits and special grants. The costs amounting to the tax payer for caring for even a handful of my donor's offspring is close to a million bucks a year.
We are still interested in hearing from others who have suffered at the hands of the NECC. If you have a child with a hereditary disability from an NECC donor, and want your donor traced to check out the veracity of his profile, the film-makers will pay for the costs of doing that. The only proviso is that you have to let the camera crew film you. You will also have the option of having litigation funded to sue the NECC/donor for fraud.

7/11/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3550

> I'm pretty sure I have seen NECC adds on Craigslist Boston.
I've seen NECC ads on Craigslist numerous times. I've also interviewed two men who claim to be former NECC donors who have shed some interesting light on their donation careers. One donor who has non-cancerous facial/jaw growths (which are large and hideous) found no mention of them in his profile despite them being obvious and most likely genetic. The growths have recurred even after surgery and are incredibly obvious to me since they increase his jaw size by over a third.
The second man told me that he had to agree to pay automatic substantial financial penalties if he had contact with a recipient or offspring and he had to sign his agreement to this when he donated. He said that the bank said that contact could only ever be made with their consent.
Knowing what I do of the NECC I actually believe both men's accounts.

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.

7/11/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3544

...I was just referring to large sperm banks in general and not NECC in particular and also more to sibling matches (and NECC has lots of sibling matches). True, it's curious that not a single sperm donor from such large a bank would post.

---k wrote:

you said that NECC has the most matches on the DSR? Can you check that, because I find it hard to believe. Not one NECC sperm donor has come forward on the DSR that I know of. Look at all the sperm donors who came forward at CCB. Now why is that?

One theory is that NECC puts the fear of god into their sperm donors -- maybe they make them sign a contract, promising to never contact their donor offspring. Maybe they tell the donors that contact will make them liable for child support. Who knows!

Another theory is that NECC has just a few sperm donors, but they tweak the profiles to make it sound like there are many sperm donors.

These are just "theories" and I doubt they are true.

7/10/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3540

I don't really want to re-open this can of worms (autism), but the genetic link - at the moment - to autism is tenuous at best... I was just reading an article (http://www.pittsburghlive.com/x/pittsburghtrib/s_329931.html?) that shows that although there MAY be some genetic links, that scientists are hard-pressed to identify what they are...there is also speculation that it is possibly environmental...speculation that there are vaccinations associated with it - in large, a complete mystery...

Now, do I think NECC was remiss in their passing on the information of common autism spectrum diagnoses among the off-spring?? ABSOLUTELY...however, I don't feel that they were wrong for continuing to sell the samples - I am sure that is partially because I don't have a child on the autism spectrum...the bottom line is that the Sperm Banks are in the business of making money...and businesses are governed by their own rule system - there are plenty of businesses out there who have shady business practices - WALMART, for instance - but people, knowing that they treat their employees shoddily and operate on a 'good ole boy' mentality, still continue to shop there...

I would choose my donor the same way...I wouldn't change a thing. We chose him based on his family's medical history - since cancer runs in my family, we wanted to be sure that our children didn't get a double whammy by having it come from two sources (if, by any chance, it is genetically linked)...secondary, was his coloring, height, education...we bought the voice tape and he seemed intelligent and eloquent in his responses...

My children have 2 parents that love them - do I think they are going to suffer by not having a "father"?? Absolutely NOT... my daughter knows that she has a donor and 2 mommies and tells anyone who asks exactly that...if they have questions, then I am open to answering them, but she is so matter-of-fact about it that ADULTS feel rather silly going any further...and children, as a general rule, are pretty accepting of pretty much everything - they don't learn self-hatred and prejudice until much later in life....? I am sure that someday one - or both - of my children will use the "I hate the way I was born" card; just to be hateful, probably when they are teenagers...and, if they don't use that one I am sure that they will use any number of a hundred other reasons to "hate" me...and, that is just a fact of life...

However, before you decide on a bank and a donor, be sure that you have - somehow - managed to come to terms that at some point in your child's life he/she will be curious/unhappy/confused about his/her origins and how s/he came into the world... then choose wisely.

7/10/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3539

I also bought sperm from NECC. I went through two donors and have a healthy baby girl. I was treated very friendly when buying the vials but when it came to a tank deposit refund it took forever to get the money back. I had to call and email repeatedly and my requests for return calls weren't answered. So when I read reports about unpleasant interaction with NECC I know what people mean. I just hope that we will never need their cooperation in regard to our daughter's health. With everything I read at this discussion site I'm more suspicious of falsified information, we will just never really know. However, to calm down it would help if people wrote about satisfying experiences with NECC. Is someone out there who actually had an ID release donor's ID released from NECC yet?

However, there are positive sides to buying from a large sperm bank. They have the most matches on the DSR. Even before my daughter was born I knew there was a halfsister and that the donor had fathered children, respectively...

7/10/07

http://health.groups.yahoo.com/group/DSR_Discussion/message/3535

Thanks for your information. I certainly agree that while they couldn't say if autism is genetic for certain or not, I'd HOPE and would wish it was required to report this info from the banks to purchasers of this sperm! I'd want to know and I think many others would as well!!!

Again thank you for sharing your experience as it helps me and others just starting the process.

