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Agonizing Choice A Brother's Survey Touches a Nerve In Abortion Fight

Mothers Were Asked How They Found Out Their Babies Had Down Syndrome

Teaching His Sister to Read

By AMY DOCKSER MARCUS Staff Reporter of THE WALL STREET JOURNAL October 3, 2005; Page A1

CAMBRIDGE, Mass. -- Earlier this year, Brian Skotko, a student at Harvard Medical School, published papers in two academic journals, based on a survey of more than 1,000 mothers. The survey asked an unusual question: How were they told that their child had Down syndrome?

One woman said that after her baby was born in 2000, "the doctor flat out told my husband that this could have been prevented... at an earlier stage." Of 141 women who learned through prenatal testing, many said they felt urged to terminate the pregnancies. One said that after learning her amniocentesis results, the doctor told her "our child would never be able to read, write or count change."



Brian Skotko

Mr. Skotko, whose sister has Down syndrome, saw his project swept up in a complicated debate over the termination of fetuses diagnosed with disabilities. It raised a provocative question: Can what a doctor says influence how a woman chooses?

This issue is being increasingly debated as the proliferation of prenatal tests is creating new ethical dilemmas. Doctors often must explain the potential impact of a particular condition on a fetus at a time when medical advances are changing what it means to live with many disabilities.

Researchers estimate there are more than 1,000 genetic tests available or in development that could be used for fetuses -- including ones for conditions that aren't life threatening, could be lessened by surgery, or don't appear until adulthood. Down syndrome is at the forefront of controversies surrounding the termination of fetuses with disabilities because in recent years medical, social and educational changes have dramatically improved the prospects for people with the condition.

At least one in 1,000 children born in the U.S. are estimated to have Down syndrome, a genetic condition that causes a range of physical and intellectual disabilities. The condition has most often been

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discovered at birth, but more parents are finding out through prenatal tests. New, less-invasive tests are increasing the likelihood that younger women will be able to find out if they are having a child with Down syndrome. Until now, the focus of testing has been on women 35 and over.

There are no national statistics on how many women continue pregnancies after receiving a diagnosis of Down syndrome. Researchers at the University of Connecticut Health Center examined birth-certificate data and, in a paper published last year in the *American Journal of Obstetrics and Gynecology*, estimated the number of Down syndrome live births in the U.S. declined 7.8% from 1989 to 2001. They suggested that the drop was due to the use of prenatal diagnosis and the termination of pregnancies.

A 1991 study of 14 hospitals in the Southeast found a more than 90% termination rate for fetuses diagnosed with certain chromosomal abnormalities including Down syndrome. A study last year reported that more than 80% of pregnancies involving a fetus with Down syndrome at Boston's Brigham and Women's Hospital were terminated in the 1980s and 1990s.

Lewis Holmes, an author of that study, says despite the high rate, he doesn't believe "the system is tilted toward termination of pregnancy." Dr. Holmes, director of genetic services at the Prenatal Diagnosis Center at Massachusetts General Hospital, says most doctors make "an enormous effort to make sure couples hear both sides." Deciding whether to continue such a pregnancy is a "personal, private agony," he says.

As testing for genetic conditions becomes more widespread, more expectant parents will face these situations. "Individuals who confront these dilemmas should have the full range of choices available to them," says Wendy Chavkin, a professor of obstetrics and gynecology at Columbia University, who is head of Physicians for Reproductive Choice and Health, a pro-abortion rights group.



Michael Williams/Mercury Pictures

Brian Skotko and his sister, Kristin, playing Yahtzee at their parents' home.

A practicing Roman Catholic, Mr. Skotko says he personally opposes the termination of any pregnancy, except when the mother's life is in danger. But he doesn't advocate overturning *Roe v. Wade*, the Supreme Court decision which guaranteed the legal right to abortion. "We have decided as a society that termination is permitted until 24 weeks of pregnancy," he says. "I respect the law."

His survey was funded by Children's Hospital Boston and a student-research fund at Harvard Medical School. Mr. Skotko says he receives no funding or support from antiabortion groups. He is in a joint program at Harvard, attending its medical school and its John F. Kennedy School of Government.

Mr. Skotko grew up with a sibling who has Down syndrome. He helped teach his sister to read and ride a bike. Today, kids with Down syndrome attend public school, often sitting in regular classrooms part of the day and joining the same sports teams as classmates.

Life expectancy for people with Down syndrome has greatly increased in recent years, partly due to better care at home and earlier intervention for health problems. In 1983, people with Down syndrome lived, on average, to the age of 25. Today, they live an average of 56 years, according to the National Down Syndrome Society, a nonprofit group based in Manhattan. The group estimates there are more than 350,000 people in the U.S. who have Down syndrome, a number it has used for about a decade.

## Many Challenges

Despite strides, people with Down syndrome still face many challenges, especially as they age. There is a shortage of independent-living facilities and job opportunities. Adults are at increased risk for a variety of medical problems, such as diabetes.

This spring, after Mr. Skotko's articles were published -- in the American Journal of Obstetrics and Gynecology and in Pediatrics, another academic journal -- he started fielding calls from doctors, disability-rights groups and others. Some of his findings were posted on antiabortion Web sites.

In March, he got a call from the office of Sen. Sam Brownback, a Kansas Republican, asking him to speak at a news conference after the introduction of the Prenatally Diagnosed Condition Awareness Act. That bill would provide \$25 million in federal funding to ensure women whose fetuses are diagnosed with Down syndrome and other conditions receive up-to-date information.

