

XYTEX

10/19	Personal Email
<p>I registered with Xytex as an open ID donor. I have always been open ID and never changed that. I also opened an account on xyconnects, which is a site for Xytex donors and donor conceived children to connect on if they both want to. The site is monitored by Xytex and all messages are reviewed by them first. Messages need to get approved by them before being sent to the recipient.</p> <p>So, one day I received my first message on xyconnects from one of my children. We were both thrilled to connect. I gave her my personal email and we started emailing directly without needing Xytex's approval. In one of her messages, she told me something I found very disturbing. She said that when she had first called Xytex on her 18th birthday to get my contact information, (her parents had chosen me partly because I was open ID) they told her I had changed to anonymous. She said she was incredibly disappointed, but felt something didn't add up. She wanted to know when/why I had changed and they didn't give her a satisfying answer. So she called several more times, each time talking to a different person who wrongly told her I had changed to anonymous.</p> <p>Fortunately, the last person she talked to told her that I was however, registered on xyconnects (a site which my daughter was completely unaware of). Why don't they tell the children and mothers about this!? Especially children looking to connect. So she registered on xyconnects and found me through my donor number. I'm so glad we were finally able to connect, but it was heartbreaking to hear that she was searching for me and was on the edge of giving up. She said she was going back and forth between hope and no hope.</p> <p>When she told me about that, I explained to her that they had made a terrible mistake and that I have always been open ID and interested in connecting. I contacted Xytex to find out why that happened and how to fix it. I was told that the mistake was due to new employees not being trained properly on the new customer service computer system. She said that they were looking in the wrong place in the computer files but that she would add a note to my file so that they would see it even if they looked in the wrong place in the future. I'm not sure what to believe.</p>	

9/18	Facebook Group
<p>I get the silent treatment from Xytex as well. Last "official" numbers a couple of years ago were 80 families and 104 kids but who knows what the real numbers are. They literally ignore my emails. What a disgrace.</p> <p>.</p>	

1/17	Facebook Group
<p>My bank stopped telling us how many siblings were recorded when they got to 75 children. That was a few years ago.</p>	

3/31/2016	Personal Email
-----------	----------------

I purchased 5 vials of a Xytex donor. I got pregnant on the 2nd cycle (which means I still have 3 vials left), although, we lost our baby at 26 weeks due to a genetic issue. After an autopsy on the baby, it was confirmed that a genetic mutation was the cause. I then had genetic testing done and the results showed that I wasn't carrying the specific gene. The doctors concluded that either the donor is carries the gene or the baby "started a new line".

Either way I wasn't allowed to use that donor anymore. Even though we told Xytex about the situation of losing a baby for genetic reasons the donor was never even made temporarily unavailable.

Now, as we've started the process again, we had to choose an other donor. I'm currently pregnant with that new donor, so I asked Xytex to take back the vials of the first donor to get reimbursed and they said no because, to them, it's a normal risk.

Have you ever heard any similar stories? I'm not asking to be reimbursed for the used vials nor for all the extra expenses the loss of the baby has put us through.

Do you think it's an ethical/legal response to not refund the vials I can't use? Even if the donor might not have the responsible gene and it could be a combination of both DNA (which is their "normal risk").

I just don't understand why they wouldn't just take them back and refund, or at the least exchange for my new donor. Now, I also have to pay for stocking fees at my clinic for a donor I can't even use.

12/16	Private Correspondence
-------	------------------------

We reported a complication with our then unborn fetus to xytex and they noted this in the donor's profile for several years following the incident. I randomly looked last year at the donor's profile only to discover that they had taken all of this information off, and inaccurately stated that the donor did not have any history of neural tube defects. I'm pretty sure I have the emails we sent back and forth to xytex originally, which proves that they were aware of the incident and agreed to flag this in his profile.

9/27/12	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/15353
---------	---

I just found out the other day that Xytex is no longer releasing the statistics on numbers of births and numbers of family units. We have been having problems with Xytex for months and this was the culmination (and I have the feeling the direct result) of several communications giving them flack about going over the stated 40 family limit. At first, they had verbiage on their site saying that a donor would be retired after 35 family units were reported (with the idea that at least 5 more reports would trickle in). When our donor reached the 35 units and we pointed it out to them that he needed to be retired, they did retire him but they took that statement off of their website. Then I found out that they were continuing to release pre-sold units to people who had not yet had children by this donor. I pointed out that I thought that was unethical and got no reply from them. Last I knew, we were at 54 children and 50 family units. When I contacted them the other day to find what the latest totals were, I was told they changed their policy and were no longer releasing numbers because "they weren't accurate".

I am so sad, angry, frustrated. And then the day after I find this out, a new pregnancy was reported in our donor group from now the 4th person that I know of that has been trying with pre-sold vials after he was retired. I expressed my feelings to our donor group and was pretty much told I was a big meanie for not rejoicing in this pregnancy. I will welcome this woman and her partner and their children but right now I just don't want this thrown in my face.

I came here to update about Xytex and hopefully to find some support for being less than thrilled with the people still trying with a retired donor.

9/6/12 Email to Alexis Rebane

We used Xytex "Open ID" sperm to conceive our three children. Recently, I wrote a letter to our Donor. I wanted to let him know that we appreciated his role in building our family...and that while we aren't interested in contact yet (because we'd like to be free to rear our children) we didn't want to wait too long (because who knows what could happen) to share our appreciation.

I asked the Xytex contact if they would share the letter with the donor (providing a copy of the letter to them) and she quickly and cheerfully replied in the affirmative. Upon delivering the letter, she then wrote back to convey a sense of his response and even answered a follow up question regarding his current health.

While our children will be able to attempt to establish contact at age 18, it was great to know that Xytex was willing and able to act as an intermediary before then.

8/9/12 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/15242>

My daughter has half siblings in Canada, Australia and the US. Those are only the ones we know of through the DSR and through Xytex.

6/16/12 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/15205>

I lived scenario one when my daughter was found to have a brain cyst at age 7 and the neurosurgeon needed critical medical information. I had to beg Xytex to help and unless she were in "immediate life threatening danger" they would not.

6/12 Email to Wendy Kramer

Dear Wendy! Today it came to my knowledge that Cryos and Xytex cooperated in early 2000. Cryos bought sperm from Xytex and gave the donors new numbers.

One example that is established is that Xytex donor ##### and Cryos ##### is the same donor.

As there are more donors (at least Cryos #1955-#1962) that are not Danish/Scandinavian I suspect that there is more than one donor sold in Scandinavia under a new number.

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

My partner and I will be trying to have a child soon, and the hardest part of the process is trying to find the "perfect" bank. It seems that every bank we liked we were able to find some damaging information which made us scared to use that bank. Xytex and Fairfax - too many kids, not enough open donors.

2/3/12 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14891>

Both Xytex and Fairfax have the greatest number of large offspring groups.

2/3/12 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14890>

We had a great experience with Xytex.

10/16/11 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14657>

I do know that Xytex Cryo International Sperm Bank (<http://xytex.com/>) provide adult photos for quite a number of their sperm donors listed in their catalogue. You have to pay to view the photos in the enhanced donor profile, but, at least, the option is available.

10/16/11 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14656>

We used xytex (xytex.com) sperm bank and had a really great experience with them. They have MANY profiles with both adult and child photos. The donor we chose has about 12 photographs. They are an American sperm bank - but they ship around the world.

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.

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

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

6/12/11 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14231>

Our [Xytex] donor was anonymous and Xytex has effectively closed the door on our discovery of *any* information. My now 19y-o son has little spoken interest in half his roots other than a recent Dr visit which resulted in the phrase - Look, we only know about the mom's side, if that helps cut some of your questions - and then there's the minor medical issues surfacing, making us wonder some about genetic pre-disposition...

So I'm ready to dig if I can, but need some hints, tips, direction, etc. Atlanta and Augusta seem rather large areas to be guessing in; lots of universities in that area, too, so seems insurmountable to begin [which may be what's holding me back].

We have done DNA testing at Cabri and I have the report; but that doesn't tell me a whole lot. According to DSR we are the only family with this donor ID, but I can't believe that's truly the case. Xytex has stamped our file in large red letters, and we are OFF LIMITS according to them [as is our donor to us]. Not looking for contact so much as updated information. When the dr used Xytex, there were only 4 numbers, and no letter codes. My dr's office has since shredded my records, I've learned; additionally, what does that mean for the status of my signature saying I wouldn't search?

5/20/11 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/14186>

Presently, all identifying records for Xytex donors (the source of most sperm used in BC) are held in Georgia, USA. This makes it a lot more expensive (and prohibitively so, for most people) to be able to actually get the records or hold those who possess them accountable, as the involvement of a U.S. court (and likely also a Canadian court) would be required.

