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Raising a challenged child

Choosing Down syndrome

Parents reject doctors' call for more widespread testing for the genetic disorder

By Heather May
The Salt Lake Tribune

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Jill Austin wasn't concerned about Down syndrome when she decided to have a blood test to screen for birth defects during her first pregnancy. After all, the risks are higher for women 35 and older, and she was only 24.

But results showed her baby had a 1-in-100 chance of having an extra chromosome. The chances increased to 1 in 50 after another test. Amniocentesis confirmed the diagnosis.

The knowledge eventually became a relief for the Cedar Hills mom. She and her husband, Jeff, were able to prepare -- and even mourn -- well in advance. By the time Joby, now 6, was born, the Austins were ready and excited.

"Her birth was a celebration," Austin remembers.

Excerpt from Down Syndrome book

[Excerpt from 'Gifts', \(06-10-07\)](#)

Still, she and much of the nation's Down syndrome community don't support new guidelines -- generated with the help of thousands of Utah women who participated in research -- that call for offering widespread screening of the genetic disorder.

The American College of Obstetricians and Gynecologists intended to empower families by expanding testing beyond women age 35 and older, the previous standard of care.

But opponents say it sends the message Down syndrome is something to eliminate, since the disorder cannot be cured.

Fearing women will end their pregnancies after the diagnosis, many Down syndrome support groups are mobilizing. They want to reach out to doctors -- who they say offer outdated information about the disorder -- and to families to show them raising a child with Down syndrome is rewarding.

"If we don't get to the doctors beforehand, there are going to be lots of people aborting children. It's scary to think these kids don't have a chance," Austin said, gazing at her daughter in their Utah County home. "It [the screening] is a form of getting rid of the Down syndrome population."

"We're pro-options." Doctors adamantly disagree.

"None of this has anything to do with termination of Down syndrome at all," said Nancy Rose, director of perinatal genetics for Intermountain

Healthcare. "It has to do with helping people get information about their pregnancies. Children with Down syndrome have special needs that need their care coordinated."

They often have problems requiring medical interventions, such as heart defects, hearing loss and, rarely, leukemia. When the condition is diagnosed during pregnancy, doctors may order additional ultrasounds and fetal echocardiograms.

"Care and support for Down syndrome kids has improved so much," Rose said. "People don't look on Down syndrome necessarily as some sort of huge family burden anymore."

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Suzie Smith, president of the Utah Down Syndrome... (Paul Fraughton/The Salt Lake Tribune)

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Utah doctors acknowledge wider screening will lead to more abortions nationally -- but expect a smaller increase here.

A 1999 study showed that nationally, 90 percent of women terminate their pregnancies after a prenatal diagnosis of Down syndrome. But Utah's rate is much lower: 8.5 percent of fetuses with Down syndrome were aborted from 1995 to 2005, according to the Utah Birth Defect Network.

With wider screening, "you're going to allow some families to choose not to have a baby with Down syndrome," said Robert Silver, an ob-gyn who is chief of the division of maternal-fetal medicine at the University of Utah School of Medicine .

"That [rate] will be different in New York or San Francisco" than in Salt Lake City, Silver predicts.

Madhuri Shah, medical director of the Utah Women's Clinic -- one of three clinics that perform abortions -- estimates she sees women seeking to abort fetuses with Down syndrome once "every few months," usually after they are told the fetus also has severe deformities.

Utah doctors say they do not encourage abortion, and may not even mention it unless the patient initiates the discussion. They do, however, refer families to Down syndrome support groups, if the parents are interested.

"We're not pro-life. We're not pro-choice. We're pro-options that fit the family," said Rose. Karrie Galloway, director of the Planned Parenthood Association of Utah, supports the new screening guidelines, saying parents should have the choice to decide what is best for their families.

"That is at the heart of choice," she said. "Not everyone is cut out to be the parent of a challenged child."

"Like any other baby." Most women will be relieved by the screening's results. Some 5,000 babies are born each year with Down syndrome, about 80 in Utah.

"In Utah, many women do these tests for reassurance their baby's normal. They're not really looking to find a problem," said Rose, the genetic counselor.

But when there is a diagnosis of Down syndrome, it's better for parents to hear it during the pregnancy than in the delivery room, said Silver.

"People can go through that period of shock, anger and mourning prior to the birth," he said. "When the birth happens they can focus on loving their child and bonding and breastfeeding."

Austin, the Cedar Hills mom, knows the diagnosis at birth can be devastating for some parents.