--- In DSR_Discussion@yahoogroups.com, d wrote:

- > i used NECC, and i don't know if they are better or worse than
- > other sperm banks. i don't care for the way they treated me
- > after i told them that my son had aspergers -- they would
- > not contact the donor or other recipients for me, to see if there
- > were other children with autism. then they kept selling our donor's
- > sperm afterwards. this seems to be the industry norm, because
- > there is no genetic test that can prove autism is genetic. well this
- > is just a bunch of bunk! it is partly genetic! i doubt the regulated
- > sperm banks in europe sell sperm after autistic children are
- > reported to them.
- > JMO. if i had to do it over again, i would find my own known
- > donor, and get to know him first, to make sure he did not
- > have asprie traits, or undiagnosed mental problems.

7/10/07

http://health.groups.yahoo.com/group/DSR_Discussion/message/3527

- > Everyone who posted how happy and great things are has not had a
- > problem and only then will you know how GREAT the vendor truly is.
- > please take the blinders off....you are a customer, they are selling
- > something. When the deal is closed good luck if you run into trouble.

I bought sperm from the NECC and there are serious hereditary issues with my kids and the NECC have not addressed them at all refusing over almost four years now to supply ANY INFORMATION. I've now been engaged in litigation with them for well over a year and we are going to appeal because they are adamant that their donors should be entitled to their medical confidentiality and not have to release any information to offspring/parents despite putting a bunch of lies on the profile and the children being conceived solely due to that.

Let me forewarn everyone that the NECC does not care one iota at all about the offspring. Zilch, nothing, not at all! They have made that absolutely clear.

They also do not return phone calls, faxes, emails, letters etc if you have any problem.

I could never recommend the NECC if you care about your children's health. Plus, the NECC are incredibly generous in judging donors looks. Ugly to me and most people I know, is described by them as very good looking and handsome.

7/5/07

http://health.groups.yahoo.com/group/DSR_Discussion/message/3450

- > My concern is picking a RELIABLE/ETHICAL sperm bank and that is why
- > I was referred to your board!

I understand your concern. Of course, choosing the man who will contribute 50% of your future child's genes is a huge decision. The bottom line is by using a donor you are ultimately entrusting that decision to the sperm bank and that is why you have to make sure that they are 100% honest with you.

I entrusted the NECC with advising me about my donor seven years ago and they seriously abused my trust. On reflection (reflecting thousands of times over and over) I cannot understand how I could have placed such a huge amount of trust for such a major thing into the hands of people who were complete strangers to me.

Now after the event I'm much wiser and realize that the bottom line for a sperm bank is to make money. All they ultimately care about is separating you from your money! They don't care about you and your dreams and ambitions, all they want to do is shift sperm.

Think for a few minutes about whether you would just hand over a lot of money to a real estate agent to buy a house that they were selling without you even being able to view it or even see a picture of it or without having your surveyor view it for you, or a friend take a look at it for you.

Well, to me my kids are like that house - just more important! I bought the sperm to procreate them from a rogue agent - the NECC. I was naive and stupid to trust them just because they talked as if they cared. Well, the truth as to how damn little (make that zero) they cared showed when I reported health issues to them and they ignored what I was reporting and carried on selling the sperm still lauding it!

So, my best advice would actually be not to rely on a sperm bank but rather comb through the DSR to find people with excess vials to sell after having had healthy, bright, attractive children from the donor.

6/29/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3363

I can tell you that in my case which until now has been pursued pro-se (litigant in person), the NECC have two law firms on the case with numerous lawyers. One set of lawyers is one of the biggest commercial law firms in the country and the second set are a boutique specialist firm in reproductive law. Their lawyers have been absolutely phenomenal in their role of just delaying everything and applying for numerous motions/applications. They churn out reams and reams of paperwork, most of it totally irrelevant and offpoint but enough to deflect the judge's focus. Also, because these are big name lawyers, I see the judges appear awed by them and almost sycophantic towards them. The American law courts are not a forum where justice is reasonably available for the little guy! It is procedurally complex, heavily reliant on written briefs and pro-se litigants are held to exactly the same standards as lawyers. Also, the judges tend to use legalese without translation into normal language and clerks at the courthouse are forbidden from explaining procedure for fear of liability. I have to spend hours every day in research which would be normally impossible for someone with two small kids - but luckily the Social Services here in MA are paying for them to go to daycamp and during school time they paid for them to go to an after school program. They get assistance because of their special needs and the fact that I am a single parent.

6/25/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3288

I think the greatest thing that upsets me about my children inheriting ectodermal dysplasia from the donor is that the NECC have never ever apologized or expressed any sympathy towards me.

For years I politely emailed and faxed them requesting information on why my children had such unusual features and never received any response at all. When I finally succeeded in getting a phone call answered, John Rizza rudely (and wrongly) suggested that I must be a really ugly hag and that's why I needed a donor! I strongly suspect that the NECC will use anything that walks in their door that can pass STD test and whose sperm squiggles after defrosting!

Looks, intelligence, personality can all be fabricated! No one will find out! They're anonymous anyway!

6/25/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3283

> I would think that if someone was donating
> with an obvious problem someone would notice that. I have an audio
> tape of my donor. He sounds pretty normal there

I'm sure the NECC noticed this guy looked way off odd - but the moral of my story is that they apparently just didn't care! Unfortunately, the NECC don't release audio tapes so I had no way of hearing what this guy sounded like.