2/11/11	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13979
<p>I have had my own struggles with Xytex in getting updated medical as well. My daughter was conceived in 1996 so not quite as early as you. He was gone from the donor list in 1997 so we apparently got him at the end of his "tenure". I know only one other reported birth exists but perhaps there may be more.</p> <p>My daughter became quite ill several years ago and I wanted an updated profile as the medical I had was 12 yrs old. I fought for years to get this. Because my daughter was not "life or death" I was refused anything. I had an unknown donor (biggest mistake ever).</p> <p>The long and short of it is, I was relentless, I barraged them with emails, I found a facebook group of Xytex employee's and tried that route, I even put a "lost and found" add in the Augusta Sunday paper looking for the donor..... Last June I got a current updated profile with medical information. It was not fantastic but it was very appreciated and helpful. Our donor reportedly declined to be known when contacted but at least he was willing to update his info. Xytex supposedly did a blast mailing to old donors.</p> <p>Stay on them...it is an up-hill battle but worth the fight.</p>	

2/10/11	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13973
<p>I wrote Xytex, just to see if my donor had signed an identity disclosure. I received a reply this morning from Xytex, saying that Identity Disclosures didn't exist in the 1980's--along with their refusal to even contact my Donor, to at least give him the option that didn't exist 26 years ago.</p> <p>What is infuriating is that my rights are not even considered. I have a right to know my biological father's medical history--and I believe he has the right to decide whether or not he wants contact with any offspring. But Xytex said it would be 'too disruptive to the donor and his family', so they won't even consider contacting him.</p> <p>So, here I am, left frustrated, a little teary-eyed and mad! I was googling legal rights of donor children, found an alliance group, which lead me back to DSR.</p> <p>Do you know of anything I can do, anyone I can talk to? It seems to me, the uppers at Xytex are making a decision about contact based on personal discretion, and I think that is ridiculous! I understand if the donor doesn't want any contact with his offspring. What I don't understand is why Xytex won't give him a chance to decide for himself.</p>	

9/24/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13635
<p>My partner got this response on Xytex' FB page. She'd posted something there about our donor would want to know what a cool person her son is & someone posted back that he should consider donating! The Xytex rep posted back apologetically and removed the donating comment. A conversation ensued and this is part of one reply... interesting, but I agree with her query: why would someone refuse to update anonymous info?? [Unless there is something they don't want known.] Our file is marked 'DO NOT CONTACT' I am told; her question was to clarify that indication.</p> <p>---</p> <p>This morning I pulled the file for the donor, and I do remember the case now. There are notes (from the year 2000) in the file about a request from someone (who I'm assuming is your partner) for updated medical information (non-identifying) from the donor. We conducted a search and found an address for him, asked if he would fill out an updated medical history form, but he declined and was unhappy that he had been contacted. His response prompted us to place a note in his file that future attempts to contact him were not to be made (unless exceptional medical circumstances were to arise).</p> <p>We've made contact (upon the request of recipients/offspring) with several different donors from years ago, and sometimes they are very willing to communicate; sometimes they provide medical updates but want no contact; and sometimes they aren't even willing to do that.</p> <p>Who knows why someone would refuse to supply non-identifying updated medical information. It's a mystery</p>	

to me.

9/8/10 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13591>

Personally, I don't see how a bank supplying a former or current donor with his donor code violates anyone's privacy. Unless the bank has something to hide--there seems to be no reasonable excuse for denying this information.

I hope that those reading this don't believe that all sperm banks adhere to this same policy. I can say with 100% certainty that Xytex will provide donor numbers to any current or past donors who seek this information.

7/23/10 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13434>

Xytex has a FB page as well now. Mostly cheerful happy posts of new parents but at least they are offering a forum for all.

5/6/10 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13208>

It looks like most of you with positive Xytex stories have children much younger than mine. Hopefully this is a sign that things are changing, too late for us though.

5/5/10 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13205>

For what it's worth--here's our experience with Xytex.

Overall, we've had a pretty good experience with Xytex. We used them last year to conceive our daughter and were generally happy with the service we received. After our twenty week ultrasound showed that our daughter had anencephaly (a severe neural tube defect with zero chance of survival), my partner delivered at twenty weeks. We contacted Xytex immediately since the doctors said her condition, while very rare, was most likely the result of a combination of genetic and environmental factors. While they did tell us that it was probably the result of just "bad luck," they did say that we should use a different donor when we started TTC again. When I called Xytex to report our situation they were not only professional, but compassionate. In the end they didn't retire the donor (2964), but did put a medical warning on his profile so when anyone clicks on his profile they are immediately made aware of our daughter's medical condition.

When we started trying this January we ended up using Xytex again--in part because we felt they handled the situation as best they could and also because they went out of their way to help us find a new donor that met our criteria. In the end while we wish our daughter's outcome had been different, we have no regrets about using Xytex and found them to be professional and courteous throughout all of our interactions.

5/5/10 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13204>

Xytex is great until you need them for something serious....polite only goes so far when you're begging for updated medical. Those with ID release are in a whole other world than the rest. And while I am happy affectional writer and others have had great interaction you must be careful that you are always keeping yourself informed of the company policies as they change without notice. I wonder if any of you were with Xytex "back in the day" when they had an online discussion group for clients? It was a very active community of people who shared a commonality...we used Xytex. About two years in to my participation I logged on one day and it was gone...abruptly, no notice, no way to contact people you had formed friendships with. The reason...the tone of the discussion started to turn against Xytex and its flip flopping rules and regulations. I don't hate them, I wouldn't even say don't use them but I think people need to know that this is risky business.

5/4/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13201
<p>My Xytex experience is actually like "afictionalwriter"'s, except that it was in 2006. We opted to use the same sperm in 2010 so that our daughter would have a chance at a full sibling - again received good service.</p> <p>I honestly don't see anything in that ID release form that looks any different from any other bank.</p>	

5/4/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13198
<p>We used Xytex in 2003. We did not use an ID release donor (we were naive about the many considerations of our decision that DSR's enlightened us about).</p> <p>I suppose there is some sort of inherent contractual agreement from our transaction by credit card over the phone, but we never signed anything for Xytex.</p> <p>We reported our birth (so few do, ID release or not). We received our long profile, as promised. We've always had polite and professional dealings with Xytex; they've promptly responded to our calls and inquiries and did not audibly or virtually flinch that we are same sex partners.</p> <p>We are fortunate that our nearly 6-year-old son seems to be developing normally (but what's with all the testosterone?).</p> <p>So...just wanted to throw in another Xytex experience.</p>	

5/4/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13196
<p>Xytex is famous for changing the rules halfway through something and not letting you know. When I had my daughter 12 yrs ago there were very few ID release donors and in the ended I chose a Xytex donor because in the "pretty pink brochures" they had stated that should you encounter a medical concern or when your child is 18 we will do whatever we can to assist in helping you find the donor. I thought (foolishly) that seemed like it was ok, not as great as an ID release but at least my daughter had an option later in life.</p> <p>When she was diagnosed with the brain cyst at age 7 I became yet one of many families duped by Xytex and false promises. What they really meant was "if your child was near death"....and the pink brochures long gone with no promises of helping...EVER. Apparently the threat of a law suit by a donor who got a certified letter from them, only to have the unknowing wife open it was enough for them to retract previous agreements. No, none of the former clients were notified of this....</p> <p>So just a warning, the fine print today may not be the fine print of tomorrow.</p>	

5/3/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13194
<p>I'm not a lawyer, so I'm sure I lost some meaning in all of the mumbo jumbo legalese... But aside from the endless "don't even think about suing us" clauses, it seems for the most part to be pretty standard ID release - basically, no promises. There isn't anything Xytex can do to compel the donor to either keep his contact info up to date or to actually make contact with your child if your child desires it after s/he turns 18. And this form is just a reminder of that fact - stinks, but there it is...</p> <p>If you were to amend the form, what exactly would you change?</p> <p>BTW, I'd be annoyed too if I received this after the fact (they should have had you sign it before purchasing the sperm).</p>	

5/3/10	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/13193
<p>I'm the parent of a child who was conceived by DC. Our donor was an open I.D. donor, and a higher price was paid for that. Or so we thought he was open ID, anyway.</p>	

AFTER the baby was born, and we called the sperm bank to report the birth, they asked us to sign an oppressive and offensive form, purportedly to even have access to the open id part of this donor. <http://www.xytex.com/pdf/id-consent-release.pdf> We haven't signed the form, and don't want to, but at the same time don't want to jeopardize our child's rights.

10/9/09 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/12189>

If I were you, I would strongly consider another bank that is more genuine than Xytex. On the surface, in the brochures, they appear to be incredibly kind, willing to help, you name it.

I used a donor who is long since out of the program. My daughter was born in 1997. She had many little problems that could frankly just be the luck of the draw...reflux, asthma, lazy eye...none of which are on my side and not reported by the donor either.

At age 5 she was diagnosed with a brain cyst. In the process of the work up the neurosurgeon wanted updated medical on the donor and Xytex was adamant that it would not help in any way unless my child was actually "having a life threatening problem and I could prove that genetics was the cause"So imagine knowing that your child has to be on the brink of death and you need proof of the cause for them to help. When I chose this bank it was primarily because they had what appeared on the surface to be a genuine sense of caring about the off spring and even said that for non-ID release off spring they would help them when they turned 18 if the wanted info on the donor. Since then the policy has changed and they never notified any of the former clients (parents).

Five years after our scare, I got an email with some basic medical info updated. No history of brain cyst but autism and Parkinson...both two very important diseases/disorders. If I had not continued to push them I would not have this information.

So....if you can, go somewhere that is very open, or make sure you pick an open donor and push Xytex with questions.

6/18/09 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11993>

Out of the clear blue I received an email today from Xytex with some updated medical information on our donor. A bio grandmother who developed Parkinson's at 70 and a bio grandfather who had a strong. Also....donor's sister has a young son with autism.

All of this is such valuable information and I am finally very grateful to Xytex for this.

I don't know if they solicited the info from the donor as he has been out of the program for about 15 years or if my nagging and blogging and facebooking prompted them to contact him. Either way it's good.

The did say the donor still wishes to remain anonymous and while this is hard to hear the fact that he is still around, still responded to Xytex and cared enough to share his update gives us hope for the future.

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

2/9/09	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11597
--------	---

I think I contacted all DSR families who used this donor, who are posted on the DSR back in December. If you are not posted on the DSR, and have used this donor- here is the notice and contact information for Xytex: Xytex regrets to announce the death of our donor AFM ####. We are in the process of contacting via certified mail all physicians and patients who have reported pregnancies and/or births for this donor. If you would like to learn more information and did not report your child's birth to Xytex or you feel Xytex may not have your current contact information on file, please contact Sue Simmons or Mary Hartley at 404.881.0426.

9/28/09	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/11204
---------	---

According to its website, Outreach Health Services, <http://www.donorspermohs.com> "is the Canadian distributor for Xytex Corporation"

8/5/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10971
--------	---

Queensland Fertility Group also uses Xytex donors. We went through QFG and chose a Xytex donor.

