A Beautiful Life

Parents of children with Down syndrome overwhelmingly say the blessings are worth the challenge. So why do only 8 percent of them escape abortion?

A Tale of Two Sessions

It took two special legislative sessions for Texas to pass a bill protecting preborn life this summer—one marked by demonstrations and discord, the other by prayer and praise.
April Acker was acutely aware of feeling that her dream was turning into a nightmare.

She was living an enviable life, earning a six-figure salary in real estate while her husband ran his own chiropractic practice near Palm Springs, Calif. And now, they were eagerly expecting their first child.

But on this day, the results of some standard prenatal tests had come in, and the news was incomprehensible: The Ackers’ baby girl had an extra chromosome on the 21st pair—Down syndrome.

The obstetrician brought up the subject of “termination.” The perinatologist repeated it.

“We were not offered hope,” Acker tells Citizen. “We were left to find information on our own—and most of what we found, at the time, was an outdated view of life expectancy.”

So despite their Christian faith and pro-life values, the Ackers began to wonder: Would they really be up to the challenge of raising a special-needs child? Might ...? The unspoken question hung in the air.

“I was bemoaning having to make this decision, knowing either way would forever impact my life,” Acker says, recalling a conversation she had with her sister one fateful day. “She looked at me, and with tears in her eyes, told me, ‘Don’t talk that way about her. That is my niece you’re talking about. If you can’t handle it, then I’ll raise her.’ ”

Acker chose life that day; her daughter, Makenna, is now 7.

Unfortunately, Acker’s experience isn’t unique: According to academic researchers, 92 percent of couples who learn of a Down syndrome pregnancy choose to abort.

“The myths and fear that have led an astonishing number of would-be parents to abort babies with Down syndrome are being turned on their heads by fresh research and families who say their special-needs children are a true blessing.”

by Rod Thomson and Karla Dial

LOOKING UP: Makenna Acker, 7, of Palm Desert, Calif., is one of about 400,000 Americans with Down syndrome—a number that is now dropping.
of babies with a prenatal diagnosis of Down syndrome are aborted every year across the United States. But as it turns out, Acker’s sister isn’t unique, either: There is a greater supply of families willing to adopt special-needs babies than there are adoptable children with Down syndrome.

**Demand and Supply**

Take, for example, what happened in Virginia this summer.

That’s when the Rev. Thomas Vander Woude of Holy Trinity Catholic Church in Gainesville found out about a young couple in another state whose preborn baby was diagnosed with Down syndrome. They had already scheduled an abortion.

Vander Woude, whose younger brother has Down syndrome, didn’t hesitate: He convinced the parents to wait 24 more hours before aborting their child.

He then put out an alert on the church’s Facebook page. Other organizations, including the International Down Syndrome Coalition (IDSC), saw it and shared it with their audiences as well.

Twenty-four hours later, the church had been inundated with responses from more than 900 people—hailing from all over the country, as well as Great Britain, Puerto Rico and the Netherlands—willing to adopt the baby, sight unseen. Vander Woude and the couple worked with an adoption agency from that point on, narrowing the list down to three before choosing the family that would be the best fit for the child.

The response didn’t surprise Dr. Charmaine Yoest, president and CEO of Americans United for Life, an advocacy organization in Washington, D.C.

“There are plenty of people out there who feel this is a calling in their lives,” she tells *Citizen*. For every baby available for adoption in the U.S., she says, 36 couples are waiting in line.

And those numbers don’t diminish for children with Down syndrome: According to Christian Homes and Special Kids (CHASK)—an Idaho-based organization that is an offshoot of the National Challenged Home-schoolers Network—children with Down syndrome are the easiest to place with adoptive families. In fact, President Thomas Bushnell says, most are placed within hours or just a few days. Many of the babies adopted by CHASK families have special needs so severe that their life expectancies are measured in weeks or months.

“It’s a lifelong ministry for them,” he explains of the 600 pre-screened Christian families in the network. “It’s much easier to find parents to adopt than the babies.”