There is no excuse whatsoever for sperm banks to lie about their donors attributes and they shouldn't really be selling sperm from donors who aren't at least averagely decent looking. Certainly no one should be faced with bizarre and unwelcome surprises about their kids' features! The sperm banks should not be abusing donor anonymity so as to pass off ugly men with obvious syndromatic characteristics as a "handsome man" "very good looking" "perfect nose" "perfect features". Abuse of such anonymity by the sperm banks is a very good reason why anonymity should be stripped. Because if the sperm banks are not trustworthy, then they should be made accountable by their claims about donors being made scrutinisable.

6/24/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3281

Ectodermal dysplasia is a blatantly obvious condition even to someone who has no medical knowledge whatsoever. It is a condition of skin, teeth, hair, nails whereby their development is abnormal. Many affected people also have unusual lips and jaws/chins and frontal bossing. There are also unseen things such as lack of sweat glands, poor mucus production and voice disorders (but those are audible). I'm pretty confident that my donor had obvious symptoms that would have been detectable at a glance. The point is that nothing at all was on the profile, and I asked numerous times for reassurance whether there was anything odd, distinct or unusual about him. I was told repeatedly - no! I have traced the guy and he is very distinctively affected. Even to a casual observer it is patently obvious that he has some disorder. His face is just not normal looking. He has only a scant amount of wispy hair, very patchy discoloured skin (because of poor healing) a voice disorder and an extremely extended chin (think Leno!). None of that was told me. I was told that he was a very good looking guy! Handsome! His features were described as very good! Perfect! His nose which is humped and bulbous was described as straight, very nice, perfect! No one told me that he talked in a hoarse croak, that he had a notoriously rotten temper or that he had sexually abused minors! If he is the poster boy for the NECC then honestly, I would be scared to find out about the others! The point is. I didn't seek perfection. I honestly wanted a guy who by normal accounts scored as at least normal in pretty much all respects! This guy is so patently not normal in so many respects! Is it really too much to expect a normally featured guy when you pay \$1800 for a few vials of sperm? I don't think so! But at the minimum at least tell me the real features and not total fiction!

6/24/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3279

I asked NECC why they kept selling our donor's sperm after I told them that our son was diagnosed with Asperger's syndrome ... and they told me it was because there was no scientific test that proved my son's Asperger's was caused by our donor.

6/22/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3275

I was in a very similar situation. Two of my friends were very keen on having children with me but I declined them both. They would also have played the role of daddy financially, emotionally and physically. I declined one was because he was adopted, drank a bit too much and I felt that since he had no knowledge of his forbears health, it was too large a risk to take. I declined the other because he was on the short side, he had a shortish temper and his mother had been suffering from angina since her early fifties. My thoughts since I was not intimately involved with them was that I would do better for my future children by getting the very best genetic material available. Sperm from a highly screened donor. I checked through over several hundred profiles before choosing the NECC donor and I did so after consulting with John Rizza. One of the chief reasons that I chose my donor besides health was that he had donated eight/nine years earlier at the age of twenty-six and he was still unmarried at 34 and John Rizza basically told me that he was unmarried since he was gay and that he was willing to become a known donor exclusively for my kids since the donor offspring kids were likely to be the only kids he would ever have. John Rizza told me of the delight that my donor had in agreeing to have contact. I felt both pleased that I could help this guy have kids and that it was a fantastic opportunity for my future kids since they then would then be the only kids he would have contact with. (this was prior to the DSR) This

reassurance wiped away a lot of the reservation that had held me for three years and I got pregnant after one insemination. I was young and fertile!

When I later tried to make contact John Rizza admitted that he had never made contact with the donor. In his affidavit to the court he said that he had tried but been unsuccessful.

6/22/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3274

The NECC carried on selling the sperm for at least five years after first receiving medical reports of autism and learning difficulties, without divulging those reports and cynically still touting the sperm as being from a donor from a huge family with no incidence whatever of any disease. They carried on selling the sperm still claiming "no notations on the file" for around two and a half years after they were informed that donor offspring were possibly afflicted with ectodermal dysplasia.

They only removed the sperm from sale after I sent them notification of legal proceedings.

The proceedings which are subject to court embargo have been ongoing for more than a year. The NECC have as their main defense that they have no liability whatsoever for negligence in screening since they are hiding behind state legislation which protects providers of organs for transplant from being sued if the dead person from whom the organ was harvested had a condition that was not known about.

I have tried to distinguish the situation where kidneys or a heart or skin is only useful for a few hours and hence only the most basic tests can be carried out, to a situation such as sperm donation where the guy is available for medical examination and questioning and his answers can be checked up on and verified for a couple of thousand dollars by any half competent PI. The NECC have refused to divulge whether they even medically examined this guy. I have the strong feeling that they in fact do not medically examine any of their donors but merely test them for mandated STDs specifically so that they can reduce their liability by saying that they rely on self-disclosure by donors exclusively.

I'm saying now what I've said before - the NECC are rogues and you are taking a real pot luck approach using them. If you use an NECC donor you are as likely to get a healthy donor as just choosing a guy randomly off the street, but you will not improve your chances, since it seems that they have no quality control at all and that might well be a purposeful thing on their part!

6/22/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3273

My kids and several half-sibs from the region are under the care of the same geneticist, and the disorder is some type of ectodermal dysplasia. There are around 180 different ectodermal dysplasias with around 7,000 US affected sufferers and you are right about the variation of manifestation within the different siblings because of each one's unique bundle of alleles.