8/4/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10956
--------	---

The following have also been added to this list (the registry notes under the facility names are more up to date than this list so be sure to check those headings):

XYTEX AFFILIATES (found in Xytex archives):

Xytex has satellite semen banks in the following locations:

Florida Institute For Reproductive Medicine (904) 399-5620, Jacksonville, Florida

Genesis Fertility Centre (604) 879-3032 Vancouver, British Columbia

North Carolina Center for Reproductive Medicine (919) 233-1680 Cary, North Carolina

Pacific Reproductive Services (415) 487-2288 San Francisco, California

Reproductive Health Associates (813) 572-5300 Clearwater, Florida

Southeastern Fertility Center (803) 881-3900 Mt. Pleasant, South Carolina

University of Connecticut Health Center (860) 679-3460 Farmington, Connecticut

Uptown Pharmacy (214) 871-8711 Dallas, Texas

Xytex Corporation at Syncor (800) 277-3210 Woburn, Massachusetts

8/4/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10954
<p>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:</p> <p>-Genesis (Canada) is a Xytex affiliate. All numbers are Xytex numbers. Xytex numbers have 3 letters before them. AFL, AFM, AGL, AGM, AHL, AJL, AJM, AIM, BFL, BFM, BGL, BGM, BIL, BJM, CFL, CFM, CGL, CGM, CHM, CJL, CJM, CJN, DFL, DHL, EFL, EFM, EGL, EGM, EHL, EJL, EJM. These are codes for hair and eye color, blood type, and height. They use the number part of the donor number only one time. Old lists had the letter D before the number, but in the donor code part they had the 3 letter code. There have been cases where the 3 letter code has changed over the years, example: an older number that used to be coded BFK was later changed to CGL.</p> <p>-Many small clinics in Canada sell Xytex sperm without telling clients it's actually from Xytex.</p>	

8/1/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10944
<p>My partner and I have had a similar thing happen. We used a donor from Xytex and we live in Brisbane, Australia. Our son was about 3 months at the time and we went to a Lesbian parents' picnic to meet other parents. To cut a long story short, us and another woman were among the last left. She had a set of twins three weeks older than our son. I was intrigued by one of the twins and wasn't sure why, until my partner out of the blue asked what fertility clinic she used, and what her donor was like. It inevitably came to donor id, and there you have it.....donor siblings 3 weeks apart. And in Brisbane.</p> <p>We knew at the time we chose our donor that there were 4 vials available. We were going to get them all but decided to wait until I conceived. And I did first go. We then called the clinic to find out that they were taken. So we knew at that stage that our son may have 1 -3 donor siblings in the same city.</p> <p>The most curious thing about it all was having harassed the fertility clinic after our son was born for more vials, I then got a random call from them a few weeks before the above meeting. Vials had been returned in early Feb, just after our son was born. Needless to say we were over the moon. It was then at the above meeting that the twins mother stated that those vials were hers. It gets even more intriguing as the twins due date was the day our son was born. They were born 3 weeks early and our son 2 days late.</p> <p>As we were discussing it all, she told us that the article about my partner and I and our son that was in a Brisbane newspaper, she said she had cut it out and had it on her fridge for a while. She told us that she wasn't sure why she did that.....we believe that we were meant to meet.</p>	

7/23/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10862
<p>I have had nothing but wonderful experiences with Xytex Corp. today I had more positive correspondence with them...and I wanted to share as I think it says a lot about them as a cryobank.</p> <p>I have been in contact w/ them for a while now, as our 19 month old was conceived by a donor from Xytex who stopped donating and who is 'sold out.' there are vials on reserve and I've been in touch w/ Xytex staff, making them well aware that we'd like to purchase some should they become available, for a sibling for our son.</p> <p>Today I was told both by e mail and a more formal letter, that our donor has updated his medical records, sharing with them that he was diagnosed and treated for kidney Cancer. He is 37 years old.</p> <p>Xytex had contacted him b/c there was a couple who wanted to 'reactivate' him (ask him to return for further donations) and he shared the information with them. He had not been diagnosed w/ Cancer at that point (I believe this was in May), but it was suspicious and he shared that with them. He also shared that he had planned on contacting them.</p> <p>Xytex called him the next month (June I believe) and he shared with them that he had the tumor removed and it was malignant...they then sent a very informative letter to people w/ vials on reserve and to those like myself who do not, but have a child from this donor.</p> <p>They advised people who had not had a child from this donor but who had vials on reserve, to exchange the vials for another donor at no cost, explaining that while they don't believe the Cancer is hereditary based on a couple of factors, they cannot be sure. They advised people like myself who have a child from him and who would like a future child from him, to discuss our particular situation w/our doctors.</p> <p>They further allowed me to write a letter to the donor which they will forward to him (he is anonymous), in which I was given the opportunity to both thank him for the best gift I have ever received in my life, wish him</p>	

well in his health and everything else in life, and ask for the specific diagnosis, as some Kidney Cancers are hereditary and some are not.

I am so grateful that both Xytex and the donor have been so open as I am well aware of how this is often not the case. I am also grateful that Xytex allowed me to get a letter to him, even though he is anonymous and for the donor to being open to this....

I of course, asked the donor for anything more he could share with our son (his contact info for the future, a letter, more information about himself, or even his first name), as I have become more deeply aware of how our son may want that in the future.

Just wanted to share with you all...while the news was a bit shocking and disturbing, it has show me how people really can be responsible, and most importantly, caring of others.

7/15/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10784
---------	---

I have had quite a few people join the DSR this week with notes saying that they are not telling their child that they are donor conceived because their husband will not allow it. For heterosexual couples out there: Did you receive any education/counseling from your doctor, facility or sperm bank in regards to disclosure? Any suggestions made? Any counseling offered to deal with infertility?

I am pointing these folks to the reading materials on the DSR's "Articles and Issues" page, the "FAQ" page and the Cambridge "Research" page for articles on the importance of (early) disclosure. I am hearing back from some of these women saying that their husbands will not read or even consider telling the kids. I wonder how we can get the sperm banks/doctors/clinics to better educate the dads? Somehow the shame of infertility needs to be dealt with as well as the fear of rejection because of not being biologically related to your children. If these families would have told right from the beginning, and been honest with their kids, it wouldn't be such a loaded issue, as now there is a secret and people have been lied to. The older donor conceived people that have found out later in life seem to be much more rattled at having been lied to, than learning hat they are donor conceived.

So far, the clinics/doctors/facilities have been unwilling to include any disclosure literature that I have sent them in their new patient packets (except for Xytex!). So the battle is getting this industry to realize the importance of honesty in families. The Cambridge Research is one step along the way....but we have not made a dent in the way this industry continues to operate.

3/21/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/10294
---------	---

Any ideas,,,,,please send them my way. I am able to ask the donor some questions. He will answer them for me and the child to be on a tape recorder. What should I ask? Kids,,, what did you want to ask your donor father? Xytex offers this along with adult photos of the donor which I am very happy about.

3/7/08	http://health.groups.yahoo.com/group/DSR_Discussion/message/4471
--------	---

Although sperm bank responsiveness pre pregnancy is important, I sure hope that no one is choosing a sperm bank before they hear about post pregnancy responsiveness. Particularly how they deal with updating of donor and family medical information, how they then share this information, how they track how many births there are for any given donor, and how they deal with donor conceived people who become curious and want to have mutual consent contact with their biological family.

Most sperm banks I know are very attentive pre pregnancy. Once they have received their money, and helped with a pregnancy, it can be a completely different story. At this point, few even tell their clients about the DSR (only 1.5% of DSR members are sent from sperm bank recommendations).

2/11/08	http://health.groups.yahoo.com/group/DSR_Discussion/message/4425
---------	---

Thanks! I've been glued to my computer for days now doing research. I did see your post previously and was impressed. Based on what I can find, TSBC, PRS and Xytex seem to be the best options for many reasons.

2/10/08	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9905
---------	---

One possible explanation for the disparity in numbers between Xytex & Fairfax is that Xytex has more donors who have been tested for and meet, Canada's screening regulations for sperm (which are different from, and reportedly tougher than, the USA regs).

Lack of compliance with Canadian regs means that:

- * not all USA sperm banks can ship to Canada

- * only sperm & donors which meet Cdn regs can be shipped to Cda, or used here by clinics & sperm banks.

- * samples from donors that were frozen before these regs were put in place a few yrs ago cannot be shipped or used here unless the donor can be found, re-tested & determined to pass the current screening regs.

As a result, some sperm from American ID release donors is available to USA patients but not to Canadians.

2/10/08 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9893>

I've been wondering the following:

Being in Canada we have only 2 choices for ID release donors. Going through Xytex or Fairfax. Can anyone shed some light as to why Xytex has so many more ID release donors available? I'm talking a HUGE difference, 42 at Xytex vs only 4 at Fairfax. Or am I not seeing Fairfax donors that are available to the US only and there are many more?

My understanding is that Xytex has 2 donation facilities where Fairfax has 7 facilities. What is Xytex doing to persuade so many more ID release donors? Are they paying them more or is this the bank that is saying they can change their mind?

I'm asking because I have an existing relationship with Fairfax and I'm switching to ID release for my next purchase.

2/10/08 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9894>

I mailed out more than 400 letters a few weeks ago to sperm banks, clinics, Reproductive Endocrinologists, and infertility doctors asking them if they would include a DSR information sheet in their "new client" packets. I only have ONE respondent- Xytex, who asked for 500 of the info sheets, to include in every new patient packet that they hand out or mail out. This information sheet tells people about the DSR and a child's possible curiosities in a very non threatening and friendly manner.

What does this tell you about the infertility industry? That they just do not want to acknowledge the needs of families post pregnancy. There is an industry meeting on March 28th, in Chicago, for further discussion on the "Feasibility of a National Donor Registry". There is not one donor conceived person that has been asked to speak or participate in any manner at this event. I am the only mother of a sperm donor conceived person asked to speak. (One egg donor mother as well) I hope that some of you will be able to attend this meeting so that the industry can hear your voices. It makes you wonder whose needs they are looking to serve in "self regulating". Certainly not the donor families....

1/30/08 http://health.groups.yahoo.com/group/DSR_Discussion/message/4382

As we did, you will need to decide what you are looking for in a donor. In your statement you wrote "figure it is better to decide on the bank first..worry about the donor from there" I would not necessarily agree. I think you and your fiancé need to decide what you are looking for from the donor. For us we wanted a donor that was Irish like my husband, open identity disclosure (so that our child/ren have the option to contact the donor if they so choose). We also were looking for similar characteristics such as height, weight, hair/eye color. But these are all things you need to decide on.

