

SUNDAY, July 15, 2007

ALASKA OUTDOORS VACATION ON THE EDGE

TRAVEL

AUTOBYTEL SEEKS TO REINVENT DRIVING ON THE WEB MARKETPLACE



EUGENE GARCIA, THE REGISTER

FLYING HIGH: Stacy Brookhyser, right, carries Laurel aloft as her husband, Mitch, holds up Roxanne at their house in Huntington Beach. Stacy Brookhyser carries the mutated gene that causes Huntington's disease, but through genetic testing, eliminated embryos that carried the gene.

Brave new baby-making

Parents are choosing embryo screening to ensure the long-term health of their children, but the technique raises ethical questions about other uses of the procedure.

What awaits beyond the horizon?

Mitch and Stacy Brookhyser of Huntington Beach feel fortunate that they were able to protect their daughters from a deadly disease that runs in their family.

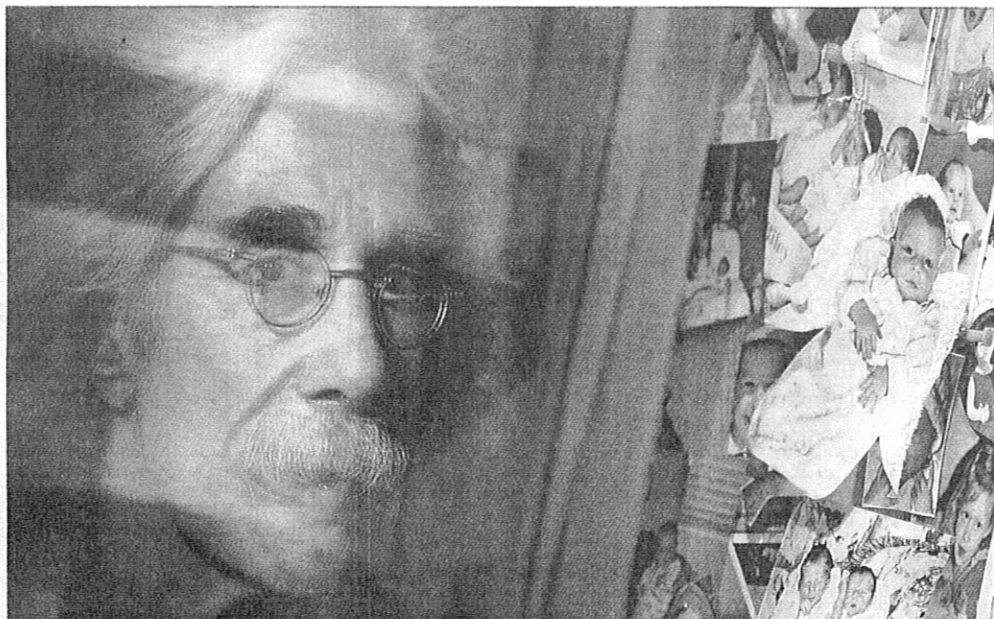
Like the Brookhyser, more and more families are turning to embryo screening to ensure that their children are born without certain genetic disorders. After in vitro fertilization, a

cell from each embryo is studied in a lab for abnormalities. Only healthy embryos are implanted in the woman seeking pregnancy.

The technique raises ethical questions because it prevents some embryos from having a chance to grow into babies. Some fertility clinics offer the procedure to determine a baby's gender.

How far will the technology go?

STORY BY BLYTHE BERNHARD ON NEWS 4



GENE SPECIALIST: Photos of babies and artwork from grateful parents cover the walls in the office of Dr. Lawrence Werlin, the Brookhysers' specialist at Coastal Fertility Medical Center in Irvine. Werlin favors national guidelines for reproductive technology.

CINDY YAMANAKA, THE REGISTER

A new breed of babies

Genetic screening to weed out embryos that potentially harbor abnormalities can help parents protect their children's future. But disability advocates, abortion opponents and others object.

By BLYTHE BERNHARD
THE ORANGE COUNTY REGISTER

Like all new parents, Stacy and Mitch Brookhyser wonder who their baby girls will grow up to be. Where will they go to school? What jobs will they choose? Who will they marry?

But there's one question they don't have to ask: whether the girls inherited a defective gene from their mother.

The Brookhysers went through in vitro fertilization and genetic screening of their embryos to ensure that their twins, Roxanne and Laurel, now 9 months old, would not develop Huntington's disease.

"We cared about our kids before we ever had them," Stacy Brookhyser said. "Doing this doesn't mean our children are perfect. It just means this is one less thing to worry about."

Hundreds of babies have been born across the country through pre-implantation genetic diagnosis — selecting certain embryos over others to weed out genetic abnormalities from muscular dystrophy to hemophilia.