Even my two daughters present differently. One has hypodontia as part of it and the other one doesn't. One has very sparse wispy hair the other just has very slow growing hair and although it's pitifully thin there is fairly even coverage. One has spoon shaped fragile nails the other has brittle tiny nails. There are differences with each. Yet, it has to be autosomal dominant because five affected half-sibs from different moms demands that to be the case.

Knowing more about the family manifestation of the disease would be immensely helpful in getting proper medical management but despite approaches to the NECC they've refused to even respond to our concerns even with the geneticist writing for assistance. We are involved in litigation and the NECC have taken the strict stance that their donor's right to medical confidentiality is paramount and trumps any supposed right of a donor offspring for vital medical information.

This matter is impounded but will probably elicit a ruling from the Supreme Judicial Court of Massachusetts in around 16 months and if not favorable in my direction I will certainly take it to the US Supreme Court.

6/20/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3263

Absolutely, disabled people have a right to exist! But we are talking here about autosomal dominant genetic disorders (50% chance of inheriting) and because such disorders don't skip generations, parents always know that if they risk conception, there's a one in two chance of a kid being disabled. As far as I am aware such affected parents think long and hard about conception in such instances.

I, however went to the NECC to find a donor with no obvious genetic problem. I knew and understood that something random could manifest or there could be a birth issue such as cerebral palsy. I was prepared and

accepting of that! But what I was not prepared for was having fraternal twin children with an autosomal genetic disorder. (Because they are fraternal twins there is no prospect that this was recessive - and in any event this disease is autosomal dominant!)

Now, had I been in a relationship with an affected man, I could have had the opportunity to decide whether to risk conception with him and have a one in two chance of having a disabled kid. Of course, I would have then been aware of what I was letting myself in for and some people do risk it because they love their affected partner so much they just want his kid and in any event he is there for the kid as dad.

My situation is that:

1. I had no knowledge of the disorder so I could not make the decision whether or not I wanted to risk conceiving a child with this disease. Hence, I was worse off than copulating couples in the decision making process and being prepared for outcome.
2. I didn't conceive these disabled kids to bond with an affected partner. Their father who has this genetic disorder lied, so that they would be conceived and left me having to look after them.
3. My kids don't have the support of a parent with this disability. A very crucial thing for learning how to cope!
4. I specifically chose the ostensibly healthiest donor that I could find sacrificing other items such as height and ethnicity. Health was my number one concern!

6/19/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3254

> I do know that my first bank was Pacific Reproductive Services in SF. I
> was required to have an in depth physical. I was the receiving mom. I
> was even checked to see if I was immune to measles, mumps and
> rubella. It came back that I was not and had to revaccinate and wait six
> months before trying again. I had to sign a form saying I would not
> become pregnant or even try to.

As a recipient of sperm I also had to get fully checked for the same things as you did. Furthermore, I had to provide a full personal and family history to show that there were no likely health problems that could affect me in rearing children as a sole mother. Because my mother died in her mid-forties from leukemia I had to get her treating physician's letter explaining that it was non-genetic type of leukemia and that it would not predispose me to getting that cancer before the child had reached the age of majority.

I took my health disclosure questionnaire to my treating clinic really carefully and didn't for one second suppose that my donor was a flat out liar!

Incidentally, I do now think that I now know who he is and it appears that two of his siblings are institutionalized and have been since birth or thereabouts (they are now in their forties) I am desperate to know why, what for?

It seems so ironic and bizarre that I was willing to concede on so much like height, ethnicity, an appealing message etc, just to get a really superbly extraordinarily healthy donor, and then he turns out to be a total liar with exceptionally poor health!

6/19/07 | http://health.groups.yahoo.com/group/DSR_Discussion/message/3252

> Fraud is a crime. If the donor intentionally misled the clinic (and
> therefore everyone involved) for financial gain then that would
> certainly be fraud and a criminal act in probably any jurisdiction.

The problem is that it's the NECC that paid the donor and they are adamant that they do not want to take any action against him.

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/3235

Today was a beautiful summery day in New England. In 90 degree heat a group of kids all born from one NECC donor ran around in swimsuits, dashing under sprinklers and clambering over play equipment. But looking on was sad for the mothers concerned. Not one kid from the families is 'normal'. Two of the kids graduating kindergarten and second grade from special schools, can't even answer to their own names. All the kids have skin disorders with big patches and welts of angry psoriasis and eczema. All the kids have just a sparse amount of wispy hair. One of the kids is legally blind. I could go on and on and on, but I won't bore you!

The point as we discussed it was that we had all gone with great hope to the NECC. We'd all passed through that very difficult stage of coming to terms with using an unseen donor and all of us had put our faith in the fact that the NECC proudly and loudly proclaimed how meticulous and selective it was in screening their donors. Well the reality is in our outcome.

For years it has been just continuous deep anguish trying to cope with evermore diagnoses of yet more and more health issues. What we all decided is that it must not happen to anyone else! No one else should experience their dreams and hopes of raising healthy kids smashed, just because the NECC feels it needs to maximize its shareholders dividends by passing on unhealthy unfit donors. It seems that the NECC will accept just about any guy that comes through its doors, that can spurt out stuff that squiggles.

