

News

Lifting things up to the Lord

By Eileen Connelly, OSU

ST. LAWRENCE DEANERY – Little Carson Kissell's engaging personality and wide smile light up the room when one meets him. During a visit with him in May, the 4-year-old was happy to make a new friend and share his books and toys, and his parents, David and Kristy, were eager to share their son's story and their faith.

Carson was born on April 7, 2007, with a rare genetic skin disorder called Epidermolysis Bullosa (EB). EB is characterized by the presence of extremely fragile skin and recurrent blister formation, resulting from minor friction or trauma. Because their skin is a fragile as a butterfly, EB patients are often dubbed "Butterfly Children." In its worst form, EB leads to eventual disfigurement, disability and early death. There is currently no cure for the disease.

Kristy Kissell's pregnancy was normal, but the couple realized something was wrong with their baby boy immediately after his birth at Good Samaritan Hospital in Cincinnati. The newborn, who was missing skin on his hands and feet, was sent to Cincinnati Children's Hospital for genetic testing, which confirmed a diagnosis of EB. The Kissells also learned they are recessive carriers of the disease.

The news was devastating for the young couple. "You think about how you're going to manage being a new parent, let alone dealing with a child with a special condition, and it's overwhelming," Kristy Kissell said.

The only treatment for EB is daily wound care and bandaging, a routine the Kissells had to master before taking Carson home. A teacher by training, Kristy Kissell is now a stay-at-home mom and Carson's primary caregiver. His dressings on certain areas are changed daily, and he is bathed every other day. The process, which includes applying a specific ointment to various wounds, dressings that become like a layer of skin and white cotton wrapping to provide additional protection, takes hours. Kristy Kissell's parents and siblings visit on a regular to help prepare and sort the dressings.

The routine can be grueling, but she said Carson tolerates it well. "He's really good. It helps that he doesn't get too squirmy. I put in a Curious George DVD and he's happy"

David Kissell, who works as the development director at St. John the Baptist Parish in Dry Ridge, said seeing how his wife manages their son's care is "inspiring. She's the saint in all this."

There are also other physical challenges related to Carson's disease. Even with eye ointment applied several times daily, he gets painful corneal abrasions that affect his vision for days. He recently had a G-Tube (feeding tube) placed into his stomach so he could receive extra feedings at night while he sleeps, his father explained.

"The hope is that the extra calories will help him gain some weight and also help to heal his wounds. He does eat via his mouth, but the majority of his calorie intake from food goes to wound healing, thus, there's not much left for his needed nutrition and weight



David and Kristy Kissell pose with their son, Carson.

COURTESY PHOTO

gain," David Kissell said. "G-tubes have become more common in recent years for kids with EB. While he was under for the surgery, he also had his teeth cleaned and his esophagus stretched — they like to take advantage of the time he's out and do as much as they can. Everything went very well and he is doing great. The doctors were extremely happy with his progress. He was getting back to his normal talkative mode just a few days after surgery. Carson is adjusting very well to his new 'tube' as he likes to call it. He never ceases to amaze us!"

Like any child, Carson loves to play, and his mother notes, "With every decision I make, I have to consider his well-being and if it's appropriate for him to be around other children. It's especially challenging in hot weather because his skin tears more easily."

The little boy is part of a weekly playgroup with the children of friends of the Kissells who have been taught about Carson's disease. They can only play together, though, if the other children are healthy, said Kristy Kissell.

Carson is also visited each week by a teacher from the Southwest School District, where the Kissells reside, and his mother hopes to eventually home school him. In addition, he has regular visits from both occupational and physical therapists.

Her son takes everything in stride, Kristy Kissell said. "We've talked about his disease a little bit, but so far, all he's really asked is why his friends don't have any boo boos yet like he does."

She admits Carson's condition attracts attention when they're out in public, but it doesn't bother her and she views it as the opportunity to educate others about EB.

For Carson's part, "as soon people start interacting with him, it has an impact. You can see their hearts melt. There's no doubt in my mind when that happens that our special little boy has a mission. We just don't know what it

is yet."

The Kissells have made it their mission to raise awareness about their son's disease and have hosted fundraising events in hopes of finding a cure for EB. Along with family members and friends, they established the Walk for EB to benefit the EB Medical Research Foundation. This year's walk, held in May, raised \$18,000.

The Kissells expressed their gratitude for the assistance they've received from the local community, their family and friends and fellow members of St. Bernard Parish in Taylor Creek. "We had great support from the parish. Father Don (Siciliano, pastor), just asked, 'what can we do for you?'" Kristy Kissell said.

Both she and her husband say their faith has been strengthened as they have watched their young son grow and coped with the daily challenges presented by his disease. "It didn't come overnight," Kristy Kissell admitted. "We had to learn to put things in God's hands. It took a lot of prayer."

"This has shown us how much is out

of our control, how much we need to trust God," her husband added. "People ask how we do it and I tell them, it's not us. It's God working through us. We try daily to remind ourselves to just live for today and not to worry about the future. As we pray together, of course, we're hoping for a cure for Carson, but we're also praying that we can instill strong faith in him. That's our role as parents."

The couple says what has also helped them come to grips with Carson's disorder are his courage and joyful spirit. "He's just a happy kid who loves to play. That's healing for us," David Kissell said.

After much prayer and discussion the Kissells decided to extend their family and are expecting their second child in December. A recent ultrasound showed Kristy Kissell's pregnancy is progressing well. Although genetic testing has shown another child has a one in four chance of also having EB, the couple is, as they believe so strongly in doing, "lifting things up to the Lord," she said. ■



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