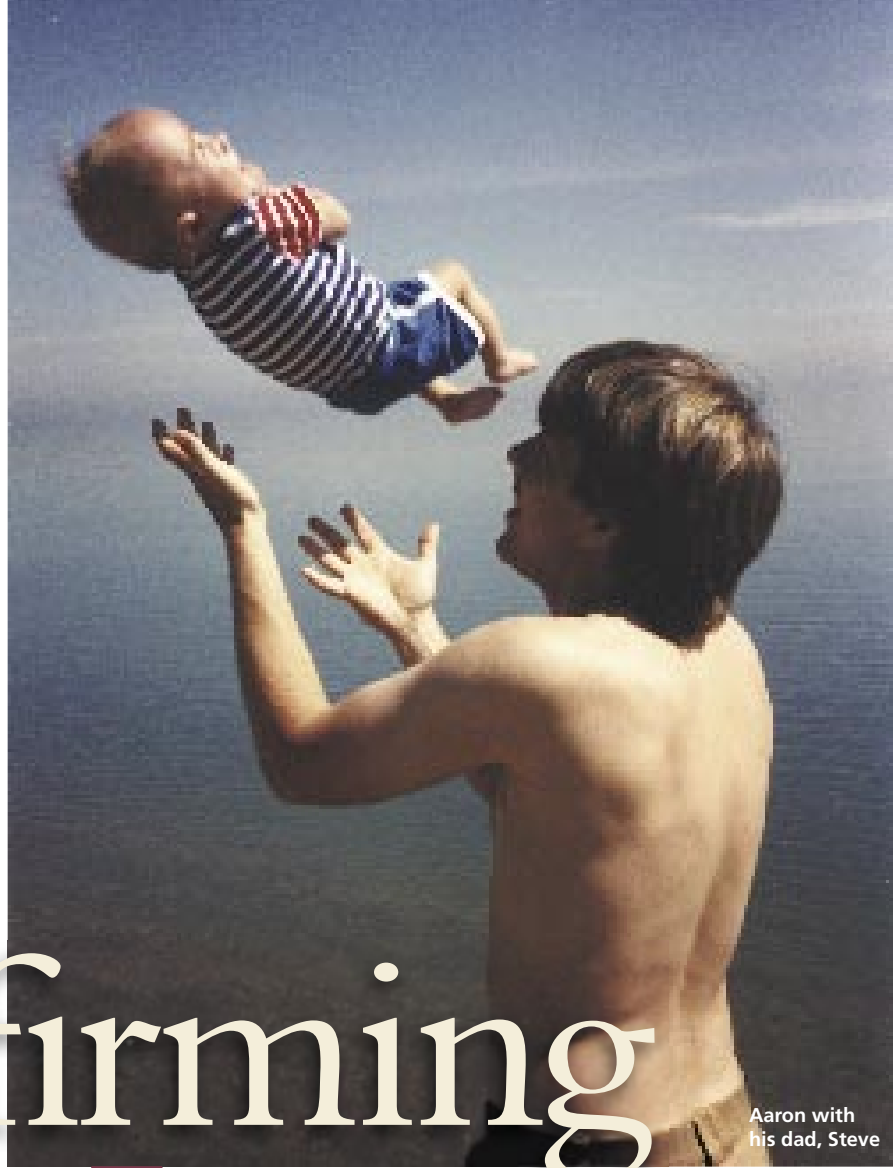


BOB SMIETANA

Trisomy 13 has not disabled a young man's ability to witness for God.



Confirming Aaron

For just a few moments, Aaron Barg got to be just like everybody else. Sitting in the front row while the photographer snapped a class picture on Confirmation Sunday at Libertyville (Illinois) Covenant Church, Aaron looked like any other ordinary teenager.

But there's nothing ordinary about Aaron, who was born with Trisomy 13. This rare genetic condition, caused by an extra thirteenth chromosome, means that Aaron was born with a weakened heart and lungs and brain damage. He is deaf and legally blind, and doctors told his parents, Steve and Susan, that Aaron would most likely die by his first birthday. If he survived beyond that point, Aaron's life would have little quality—he would never speak, walk, or feed himself.