Once we did that, we started looking into banks. I personally stayed away from NECC because of bad comments made against them from people on the DSR as well as Fairfax because of the donor 1084 story. It was recommended to try PRS, CCB and TSBC. I did not have much luck with CCB, but found a few we liked w/ PRS and TSBC. However, we were not totally satisfied. I then found Xytex and I don't know how to describe it, but they just felt 'right.' We liked the idea that they offered childhood to adult photos. I felt that a donor would not lie about themselves or any info provided b/c they are offering a photo. (Just my rationale).

Anywho, we did end up choosing a donor from Xytex and they have been so helpful to me. When I have had questions they are very pleasant. They even provide more information than is necessarily on the donor's profile. Like whom they think he looks like, personality traits, etc.

For us Xytex just seemed to be the best fit and what we were looking for. In the end the donor is Irish has good

education, but looks nothing like my husband. We are ok with that b/c any child/ren born could look like me anyway.

1/27/08 http://health.groups.yahoo.com/group/DSR_Discussion/message/4369

I have a beautiful Xytex daughter but I would caution you to be very sure you want anonymous donor (if you do) because Xytex holds a very firm line on helping you with any problems after your child is born if you picked non-ID release.

1/28/08 http://health.groups.yahoo.com/group/DSR_Discussion/message/4366

I HIGHLY recommend Xytex Corp....very prof, warm and helpful and a huge amount of donors, both anon and willing to be known. Couldn't love my son more!!! ;)

11/3/07 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9180>

Don't be fooled by Xytex..they are self serving and trust me unwilling to help when push comes to shove...email me offline for more.

11/2/07 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9177>

I have a 15 year old daughter using Xytex. They have helped all that they could. I used the live chat and found it very helpful. I would have liked to have gotten more information, but things were very limited at the time of my DI. I had never reported the birth (because I was never given any information to do so) until I spoke with the live chat person. I was sent the paperwork and responded. I did find out that my daughter does have 2 siblings (twins-a boy and a girl) that live in another country that could not be disclosed. This is as much information that I could get. I do want to stress that Xytex was as helpful as they could be.

11/1/07 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9173>

I too have only had positive experiences with Xytex. We used them to conceive our now 2.5 year old daughter, and I've used the live chat function at least 6-8 times! Every couple of months I ask if there are any more live births. So far, we have 5 girls :) Donor is nondisclosure and we are not on the DSR site, just lurkers :)

10/30/07 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9165>

Glad Xytex worked well for you this last interaction. The "chat live" feature's been around for a while, but I've not used it.

We've always had positive interactions with Xytex. From my initial ordering, in which I was a bit unsure and shy and Xytex was helpful, professional and unfazed that I was ordering a sample for my same sex partner. After the birth of our child, we reported it to Xytex and received a nice, expanded donor profile, as promised. We knew about the firm's request that we report the birth, but no one at Xytex offered to send us a birth report card. We didn't expect them to since we received it with the paperwork accompanying our vials. Perhaps your ob/gyn/whoever misplaced it or didn't provide it to you 16 years ago (or perhaps Xytex didn't have such a means in place 16 years ago)? As far as the expanded donor family history/medical profile goes, it's my understanding that we could have had that up front, for \$25, but Xytex sends it gratis as a courtesy for reporting births.

When our donor showed up on the Xytex site again, after we thought his vials were gone, Xytex promptly responded to my email inquiry and informed me that the new marketing director wanted all donors with specimens on the site (ours only had one unwashed vial left).

Xytex also confirmed one lone pregnancy from our donor...since we reported it, apparently that's us. They've never warned us DO NOT CONTACT DONOR but we've never bothered them with any such queries. In our experience over the last four years, we find Xytex very responsive to phone and email queries.

10/29/07	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9163
<p>Xytex has revamped their website [since my last visit there] and their live chat feature is not bad. I at least have now learned that my donor has one reported birth of a daughter. They have no report of my 15.5YO son. [but will soon!] He's not on their website bc he is no longer an active donor [which would be a good thing, I think]. I have NEVER had one of their folk offer to send me the birth report card, which will in turn open me to the medical / donor info, which I have also never been offered... I've only been told DO NOT CONTACT DONOR -- which wasn't my intent anyway -- so I feel a wee bit of glee today. Of course, they could not tell me anything about the girl -- year of birth, geographic area, etc -- but I'll hope her folks sign on the DSR some day.</p>	
10/22/07	Email to Wendy Kramer
<p>I personally used Xytex, and did not experience any problems. Counts were always good etc as far as quality. From a medical perspective, after purchasing sperm, I received communication from Xytex about a medical condition of an offspring for my donor. The offspring had hydrocephaly, apparently when this occurs, there is a very slight chance of this condition being hereditary (I think I remember 1% or something like that), but there is only a maternal connection, not a paternal connection at all. So people were notified and the donor was pulled from circulation. I thought this was very thorough and probably even overkill on their part, given the lack of paternal connection with the condition when there is a link at all (rare). I had just frozen the embryos so after my own research online, I determined that there was no discernable risk and used the embryos. Both kids are healthy and perfect in every way. :)</p> <p>In another contact with them, one of the workers actually shared the donors first name on request when I explained why I would like it (i.e. less impersonal than "the donor" when talking to my kids). She thought it was non-identifying so that was ok.</p> <p>So overall, I have been a bit surprised to hear issues with them, as that has not been my experience at all, and they were the only bank to have photos at the time I looked, which was something important for me. I only wish they had had ID release. In fact, if I had a complaint it would be that they are not retroactively finding donors for ID release. When I talked with the contact about the name, she indicated that he had said he would be open to contact every time he donated, so at least back in 2000, they were thinking about ID release obviously but it had not occurred yet, but they are not pursuing this option at the moment.</p>	
10/20/07	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9113
<p>In response to message 9104, below: I can definitely vouch for that. A couple of months ago I wrote to them about getting some more info on the donor and they referred me to the DSR site, not knowing I was already a member.</p>	
10/16/07	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9104
<p>Even though I personally am disenchanted with Xytex they did tell me they refer many callers to the DSR so that is one positive.</p>	
10/4/07	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/9006
<p>According to Xytex my file is marked 'DO NOT CONTACT' referring to the donor. Guess I or someone else overstepped our 'bounds'.</p>	
9/19/07	http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8951
<p>Not sure if I am the one who you heard the story about the donors wife opening his mail but I first "broke" the story on the DSR three years ago when I was looking for medical information from Xytex. My child was not in imminent life threatening danger so Xytex would not pursue the donor's medical update but it was at that time that a "counselor" who was actually very nice told me that they had sent the certified mail to a donor on a families behalf and the uninformed wife opened it. Yes a law suit was threatened. Since then Xytex has retracted all its promises to help offspring on non-DI donors something they proudly touted in their literature</p>	

in 1996 and 1997 but have since removed. I work in health care and am fully aware of HIPPA but if I am not mistaken opening up someone else's mail is also a crime....wife or not.....certified mail to boot!!!!
It is all a delicate, uncharted area that I continue to be frustrated with...

9/20/07 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8953>

Not sure if you have children of your own now with your wife but imagine just for a moment to be in my shoes.....your beautiful, intelligent, funny child turns pale, begins dry heaving, begins crying, moaning in pain with severe headaches....this goes on for over a year on and off....finally when she is 7 your pediatrician orders an MRI. You're at the office, in a staff meeting when your cell phone rings and your stomach sinks when you see on the caller ID it is your pediatrician's office. Your child's doctor tells you that your beautiful, intelligent, funny child has a "brain cyst, pressing on the brain stem causing a mass effect". A neurosurgery appointment has already been set up by the office.

You take above mentioned light of your life to the Children's Hospital and they want a full medical history of both sides.....you panic, for the first time you realize you may have a problem. You spend countless hours on the phone with Xytex and all the "suits" who give you nothing but the company line and tell you that unless your child is dying, call back....

Somehow a certified letter to the donor pales in comparison....in my book anyway.

9/17/07 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8946>

Both Xytex and Fairfax offer adult photos of donors now. Fairfax calls them "Lifetime photos" (you get a series of about ten, from infancy to current day), but you have to sign paperwork to even get the photos, basically stating you will not post the pictures anywhere. Xytex actually posts them online, if you pay their membership fee (at least this was true 18 months ago when I was looking for a donor there.)

9/16/07 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8937>

My experience with Xytex is they will not provide any medical update for any "past donors" unless your child is in a "life and death situation and you can prove there may be a genetic link".....

Apparently a cyst in your 7 yr olds brain causing severe neurological headaches was not life threatening enough....buyer beware!!!

9/15/07 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8918>

The issue of known vs unknown was never, not once discussed by my clinic nor the mandatory psychologist they sent me to first who was employed by them. I never gave it a second thought because the Xytex literature was VERY clear that at 18 they would assist ANY offspring to locate a donor if they chose to. Only after they encountered a legal issue did they rescind this in their paperwork. None of the smiling, happy, oh so helpful staff will you talk to these days will even discuss it.....

8/1/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3735

I have just had 48hours of email exchanges with Xytex on my own issues of off spring, reporting etc. Astrid, you can go to the website and there is a place for clicking to actually "talk" with someone online...of course half the time no one is available but you can email them the message. In 1996 when I purchased my sperm I got the long and short profile (for a fee), no pic of any kind was available. The donor was born in 1971, first donated at age 18 so 1989. It was updated in 1996 but the donor disappeared of any lists in 1997. I am not clear if he donated all those years of if he just had vials available. My hunch is he left the program in 1996 and they did an exit health assessment and update. Thy confirmed only two reported births mine being one of them We have a 1/2 sib somewhere in Canada....born 1996 the year before my daughter.

They are very tight lipped about giving out any info but be persistent. The also are very familiar with the DSR.

7/31/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3726

Yes it does. We know of a few of these situations on the DSR. Donors showing up on several sperm bank or clinic's lists- with different numbers. Sperm alone as well as the men themselves going among several banks. Not very settling, is it?
> -So does this mean my donor could be under a different # at a bank
> not called Xytex?