For a fatal disease such as Huntington's, eliminating affected embryos is currently the only hope for a "cure."

Stacy Brookhyser, like her mother, aunt and grandmother, has a gene aberration that always

leads to Huntington's disease. If a cure is not found, the 31-year-old will probably develop symptoms in her late 50s or early 60s. The devastating illness affects almost every aspect of brain function, causing its sufferers to eventually lose mobility and cognitive skills.

If conceived naturally, the Brookhysers' children would have a 50 percent chance of inheriting the defective gene and therefore the disease. While it's possible to test a fetus during pregnancy and then decide on an abortion, the Brookhysers wanted to test the embryos before Stacy became pregnant. The technology gave them some control over the insidious disease, she said.

First, the couple had to prepare for in vitro fertilization, in which a woman's ovaries are stimulated with drugs to release extra eggs. The eggs are collected surgically and fertilized with sperm in the lab. When the embryos grow to eight cells a few days later, one cell is removed and tested for the malformed gene. Three of the Brookhysers' embryos tested negative and were implanted in Stacy's uterus.

The cost of the procedure is pro-

Screening embryos for genetic disease

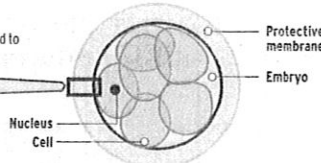
Some fertility clinics allow couples to test embryos for genetic disease through pre-implantation genetic diagnosis. The process involves collecting DNA from a single cell, then using polymerase chain reaction to copy DNA for testing. First, geneticists examine similar blood and cheek cells from parents to help trace the mutation.

How embryos are screened:

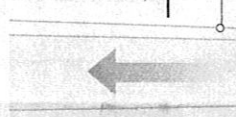
Separating out cell with PGD

1 Three-day-old embryo is examined to find cell where nucleus is visible.

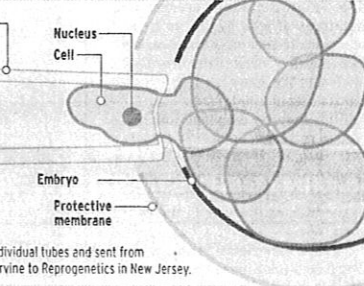
Long thin tube, called pipette, is loaded with a chemical that opens the protective membrane.



2 Pipette used to extract desired cell from embryo.



Careful removal of one cell does not compromise embryo.

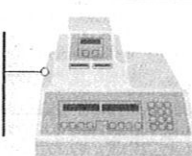


3 In this case, cells were placed in individual tubes and sent from Coastal Fertility Medical Center in Irvine to Reprogenetics in New Jersey.

Analyzing DNA with PCR

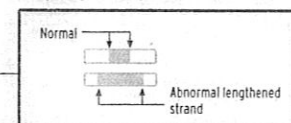
4 Tubes are incubated; heat causes cell to release DNA.

5 The samples, along with chemicals, are placed inside a reactor that photocopies the DNA. Multiple copies are necessary to locate a possible mutation.



6 DNA photocopies are placed inside a sequencer, which generates a chart for analysis by geneticist.

7 Single-gene disorder mutations can include extra, missing or rearranged letters but Huntington's is represented by a lengthened DNA strand. Embryos unaffected by the Huntington's gene are implanted in mother's uterus.



Sources: Coastal Fertility Medical Center in Irvine; Reprogenetics in San Francisco and Livingston, N.J.

Graphics reporting by Chantal Lamers, Molly Zisk / The Register

What people are saying

"Pre-implantation genetic diagnosis allows parents to make positive choices in favor of embryos they want to gestate. Eliminating disease if we can do so is not a bad thing."

JUDITH DAAR
MEDICAL ETHICIST,
UCI

"I truly believe that God gave us this technology to be able to protect our next generation."

STACY
BROOKHYSER
MOTHER OF TWIN
GIRLS WHOSE
EMBRYOS WERE
SCREENED FOR
HUNTINGTON'S
DISEASE

"If this were put into place, it would almost come close to a cure for this awful disease."

DR. NEAL
HERMANOWICZ
DIRECTOR OF THE
HUNTINGTON'S
DISEASE CLINIC
AT UCI

"It's wrong to screen which embryos are worthy of having a chance to be born and which aren't."

RON STODDART
DIRECTOR OF
NIGHTLIGHT
CHRISTIAN
ADOPTIONS IN
FULLERTON, WHICH
FACILITATES
FROZEN EMBRYO
ADOPTIONS

"If pre-implantation genetic diagnosis is typically used to weed out and decide who to destroy, you're killing a human being."

STEPHEN NAPIER
STAFF ETHICIST
AT NATIONAL
CATHOLIC
BIOETHICS CENTER

"You can find genetic defects that have the potential of being life-threatening. You can hopefully prevent those from being transmitted to future generations."

