

Genetic embryo screening: Questions grow along with number of procedures

April 5 2009, By Laurie Goering

Karin Cohn carries a genetic defect that led a half-dozen members of her family to develop early breast or ovarian cancer. She firmly supports allowing families like hers to screen embryos for the defect to ensure no future generations carry it.

But with one daughter born before the genetic test was approved in Britain, she is uneasy with the idea of using the procedure to ensure a second baby in her family is healthy.

"If I didn't have kids now, would I do it? Without question. I think it's an amazing thing," the 38-year-old said. But for her, the prospect of raising a protected child alongside a vulnerable one feels unfair, and she has opted to have no more children.

Both the number of families checking embryos for genetic defects, and the number of conditions being tested for, are growing rapidly around the world. Last year, the leading U.S. [genetic diagnosis](#) clinic -- the world's largest -- carried out more than 1,800 tests, aimed at weeding out embryos that carried worrisome family conditions from sickle cell [anemia](#) to [cystic fibrosis](#).

But figuring out the ethical and regulatory guidelines for such screening is proving more difficult. Testing that at first focused on eliminating genetic defects certain to cause early suffering and death has now been expanded to include defects like genetically linked breast and [ovarian cancer](#), which are not always fatal, hit somewhat later in life and affect

50 to 85 percent of those who carry the gene rather than 100 percent.

In the United States -- though not in Britain -- families can also use [genetic testing](#) to ensure they have children of a particular sex. Still, doctors say, expanded embryo screening is probably not a slippery slope toward designer babies, not only because the process is costly and difficult but also because the number of embryos is limited and finding one that includes a number of desired traits would be very difficult.

"The things you might want to select for in a child -- intelligence, athletic prowess, body stature -- involve not single genes but many, many genes," said Mark Hughes, director of the Detroit-based Genesis Genetics Institute, the world's largest embryo testing lab. "No one in their right mind, or even out of it, would go through the psychological and financial hoops for something trivial."

Testing embryos in an effort to weed out genetic defects -- or to produce a younger sibling who could be a stem cell donor for a sick sibling -- is not cheap. The procedure, used in conjunction with in-vitro fertilization, costs about \$3,500 in the United States and twice that in Britain.

But it is significantly easier in the United States, where clinics are licensed but the individual procedures are not. In Britain each instance of "pre-implantation genetic diagnosis" has to be registered with the British Human Fertilization and Embryology Authority. That government agency has approved testing for just over 70 genetic defects after intensive public consultation about what is a serious enough problem to justify trying to eliminate it.

In the United States, by comparison, Genesis Genetics has already done testing for 171 genetic defects, Hughes said. In the U.S. "there is no approval mechanism. No one is saying you can do this to save a sibling but you can't do this for BRCA1," the breast cancer gene prevalent in

Cohn's family, Hughes said.

He sees no problem in that approach, but others argue there may be good reason to limit the type of genetic defects families are allowed to screen out.

In public hearings on Britain, "quite a lot of people felt there could well be treatment (for some conditions) by the time these children grow up, and then (their condition) won't be an issue," said Clare Williams, a bioethics specialist at King's College London.

A new study by Johns Hopkins University researchers also shows that, as of 2006, 65 percent of close to 200 U.S. clinics carrying out screening on embryos allowed parents to select the sex of the embryo implanted, even if the child was their first or they were not trying to create a family with a balanced numbers of girls and boys.

That -- and a recent scandal in which a California-based genetics lab advertised its ability (since disproved) to create babies with chosen eye and hair color -- have raised concerns among many Americans about the genetic selection of embryos.

Nearly 40 percent, according to the Johns Hopkins study, believe the process should be more closely regulated for ethical reasons; an additional 19 percent think it should be banned altogether, on grounds ranging from a belief that discarding any embryo is immoral to worries that selecting against certain diseases devalues the lives of those now living with them.

Families like the Cohn's, however, say genetic testing of embryos is crucial to assisting families like theirs bring an end to long family histories of suffering.

Cohn, after seeing her mother and sister stricken with cancer, has undergone a double mastectomy and, more recently, removal of her ovaries to try to ensure she lives long enough to see her daughter, now 7, grow up. Doctors told her that without the surgery she had a 90 percent risk of developing cancer.

Unless less invasive cancer therapies arise, she would "absolutely" advise her daughter to use genetic testing to ensure her own children are free from the defective gene.

People who have lost a family member to a genetic disease often "feel motivated to do anything possible to avoid having a child go through the same suffering," said Paul Serhal, medical director of the assisted conception unit at University College London.

The January birth of Britain's first baby girl selected to be free of the same breast cancer gene has spurred a rush of people inquiring about the procedure, said Serhal, whose hospital carried out the screening. Genesis Genetics reports its number of procedures is growing about 20 percent each year.

That growth is expected to continue, particularly with Britain's public health service now paying for the treatments in some cases and U.S. health insurance companies also eyeing appeals to fund the procedure as a potentially cheaper alternative to paying for years of treatment for a child certain to suffer severe health problems, said Paula Wood, a spokeswoman for Britain's Human Fertilization and Embryology Authority.

Whether such coverage could eventually lead to pressure on families with deadly genes to undergo the embryo screening or face loss of benefits remains a worry.

"I have high hopes this field will be obsolete in 15 or 20 years and we'll have stem cells and cures for these (conditions)," Hughes said. But for now, "people are looking for alternatives to throwing the genetic dice."

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