Gabe Lyons—founder of Q, a six-year-old organization that challenges Christians to engage the culture—was shocked to realize that his son, Cade, was the survivor of a purposeful extinction. He started researching the condition 11 years ago.

“That’s when I first heard that 92 percent of kids with Down syndrome were being terminated. I couldn’t believe that was true,” he tells *Citizen*. “I thought it might be another shock tactic to try to raise awareness—but the more I looked into it, the more I realized it was a very widely reported number.”

**‘Wrongful Life’**

Why so much abortion? In a word, fear.

“It’s been reported that insurance companies don’t want this kind of liability and expense—55 percent of children with Down syndrome might have to have a heart surgery in their first year of life,” Lyons says.

That puts pressure on doctors, who also fear being sued by parents with “imperfect” babies.

“People are familiar with wrongful death lawsuits, but there are actually wrongful life lawsuits,” Bushnell explains, “so (doctors) give patients the worst-case scenario.”

But when Down diagnoses are concerned, it appears that pressure goes both ways. When prenatal tests suggested IDSC Executive Director Linda Nargi’s first child had Down syndrome, the first question her doctor asked was when she wanted to schedule the termination. She didn’t—but the obstetrician continued to tell her and her husband what a “burden” the baby would be, both to them and society. He kept it up until they found a new doctor.

“Most parents will report that the pressure is on to terminate as soon as that diagnosis is revealed,” Lyons says. “It’s like, ‘You’re dumb if you don’t terminate.’”

Then there are the tests themselves, which are many; some of the most common go by names like “Harmony,” “MaterniT21” and “Verify.” They’ve multiplied since coming into use over the last several years and continue to evolve. Though they are not mandatory under any state’s laws, doctors use them so routinely that some patients—like Acker—don’t even know their preborn babies are being screened for Down syndrome until the results come in.

Those tests are performed through blood analysis and miss 8 percent of Down syndrome cases, according to an article published in the Oct. 9 issue of the *Harvard Gazette*—a number coinciding exactly with the percentage of children with Down syndrome who escape abortion. When the results are positive, doctors generally recommend that women undergo amniocentesis testing. But those tests don’t yield significantly different results from the newest
generation of blood panel screenings, and inserting a long needle into the placental sac carries its own slight risk of causing a miscarriage.

“There’s no question there are false positives,” Lyons tells Citizen. “I was speaking at a church a month ago, and a woman introduced me to her daughter. Her tests said she might have Down syndrome. She’d been pressured to terminate, but decided not to—and here was her daughter, 10 years later, with no genetic conditions at all.”

‘A Beautiful Life’

Though left-leaning activists and even many members of the medical community say abortion is best when parents receive a Down diagnosis, scientific research suggests that despite the struggles people with Down syndrome may face, their lives are worth living—and the lives of the people around them are enhanced by their presence. Dr. Brian Skotko, a geneticist and codirector of the Down Syndrome Program at Massachusetts General Hospital, worked with other researchers to conduct a ground-breaking study of 3,000 parents and siblings of people with the condition nationwide. According to the results, published in the October 2011 edition of the American Journal of Medical Genetics, nearly 80 percent of the parents responding said their child had given them a more positive outlook on life. Nearly 90 percent of the siblings said having a brother or sister with Down syndrome had made them better people. And an overwhelming 96 percent of the people with Down syndrome said they were happy with their lives, themselves and their appearance. By comparison, only 59 percent of people in the general public report feeling that kind of satisfaction and self-esteem.

“Handicapped children show us how to have joy in the midst of suffering,” says Yoest. And for all her early trepidation, Acker wouldn’t change a thing about her life with Makenna. “It’s a beautiful life,” she says. “I kind of wish more people could experience it.”

Legally, the word about the upside of Down syndrome appears to be getting out: Earlier this year, North Dakota became the first state in the union to ban abortion based on genetic anomalies such as Down syndrome. Though Planned Parenthood challenged the law in court, a federal judge in September dismissed the suit. Now, North Dakota medical professionals are required to provide women with more information about Down syndrome than what Acker or Nargi received from their doctors, and are barred from pushing for abortion to avoid lawsuits.