7/31/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3722

I forgot to mention that when I went through Xytex's archives on the Wayback Machine last fall, I found this, which Wendy has put on her blog. I don't remember which year it was posted, though, so I don't know what years this is referring to, or if it is still true. So people who used Xytex should probably look at any listings under these places that are on the registry to see if any of the postings look familiar (and those who used these places should look under Xytex). I know that Xytex and PRS have different types of donor numbers, so don't know if they shared donors or what, and if so they must have changed the numbers. Maybe they both just used their own donors even though they were connected.

XYTEX AFFILIATES

Xytex has satellite semen banks in the following locations:

Florida Institute For Reproductive Medicine (904) 399-5620, Jacksonville, Florida

Genesis Fertility Centre (604) 879-3032 Vancouver, British Columbia

North Carolina Center for Reproductive Medicine (919) 233-1680 Cary, North Carolina

Pacific Reproductive Services (415) 487-2288 San Francisco, California

Reproductive Health Associates (813) 572-5300 Clearwater, Florida

Southeastern Fertility Center (803) 881-3900 Mt. Pleasant, South Carolina

University of Connecticut Health Center (860) 679-3460 Farmington, Connecticut

Uptown Pharmacy (214) 871-8711 Dallas, Texas

Xytex Corporation at Syncor (800) 277-3210 Woburn, Massachusetts

7/26/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3693

Yes...and Xytex sends the donor's complete profile upon receiving a successful birth report from the recipients/clients. I agree it's easy, but perhaps folks are distracted with the new addition and forget...or assume the doctor will do it (a real faulty assumption). I've talked to many moms who never reported for whatever reason (and usually do report after we've talked).

7/26/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3692

I know Xytex makes it very easy to report a birth-they include a post card w/ postage paid 'birth report card.' It was very simple to fill it out and I can't believe that people can't do such a small thing! Also, I was so thrilled to have a baby, and so grateful for such a thing as sperm banks, and so grateful to our donor, I filled it out with glee.

7/25/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3684

My child has a brain cyst diagnosed at age seven after years of violent headaches. I can't get Xytex to even update a medical history or put my information in his record (he is long retired). I have no idea if anyone in his family has had an issue like this, he himself was only 18 when he donated so I assume he has nieces/nephews maybe kids of his own by now. I can't prove the cyst is hereditary because I can't access his information.....All I want is information, no one's privacy needs to be breached.....they simply don't care.

7/11/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3548

As much as I am angry with Xytex and there interpersonal relations with families post conception I am happy with the outcome.....brain cyst and all I would not have it any other way. Our medical issue pales in comparison to some other poster and I really truly feel there frustration and pain.

Most of us had the stress of trying to conceive or dealing with infertility like Nicole mentioned but once you're

a parent nothing in the world compares to the stress you feel when your child has been wronged, hurt, suffered.....

7/10/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3537

I'm from Canada and dealt with a clinic who uses sperm from Xytex. It may be that the nurse was just concerned that because I had a daughter, and there were two boys born within a couple of months that she told me. Concerned about them meeting in the future and having a relationship, they would be either in the same year at school or one grade higher and we all live in the same city, which is small in the whole scheme of things. Since then I have had a second child, a boy, and when I went into the clinic again, the nurse told me that there had been two girls born later the same year as my daughter, I was the only one who had a second child to the same donor. So I know there are three boys and three girls from my donor in my geographical area. I don't know though how many there may be throughout North America, likely Canada mostly, as he was a Canadian donor from the now closed Canadian Xytex clinic in Toronto. I have found one boy 7 weeks younger than my daughter, purely by coincidence!

7/9/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3522

I am reading all of these responses and trying not to take a cynical look. Nicole wrote to me that she was sorry about my daughter having a brain cyst and of course Xytex can't test for everything. That is not the point of the post or my feelings about and some other banks. I did not and do not hold them in any way responsible for my daughter having a problem, I hold them responsible for being insensitive, disengaged, cold, uncaring, unwilling to help when I called for an updated medical history or an attempt by them only at contacting the donor to see if this has come up in his family. I don't care that my kid is a knock out....which she is....I don't care that the donor had so many million sperm.....what I care about is people being accountable. 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. I am not discouraging anyone from using Xytex or any other bank but please take the blinders off....your a customer, they are selling something. When the deal is closed good luck if you run into trouble. Some of the posts seem to think that since there kids came out beautiful (a recurring theme I might add) and some high school graduate answered the phone all happy and upbeat that constitutes a positive experience. You never know what life holds in store for your child....hopefully you never will need to call that bubbly, helpful phone rep and beg for information.....

My daughter is doing fine, thriving but not because of anything Xytex did. I hope this cyst stays the size it is and her life continues to be fruitful but please.....unless you have ever NEEDED there help you don't have a clue....and while I don't want to minimize those with lousy samples and low counts that is not the kind of help I mean.

7/9/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3520

It's possible I'm wrong, but my understanding is that all anonymous donors at Xytex provide either a child and/or adult photo. Again, this could be incorrect. I do know that we used an anonymous donor, and we do have an adult photo. That was only in 2006....

I totally agree w/ all you said about Xytex! Our baby also exceeds all expectations I or my partner could have had. He's AMAZING. We love him to death....

7/9/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3518

They were great with us...professional, non-judgmental, delivered as promised and our nearly 3-y-o is beyond initial hopes. Unlike many, we didn't care about a photo-match (felt it might conjure too many preconceptions/expectations) and our anon donor didn't provide any. We went for health/longevity of donor/family and ethnic background (to more match me, the non-birth mom). Therefore, at least in 2003, Xytex did not provide images (child or adult) for all its donors, contrary to what a previous poster stated. Perhaps it's different now...

7/9/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3517

I must second the Xytex experience. My re also said that the sperm count was very high in my vial which resulted in my healthy, gorgeous, sweet, calm, smiley, affectionate and just PERFECT 6 month old baby boy. And again, I found them to be very helpful and open with me. They also had the largest selection of African American donors of all the banks I looked at.

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

For me, CCB had very low sperm counts, and I never got a refund. Xytex had extremely high sperm counts, and once when there was a problem, they came in on the weekend and shipped something on the next plane so I wouldn't waste a cycle.

My best friend has two lovely kids via CCB, and she didn't have this problem, but that was 12 years ago. Also, I've had emails from people who didn't like Xytex, but I loved them. And I especially love my new bouncing baby boy, born healthy as can be at 8 pounds 8 ounces!

I got on the DSR about six months before I started using donor sperm, because I needed to check in and see what it was all about, before I took such a giant step. My bias was to use a known donor. But I was tired of waiting and running out of fertility. I contacted several donor families before choosing the sperm number/bank to use, and I found that worked well.

7/7/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3484

I think no matter how many people you poll on this question you are always going to get a group who had what they would determine a negative experience. I think the initial part of "picking and eventually purchasing" is not always the best way to judge how good a sperm bank is. During that phase they are marketing....as hard as this is to say, this is a business to them not a group of philanthropists. I found Xytex great in the beginning and seven years later my feelings have changed due to my own negative interactions with them. If you see a pattern of behavior from a bank by posters I think you need to steer clear but keep in mind no place is going to be perfect.

7/6/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3481

I used Xytex and they just tell you if there are reported pregnancy(ies) or not...no number, no method, nothing. Mine had no reported pregnancies (though he was still quite 'new') and I got prego each time I tried (first time chem preg, second time resulted in my son)....so you can't just rely on reported pregnancies I think....

7/6/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3480

I used Xytex in Georgia and couldn't have been happier. Everyone there is super sweet, helpful and knowledgeable. And the donor picking is great-there are even adult photos for anonymous donors. my iui's resulted in one chem preg :(and one little 6 month old boy who is sweet natured, easy going, gorgeous, smart and alert, very social and personable. i highly recommend them.

6/26/07 http://health.groups.yahoo.com/group/DSR_Discussion/message/3300

For me personally, I do have a bias about using only an id release donor with an adult photograph and some sort of consistent contact with staff. I was tickled when the staff at Xytex asked me questions, and led me away from one donor I was considering, and towards another, providing pictures, stories of interactions, tapes of conversations. Even if it's a gut response, I wanted that. Apparently many families value anonymity so much, that they don't want to know all that much about the donor. And that's fine too.

5/28/07 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8547>

No where else have I seen more honestly about the good and the bad of sperm banks. I am not sure where you "recently learned" that people were afraid to post negative things but my experience does not support that. Actually, Xytex use to have a board for "customers" to post on and when that board got heated and began expressing negative comments about the company it was them that abruptly shut the board down.

11/4/06 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8087>

In response to message 8086, below:

Thanks so much for this information, that is what I was suspecting. I have been in contact with someone who matches another posting with the numbers but not the letters. With this new information, they can be more sure that their kids are in fact siblings. By the way, this is from the Xytex website on what the letters represent. They are just coding for the hair and eye color, blood type, and height. Maybe over time some of the donors change with hair and eye color or height and that is why the letters change?

CHOOSING A DONOR GROUP

Create a donor group code by selecting one letter from each of the three sections below:

COLORING (see below)

Dark Hair/Dark Eyes	A
Dark Hair/Light Eyes	B
Light Hair/Light Eyes	C
Light Hair/Dark Eyes	D
Black Donors	E

BLOOD TYPE

O+ Blood Type	F
A+ Blood Type	G
B+ Blood Type	H
AB+ Blood Type	I
Rh- Blood Type	J

HEIGHT (Feet; Inches)

Donors Under 5' 7" Tall	K
Donors 5' 7" to 5' 11" Tall	L
Donors 6' 0" to 6' 4" Tall	M
Donors 6' 5" and Taller	N

Example: Desired characteristics are dark hair, light eyes, A + blood type and height of 5' 9". The Donor Group will be BGL.

"Dark Hair": Black, Dark Brown, Medium Brown, Light Brown, and Auburn.

"Light Hair": Lightest Brown, Blonde (all shades), and Reds.

"Dark Eyes": Black, Dark Brown, and Light Brown.

"Light Eyes": Blue, Green, Grey, Hazel.

