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Family learns to dance in rain

Dr. Nell Mohney

Inspiration

Jada Daves is tall and blond and beautiful. She also is an impressive Christian motivational speaker. I met her several years ago at a luncheon for Scenic City Women's Network (a network of Christian professional women).

Then last summer, Jada and her husband, Kevin, an information technology senior developer, and their five children made national news. It centered on their youngest child, 21-monthold Shafer. From his emergency Caesarean section birth to an early surgery for a congenital diaphragmatic hernia to a later diagnosis of the lifethreatening Denys-Drash syndrome.

Denys-Drash syndrome is a chronic disease so rare that only 200 cases have been reported in medical history. This disease leads to kidney failure in the patient by age 3 and the risk of a kidney cancer called Wilms tumor.

On Shafer's first birthday, his kidneys failed. He was taken to Vanderbilt University Medical Center, where his kidneys were removed and he was placed on an 11-hour dialysis routine. Then the search for a kidney transplant began. Parents are not usually good matches for their children's organs. In Jada, however, there was a perfect match.

It takes at least three out of six antigens to match before a transplant can be successful. When the doctor called Jada, she said, "We have the most amazing news. We can't make this call often, but you are a six-for-six match for Shafer." Jada replied, "For me to be a six-for-six match is just crazy, miraculous."

The entire family moved to a rental house in Nashville for the summer. They would be there for the two surgeries and needed to remain for six weeks for follow-up tests.

Jada said to the four older children, all under 9 years of age: "I need you to be strong and to pray for Mommy and baby Shafer. OK?" Between their sobs, they were nodding to say they would do it. On the evening before surgery, the family met together to sing a goodbye song to the dialysis machine, which had kept Shafer alive for the transplant, to hug each other and to pray for God's guidance during the surgeries.

The following day, June 22, 2011, at 9:03 a.m., the first incision was made in Jada's body. At 12:21, Jada's kidney was placed in a sterile container, and a call was made to the transplant team waiting next door. A large group of extended family members and friends from Chattanooga were in an adjacent room. All were wearing blue Tshirts with "Team Shafer" written across the front.

Kevin and Jada are grateful for successful surgeries and look forward to what the future holds. They know Shafer's disease is lifelong and that he will continue to need medical treatment. Yet, they feel they can better manage the path ahead. They have adopted a family motto: "Life isn't waiting for the storm to pass; it's learning to dance in the rain."

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