

Parents with sick kids turning to siblings' stem cells

By Rita Rubin, USA TODAY, 5/5/2004

Couples who need a stem cell donor for a child desperately ill with leukemia or anemia are turning to reproductive genetics clinics to help them conceive one, says a report Wednesday about the controversial approach.

Some ethicists have expressed concern about using technology to create children who would be tissue donors for siblings. They cite a lack of information about the impact on the children involved.

The clinics use a technique called preimplantation genetic diagnosis, or PGD, to screen embryos created by in vitro fertilization to see if their tissue matches the sick child's. Each embryo has a 1-in-4 chance of being a perfect match — not the best of odds for couples trying to conceive a donor naturally.

Only embryos with the same tissue type as an ailing sibling are transferred to the mother's uterus. After birth, blood from the baby's umbilical cord could be used to treat the sick sibling.

Diseases targeted

Couples studied had children with these rare diseases:

Acute lymphoid leukemia: 3,800 new cases a year. Most common form of leukemia in young children.

Acute myeloid leukemia: 10,600 new cases a year.

Diamond Blackfan anemia: 350 cases in U.S. and Canada.

Sources: *National Cancer Institute and Diamond Blackfan Anemia Foundation.*

PGD has been used for about 15 years to detect life-threatening, early-onset genetic diseases before an embryo is put in a woman's uterus. Over the past decade, about 1,000 children have been born after PGD found that they did not have cystic fibrosis, Fanconi anemia or another genetic disease that had affected a brother or sister.

In cases in which the genetic disease could be treated with stem cells, unaffected embryos also were tested to see whether the child would be a tissue match with a sick sibling.

Though the original use of PGD to diagnose genetic disorders is widely accepted, the use of the technique

solely to create a stem cell donor is controversial. The United Kingdom banned such use of PGD in 2002 because it doesn't benefit the resulting child.

In Wednesday's *Journal of the American Medical Association*, scientists from the Reproductive Genetics Institute in Chicago report their experience using PGD to tissue-type embryos from nine couples who had a child with leukemia or a rare type of anemia. Five babies were born as a result. Senior author Anver Kuliev says his institute has now used the technique with more than two dozen couples.

Kuliev, whose center charges \$3,000 per in vitro cycle for PGD tissue-typing, says all of the couples had been planning on having more children.

But Susan Wolf, a law and medicine professor at the University of Minnesota, asks how doctors can know couples' true motives. Wolf and others have called for safeguards to protect children born after PGD tissue-typing until they are old enough to decide whether they want to donate more tissue to their sibling if needed.