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When a disease is donated

Mom's quest to warn daughter's offspring goes to the heart of a thorny debate on sperm, egg donors

By Judith Graham

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Dr. Jennifer Schneider pleaded to be allowed to contact the families whose children were conceived through her daughter's donated eggs. Her daughter had died of colon cancer, she said, and the parents deserved to know.

But the agency her daughter had worked with said it could not help because the paperwork had been disposed of, Schneider said. Such brokers place a high premium on protecting the privacy of donors, who usually are promised their identities will not be disclosed without their express permission.

These conflicting priorities will be on the agenda Friday in Chicago at the first national conference devoted to exploring the creation of a U.S. registry of egg and sperm donors. The discussion promises to be heated as participants debate what data should be included in a registry, who should have access and how it should be managed.

Although Australia, Britain, Sweden and a few other countries maintain such registries, U.S. organizations dealing with egg and sperm donors operate with little oversight or coordination of policies. Not all keep good records of who donates to whom. Some will help donors and families make contact upon request; others won't.

As the Chicago meeting approaches, the three largest fertility clinics in the U.S. for the first time say they plan to endorse the concept of a registry, albeit on a restricted basis, said Dr. Charles Sims, medical officer of California Cryobank. The company has prepared a proposal with Xytex Corp. and Fairfax Cryobank.

He said executives would suggest that a voluntary registry serve as a long-term archive of information about donors, recipient families and offspring.

"There's a concern by a lot of people that information linking a child to his or her genetic or biological origins could be hopelessly lost" if sperm banks, egg donor agencies or fertility clinics go out of business, Sims said.

But Sims said one major condition must be met: that "all privacy rights are respected."

"We get very worried about changing the rules in the middle of the game," said Sean Tipton, director of public affairs for the American Society of Reproductive Medicine. "We are opposed to proposals that remove anonymity."

At least 8,000 babies are born each year in the U.S. from donated eggs or embryos, according to reports from the federal Centers for Disease Control and Prevention.

The number of babies born through sperm donation is much harder to estimate because no one is required to report them. A conservative estimate, derived from a 2005 survey of the leading sperm banks, is 5,000 a year. Other estimates put the number in the tens of thousands.

No one knows how often donors are contributing eggs and sperm. Many experts believe that voluntary guidelines—a maximum of six cycles of egg donation for women, a maximum of 25 families receiving sperm from men—may not be routinely followed.

A registry could track that issue, as well as provide a way to assemble important medical information about donors and their offspring. Wrenching situations have cropped up across the country as families discover that children conceived with donor sperm have devastating genetically linked conditions.

In Michigan, for instance, five donor-conceived offspring were found to share a genetic mutation for severe congenital neutropenia, a rare blood disease. The four families involved all sought medical advice from the same medical specialist and learned that all had used the same sperm donor.

This month, Oprah Winfrey's magazine is running a feature on several families who used the same sperm donor and whose children have mild autism or developmental disorders. And in December, the Los Angeles Times wrote of a gay California couple whose young daughter, conceived with a donor egg, developed Tay-Sachs, a fatal genetically inherited neurological disease.

"Our position is that as much relevant medical information as possible should be kept" in a registry without revealing the donors' identities, Tipton said.

Still, it's unclear how the registry would work in practice.

Currently, sperm and egg donors supply detailed family histories and take extensive medical tests before being accepted by an agency or matched with families. But there's no obligation for agencies or sperm banks to determine if donors' medical conditions change later on.

If updating donors' medical profiles became an expectation, Tipton asked, who would gather the information and who would pay? If a potentially serious medical problem arose, who would be responsible for alerting other families or donor offspring? What about the potential for legal liability?

Nanette Elster, director of the Health Law Institute at DePaul College of Law and organizer of the conference, wondered if there could be a way to ask donors for relevant information even if they have said they want no further contact.

For some, an even broader issue is at stake: the fundamental right of children to know where they come from. Already an issue in adoption, the question is emerging now in the world of artificial reproduction.

"It's a scandalous situation," fumed Nigel Cameron, president of the Institute on Biotechnology and the Human Future at the Illinois Institute of Technology. "Children have been regarded as almost entirely instrumental in this enterprise, as if they were there exclusively for the benefit of industry and the benefit of parents. And guess what, this is all about them."

On the topic of a registry, Cameron said: "Anything that brings some kind of order into the situation and ensures that children have access to their own genetic and biological information is going to be better."

Wendy Kramer is skeptical that the burgeoning and largely unregulated fertility industry has children's best interests at heart. For seven years, Kramer has run the Donor Sibling Registry, a private Internet-based operation that helps individuals or families search for sperm and egg donors.

"My experience is, I've reached out to sperm banks, donor agencies and clinics over and over, and every time I get no response," she said. "They make it very hard for donors and offspring to share information and make contact, and I think that's wrong."

In her view, a voluntary registry won't work because information will be incomplete.

"What we need is mandatory reporting of who's donating, where, how often, what their profiles are, and how many offspring are born," she said.

At the very least, experts note, such reporting could help avoid what's called "inadvertent consanguinity"—the possibility that half-siblings, unaware of their biological relationship, would become sexual partners.

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