BioNews

Comment

The case for comprehensive medical testing of gamete donors

26 May 2009

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Appeared in BioNews 509

The Donor Sibling Registry ('DSR') is a non-profit web-based worldwide organisation dedicated to educating, connecting and supporting those affected by gamete donation, including donors, recipients and offspring. At 25,000 members, the DSR has connected 7000 genetic first degree relatives; hundreds of donors enjoy contact with offspring and thousands of half-siblings interact together.

However, the DSR doesn't just generate genetically-related joy - it also shines light on serious genetic concerns about gamete donation. Frequently the DSR counsels recipients whose children have inherited undisclosed genetic disorders, or who have discovered their donor was dishonest regarding health, or that the sperm bank didn't notify them about reported illness or amended the medical profile.

The number and severity of these health matters is discomfiting. Since US donors can father many offspring (one DSR donor has more than 120 known offspring) donors can transmit disease to scores of children.

Ranking only second to seeking contact with genetic relatives, DSR members cite interest in sharing or warning about health issues. The DSR is the only facility whereby donors, recipients and offspring can unrestrictedly and immediately share medical information. Thousands use it for this purpose.

Currently, many US sperm banks either refuse to update donor/offspring medical information or, even if they accept updates, refuse to share the information, or make the process of reporting so complex or expensive that donors and recipients simply cannot comply or afford it.

Amazingly, in this era of genomic sequencing, some US sperm banks don't carry out basic genetic screening techniques such as karyotyping - a test to look for chromosomal abnormalities which might cause genetic problems. Recently, the DSR undertook to notify recipients that a New England Cryogenic Center ('NECC') donor had a balanced translocation of chromosomes manifesting in offspring as an imbalanced translocation with consequent severe retardation, deafness, blindness and immobility. The DSR took on this task because the NECC was intransigently refusing to notify recipients. The DSR not only notified recipient members, it also trawled its database to find discussion group visitors mentioning that particular donor.

Yet more frustrating than the time and cost expended doing such activity, is the fact that were the NECC simply kartyotyping, this donor would have been excluded for having pieces of his 10 and 22 chromosomes swapped around. Tragically the cost of karyotyping is less than the price the NECC charges for a single vial of sperm: $400 v $530.

Despite providing a clearinghouse for medical updating, the DSR knows it can't reach all affected recipients. Unfortunately the sperm banks - who could so easily notify recipients - rarely do. They ignore their moral and obvious obligation to prevent sick children being procreated even when they know a donor is transmitting hereditary illness.

In 2006 when five babies conceived by the same donor were diagnosed by a leading medical expert as suffering from a rare disorder called severe congenital neutropenia, the New York Times reported that when International Cryogenics heard about the problem 'it did not notify other recipients ... at first because the company's own genetics consultant questioned Dr. Boxer's findings, and later because the company reasoned that even if other children had developed the disease their families would already know it'.

But such reasoning is faulty. Recipients often store sperm for years and reserve vials are frequently gifted if not needed. Also, embryos can be frozen for years before using. Recipients clearly need to be warned about hereditary disorders to prevent unnecessarily sick children being born.

The few genetic tests US sperm banks perform, they skimp on. Only Jewish and French-Canadian donors are tested for Tay-Sachs, ignoring the reality that although those ethnicities are more likely to carry the mutation, there is still risk in other groups. Tragically, offspring have inherited Tay-Sachs due to this policy.

Despite larger sperm banks grossing a million to two million dollars per donor through sale of vials, plus around the same amount again through selling profiles, consultations and vial storage, US sperm banks generally shun genetic testing. The less screening carried out, the fewer donors need be disqualified and fewer tests also equals less cost.

The sacrificing of offspring's health to profits goes on. In the case of Johnson v California Cryobank (No. B137002, 2000 WL 638843), the doctors deliberately rewrote a page within the donor's medical profile deleting information the donor provided indicating kidney disease in his family. This led to the conception of a girl who by the unusually tender age of six had kidney failure. Because Autosomal Dominant Polycystic Kidney Disease normally strikes sufferers in their forties, doubtless the doctors thought any prospect of litigation would be long tolled before the anticipated wave of offspring sufferers would manifest. Since 1500 vials of the affected donor were sold, based upon conservative estimates around 75 offspring will ultimately be struck with kidney disease.

The DSR believes that just as self-regulation failed with monetary banks, it has failed with sperm banks. Therefore, to protect donors, recipients and offspring, the DSR is calling for the implementation of strict regulation, mandatory genetic testing and the establishment of a central gamete donor registry run by an independent authority.

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Writing in the 26 May 2009 edition of BioNews, the Donor Sibling Registry reported about the recent birth of a severely handicapped and profoundly retarded baby girl who had inherited an unbalanced translocation from New England Cryogenic Center sperm donor D-250. Now, the same problem has been disclosed as occurring at the London Women's Clinic. A donor was found to be a balanced translocation carrier only after his semen had been widely commercialised. A couple had to destroy 22 embryos c...[Read More]

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