DR. LAWRENCE
WERLIN
FERTILITY
SPECIALIST,
COASTAL FERTILITY
MEDICAL CENTER
IN IRVINE

Procedure's cost can be prohibitive

FROM PAGE 4

hibitive for many families. Embryo testing costs about \$5,000, on top of \$10,000 to \$15,000 for the in vitro fertilization treatments. The Brookhysers, who live in Huntington Beach, have health insurance through Mitch's job with the Los Angeles County Fire Department. The insurance plan reimbursed 70 percent of one round of the screening and fertilization, which resulted in the birth of the twins.

ETHICAL DEBATE

Embryo selection has also been used to prevent the births of children with Down syndrome, cystic fibrosis and Tay-Sachs disease, among about 100 other conditions that are linked to a particular gene or chromosome abnormality.

Some disability advocates say the screening is a form of discrimination and implies that a life with a disability or illness is not worth living.

Groups against abortion are opposed to the procedure because it involves the destruction of embryos.

"The basic objection is the clearest objection: It destroys human beings," said Stephen Napier, a staff ethicist for the National Catholic Bioethics Center in Philadelphia.

Other critics fear that embryo screening is a form of eugenics - selective breeding - and a steppingstone to choosing only those babies who will grow up athletic, beautiful and smart.

Scientists say those fears are premature, because characteristics such as height and intelligence are controlled by many genetic and environ-

Genetic conditions

Pre-implantation genetic diagnosis can be used to screen embryos for more than 100 conditions, including:

- Achondroplasia
- Breast cancer, genes 1 and 2
- Cystic fibrosis
- Down syndrome
- Duchenne muscular dystrophy
- Fragile X syndrome
- Huntington's disease
- Marfan syndrome
- Retinitis pigmentosa
- Sickle cell anemia
- Tay-Sachs disease
- Turner syndrome

mental factors that can't be controlled in a laboratory.

Nevertheless, some European countries have banned certain types of embryo screening on moral grounds. In the United States, there are no restrictions on how the technology can be used. One local ethicist said that's a good thing.

"It's a technology that should be available to parents to utilize as they see fit for their family formation," said Judith Daar, a professor at Whittier Law School in Costa Mesa who also serves on UC Irvine's medical ethics committee.

Others are opposed to the screening for less deadly or late-onset diseases. For example, those who carry a gene that puts them at high risk for breast cancer won't necessarily get the disease. And if they do, it could be 50 years down the line, after unknown advancements in treatment.

Dr. Lawrence Werlin, the Brookhysers' specialist at Coastal Fertility Medical Center in Irvine, said he favors national guidelines for reproductive technology.

"You have to be careful," Werlin said.

"Are you eliminating an

embryo that could have had a good future?"

OTHER IMPLICATIONS

While screening for specific genetic defects is the main reason the technique was invented, there are other, more controversial uses. Several fertility clinics in Orange County offer embryo screening to choose the sex of the baby.

According to a Johns Hopkins University study, most Americans approve of embryo testing for medical purposes. A minority felt the same way about using it for gender selection.

Sperm sorting is a less costly - and less controversial - method of gender selection because it doesn't involve the elimination of embryos. But it's also less reliable. Embryo screening is virtually perfect in predicting gender.

It's not always about balancing the family or preferring one sex. Some parents decide to choose the sex of their baby because they are worried about passing on a disease that primarily strikes boys or girls.

Many fertility clinics offer embryo screening on demand to any couple undergoing in vitro fertilization. After screening for chromosomal abnormalities that can lead to miscarriage, only the healthiest embryos are chosen to be implanted.

Lately, the use of embryo screening as an infertility treatment has come under scrutiny by researchers, with some experts saying the technique is oversold by fertility clinics. Embryo screening prior to implantation resulted in a lower birth rate, when compared to in vitro fertilization alone, in a large Dutch study published this month in the New England Journal of Medicine.

Because fertility treatments are largely unregulated in the United States, it is unclear exactly how many children have developed from embryos that have been



EUGENE GARCIA, THE REGISTER

AT HOME: Stacy Brookhysers, right, kisses Roxanne, held by her husband, Mitch, in their house in Huntington Beach. She holds Laurel in her lap.

screened for any reason.

For the Brookhysers, the costs and questions surrounding pre-implantation genetic diagnosis were well worth it, knowing their children would be spared from a deadly dis-

ease that robs people of their minds and bodies.

"I'm mostly afraid of losing who I am and not being able to control it," said Stacy Brookhysers, as she held Laurel on her lap and looked over at her

husband, who was holding Roxanne.

"They'll never have to worry about it."

CONTACT THE WRITER:
714-796-6880 or
bbernhard@ocregister.com