For people to go through that to be sad when your baby is born," she pauses, tears in her voice, "for me personally, I'm glad I knew."

Kecia and Kristopher Cox were stunned to learn at the birth of their now 3-month-old daughter Bree that she had Down syndrome.

"Had we known, maybe we could have read up and been a little more prepared. At the same time, what we've found is she's a baby just like any other baby we've had," said Kristopher Cox. "She might be a little different, have her own challenges, but what kid doesn't?"

While an ultrasound had raised the possibility of Down syndrome, the Murray couple decided against further testing, knowing it wouldn't change how they felt about their baby.

"She means the world." Jeff Botkin, a medical ethicist at the University of Utah, said doctors and patients need to have such discussions if genetic screening is expanded. If the patients know they won't seek an abortion, for example, getting tested may not make sense.

"This is a test that gets to some of the most sensitive issues that people have in our society," he said. "It's about what we think of our children, what are we willing to accept."

"You want people to go into that testing with a thorough understanding of the pros and the cons."

Groups like the National Down Syndrome Congress emphasize the cons. It sees the screening guidelines as "tacit approval for terminating pregnancies," according to its position statement. The group and the National Down Syndrome Society say doctors or genetic counselors emphasize medical problems at the expense of what such children can bring to a family.

Suzie Smith, president of the Utah Down Syndrome Foundation, also opposes the new guidelines.

"Just to screen to wipe out a whole disability -- that's what I feel like they're doing," said Smith, who knew her daughter Lily had Down syndrome before she adopted her seven years ago. "Until you've been around someone with a disability, you don't know what you can learn from them or what they'll teach you."

The Holladay family can't imagine life without the little girl, who calls from the kitchen: "Mom? I love you so much."

"We can see her growing up but at the same time she's always that sweet baby," Smith said.

That's why she and Austin, vice president of a Utah County support group, want to reach women with a prenatal diagnosis and offer the chance to meet their daughters, before any decisions are made about the pregnancy.

Austin knows just what she will say:

"I have been touched by having a child with Down syndrome in my life. She means the world to us and we wouldn't change her in any way. Life is beautiful with Joby in it."

hmay@sltrib.com

Author's Down Syndrome stories

[Mom gathers stories from other moms. \(06-10-07\)](#)



The guidelines

The American College of Obstetricians and Gynecologists issued guidelines earlier this year saying all pregnant women, regardless of age, should be offered screening for Down syndrome. That's a change from focusing on women over age 35.

While older mothers are at higher risk, more babies with Down syndrome are born to younger mothers because they have more children.

Until recent years, amniocentesis -- using a needle to collect a sample of amniotic fluid -- was the standard but invasive test for Down syndrome. It carries a small risk of miscarriage.

But the new, non-invasive screening -- using ultrasound images and a blood test -- is helping assess who is at risk with low false positive rates, reducing the need for amniocentesis.

And it's thanks in large part to Utah women.

More women from Utah than anywhere else -- some 12,000 -- participated in a national study to detect the best method for screening for Down syndrome. Results released in 2005 found the new tests, used in the first and second trimester, increase the detection rate to around 90 percent, up from as low as 60 percent with earlier screening tests.

The false positive rate improved from around 5 percent to 1 percent.

What is Down syndrome?

The chromosomal disorder is caused by an error in cell division that results in the presence of an additional third chromosome 21 and is the most frequent genetic cause of mild to moderate mental retardation. Named after John Langdon Down, the first physician to identify the syndrome, Down syndrome occurs in all races and economic groups.

Source: National Institutes of Health

* Utah Down Syndrome Foundation, with links to national organizations: www.udsf.org/

* Up with Downs, Utah County: momtoaliandshae.tripod.com/upwithdownsutahcounty/

* Uptown Downs of Salt Lake City: www.uptowndowns.com/

* Primary Children's Medical Center hosts a Down syndrome clinic on the fourth Tuesday of every month. For an appointment, call (801) 662-1600.

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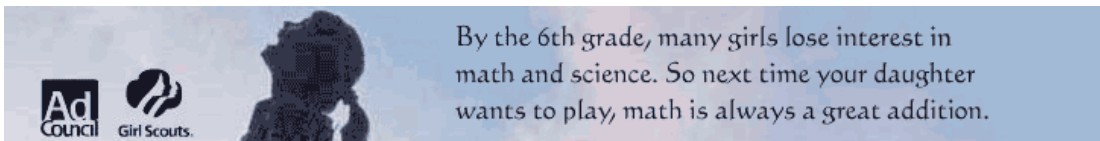
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