11/4/06 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/8086>

I have been in contact with Xytex trying to get information on my DI daughter. Our donor had 3 letters before his number. When I received information on him, the 3 letters were different from mine. They told me that those letters only represent specific things that we requested. The number is what actually identifies the donor. Only 1 donor will have that number.

10/20/06 http://health.groups.yahoo.com/group/DSR_Discussion/message/2693

I have to jump in here regarding Xytex. I have a 9 yr old daughter conceived with a Xytex donor. When I made my donor choice close to 10 yrs ago ID release was really just coming around and I found that the match that was most comfortable for me was a non-ID donor. As a nurse who worked in neonatology and OB I was very detailed in gathering information on the long term published compliance of Xytex's willingness to help offspring and parents. I felt comfortable with what they said and had no reason to doubt them.

At age 7 my daughter was diagnosed with a cyst in her brain that on MRI seemed to be putting some pressure on the brain stem. She has had a full year of "serial MRIs" every 3 months to monitor this. She suffered with

severe headaches. I contacted Xytex and tried to get recent medical info on the donor as he was over 10 yrs old and he was retired. They refused to contact the donor for any updated medical. They refused to contact the only other reported live offspring to see if they had problems. They refused to even make a note in the file should either the donor or the other child inquire. I was told unless my daughter was in a "life and death" situation they would take no action. I was interviewed by the Augusta Chronicles reporter Tom Corwin last year in which I expressed my serious concern about Xytex's willingness to help anyone once the child has been born. I spoke with Mary Hartley at Xytex and while she was incredible nice and told me her personal view is for openness, Xytex regrets they cannot help me. She cited a law suit in which they sent a certified letter to a donor to get information for a Di child with some problems and the donor's wife opened the mail. She never knew he had been a donor and I guess he threatened to sue. Now they help no one. When they are looking to make a buck off you they are more than willing to assist.....when you have a problem your on your own!!!!

10/19/06 http://health.groups.yahoo.com/group/DSR_Discussion/message/2687

I'll have to throw kudos in for Xytex, even though we never used them and never will. I've talked to every major sperm bank in the US in the last 2 months, often to the directors. At length discussions, taking up to an hour in some cases. And Xytex came across completely professional and caring and I believe that they would definitely pull a donor if a situation arose where is needed to be done. The reason we won't use Xytex is because they will not ship to home and we have no desire to have a doctor involved, and because they are unreasonably expensive, to the point where I am a little put off by it. Same with TSBC. But I wouldn't have any qualms about Xytex from a health standpoint.

3/14/06 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/6399>

I just wanted to update some information I received today regarding BFM #### births. The total number of lives births for this donor has now (according to Xytex) jumped to 30! 11 girls, 12 boys, and 7 listed as unknown... WOW

1/26/06 http://health.groups.yahoo.com/group/DSR_Discussion/message/1352

I am also finding this discussion very interesting. During my first pregnancy via ADI (Xytex), I developed a blood clot. To make a long story short, in addition to learning that I have a heritable clotting factor problem, I was found to be a carrier of Alpha Thalassemia (actually, to have Alpha Thalassemia Minor with two of four deletions, for those of you who know something about this), which is VERY rare for persons of North American heritage and which can be fatal if my donor also was a carrier. At a very early stage of my pregnancy, I tried to get information about my donor's status for the sake of my unborn child. Turns out, because it is so rare in people who share my donor's ethnicity, he had not been tested. Xytex did agree, with my clinic advocating on my behalf, to send a letter to the donor but apparently that letter was returned to sender due to a change in address. That was all that the bank was willing to do.

Now fortunately, I have gone on to have two phenotypically healthy children with the assistance of this same anonymous donor (though they will also be carriers because of my status but hopefully not to the same degree as I am), but I still shudder to think what could have happened here. . .

10/27/05 http://health.groups.yahoo.com/group/DSR_Discussion/message/1125

I just wanted to echo that when I needed medical information about my donor while pregnant, Xytex was not terribly helpful. As my clinic advocated on my behalf, Xytex did send a letter to the donor's last known address but it was returned and no further effort was put forth. Fortunately, neither my child nor I suffered any devastating effects but it was very scary and, in my opinion, negligent. I'm sorry to hear that others have similar stories.

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

I've been thinking about this, and it occurs to me that so many sperm banks are getting away with all kinds of nonsense (changing at a whim the number of clients who can buy particular sperm; not following their own

procedures; misleading parents, etc.). This may be because they constantly have new customers, and those customers have no other way to really check a particular bank's ethics. But what if there were a list that rated sperm banks, a website where people could post their experiences with sperm banks, how they lie and mislead (or even how they keep the spirit of the bargains they make), so that those who use ART can get a better sense of how these sperm banks really are. Sounds like Xytex and California Cryobank are huge offenders, I know with my bank, had I known that they played fast and loose with definitions of what constituted family and on their own would increase the number of clients who could use a particular donor I may have looked somewhere else.

10/9/05 http://health.groups.yahoo.com/group/DSR_Discussion/message/1096

How frustrating is it to be held accountable for wanting information about our donor when ID release wasn't even an option when we embarked on this journey?? How much of a stretch is it to expect/ask the cryobank to contact the donor and 'grandfather' him into the ID release program?? I think it is reprehensible for the cryobanks to hide behind the agreements they made with the donors before progress made ID release an actuality. I was 'promised' verbally by my cryobank that efforts would be made upon my children's 18th birthday to contact the father and ask if he was willing to meet them. I have contacted Xytex whose representative now says that because of the backlash they have had from other donors who have been approached that they will absolutely not try to contact my donor. Fortunately my children express little interest in their paternal origins, but I would like them to have the option when it becomes important to them. It galls me that the cryobanks are all about profit and damn the children they are partially responsible for producing. It is truly a business without conscience. In what other realm of our society would we allow someone to create a child and abandon them? Cryobanks should be held as socially accountable as every other person responsible for the welfare of children.

9/4/05 http://health.groups.yahoo.com/group/DSR_Discussion/message/1006

Augusta Chronicle Article:

Despite my numerous calls and emails I have received little to know help for Xytex in either locating my daughter's donor or getting update medical information. A ten year old update that you sent me is unacceptable.

In 1996 your literature stated: "As recommended by the American Society for Reproductive Medicine Xytex respects the privacy and rights of our donors. We do not release identifying informations such as name, address or social security numbers on our donors. However, if a donor child contacts Xytex after age 18 we will attempt to contact the donor and determine his willingness to meet the child".

First of all you have bent this so called "policy" numerous times as is well documented in the DI community and the article published in the Augusta Chronicle. Secondly, no where in your "policy" do I see anything about the rights of the children....are they simply the by-product? Are they not factored into the equation? You must realize now your antiquated approach from the 80's and 90's has been detrimental to an entire population of DI children. Who are you here to help, the bottom line of Xytex, the parents, the off spring? Your motives are unclear and suspect. Your lack of response to many of us makes us feel like your hiding something.

My daughter is Hannah the 8yr old mentioned in the article. Not only would you not help me unless she was literally dying, I was told Xytex now "regretted" promising to help when kids reach age 18 and they could not stand by that any longer.

I hope more articles run about what sperm banks are doing to hurt not help families. If I had any idea you would respond the way you have, I would never have made the choices I did.

Please, I am begging you to reconsider.

8/30/05 http://health.groups.yahoo.com/group/DSR_Discussion/message/985

The fertility clinic I used directed me to pick the donor from Xytex. At both the following stages - a viable pregnancy and then when a live birth took place - I had to fill in paperwork - which the clinic sent to Xytex. Not sure if this is a regulation since the samples are an imported good into Canada but seemed I had a bit of paperwork to complete. So they are perfectly aware of the pregnancies and births - at least from the clinic I used in Vancouver, Canada.

8/25/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/918
<p>I have been battling Xytex once again the past few weeks. I would advise you to contact Mary Hartley at the Atlanta office. She is very open, and from what I've heard even instigated contact between donors and recipients. My battles right now are to get my donor number, which is being denied to me, and Mary Hartley basically told me I was too old to have any information still around, but your daughter is young enough that there might still be info. I wish I had something definite to tell you, but Mary Hartley is the key person left there, since David Towles was fired a couple years ago.</p>	
8/25/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/915
<p>My soon to be 8 yr old DI daughter has been asking for at least two years when and if she would ever be able to know or meet who the donor was. Her donor was only 18 and was part of the non-ID release trend at Xytex back in the 80's. When a recent medical scare caused me to contract them they resisted helping me even gather a more updated medical history or passing on my daughter's medical info for possible children of the donor and the other DI child I know of. We are talking about a brain cyst not something incidental.</p>	
8/19/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/893
<p>18 years ago, CCB was one of the major sperm banks (likewise Idant) that raised loud objections to the idea that The Sperm Bank of California had the courage to buck the century-old system of total anonymity with its Identity Release Donors. Cappy Rothman was the biggest critic of it at that time. Like so many banks at that time, any potential donor that mentioned an interest in these future children, or even saw them as "their" genetic children were automatically screened out of the programs. Remember in those days not so long ago, only married couples were allowed access to donor insemination and banks actively promoted secrecy within families. Single women and lesbians resorted to other methods not sanctioned by infertility clinics. When CCB and Xytex began losing recipients who went over to TSBC, they started to realize that their clients were not going to put up with their intimidation, strict rules, and arrogance. It began known that there was another bank that actually listened to infertile people and offered them CHOICES. It wasn't until TSBC grew in popularity because of their willingness to be covered in the media, that other sperm banks began to offer some choices, although never on the level of openness that TSBC's "Yes Donors" program offers. I would imagine that CCB is not contacting the donors from the earlier programs before they instituted their "Willing to be Known" donor program, which is a very weak version of Identity Release. Xytex appeared to have a growing level of openness and willingness to help DI children, but it looks like they are now regressing to the norm.</p> <p>I am not pushing TSBC here. I don't like the fact that they still carry some "No Donors." Although I advocate choice, I don't believe that choice means ID Release versus anonymous donors. The choice should be up to the DI person conceived to make decisions about whether or not to contact his/her genetic donor.</p> <p>For TSBC to offer the choice of anonymous donors is to deny the person conceived any right to choose to make connections to his/her genealogical heritage. It's not the same as someone having no choice because they were born through a private affair. In DI, society is directly involved with the conception and it is controlled by professionals who swear an oath to "Do No Harm." The assumption of harm must be taken since there is no proof that secrecy doesn't do harm. It is not up to us to prove that secrecy does harm. We DI adults know that it does. Rather it is up to the profession to prove that it doesn't, which they can't because secrecy prevents the openness necessary to make any legitimate study. In any other medical procedure, there is an explicit obligation to examine the outcome to ensure that there is no harm, or that the good of the procedure outweighs the harm. With DI we can't know that without first eliminating secrecy and especially anonymity. The answers must come from the donor conceived person himself, not as interpreted by his parents or his parents' fertility doctor. The medical profession washes its hands of responsibility for creating life in this manner by claiming that the birth of a baby is a sign of DI success. We all know that this is an extremely narrow view that dismisses the importance of the sociological and psychological impact of DI on parents, donors, DI children, DI adults as well as the spouses of DI adults and their children.</p>	
8/1/05	http://health.groups.yahoo.com/group/DSR_Discussion/message/784
<p>I spoke with Mary Hartly at Xytex numerous times and she had Xytex's medical director review my request.</p>	