We are angry and we want to prevent this happening to anyone else! We want to get legislation passed in MA that makes donor fraud a crime. What the NECC have done to us is worse than all the crimes we have ever experienced - including rape and robbery!

4/11/07

<http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8484>

I've had a fair number of people respond to my prior posting about the litigation group against the NECC. Interestingly, most of the respondents have voiced their worries about the fact that absolutely no NECC donors have posted on the DSR. Other recipients have expressed doubts that the information divulged to them is correct. Such worries have emanated from apparently very inconsistent information about the same donor being released to different recipients. A recurring theme is that their children are unusually short despite having chosen reputedly taller donors.

Since it is of such significant concern to recipients and offspring to know that they have received correct information about their donors, I shall be establishing a website particularly for the swapping of NECC donor information and hints about searching out donor identities. A special service will be offered where alumni lists from Boston area universities will be obtainable at a nominal cost. However you should beware that people are reporting that so far reputedly Harvard and MIT donors have not been checking out!

4/2/07

http://health.groups.yahoo.com/group/DSR_Discussion/message/2998

A group of NECC recipients is forming in order to prepare for litigation against the New England Cryogenic Center. If you want to join this group please email directly to the author of this posting.

Please provide a brief description of your complaint. Some of the issues that we are currently dealing with include:

- Removal of the donor's identity release status
- Undisclosed genetic disorders.
- Unusual and unattractive physical features.
- Voice disorders.

Large numbers of autistic children in the sibling cohort.
Extreme low height amongst the sibling cohort despite the donor being described as a strapping man.
Misrepresentation of the donor's academic background. Claims that the donor was a Harvard or MIT student
have not borne out when the recipients performed their research.
Auto-immune disorders such as psoriasis and rheumatoid arthritis.
Extreme pressure being applied to select a particular donor.
The group will have access to some leading academics and lawyers in the reproductive law area who will be acting pro-bono. If you have issues with the NECC don't battle them alone, join together and get your voice heard. After all, you owe it to your kids!

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 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!

3/12/07 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8409>

I have a healthy, beautiful, extremely bright daughter born via a NECC donor. I would use the NECC again in a heartbeat, and I would recommend it to others, as well!

3/11/07 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8404>

Actually, I come from a family with absolutely no heart disease, high blood pressure, diabetes or hereditary cancers going back for more than three generations. My father's family has been medically noted and studied for extreme longevity with his grandmother dying at 108 and almost all members living well beyond the age of ninety, with several other centenarians, all in robust health. My mother's family is almost as long lived. My maternal grandmother will be 97 this year and she still drives like a boy racer. I can honestly say that apart from mild acne none of us have ever had any skin issues and our teeth are naturally straight and strong. There are actually some truly very healthy families around and I wanted my kids to inherit as good genes as I did to have as problem free an existence as possible.
I am daily sad from the fact that my six year old daughter is virtually crippled with her rheumatoid arthritis as is her six year old half sibling. I cried tears of deep anguish for my other daughter when ugly patches of psoriasis started afflicting her face. Her legs and torso were already full of sore red angry psoriatic plaques. Her half-sibling has had psoriasis since five years of age and I know about her self-consciousness. I know that both my children will have to endure significant and expensive dental work to give them normal teeth. I regard the New England Cryogenic Center as contemptible and immoral for putting business before care for their clients by accepting such a genetically problematic donor and passing off his sperm as highly desirable. I have absolutely no doubt whatsoever that the New England Cryogenic Center intentionally sold the sperm despite knowing that there was an overwhelmingly strong likelihood that offspring would suffer lifelong disabilities.
My dealings with the New England Cryogenic Center have convinced me that they have very lax standards

for vetting donors. Also, if people are at all concerned about donor looks I have also visited their offices and I can vouch first hand that I saw a donor coming in to do his business and he was so ugly I was literally incredulous that they had the gall to sell sperm from such a man to unsuspecting clients. Is it any wonder that the NECC doesn't make available any photos of its donors?

Had I previously been aware of the NECC's lack of care for the quality of its donors then I would never have entrusted them to provide me with the genetic material for my children. If the DSR had existed at that time then perhaps I would have been able to avoid my anguish and could have had other children with less health issues, less pain and more prospects in life!

The DSR has a huge role to play in enabling families to communicate the health issues of offspring so that future families can be spared unnecessary pain and suffering.

3/9/07

<http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8401>

I would seriously advise joining the DSR as a paid up member before even actually trying for pregnancy. The reason is really simple. You owe it to your future child and yourself to do as much homework as possible on your donor.

I selected a donor just shortly before the launch of the DSR and so unfortunately I had no forum in which to meet others who had used my donor. I actually thought that I knew everything that was important to know about him. After perusing more than 200 profiles which cost me around \$3,000 I eventually found a donor with the healthiest background out of them all, literally a clean health record for three generations of an extremely large family. Only one minor health issue was recorded and that was a heart attack suffered by his 84 year old grandfather.

When I quizzed the New England Cryogenic Center about this donor I was told all the things that were important to me. He had great looks, with beautiful "perfect features". He was very personable, articulate, charming, kind, humorous and most of all he was willing to be known. Having already donated for several years the NECC reported to me that there were already a handful of births of beautiful healthy children. Well, the basic fact is that of those prior born children two girls had autism and the NECC had already been informed about that before I had my children. From our group of siblings most of the kids are multiply affected with skin disorders, dental anomalies, growth disorders, sweating deficiency, mucus deficiency, severe eczema and asthma, psoriasis and rheumatoid arthritis. Learning disabilities and autism are rampant. We also think we have traced our donor and we would scale him as well below normal levels of attractiveness. What is more, the NECC have told me that the donor is now no longer willing to be known to his offspring.

