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Few Risks Seen to the Children of 1st Cousins

By DENISE GRADY

Contrary to widely held beliefs and longstanding taboos in America, first cousins can have children together without a great risk of birth defects or genetic disease, scientists are reporting today. They say there is no biological reason to discourage cousins from marrying.

First cousins are somewhat more likely than unrelated parents to have a child with a serious birth defect, mental retardation or genetic disease, but their increased risk is nowhere near as large as most people think, the scientists said.

In the general population, the risk that a child will be born with a serious problem like spina bifida or cystic fibrosis is 3 percent to 4 percent; to that background risk, first cousins must add another 1.7 to 2.8 percentage points, the report said.

Although the increase represents a near doubling of the risk, the result is still not considered large enough to discourage cousins from having children, said Dr. Arno Motulsky, a professor emeritus of medicine and genome sciences at the University of Washington, and the senior author of the report.

"In terms of general risks in life it's not very high," Dr. Motulsky said. Even at its worst, 7 percent, he said, "93 percent of the time, nothing is going to happen."

The report is in today's issue of *The Journal of Genetic Counseling*.

"As genetic advisers," Dr. Motulsky said, "we give people all the various possibilities and risks and leave it up to them to make a decision. Some might decide a doubling of the risk is not something they want to face."

He and his colleagues said no one questioned the right of people with genetic disorders to have children, even though some have far higher levels of risk than first cousins. For example, people with Huntington's disease, a severe neurological disorder that comes on in adulthood, have a 50 percent chance of passing the disease to their children.

The researchers, a panel convened by the National Society of Genetic Counselors, based their conclusions on a review of six major studies conducted from 1965 to August 2000, involving many thousands of births.

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Dr. Motulsky said medical geneticists had known for a long time that there was little or no harm in cousins marrying and having children. "Somehow, this hasn't become general knowledge," even among doctors, he said.

Twenty-four states have laws forbidding first cousins from marrying, and seven states have limits like requiring genetic counseling. But no countries in Europe have such prohibitions, and in parts of the Middle East, Africa and Asia, marriages between cousins are considered preferable.

"In some parts of the world," the report says, "20 to 60 percent of all marriages are between close biological relatives."

Dr. Motulsky said many immigrants from cultures where cousin marriages are common expect to continue the tradition in the United States, and doctors and genetic counselors should respect their wishes.

Laws against cousin marriage should be abolished, he said. Even though longstanding ones reflect a view that such marriages are "really bad," he said, "the data show it isn't that bad."

Dr. Motulsky said researchers did not know why marriage between cousins was viewed with such distaste in the United States. He said some of the revulsion might have stemmed from the eugenics movement, which intended to improve the human race by deciding who should be allowed to breed. The movement flourished in this country early in the 20th century.

It is not known how many cousins marry or live together. Estimates of marriages between related people, which include first cousins and more distant ones, range from less than 0.1 percent of the general population to 1.5 percent. In the past, small studies have found much higher rates in some areas. A survey in 1942 found 18.7 percent in a small town in Kentucky and a 1980 study found 33 percent in a Mennonite community in Kansas.

The report made a point of saying that the term "incest" should not be applied to cousins but only to sexual relations between siblings or between parents and children. Babies who result from those unions are thought to be at significantly higher risk of genetic problems, the report said, but there is not enough data to be sure.

The new report says that genetic counselors should advise cousins who want to have children together in much the same way they advise everybody else and that no extra genetic tests are required before conception.

The guidelines urge counselors to take a thorough family history and, as they do for all clients, look for any diseases that might run in the family or in the clients' ethnic groups and order tests accordingly. During pregnancy, the woman should have the standard blood tests used to screen for certain neurological problems and other disorders and an ultrasound examination.

Their children should be tested as newborns for deafness and certain rare metabolic

diseases — tests already given to all newborns in some parts of the country. These are among the conditions that may be slightly more likely to occur in children whose parents are cousins. Some of the metabolic problems are treatable, and children with hearing losses do better if they get help early in life.

Dr. Motulsky said that the panel of experts began working on the cousin question about two years ago after a survey of counselors found a lot of variability — and misinformation — in the advice given to people who wanted to know whether cousins could safely have children together.

The president-elect of the National Society of Genetic Counselors, Robin L. Bennett, who is a co-author of the report and a genetic counselor at the University of Washington, said: "Just this week I saw a 23-year-old woman whose parents were cousins, and she was told to have a tubal ligation, which she did at the age 21, because of the risk to her children. And there's no risk to her children. People are getting this information from small-town doctors who may not know the risk, don't have access to this information and just assume it's a big risk."

The young woman hopes to have the operation reversed, Ms. Bennett said.

The article in the geneticists' journal includes a personal account from a woman who said she had lived with her cousin for six years, "and we are madly in love." When she became pregnant, she said, her gynecologist warned that the child would be sickly and urged her to have an abortion. A relative predicted that the baby would be retarded. She had the abortion, she said, and called it "the worst mistake of my life."

When she learned later that the increased risk of birth defects was actually quite small, she said, "I cried and cried. "

The small increase in risk is thought to occur because related people may be carrying some of the same disease-causing genes, inherited from common ancestors. The problems arise from recessive genes, which have no effect on people who carry single copies, but can cause disease in a person who inherits two copies of the gene, one from each parent. When two carriers of a recessive gene have a child, the child has a one-in-four chance of inheriting two copies of that gene. When that happens, disease can result. Cystic fibrosis and the fatal Tay-Sachs disease, for example, are caused by recessive genes. Unrelated people share fewer genes and so their risk of illness caused by recessive genes is a bit lower.

Keith T., 30, said he married his cousin seven years ago and in 1998, frustrated by the lack of information for cousins who wanted to marry, he started a Web site, cousincouples.com. It is full of postings from people who say they have married their cousins or want to do so.

The site highlights famous people who married their first cousins, including Charles Darwin, who, with Emma Wedgwood, had 10 children, all healthy, some brilliant. Mr. T. asked that his full name not be used because he said he did business in a small town and feared that he would lose customers if they found out his wife was also his cousin.

"If someone told me when I was young that I'd marry my cousin I would have said they were crazy," he said. "I thought the idea of marrying your cousin was kind of icky."

Mr. T. said he was relieved to learn years ago that cousins' risks of birth defects, while higher than those of unrelated people, were still relatively low, and that he and his wife hoped to have children.

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