They just kept saying unless it was life threatening they would not provide me any info. As I said, the cyst is stable and she is having MRI's every three months. She has violent headaches associated with this but is otherwise doing well. If it should grow (and I pray it does not) she could need a shunt. That is not life threatening enough for Xytex.

Mary Hartly told me that she realizes that the companies "language" on the web site may have misguided people into thinking they would help locate non-ID donors but recent legal threats by donors has now stopped all efforts. I would never have used this company if I had any idea they would change their philosophy on helping search for donors. I am not in a position to hire a lawyer so what choices do I have?

7/31/05 http://health.groups.yahoo.com/group/DSR_Discussion/message/782

I agree wholeheartedly. I have been going round and round with Xytex for two years now and they refuse to help in anyway stating the party line. My daughter now has a brain cyst that for now is stable. When I reached out for more medical info from them they states unless it was life threatening they would not help....I now question there integrity and honesty and realize nothing they do is in the best interests of the children.

7/21/05 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/5146>

There is a lot of discussion about disclosure of identity, particularly for those donors who participated in the Xytex program prior to 'donor consent' becoming a part of their program. My children's donor, 2366, was one of their donors in 1989 when I conceived, yet he was offered the opportunity BY XYTEX to add a photo profile in 1993, which he did. I can't understand why the same courtesy can't be extended to consent! It seems simple enough to retroactively survey donors for willingness to give their identity when offspring turn 18. What gets under my skin is XYTEX will offer a 'service' when it reaches their bottom line (i.e., donor photo profile = fee for obtaining pictures and greater potential sales of sperm) but they turn a cold shoulder when there's no buck in it for them. How sad.

6/5/05 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4664>

Well, I'm in a state of shock and dismay. I went online to Xytex to see if they too had added a donor sibling registry but, of course they had not. Interestingly enough I found that our donor had recently posted his adult picture and so we got to see him for the first time. It was a surreal experience although I don't see any real physical traits shared except perhaps hair color and the shape of the mouth. As I was rereading his information I was stunned to find this: right there in the beginning information on him is the horrible news that he is listed as a NO to being part of the donor identity program. This was the MOST IMPORTANT aspect to us in choosing a donor and we asked our fertility clinic for a listing of ONLY those donors they had on hand from Xytex that were listed as YES donors and took them at their word. Unfortunately, only one other donor remains on that list as active at Xytex and he IS a yes donor which leads me to believe that someone was provided incorrect and terribly life altering information for us!

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

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

Donor Michael Beany wrote, in a semi-autobiographical novel "Children of Eden," about donating at three different clinics at the same time in London during the sixties. These clinics compete with each other so I doubt they share their databases about their donors. Since the counts and quality drop with too frequent donations, I doubt this happens much or the donors would not be acceptable. Nothing theoretically stops a retired donor from donating under another ID number at another clinic after he reaches his first clinic's limit (those that

have such limits). I remember an interview several years ago with a Canadian RE who said that he didn't have the resources to check out a donor's background or medical history. As he said, he was not "the morality police."

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

2/9/05 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4120>

February 9, 2005

Xytex Corporation

1100 Emmett St.

Augusta, Georgia 30904

Attn: Armand Karow, President

Dear Armand,

Thank you for your interest and inquiry in the Donor Sibling Registry. First of all, let me stress that we are a Donor Sibling Registry. Although donors are welcomed on our site, the focus and purpose of our Registry is to unite half-siblings born from the same donor who wish to be united with each other.

Your letter seems to be focused specifically on the donor-offspring issues. Although most recipients do sign an agreement before being inseminated (I didn't), I don't think they, or the sperm banks may be fully aware of the curiosity that may show up in their children before or after the age of 18. These recipients have not been counseled by the doctors or sperm banks to expect anything resembling this curiosity that we now are seeing from donor conceived people. Although the sperm donor also signs an anonymity agreement, I don't think they realize the curiosity that they too may have as the years pass. I have heard this expressed by several donors on our site.

I understand that the agreement signed by many recipients and donors is to refrain from searching- this is why our site was created, for curious people who don't want to invade anyone's privacy, but who wish to be found. Many of the children searching for their half siblings are not "encouraged" by their parents to search. It is their own curiosity regarding their invisible family that fuels the search, and the parents are simply trying to accommodate their yearnings to find their answers. This, again, is the reason that the Registry was founded. My son, at age 10, had a curiosity that I believed needed to be acknowledged and supported. I believe that he has every right to be curious and every right to make himself available to others in his biological family that may be searching.

You say that "the American courts deciding that donors that become "involved" in the lives of their minor offspring lose their freedom from liability for financial support...". Please reference the specific cases that you refer to as I cannot find any court case, judgment or ruling that reflects this. I would think that any cases where this issue has been raised are extremely rare, and they would receive quite a bit of attention. The only case that came close, that I can reference, was from a non-anonymous donor. The California State Law-Civil Code #7613 California Uniform Parentage Act (b), states "The donor of semen provided to a licensed physician and surgeon for use in artificial insemination of a woman other than the donor's wife is treated in law as if her were not the natural father of the child". I realize that this is a state by state and a case by case ruling and would hope that each case would be looked at individually.

One case that I am familiar with regarding the uniting of a donor and offspring is one from Xytex involving Katie Whittaker and Bobby Gerardot. It would appear that your sperm bank looked at this case on an individual basis, because of the actions that you took in facilitating the exchange of information with an offspring who was 4 months shy of turning 18 years old. It would appear that you acknowledged the importance that this young woman placed on connecting with her biological heritage.

So then, to address your second question, it would be hard for me to "inform donors who are agreeable to participating in the DSR about the possible legal consequences", because I am unaware of any.

It appears that the sperm banks attempt to instill a fear in those of us who prefer greater openness. My personal opinion is that I have seen such a lack of accountability within the sperm banking business that I can understand why the secrecy. For example, most sperm banks have no idea how many children are actually born from each donor. Most sperm banks do not have a way to contact the families or donors in case of important medical information that would need to be shared. I know of sperm banks that have actually refused to share important medical information with offspring. These things I am intimately familiar with and have many, many cases that I know of. The infertility industry in general continues to send the message of a belief in secrecy and does not want to be challenged in their unregulated power. I think it is time that they face the reality of the needs and curiosity of these children that they have helped to create and take the appropriate

responsibility in facilitating their needs. This is not just about the business of selling sperm, this is about the children that are created and the complicated issues that are now starting to arise and need to be faced head on.

I don't have the answers Armand, but I do have plenty of questions and a desire to have this industry move forward in an accountable and compassionate way. The sperm banks can't bury their heads in the sand anymore. This is about the needs and rights of the donor conceived.

Sincerely,

Wendy Kramer

Director, Donor Sibling Registry

2/9/05 http://health.groups.yahoo.com/group/DSR_Discussion/message/685

Thanks to all who replied and offered support and advice for how to deal with Xytex. I lost all faith in them when they abruptly shut down the bulletin boards on there website that many of the offspring and DI moms posted on. When posters said anything negative about the company they always denied/disputed. I also thing the attempts to match siblings was a sore spot for them.

With that said, Mary Hartly at Xytex was supportive and seemed to care but I will say that my email to her went unanswered for a week until I called her. I realize they are in a tough spot as are other banks but time and things have changed and the secrecy has to stop. Aside from the medical issue, my daughter has been extremely vocal about wanted to know but not meet who her DI father is and wants to be acknowledged. If I had been married I think (could be wrong) that sense of "I am different" or "I don't fit in" would be less for her.

2/6/05 http://health.groups.yahoo.com/group/DSR_Discussion/message/680

In 2002 my daughter and I were having a battle royal, she was 16 at the time. I finally saw the light and knew I had to tell her that her daddy was not her biological father. (I am hoping I am not offending anyone with my definitions) Anyway, she grabbed the ball and ran with it. She was so relieved to find out why she didn't feel like the rest of us. SHE called Xytex, she did all the work. I did my best to support her every step, but I did not do it for her. I warned her about the potential pit falls, but she felt strong enough to deal with it all. Long and short, she spoke with an employee at Xytex (this correspondence took over a year back and forth) and insisted they should give her the profile they had on her donor. When I chose di I did not research. My doc simply requested an rh negative donor with light eyes from the south. (My husband requested light eyes and a southern boy) At any rate it turns out that my donor was adopted. Xytex had no history for her to see. THEY volunteered to contact the donor and attempt to get more info for her. She agreed. And the donor agreed to share. And with the gods smiling on us, the donor's wife was supportive.