But Aaron defied expectations. Now fifteen, Aaron is a handsome boy with blond hair and a face that lights up when someone he knows comes by. Bend down by his wheelchair and he'll

pull your face close to his, stare deeply into your eyes, and stroke your face. Though he can't speak, his eyes and hands tell you that he knows you are there. While he can't walk, he can move his wheelchair, feed himself, and even communicate using five hand signals.

The idea to have Aaron confirmed began two years ago with Dwight Nelson, pastor of Libertyville Covenant. While at Aaron's thirteenth birthday party, Nelson noticed a picture of his baptism. The next logical step in Aaron's Christian journey, Nelson realized, was confirmation. He talked the idea over with Brian Zahasky, the church's youth pastor, and then called the Bargs one night in the fall of 2003.

The invitation caught the Bargs off guard. "How would we do this?" Steve wondered. "Aaron can't learn Bible verses, he can't go through catechism, he can't sit in a class for forty-five minutes like the other confirmands."

Nelson told the Bargs that he wasn't sure how all the details would work out, but he felt it was important that Aaron be confirmed.

"He told us that confirmation has three parts," says Susan. "One part is the Bible, walking through the Bible and learning the foundations of the faith—something Aaron could not be a part of."

The second part is prayer, Nelson went on. Confirmands are presented before the congregation and the congregation is charged to pray for the confirmands as they move into the adulthood of their faith. Aaron could be included in that prayer.

The third part is an affirmation that God is at work in the lives of confirmands. "It is clear from being around him, that Jesus Christ is in Aaron's life," Nelson says. "People have come to faith

in Christ by observing him and the care he receives. So we must confirm what is evident, what we see—the presence of Jesus Christ in Aaron."

The Bargs have always believed God has a plan for Aaron. "We realized early on that Aaron is on a mission from God to change people's lives," Steve says.

When Aaron was three months old, he developed a hernia that left him in constant pain. The Bargs found a surgeon who could repair the problem. Finding an anesthesiologist proved more difficult.

For most anesthesiologists, the risk was too high. They felt any operation could kill Aaron. Finally, during a medical visit, Susan asked an anesthesiologist if he would like to hold Aaron. The doctor took Aaron in his arms and held him for an hour, then agreed to assist in the operation. Aaron has needed several operations since then, and the same anesthesiologist has helped with them all.

"He held Aaron, and Aaron became a human being," Susan says, "not a stastic, not a piece of medical research on

"We realized early on that Aaron is on a mission from God to change people's lives," Steve says.

a piece of paper—but a human being with a name who responds to touch and cuddling and love."

A few years later, one of the Bargs' friends became a Christian after spending time with Aaron. The Bargs were out, and their friend Tim was babysitting Aaron. Tim had been going through a tough time, trying to sort out what he really believed about God.

While holding him, Tim suddenly became aware of Aaron's heartbeat. Something about that experience changed him. Describing it in a letter to the Bargs, Tim wrote: "His heartbeat resounded powerfully with life—life that could not be stolen by the odds he faced. The knowledge of Christ was in my head but not in my heart. Hearing Aaron's heart changed that."

As Aaron grew, it became harder for the Bargs to find ways for him to participate in church life. He outgrew the nursery, and Sunday school was not a workable option. When he was eight, Neale and Marilyn Murray offered to spend time with Aaron on Sunday mornings. They were joined by Nancy and Roger Swanson and George and Sharon Lemke—the three couples take turns supporting Aaron at church.

Still, he was often separated from his peers. That changed as Aaron began to

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The 2005 Confirmation class at Libertyville Covenant Church

participate in confirmation. He would come at the beginning of each week's class and spend a few minutes with the other students. They also spent time together socially. The boys in the class spent several evenings at the Bargs' house; baking cookies for the local homeless shelter one night and just hanging out with him on another when the Bargs were at a meeting for confirmation parents. Those times allowed them to get to know Aaron on his own terms.