In short, be wary of the claims that sperm banks make. They operate first and foremost as a business! Especially the NECC!

If you have the chance to verify that there are really healthy normally developing offspring already that is far more authoritative than a quite possibly fictitious profile.

I would also do your homework on whether any donors have signed up on the DSR from the sperm bank in question. The fact is that no NECC donor has ever signed up on the DSR which either means no donor can identify himself from the enhanced fictitious profile or that the NECC is putting a huge pressure on them not to make contact with offspring!

Either way, it doesn't appear to be good news for NECC offspring!

11/2/06

<http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8083>

I have a terrific, healthy, happy daughter via a donor from the NECC. She is 5 years old. She is more wonderful than I could have dreamed, and if I were going to have another child, I would definitely want to use the same donor.

11/1/06

<http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8079>

I used NECC and have a beautiful HEALTHY 19 month old daughter. As far as I know the profile was accurate. So, Yes, I have had GREAT experience with NECC and if we decide for #3 baby, we will go back and use the same donor.

10/23/06	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8053
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NECC are only different from the other banks in that they seem to exercise an iron-fisted control over their donors. Thus, you never hear of a single one of them posting on the DSR, or describing in any way (positive or negative) the practices of NECC. That, in it's own right, is a little scary.
That is no indication that their donors are qualified more or less rigorously than other banks. If you are pregnant, then you have reached a status where 97% of the outcomes are "healthy and unremarkable." So don't worry yourself without cause.
And no, no one knows anything about DI. No one even knows how much of it goes on. No one knows how many babies are born using DI. No one knows how many of those have any health issues at all, or whether any particular ones are more prevalent. There is no rational excuse for this state of ignorance, except to say this: It exists because the sperm banks prefer it, and fight avidly to preserve it.

9/18/06	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/7910
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I am experiencing some confusion with a sperm bank about identity release issues. I was wondering if there are any women out there who have used New England Cryogenics (NECC) and think they have an identity release donor. If you think you picked a willing to be known donor do you feel that the bank has provided you enough reassurance about locating this donor when your child turns 18. Did you get a contract? Would any of you be willing to e mail me privately and let me know what your understanding with this bank is? Also are there any of you who are having any issues with NECC that you are concerned about?

7/8/06	http://health.groups.yahoo.com/group/DSR_Discussion/message/2266
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The NECC is a very large sperm bank and the only large sperm bank without even a single donor posting. Who else thinks that's very strange?

3/24/06	http://health.groups.yahoo.com/group/DSR_Discussion/message/1342
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So what medical problems do the offspring have: Well let's start on a non-comprehensive list: Severe mental retardation, severe autism, learning difficulties, developmental delay, growth retardation, voice disorders, speech issues, a tendency to severe upper respiratory infections leading to hospitalization for pneumonia and breathing difficulties, susceptibility to severe bacterial infections leading to long stay hospitalization, chronic severe constipation, sudden unexplained plummeting of blood sugar leading to hypoglycemic coma, asthma, eczema, allergies, poor healing skin, poor nail growth, sparse exceedingly slow growing patchy hair (a child aged five should have a full head of hair) dental issues, significant frontal bossing, low nasal bridge, behavioural difficulties, significant emotional immaturity, impulsive uncontrolled behaviour, socialisation difficulties, plus more.
(the above is in reference to 1-23-06 message 1340 at http://health.groups.yahoo.com/group/DSR_Discussion/message/1340 .
I too have a few reservations after reading the entire blog at www.NewEnglandCryogenicCenter.com. DIMom starts out very strong and never lets up but at the end of it all, she never once mentions what she's so all fired up about.)

3/16/06	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6423
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Hi, I just thought that I would chime in on this topic since I have conceived by using a NECC donor. First, I wanted to let you know that even though you are using NECC to buy your specimen, your specimen might not have originated at that bank. Secondly, even though you think your donor is only available at NECC there is a chance that your child could have siblings from another bank b/c NECC sells some of their inventory to smaller banks. So you may want to ask these direct questions when buying from them. That all being said, I have had nothing but positive experiences from NECC and would use them again! Our clinic said that our donor had high motility and was a very good specimen. After I gave birth, I had a feeling that our donor might have originated from a different bank so I called NECC. They confirmed that our donor B### did in fact come from Rocky Mountain Cryobank. They also told me that our donor's remaining inventory was sold to Fletcher Allen (FAHC) in Vermont.