2/5/05 http://health.groups.yahoo.com/group/DSR_Discussion/message/676

Pineal cysts are not all that uncommon from what I have been told and researched. I am actually a nurse and my daughter is getting her care at Children's in Boston so I feel good about what they have to say. The issue is, is the cyst growing and does it have any malignant qualities. The safest approach is serial MRIs to assess the size. Due to its location surgery would be a last resort I am told. My intention had been to help my daughter look for her donor is she chose. Since she could really understand her origins, she has consistently said she wants to know who he is. I had asked Xytex, could they forward this medical piece to him and request an updated medical so I could see if even he had children now and if they had any issues. Again citing privacy they said no. Unless she is in a life threatening position they will not help. I find there actions reprehensible, uncaring and unfeeling.

2/3/05 http://health.groups.yahoo.com/group/DSR_Discussion/message/674

I am a DI mom/single to a now 7 year old. She is bright, active and very funny....She began having headaches when she was 6 or so and for a year my pediatrician said we would watch them. At her 7 year old checkup she decided an MRI was in order. Long story short, three MRIs and a neurosurgeon later we are still in a watch and see mode as they found a cyst in the pineal area of her brain that may be causing some pressure. I contacted Xytex to see if I could get more updated medical history as my non ID donor is long since retired. I spoke with

Mary Hartly who sympathized with me but said unless I could prove there was a genetic link to what was wrong they could not/would not assist me. While she herself is a proponent of connecting donors and offspring its sounds like Xytex for all its bragging is not. I would think the donor and or any other offspring would want to know about this but again Xytex does not unless its genetic. At this point we don't know but frankly I don't want to wait until it may be too late.

1/28/05 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/4019>

Hi all (especially donors),
I am preparing a response to a letter I received from the President of Xytex that questions a donors rights, and our website. If anyone can offer advise on this particular item that was brought up, I'd greatly appreciate it:
...American courts deciding that donors that become "involved" in the lives of their donor offspring lose their freedom from liability for financial support of the child. It is my understanding that this shield against financial liability is lost even if there is a casual visit or meeting or introduction of the two- the donor and an offspring. The legal theory is that this demonstrates a willingness of the donor to be involved in the child's life and therefore makes the donor subject to financial support of the child in the absence of other sufficient support."

11/3/04 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3673>

We were notified through Xytex of a child with Down's Syndrome (one of a set of twins - with a healthy sibling) produced by our donor... Guess every clinic has their own policy on whether or not to share medical info.

10/31/04 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3662>

One being Xytex knew full well that I was adopted but chose to let me through the screening process because of my blood type which is A Neg. It was my understanding at the time Rh neg donors were at a premium.

6/23/04 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3322>

We sent a thank you letter to our donor through Xytex after our son was born and they seemed okay with it...no idea of course if they ever really gave our donor the letter but they made no objections to my request. I spoke with "Caroline" (1 800 277 3210) through email and the donor counselor in the Atlanta office who passed the letter along was "Mary Hartley" (1 404 881 0426)...maybe they would help...
Xytex is supposed to be open to helping you contact your donor regardless of status at time of donation - of course donor still has right to refuse contact! Once your child has reached 18yrs you might have more success...

3/9/04 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/3066>

FWIW, at Xytex, I am pretty sure they know their number. The "number" at Xytex consists of 3 or 4 letters followed by 3 or 4 numbers. When the donor I used was on a conference call, instead of using his name, they would say "####, what do you think about..." and that was indeed his number, so I would say at Xytex they do have that knowledge.

1/22/04 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/2801>

We had a similar difficulty in that when we checked with our bank (Xytex) the birth of our son had not been recorded. They said they had not been notified by our clinic but we HAD notified our clinic and in fact are a member of a donor support group - so they DID know...does make you wonder for sure how banks are able to keep track at all of numbers by each donor when not everything is recorded!

8/21/03 http://health.groups.yahoo.com/group/DSR_Discussion/message/311

Over a year ago, when my partner and I decided to have children, obviously we either had to use a known donor or go with a sperm bank. We chose the sperm bank because I never wanted the donor to come back and

say, "I know I was only donating, but now that I see the baby I want to be a father". That terrifies me!! My partner and I are going to be mom and mom. We are raising the child together and do not want input from a 3rd party. Anyway, when starting my research on sperm banks, I found out that Xytex had adult photos of their donors. After doing more research it appeared that they were the ONLY bank to have adult photos, so my decision was made. I was only going to use a donor with a photo because suddenly I couldn't imagine NOT knowing what this person looked like!! As time has passed and we have been trying to conceive, that still holds true for me, but now I realize that the photo is not so much for me....but for my child. I realized very quickly into our TTC journey that I wanted to do everything possible for this child if they wanted to know this donor someday. I knew there were "yes" donors from TSBC and after some research realized that PRS also had the open identity policy, but neither of them had the photo option. We finally picked a donor with an adult photo, baby photo, and a guy who participated in the open identity program. My thoughts were that in 18 years the child would at least know his full name, have identifying information, and a last known address (but that will probably be useless in 18 years!). I put myself in my child's shoes and realized that this was not my decision to make, but it was the child's decision!! Heck, my kid may never even ask or care, but if he/she does I can at least sit them down and say "This is him and when you are 18 we will call the sperm bank and get his name". Then...if the child wants to know more and possibly locate him, we can go from there. At least we have the info. and can choose to do whatever we want with it.

8/13/03 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/1774>

I just learned from Xytex (in requesting either an audiofile or an adult photo - neither of which is available) that our donor BFM #### has 15 live births recorded. That means my son has 14 half siblings out there in the world. Truly awestruck is how I can be described right now. Perhaps this kind of registry will prevent our children from accidentally marrying each other!

8/5/03 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/1658>

Not only does Xytex offer Identity Release, they now offer MP3's of conversations set-up with the donor. I recently request an audio of donor DFL #### and was pleased that the donor agreed to have a session. You can ask questions in advance before the interview. I was also able to receive photos of him as a child, around 7 years old and him as an adult. The voice does not match the photo to me. The audio helped me get a better feel of the donor and his personality and life style. It was a good investment. If anyone has received specimens from Xytex, you can write them and request an audio of your donor. It is up to the donor though if he agrees to an interview.

7/31/03 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/1616>

Last week, I asked someone at Xytex if they allowed 10 offspring/families per donor, five in the state and five outside. They told me that, since they ship internationally, they have been able to raise the number but that they don't disclose what the new number is.....

6/18/03 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/1295>

David is now selling antiques according to a poster here who knew him fairly well. I am sure he was/is a great guy and made a lot of advances for Xytex. My only issue with the company is there unwillingness to address the concerns of offspring from non-ID release donors from years ago before all the advances in openness. When the subject came up on the Xytex message boards and some posters expressed frustration with the company the board was pulled instantly....no explanation. Many people had developed strong bonds with other mothers and offspring and I found it very cold to just drop the entire thing.

6/17/03 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/1278>

I used Xytex in 1997 when I got PG with my daughter who is now 5. They were efficient and at the time priced reasonable (although my insurance covered) and had what seemed like a good donor pool. One thing back then was that there were very few donors with ID release. They seem to have quite a bit more now. My complaint

about them is that I tried a few months ago to see if they would contact our donor and see if he would consider changing his donor ID status or if they would notify him that we had made contact in his file. The genetic counselor at the time was very reassuring and all but said they would send him a certified letter. Within a day or two she wrote that her boss had said no due to a previous "almost legal" problem they had sending certified mail to an old donor and his wife opened it and he threatened to sue. I have found a lot of miscommunication and misinformation and the people who answer the phone border on rude sometimes. David Towles is some big shot there and he has been on a lot of talk shows and professes to really want to help those looking but my attempts seemed to fall on deaf ears. I can only hope things change down the road.

4/7/03 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/538>

I have a five yr old DI daughter (I am a single mom) conceived from a Xytex donor now retired. He was non-ID release and at the time I did not give it any thought. I have to say that now its my one regret. My daughter asks many questions and I am very open and honest but I wish I could tell her that some day her donor could be contacted. I initiated some dialog with Xytex late last year and tried to see if they would contact my donor and ask him to reconsider ID release when offspring turn 18. At first the genetic counselor seemed very positive and optimistic that they would do that and then abruptly she said no for legal reasons. She left the job right after that and then Xytex pulled the posting forum so I am concerned about the willingness of them to REALLY help although they boast about it.

2/10/03 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/395>

Because of Xytex's new price increase on id release donors, I decided to check out Fairfax because I've heard such great things about them. When I called and asked if they even offer id release the woman was almost rude and sounded PROUD to say they were a completely anonymous bank. There is no way I would use Fairfax because of this reason. Looks like I will have to stick with Xytex, but I will write to CCB and Fairfax if it will help the cause of this list. Maybe we could also call Xytex and talk to their marketing director (I think his name is Jason?) and tell him that it's not fair to raise their prices by \$100/vial for id release donors!!!!!!!!!!!!!! These places don't care about the lives touched by this process....all they worry about is how much money they will make off of us.

2/9/03 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/389>

I am also EXTREMELY upset over the Xytex price increase!! Unfortunately, I want an adult photo AND identity release, so I will have to pay the \$300/vial. :::sigh::: I actually had a good crying spell the other day over this. WHY does this process have to be so expensive?? We have 4 vials left on our donor, also, and I'm thinking about moving on to IVF ASAP if these vials don't work. It's SO frustrating!!!!!!!!!!!!!!!!!! I also called Xytex and told them how upset I was over them yanking their forum. It was so mean and I lost touch with a lot of women because of that. I never THOUGHT to even get their emails since we communicated on the forum so frequently!!

2/9/03 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/387>

I'm also upset with Xytex. I loved the Di Forum and was upset when they took it away. Now, on top of changing other prices, they have increased the I.D. release donors by \$100.00. It is now \$300.00 for unwashed and \$340.00 for washed units. That is ludicrous. I have 4 units left of my donor. If I get pregnant from one of them, I can't believe I will have to pay that much to have a biological sibling. If I *don't get* pregnant from my purchased units, I'm changing banks immediately.

2/9/03 <http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/386>

I have had several exchanges with Xytex over this issue and they are adamant at not facilitating anything it seems. They recently pulled the forum that allowed past and future DI parents to communicate with each other. It was literally removed one day with no explanation at all. I find it amazing at how they consider themselves at the "leading edge of DI" but they don't recognize the need for a registry or support system.