Then there was the night the class went bowling. Most lanes have equipment that allows people in wheelchairs to bowl—generally a metal tube big enough for the ball to fit through. But this lane didn't. The Bargs and Zahasky let the students solve this problem.

"Aaron's going to bowl," Zahasky



Aaron, age five, at a dolphin/human therapy program in Key West, Florida.



Susan, Hannah, Aaron, and Steve Barga

can't have a relationship with God when you are always distant from him. There must be a way to draw close, to listen to what God is saying. Sometimes he uses a quiet voice—you may have to come closer than is comfortable for you. We draw close to God by listening to his word, by receiving the sacraments, by engaging in worship. That is when we receive his blessing.

Aaron's confirmation was the realization of a dream the Bargs had given up long ago. When you get the news that your child is disabled and may not live very long, Steve says, all the hopes you had for them—playing catch in the backyard, running on the beach, watching them grow, and seeing them graduate from high school or college—were dashed.

"You go through a grieving process just like if someone died," he says. "Be-

"I suppose I was seeing Aaron at that moment as God sees him all the time—just one of his own children different in body but not in spirit."

said, "and they are going to have to figure out how to make that happen."

The students came up with an ingenious solution. They wedged the ball between Aaron's footrest, and then Matt Anderson lined Aaron up at the back of the lane, pushed him forward, and then stopped short of the foul line.

It worked so well, Susan says, that Aaron almost got a better score than some of his friends, a fact that Anderson acknowledged during the confirmation service.

Anderson said that though he has known Aaron for most of his life, he's always been nervous around people with disabilities. That changed as they went through confirmation together. He also came to appreciate the way that Aaron will focus intensely on the person he's interacting with. "He can really understand you and pick up how you are feeling," Anderson says.

During the confirmation service, after showing a series of photos from Aaron's life, Nelson spoke about some of the lessons that Aaron and his classmates had learned together about what it means to know God. Here's an excerpt:

If you want to greet Aaron or spend some time with him, you begin by simply touching his shoulder. That lets him know that there is a person nearby who wants to interact with him. It does not work to wave to Aaron from across the room, or to say "Good morning" as you rush past him. To greet Aaron and get his attention, it helps to begin by touching his shoulder.

Next, you must draw close to him, for his ability to see and hear is very limited. You need to get closer to him than is normally a comfortable distance. When you make yourself known in that way, he may well smile, he may well want to touch you, take hold of your hair, and give you a hug, shake hands. And as you enter his life in that way, you feel blessed by him.

This is what Aaron teaches us about knowing God and letting God be our teacher. First, it does not work to shout a greeting to God as we rush by him in a hurry to be busy. If you want to know God, to be taught by him, to follow Christ, you must touch him. . . . To follow God you have to come into his presence, you have to quiet your mind and heart. You touch God by singing a song of praise or by reading a psalm or praying with praise and thanks.

Next, we must draw close to God. You

cause all these dreams have died."

One of those dreams came back to life when Nelson called two years ago. "All wrapped up in that simple phone call from Dwight was an understanding that Aaron was going to graduate," Steve says.

When it came time for the confirmation photo, the photographer insisted that Aaron be in a regular chair, not his wheelchair. The idea was a practical one—so Aaron would have better posture in the picture. But it had a deeper meaning for Twyla Becker, the Bargs' next-door neighbor and one of their closest friends.

Becker walked into the sanctuary, and when she didn't see Aaron sitting in his wheelchair she thought he was being left out. She panicked and raced to find the Bargs. Look again, they told her—Aaron is there.

"After I walked back into the sanctuary, I saw Aaron, right in the middle of all the kids, looking just like one of the them—no wheelchair," Becker says. "I suppose I was seeing Aaron at that moment as God sees him all the time—just one of his own children different in body but not in spirit." □