“Let’s not decide in the womb if a child is going to be happy in society,” says state Rep. Bette Grande, R-Fargo, who sponsored the bill. “Why force these mothers to make that decision?”

Grande’s bill was based on model legislation provided by Americans United for Life. Several states—including Massachusetts, Missouri and Virginia—recently have passed laws requiring doctors to provide expectant mothers with the most up-to-date, evidence-based, written information on Down syndrome.

Though California has yet to join that list, April Acker has found a new avenue of ministry over the last eight years: When other parents at her doctor’s office find out their baby may have Down syndrome, they now are given information about the condition—and Acker’s phone number.

“I have an opportunity to share my experience,” she says. “And hopefully, to save a life.”

RICHER FOR IT: Twelve-year-old Cade Lyons (top right) spends some quality time with his father, Gabe, and younger siblings near the Statue of Liberty on Father’s Day. Cade attends a regular junior high school. Neither Pierce, 10, nor Kennedy, 8, have Down syndrome, though chances for it are higher for all younger siblings of people with the condition.
Like many other parents, Rick Smith didn’t know much about Down syndrome when doctors told him his newborn, Noah, had it. So, like many other parents, he went to the Internet to find out what he needed to know.

“I was trying to find videos of what it was like for the families, and had a really hard time finding anything positive,” Smith, who is director of digital ministries at Watermark Church in Dallas, tells Citizen. “There were lots of comedians, lots of people making fun.” So Smith started his own blog, Noahsdad.com, shooting a simple 60-second video of his son every day and posting it online.

The posts went viral. As Noah is celebrating his third birthday this month, more than 54,000 people will get a glimpse of it through Facebook and nearly 11,000 on Twitter—not to mention a few thousand others spread across Google+, YouTube and Instagram.

“God’s really opened up a door to minister to people through what we do,” Smith says. “It’s not a Christian thing. It’s not even a pro-life thing—we just want to show the world what it’s like to raise a child with Down syndrome. Noah’s not sick. Noah’s not suffering. He doesn’t need someone to pray his Down syndrome away. He’s just a normal boy who happens to have three copies of his 21st chromosome.

“There’s never been a better time in history to be born with Down syndrome,” he adds. “These kids today are driving, graduating from college, getting jobs, getting married. There’s a study showing that the average IQ of people with Down syndrome has actually increased over the last decade. That’s because of early intervention. It’s totally different than it was 30 or 40 years ago.”

Everyday citizens can do a lot to change the conversation doctors have with their patients about Down syndrome. Smith suggests:

- **Take your child to the doctor with you.** Younger siblings of children with Down syndrome carry higher chances of having the condition. So when women go to see their obstetricians or gynecologists, they can introduce their doctors to the child who has Down syndrome. Many medical professionals dispensing information to expectant parents have no firsthand or even secondhand experiences with people with the condition.

- **Keep your obstetrician updated.** Send him or her an annual letter, detailing the milestones your child with Down syndrome passed this year. This is particularly helpful if your doctor urged you to have an abortion.

- **Make yourself available.** Let your doctor know you’re willing to tell other expectant parents about your experiences as the parent of a child with Down syndrome, and encourage him or her to pass along your contact information.

“We need people to share the good stories to drown out the negative,” Smith says. “We need to honor and celebrate the little life that’s in that tummy. ‘It’s going to be different, but it’s going to be OK—and congratulations.’

“That’s what parents need to hear.”

FOR MORE INFORMATION

To find out more about the International Down Syndrome Coalition, visit www.theidsc.org. For more information on CHASK, visit www.chask.org. Parents receiving a prenatal diagnosis may find helpful information at www.lettercase.org or www.brightertomorrows.org, while expectant fathers in particular may find support at www.noahsdad.com. For model legislation that can be used in your state, visit www.aul.org.