3/13/06	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6391
<p>I have a wonderful child conceived with sperm from NECC. We have met several of her half sibs and all are great kids. I have had no problems with them.</p>	

3/12/06	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6388
<p>Please be aware that many women have had negative experiences with NECC as they are not always entirely truthful or responsive to any concerns that Mothers have had..I will be happy to tell you more about my experiences with them...please e mail me privately</p>	

3/11/06	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6386
<p>I will say this as gently as possible since you are already invested in NECC. They have a very bad reputation. For more reasons why I personally decided not to use them, I will tell you my stories offline.</p>	

12/15/05	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/5801
<p>I've had numerous health problems since birth with my NECC conceived daughters. Problems have included chronic constipation, failure to thrive, very heavy chest colds leading on four occasions to pneumonia, two bouts of mastoiditis (a very serious condition that only affects 1/25,000 children and is similar in effect to meningitis) The doctors suspected cystic fibrosis which is a hereditary condition and can only be found if both parents are carriers. I knew that I was a CF carrier and that was the primary reason I had looked to a sperm bank in order to get a screened donor. Before buying the sperm I had asked very carefully about their CF screening. I was assured that every donor was screened for 86 mutations. Hence, after the doctor had raised the issue of CF I contacted the NECC and asked for the details of the donor's CF screening – which mutations and results. However, despite numerous phone calls, emails and messages there has been stunning silence. The NECC have not been able to produce any CF screening. Did they forget to screen, deliberately lie about the screening or have they mislaid the results? Any of those scenarios is very scary. They all amount to at the least incompetence and potentially even fraud.</p>	

11/20/05	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/5622
<p>Just a note to warn people that if they use an NECC donor they should be aware that the description that they receive about the donor might be very erroneous. I have traced our donor and there is absolutely no way I would have selected him had I been given an accurate description. The NECC seem to approach the sale of sperm using the same tactics as second-hand car salesmen. However, the handicap with buying sperm is that there can be no caveat emptor since you can't check out a man whom you can't meet in the same way as you can examine a car. Please be very cautious about using the NECC. My story is frightening and I would hate anyone else to go through such anguish. I would certainly advise people to use more honest banks if possible. You owe your future child the very best prospects in life!</p>	

10/28/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/1127
<p>I see no reason why the site should not be set out like the Donor Sibling Registry with a list of Sperm Banks and comments posted by users about the Sperm Banks. Then potential users can wade through the comments and query the posters for more information if required or wanted. I for one would have been grateful for such a reference facility and if it would have prevented me from using the NECC then so much the better. I have traced my donor and there is almost no resemblance to the description provided by the NECC and what he is actually like. However, the DNA test says he is the donor. For all those thinking about using the NECC my advice is to steer as clear as you can get.</p>	

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9/16/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/1036
<p>I used NECC and they do not provide the birthday to recipients, but it is printed on the vials that are shipped to the RE along with the donor number. One time while ttc#2 with the same donor I asked to keep the vial as a souvenir and noticed the birthdate.</p>	

8/05	NECC Craigslist ad
<p>New England Cryogenic Center, Inc. (NECC) is looking for men for their sperm donor program of all ethnic backgrounds who meet the criteria listed below:</p> <ul style="list-style-type: none"> o Between the Ages of: 18 - 35 o Between the Height of: 5'8" – 6'4" o Currently in college or a Graduate <p>If you meet these initial requirements and are interested in earning up to \$5000 in 6 months with a minimal time investment, please respond to cbishop@necryogenic.com and request an application. Once completed, send all forms to 153 Needham St. Newton, MA 02464. Please call (800) 991-4999 within 10 days to see if you qualify for our donor program. Helping couples conceive means giving the gift of life. Our staff and clients thank you in advance for your interest.</p>	

8/10/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/812
<p>Here's an excerpt from a college mag article written 5 years ago by a student pondering a job in sperm donation:</p> <ol style="list-style-type: none"> 1) Amount I get paid per hour at my job, in dollars: 9 2) Amount paid for each sperm donation made to the New England Cryogenic Center (NECC), in dollars: 70 3) Time I spend at my job each week, in hours: 10 4) Time needed to make a donation to NECC, in minutes: 3 5) Maximum time I can work at my job each week, in hours: 17 6) Maximum donations NECC will accept from a single person each month: 8 7) Maximum amount I can make each month working at my job, in dollars: 612 8) Maximum amount I can make each month "working" for the NECC, in dollars: 560 9) Time required for me to make \$560 at work, in hours: 62.2 10) Time required for me to make \$560 "working" at NECC, in hours: 2/5 11) Amount I would make if I "worked" 62.2 hours for the NECC, in dollars: 87,110.80 12) Time required for me to make \$87,110.80 at work, in hours: 9,679 13) Number of times I've thought of "working" for the NECC: 568 <p>Sources: 1, 3, 5, 7) personal knowledge; 2, 6) the Harvard Crimson; 4) reasonable estimation; 8, 9, 10, 11, 12) simple arithmetic; 13) conservative estimation. — Compiled by Phuoc La</p>	

8/10/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/798
<p>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 a egg donor but actually wound up meeting a prospective</p>	

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.

-----Original Message-----

From: -----

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.

3/18/05 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4349>

I am a parent who has a child(ren) from a NECC donor. I started dealing with this facility back in 2000 and couldn't have been more pleased. They have always handled all my questions in a very professional way. This center has even offered me more than ample information when the last vials of our donor were purchased by another clinic in the N.E. I have since spoken with the NE clinic that bought the rest of our donor and they said that they always use NECC b/c they are professional, provide high quality specimen and offer good screening/testing.

My experience over the past 5yrs with this bank has been great!

3/14/05 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4298>

NECC For those who accuse my posting as a con I can only say that "I wish". Unfortunately, there are significant medical issues here. Also, the relevance of the "perfect nose" is that the nose is one of the features affected by the syndrome giving the typical appearance of the syndrome. What I was saying is that totally inaccurate and misleading information was given to me making it impossible for me to sus out that something was wrong.