The bill grew out of hearings that Sen. Brownback, who opposes abortion, held last year on the implications of prenatal testing on Down syndrome. Sen. Edward Kennedy, a Massachusetts Democrat who is pro-abortion rights, introduced the bill in the Senate with him. Sen. Kennedy had a sister who had an intellectual disability and another Kennedy sister founded the Special Olympics.

Mr. Skotko kept working on his speech on the flight to Washington, struggling, he says, to focus on his research, not his personal opinions. He worried that politicians with strong views on either side of the abortion debate "might warp the opinions of the mothers in my survey." He hadn't asked the mothers if they were for or against abortion rights.

At the news conference, Mr. Skotko sat in the front row as politicians spoke first. After discussing his survey, he introduced Beth Allard, the mother of a child with Down syndrome who had flown with him from Boston.

Mrs. Allard told the audience about the day she received the results of her prenatal test. "It was as if we were handed a death sentence," she said. Instead of offering referrals or support, she said doctors told her and her husband the child would be "constantly hanging off of you, drooling, unable to speak, read or write." They were warned that if they had other children, "he will just become more of a burden," Mrs. Allard said. She felt "like I'd done something wrong."

The couple decided to continue the pregnancy. They say their son, Benjamin, now 6, is doing well. Mrs. Allard has since had another child, who doesn't have Down syndrome.

Mr. Skotko's mentor, Allen Crocker -- a 79-year-old doctor who has worked with people who have Down syndrome for decades -- says he is troubled by how often such pregnancies are terminated. Yet when Mr. Skotko went to Washington to speak, Dr. Crocker was concerned.

The idea of legislation to help doctors give patients information "seems like neutral ground," Dr. Crocker says, "but it is not." The director of the Down syndrome clinic at Children's Hospital Boston worries that political pressure could encourage efforts to identify physicians who discuss termination and those who don't. He says it is crucial that conversations between doctors and expectant parents remain private. "The stakes are huge," he says.

In April, Mr. Skotko got a call from the producer of a Michigan-based Christian radio program, "The Bob Dutko Show." The producer had seen an article about the survey on an antiabortion Web site and invited Mr. Skotko on the program. The next day, during a 20-minute break between classes, he called in.

Mr. Skotko says he tried to keep his answers focused on what the mothers said. When asked whether doctors have a "predisposition to abortion" after a diagnosis of Down syndrome, Mr. Skotko replied that "is not being answered by my study." When the host said "it's a huge insult" to people with disabilities when women choose to terminate a pregnancy after learning the fetus has Down syndrome, Mr. Skotko didn't respond. Instead, he concluded by saying: "I hope everyone takes an opportunity to meet someone with Down syndrome."

His sister Kristin, 25, lives with her parents in a suburb of Cleveland. In her room hang medals she has won in swimming, bowling, basketball and other Special Olympics competitions. On a recent day, she had just returned from one of her three part-time jobs, cleaning at a recreation center. "I get bored at home," she said. She talked about how her life is different from that of her two siblings. "I can't drive," she said. "I can't move out." But she added, "I'm not different than other people."

Mr. Skotko got the idea for his survey after he co-authored a book about the achievements of people with Down syndrome. It included a page on his sister, and the time she won a dance contest. While researching the book, he received hundreds of letters from mothers citing their children's accomplishments. Many also recounted the painful way they learned of the diagnosis.

The survey became a family project. Mr. Skotko first sent the 11-page questionnaire to his mother for feedback. His parents, grandmother, Kristin, and their sister, Allison, 22, stuffed 3,000 envelopes at the kitchen table. Surveys went out to members of five Down syndrome parent-support groups across the country.

Of 1,126 responses, close to 1,000 were from women like Mr. Skotko's mother -- who didn't have prenatal testing and learned at delivery that their child had Down syndrome. Many said they weren't given adequate or current information on the condition. Others said they felt anxious and guilty about their child's birth.

Among the smaller group who found out through prenatal testing, many said they underwent the tests convinced they would continue the pregnancy no matter what, or were undecided about what action they would take.

### **A 'Constructive' Message**

In his article on prenatal diagnosis, Mr. Skotko noted limitations of his survey, including the sample size and the fact that women were recalling emotional events that happened years ago. But he wrote that the mothers offered a "constructive" message, suggesting ways to improve the process. They asked that doctors not begin by saying things like, "Unfortunately, I have some bad news." They said parents should hear about the range of possibilities for children with Down syndrome, including success stories. They appreciated doctors who gave them contacts for local support groups.

One morning, Mr. Skotko and Dr. Crocker went to the Museum of Fine Arts in Boston. In the basement, a picture of Mary and the Christ child had been taken out of storage and propped against a wall. An art historian wrote a 1982 paper suggesting the child in the painting appeared to have similar features to that of a child with Down syndrome.

When the museum purchased the picture in the 1930s, it was thought to be by 15th-century Italian painter Andrea Mantegna. Now historians believe it was painted by a lesser artist, imitating him.

The two men worked from a checklist used by doctors when they make a diagnosis of Down syndrome. The child appeared to have some of the features, such as a protruding tongue, a gap between his first and second toes, and short, broad hands. But other traits were impossible to determine. "This person

doesn't shout Down syndrome at you, but there are features that are very suggestive," said Dr. Crocker.

Frederick Ilchman, assistant curator of paintings at the museum, listened as they debated. He thinks the features that make the baby look like someone with Down syndrome were unintentional.

Mr. Skotko was reluctant to give up on the possibility that the artist was "someone like me, living in the 15th century, who had a brother or a sister with Down syndrome," he said, and chose to use the child as a model.

He looked at the painting one more time. "I lean towards being a believer," he said.

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