

'A blessing beyond measure'



Despite having a rare neurologic disorder, Emily Joost still joins her parents, Elaine and Lyndon, on family vacations.

Raising disabled child brings **UNTOLD JOY** for Joosts

By Cheryl Hemmer

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When Elaine Joost was four months pregnant, doctors told her the baby girl she was carrying had severe abnormalities and offered her an abortion. She and her husband, Lyndon, immediately declined, but the doctors continued to push for abortion.

Instead, the Joosts, of Swansea, named the baby that day as “a commitment to God and as a sign to others that she is a child of God, a gift from Him, and a human life to be treasured.”

Her name is Emily.

Emily turned 21 years old in July. During those 21 years, she has never taken a step or spoken a word. But she continues to make an impact in the lives of those who know her.

Emily was a surprise baby. The Joosts youngest child was 11 years old and their oldest was a senior in high school when they learned Elaine was pregnant.

“We thought we had reached a point in life when we would have a little free time,” said Lyndon. “God had other plans for us.”

Very early in the pregnancy, Elaine began hemorrhaging. Doctors were able to stabilize her, but noticed some concerns during the ultrasound and sent her to a hospital in St. Louis, where doctors noticed abnormalities in the size of the head. They followed the progress of the baby, and at Elaine’s 4-month visit, incorrectly diagnosed her with cytomegalovirus (CMV). The Joosts were told Elaine would probably not carry the baby to term and if she

did, the baby likely would not survive the first day.

This is the point at which they offered Elaine an abortion. And it is the point that the Joosts declined without hesitation.

“If she lives a day, she lives a day,” said Elaine. “But we aren’t going to be the ones to decide that.”

The diagnosis turned out to be false. CMV is passed to a baby in utero from the mother. Elaine was tested and was negative for CMV. They returned to the doctors to tell them of Elaine’s negative test, only to have the doctors insist Emily had CMV and for Elaine to have an abortion. They did not return.

They knew, however, that the baby had some serious abnormalities and they would be raising a child with disabilities.

“I have been involved with pro-life things all my life,” Elaine said. “Now God was giving me the opportunity to not just talk the talk, but walk the walk.”

“We asked ourselves, ‘How are we going to do this?’” Lyndon said. “We went through all the ‘pro-choice’ arguments: Elaine will have to quit working. It’s going to be very difficult. We will be bringing a baby into this world with severe disabilities. Yes, yes and yes. Emily was our daughter and those issues didn’t change that.”

Emily was born on July 6, 1999. Even her birth was difficult. Elaine was in labor for 48 hours before she eventually had to have a Caesarean section.

Her Apgar scores were high, but Emily had fluid on the brain. Doctors placed a shunt in her brain to drain the fluid, but it was evident she had severe brain abnormalities. The part that connects the left and right sides of the brain is missing and, therefore, the two halves are not connected.

Emily began having seizures when she was 3 weeks old. A neurologist was trying to control the seizures with medication that can negatively impact vision, so he scheduled her for an ophthalmology exam to determine a baseline.

During the visit, it was the ophthalmologist who was able to correctly diagnose Emily's condition.

"He looked into her eyes and was able to tell us she has Aicardi Syndrome," Lyndon said.

Aicardi Syndrome, named after the French doctor who discovered it, is a very rare neurologic disorder. The genetic basis or mutation that causes it has yet to be identified. At the time of her diagnosis, Emily was believed to be one of fewer than 500 people worldwide with the mutation. Today's estimate is that there are about 4,000 cases in the world. It affects females almost exclusively, primarily because it is fatal for males. Girls born with the condition have a varied life expectancy.

Emily cannot walk. Her parents carry her from her wheelchair to the couch to her bed and back again. She has seizures almost daily. They feed her through a feeding tube. They tend to her bathing and toileting needs. They do not know how much she can see because she has holes in her retina, which is a symptom of the syndrome. She cannot communicate with them, but they said she seems to be aware of some conversations. She enjoys music and physical touch.

Emily has had numerous shunt replacements in the last 15 years. She has also had spinal fusion surgery and, therefore, has two 18-inch rods in her back.

"Yet with all that, she is exactly who God intended her to be," said Elaine. "We are humbled that God chose our family to give her to and to be blessed with that responsibility.

"We feel blessed for every year we have with her. It's hard for other people to understand. They see difficulties and limitations. And it is difficult. But we don't look at her any differently than we look at our other kids. And they don't look at her any differently either."

The Joosts have three other children, Matt, Katie and Andy, who all live close to their parents.

"Emily has taught all of us to be different," Lyndon said. "She has taught us patience and tolerance. She has changed our priorities. I have learned that I am not in control and that I don't

have to be in control."

"One of our biggest blessings is seeing the impact she can have on people without saying a word," Elaine said.

Elaine said another blessing is the friends they have made through Emily. The Joosts attend a family conference every other summer with about 100 other families affected by Aicardi Syndrome.

"We have gotten to be good friends with a number of them," Elaine said. "It's good to talk with people who are going through the same experiences we are. And it's sad when one of the girls with Aicardi dies."

There is currently no treatment for Aicardi Syndrome. Three universities have been researching the condition, but there have been no significant discoveries since the Joosts first heard of it.

In the meantime, the Joosts say they will continue to give Emily the best life

they can. Emily has attended school in Freeburg since she was 3 years old. She accompanies her family to church, restaurants and vacations.

Lyndon and Elaine continue to be advocates for the life of the unborn, and especially now for children with disabilities.

"We want a woman facing a crisis pregnancy such as ours to allow the child to be born," said Elaine. "If the parents feel they are unable to care for a child with disabilities, there are people who specifically want to adopt a special needs baby. Someone will be there to love the baby, even if it can't be the biological parents. Let the child be born. Let the child have a life."

Elaine and Lyndon Joost feel blessed to experience the joy of raising a child with disabilities.

"We would say YES again — knowing all the challenges — in a heartbeat! She is a blessing beyond measure!"



Correction

In the feature on Kristi Hofferber in the June-July issue, it was reported that while Kristi's adoption was closed, her adoptive mother had worked at the hospital where Kristi was born and had come across the name in hospital records.

What should have been reported was that while the adoption was closed, Kristi's parents received a paper from their attorney, shortly after she was adopted, that had the names of her biological mother and her parents on it.



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