I only found out recently that the various different things that had given me concern about my daughters were not disparate problems but were actually all likely to be connected as symptoms that all relate to a particular syndrome. It was a revelation and quite distressing. My daughters are darlings and very precious to me but it is very upsetting to find out that I have children who could be affected by a syndrome that should have been vetted out by the clinic. As regards the questions about half-siblings. Boys would not be affected at all because the syndrome is X linked and hence a man would pass it on to all daughters and no sons.

As for all the discussion of recessive traits. This syndrome has no recessive capacity. It only requires one affected copy of the gene on the X chromosome and has full expression in every affected male. On females it is somewhat muted but is still not recessive.

My contention is that sperm banks must take their responsibility for screening for evident traits seriously. Of course they can't be responsible for hidden genetic problems but they must take responsibility for things that are patently apparent. They should conduct careful physicals by physicians and geneticists. They have our children and their descendants' health at stake.

3/13/05 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4279>

I'm not sure this will make you feel any better but years ago when I was researching sperm banks in Boston, I found that NECC had a bad reputation for being disorganized, inconsistent and unprofessional in their relationships with consumers. In my calls to them I found them to be slightly flaky and decided not to take a chance on them, even though at that time they offered more openness than other sperm banks. I can't offer much help in dealing with them since I think the organization is basically unprofessional, and you won't change them.

3/13/05 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4275>

In reference to my two postings yesterday I have received several private emails about the lack of response from the NECC. Apparently two other people have also had problems in gaining a response from the NECC. Like me as soon as they communicated that there were problem issues the gates of communication were closed to them. In my first notification to the NECC that there was a problem I spoke to John Rizza via

phone. I told him that I had noticed problems with both my small daughters developing noses and without indicating any concern about them, he suggested that I should start saving up for a nose job. I thought it was a very inappropriate response. I was especially concerned with the response since he did not seem to find the information surprising but yet he had told me prior to selection that the donor had a perfect nose. The allegedly "perfect nose" had become one the primary determinants in my selecting the donor. Has anyone else encountered the same behaviour at the NECC or other banks?

What lies are being peddled to us by these huge profit making enterprises in order to persuade us to buy their sperm? I now doubt absolutely everything that I was told about my daughters donor. Many times a day I look at them and wonder whether there was even one item of truth told to me about the donor. Certainly, I also don't believe that the donor was as tall as claimed in the profile. Was the donor also a drug addict, criminal? What type of unsavory characters are the clinic passing off as smart young college students? I can only wonder! I thought I was choosing a very academically gifted man and yet my daughters even at age four are around the least able in their nursery class (I was a precociously smart child). No, I am not a pushy parent but they really have great difficulty in performing a lot of age appropriate tasks and seem unable to even be able up to count up to five properly.

Lack of faith in the background information of the donor is not the best way of establishing a family using DI.

3/12/05 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4273>

I know what you mean when you say that you don't expect a response from NECC. The bank that I used (Rocky Mountain Cryobank) closed several years ago. (Their inventory was purchased by NECC, by the way.) I've tried contacting the owners/director of RMC, but they haven't responded. They also didn't return calls when Jackson Hole News & Guide (where RMC was located) did a story about my daughters in Nov. 2003. Thankfully, none of my questions relate to the health of my children. As I see it, the cryobanks have nothing to gain and everything to lose by changing the way they do business. They operate behind a curtain of secrecy, giving them complete control. Who will ever know when mistakes are made or things go wrong? There's no regulation or accountability. How do we even know if the information we're given about our donors isn't altered or even fabricated by the cryobanks themselves? With anonymous donors there's virtually no way of checking or verifying the accuracy of any of the information. These issues of secrecy and lack of accountability need to be changed.

3/12/05 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4271>

I conceived my daughters in 2000 from sperm sourced through the New England Cryogenic Center (NECC). Prior to buying the sperm I consulted in depth with the director John Rizza and told him of my desired attributes for the donor. John Rizza appeared to be very helpful and recommended without reservation a particular donor. Going on his advice I ordered that donor's sperm but I now have non-identical twin daughters regarding whom I have a whole host of problems and concerns regarding their medical condition, height, appearance, intelligence, behaviour and other things. Without going into details I can tell you that they have been in hospital a lot, they have been excluded from nursery because of ADD type behaviour and they are currently being genetically tested for a syndrome which their appearance is highly indicative of. In addition they are both much shorter than would be expected with one being only in the 2nd percentile. Of course I have been keen on trying to gain further information from the NECC but despite emails and phone calls I have had no success in getting any further information or explanation and virtually all emails and messages have been totally unresponded to. As a consequence I want to warn other people of my experiences with the NECC.

4/1/04 | <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3124>

I understand your concerns. I used a donor from Rocky Mountain Cryobank (now closed) to conceive my 2 daughters. When RMC closed, their inventory was sold to New England Cryogenic Center. NECC was wise enough to keep the same donor numbers used at RMC, however, they failed to notify the recipients (and donors, I'm sure) of this change. (Recipients of NECC assumed their donors were from NECC.) Without this information, the chances of a donor/offspring match are almost impossible. A sibling/sibling match would

be equally as difficult if the children were conceived both before and after the sale to NECC. Seems to me a national registry of some sort would eliminate this type of problem.