

Registry may track egg, sperm donors

The plight of a Rancho Mirage girl born with Tay-Sachs sparks effort in getting more information to parents.

By William Heisel, Los Angeles Times Staff Writer

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Troubled by the health history and backgrounds of some anonymous egg and sperm donors, leaders in the fertility industry have said in recent weeks that they would create a national registry to track donors and birth outcomes.

In response to a Dec. 9 article in The Times about a child born with a terminal genetic disease, representatives from the Society for Assisted Reproductive Technology, a fertility industry organization, said they intend to record the histories of donors and surrogate mothers to help prevent such tragedies.

The Times article was about a girl from Rancho Mirage, conceived with the help of an anonymous egg donor, who was born with Tay-Sachs. She is nearly 2, and the neurological disease probably will kill her before she turns 5.

The gay couple who chose the donor did not know that she was a carrier of the Tay-Sachs mutation, nor did the donor herself. For a child to get the disease, both biological parents must be Tay-Sachs carriers. One of the men, whose sperm was used to fertilize the donor's egg, also carried the mutation but was unaware that he did.

After learning about the child with Tay-Sachs, neither the egg donor nor the agency that hired her attempted to contact the other families and agencies that used the donor's eggs. Some families may have embryos not yet implanted.

No system exists to alert couples to such problems or to prevent donors from continuing to provide eggs or sperm after they have been found to have genetic disorders or other problems.

"If you have a case of a donor who is a carrier for Tay-Sachs, there is no mechanism in place right now to let other parents and

agencies know. We need to change that," said Dr. David Grainger, a Wichita, Kan., fertility specialist and a member of the reproductive technology society's executive council.

Grainger warned, however, that such a tracking system faces significant obstacles and probably will take some time to put in place.

Egg and sperm donors are for the most part anonymous. The Centers for Disease Control and Prevention requires fertility centers to provide detailed data on pregnancy outcomes: the number of attempts at pregnancy, the type of technology used, whether the treatment resulted in multiple fetuses.

But the CDC, which works closely with the reproductive technology society in gathering fertility data, does not keep track of individual donors' histories, diseases or other problems, nor does it link their names to outcomes.

A registry would work something like this: Donation agencies and fertility clinics would submit identifying information about donors and surrogates, including Social Security numbers and birth dates. That information would be linked to results of drug tests, sexually transmitted disease tests and genetic screenings. And all of that data would be linked to outcome information supplied by obstetricians.

Clinics would stay in touch with recipient parents to find out if children had developed any genetic abnormalities. All the information potentially would be available to agencies when a person applied to be a donor and to clinics when prospective parents went to them seeking to use a certain donor.

The success of the registry would depend in large part on whether the Society for Assisted Reproductive Technology and its parent organization, the American Society for Reproductive Medicine, are able to persuade donors, doctors, agency directors and patients to cooperate.

"We live in a very mobile society, and there's no way to track everybody's movements or to force them to stay in touch," said Dr. Robert Rebar, the executive director of the American Society for

Reproductive Medicine. "It's a significant challenge, but we'll get there because we have to get there."

A committee of doctors and other fertility experts is to meet in March to discuss the first steps toward a registry, Rebar said. Another committee is working on new guidelines for donor genetic screenings.

Participation in a registry probably would be left up to individual donors and surrogates. Industry leaders hope that participation would function as a seal of quality to help guide consumers.

Although a mandatory registry tracks all donors in Britain, fertility experts in the United States fear such a requirement would scare away donors here.

Word of the U.S. industry's effort drew praise from some donation agencies and fertility doctors around the country.

Stephanie Scott, who runs a surrogacy and egg donation agency in Dallas called Simple Surrogacy, said that she has found some prospective surrogate mothers to have such problems as sexually transmitted diseases and drug addictions. She rejected them, she said, only to learn that they were hired by other agencies.

"One of them had a laundry list of criminal convictions, most of them for drugs. I called some of the agencies that were advertising this surrogate, and one of them told me to mind my own business," Scott said. "If we had a registry, and a surrogate tested positive for herpes, then it would be easy to check and no one would hire her."

Calls for stricter controls have increased as cases have come to light about donors who have passed genetic diseases to one or more families.

Donors often work with several agencies at the same time, fertility experts say, and one agency may not know about the results of an egg donation through another agency.

That's the case with Alexandra Gammelgard, the 23-year-old sales representative whose donated egg resulted in the birth of the Rancho Mirage baby with Tay-Sachs. She worked with Surrogate

Alternatives, the Chula Vista agency hired by the couple, just once, the agency said. But she said she also worked with two other agencies and believes that three other children were born besides the child with Tay-Sachs.

Surrogate Alternatives said it did not know -- and never asked -- which other agencies Gammelgard worked with.

Gammelgard said that because of the Times article, she decided that she would contact the other agencies she worked with and ask them to tell families that used her eggs about her Tay-Sachs mutation.

"I see myself a lot in that little girl, and that wasn't something I was expecting," Gammelgard said. "I'm just sick over the whole thing. I wish there could have been anything I could have done differently."

Gammelgard's biological daughter, Krystie Karl-Steiger, is being treated in Minneapolis at the University of Minnesota Children's Hospital, Fairview, for Tay-Sachs. She has lost most of her sight, speech and movement. She has undergone an experimental stem cell transplant that doctors hope will reverse the disease, although Tay-Sachs has never before been cured.

Critics of the industry dismissed the possibility that it could adequately track donors.

Wendy Kramer runs the country's most extensive network for children and parents attempting to connect with sperm and egg donors. She has about 15,000 people registered at her website, www.donorsiblingregistry.com, including more than 600 donors.

"Not that I think the government can do a good job regulating, but I question whose needs the industry is going to serve by self-regulating," Kramer said. "I don't believe that they honestly are going to serve the needs of the kids."