

## Addressing psychosocial needs of cardiac patients' families

Ellen and Bo Boyer's first child, a daughter they named Brett, was diagnosed with a congenital heart defect (CHD) while in utero. The couple was told that their beloved daughter would require open heart surgery to survive.

For most, an atrioventricular septal defect is repairable 97% of the time.

For Ellen Boyer, the thought of Brett being in the 3% never crossed her mind.

Despite attempts from the medical team to check on the well-being of the parents after the surgery, the Boyers' sole focus was their daughter.

"We were not expecting for surgery not to go our way," said Ellen Boyer. "I was blindsided and had not let myself go there. When it happened and people wanted to talk to us, we were not open to it.

"The wheels have been turning ever since," admitted Boyer. "We knew that something was missing in the overall treatment of CHD."

The Boyers hope they have found the missing piece of the treatment plan for families along their cardiovascular journey and that other pediatric hospitals follow suit.

The Brett Boyer Foundation recently made a gift in Brett's memory to support the hiring of a psychologist in the Department of Pediatrics aimed at supporting the Pediatric Heart and Vascular Institute at Monroe Carell Jr. Children's Hospital at Vanderbilt.

"While the team can heal children's hearts, there was still an emotional and mental component that needed to be addressed. We figured that if a rapport with a

psychosocial expert was established on the front end, perhaps more families would be open to talking about their experiences. It's important to have an expert, someone trained, to provide tools to manage a family's emotions."

In preparation for designating funds to assist with creating this new position, the Boyers asked other CHD parents for input. The responses flooded in with an overwhelming call for emotional support. It was the confirmation the Boyers needed to proceed with their plans.

Discussions with Scott Baldwin, MD, chief of the Thomas P. Graham Jr. Division of Cardiology, have been ongoing for more than a year. While the COVID-19 pandemic slowed down progress, it also heightened the need for psychosocial support of families dealing with serious medical issues.

An estimated 40,000 children are born with CHD in the United States annually.

At Children's Hospital, the teams perform about 475 cardiac surgeries each year. The clinic sees 17,000 outpatient visits a year.

For many cases of CHD, diagnosis of the defect is found in utero. All cases differ, and some require multiple surgeries over a period of time.

"Parents and families of children with congenital heart disease can experience profound stress from the time of diagnosis, through hospitalizations, surgeries, and for years to follow, impacting the child's development and the health of the entire family," said David Bichell, MD, chief of Pediatric Cardiac Surgery. "Recognizing the special emotional toll that heart problems bring to a family, the far-reaching emotional trauma of hospitalizations, and the unfilled need for professional mental health support for congenital heart families, the Boyers have stepped in as a force for positive change." 🦋

## Pediatric COVID-19 vaccine trial underway

Monroe Carell Jr. Children's Hospital at Vanderbilt is part of a phase 2/3 clinical trial to study the safety and efficacy of the Moderna COVID-19 vaccine in children.

Researchers in the Vanderbilt Vaccine Research Program enrolled at least 100 healthy children, ages 6 months to 11 years, over the course of one to two months. The trials will follow an age de-escalation, dose escalation approach, where small doses of the vaccine are evaluated in older children first, followed by younger children. This allows the researchers to decide the best dose to use in different age groups. In this case, the study will first look at children 6 to 11 years old; then 2- to 5-year-olds; and finally, ages 6 months to up to 2 years.

"If our children are going to be in school and grandparents are going to enjoy extended visits with grandchildren, we may have to vaccinate our children. Therefore, we need to evaluate the vaccine in children in order to optimize the use of COVID-19 vaccines," said C. Buddy Creech, MD, MPH, director of the Vanderbilt Vaccine Research Program and associate professor of Pediatric Infectious Diseases.

Creech said age de-escalation is used to ensure the appropriate vaccine dose and effectiveness for each age group, especially since immune system behavior varies among different ages. 🦋



Bo and Ellen Boyer with their daughter, Brett

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