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Broken Hearts Mended

Families of children with heart defects wonder why the most common birth defect is so unknown.

By Lauren Glendenning

February 14, 2007

Jeff and Lisa Greenfield knew something was wrong with their newborn daughter when their doctor entered the room carrying a 3D model of a human heart.

Like thousands of other families, the Greenfields found out their child, Alexandra, has a Congenital Heart Defect, or CHD. They also discovered a statistic about their daughter's condition that astounded them.

"We had no idea it was the number one birth defect," said Jeff Greenfield, a Fairfax City Councilmember.

Congenital means that the baby is born with the condition.

Not only are CHDs the most commonly-occurring birth defects in the United States, they are also the most deadly. CHDs make up one-third of all birth defect-related deaths, according to the Children's Heart Foundation. The foundation also reports that twice as many children die from CHDs each year than from all types of childhood cancer combined, but funding for pediatric cancer research is five times greater than for CHD. About one in 100 children in the United States are born with a CHD, or about 40,000 per year.

"Valentine's Day is the perfect time to bring families, health professionals and local organizations together, and to draw attention to the needs of the congenital heart community," said Mona Barmash, who is the Philadelphia mother of a young adult with complex CHD and the founder of the Congenital Heart Information Network, or tchin.org.

"For parents and families of kids and adults with heart defects, Feb. 14 means hope and remembrance."

The Greenfields, and several other parents of children with

CHDs, want to raise awareness about the condition. They want people to realize that it's common, deadly and under-funded. Terri Grabb, a mother in Clifton, wants more research so families don't have to go through what hers did. Last year, her 23-month-old son, Corbin, died from his CHD. Grabb and her husband, Travis Grabb, had three healthy boys at the time of her pregnancy with Corbin. She said she did everything right in the pregnancy: she gained the right amount of weight, ate the right foods and took all of the necessary vitamins.

"It's a silent killer; nobody ever hears about it," said Terri Grabb. "People assume my son died from cancer."

The detection process for CHD has not been perfected. While some cases of CHD are detected prenatally, others are not diagnosed until days, weeks, months or years later. Some cases go unnoticed until adolescence or adulthood, according to tchin.org.

Early detection is possible through a regular sonogram during pregnancy. Lisa Greenfield had at least eight sonograms during her pregnancy with Alexandra, she said, and not once did anyone notice the missing chamber of Alexandra's heart. The technicians who read the sonograms have a checklist that includes all of the vital organs, and it still went unnoticed. The Greenfields were

More

Feb. 7-14 is Congenital Heart Defect Awareness Week. To learn more about the disease, visit tchin.org; www.congenitalheartdefects.com; tenderheartkids.org or www.childrensheartfoundation.org.



Photo by Lauren Glendenning/The Connection

Jeff and Lisa Greenfield found out their infant daughter, Alexandra, has a Congenital Heart Defect shortly after she was born.

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shocked at the lack of attention, especially since the defect is so common and so dangerous. "If there's a chamber of the heart missing, you don't miss that," said Jeff Greenfield.

BECKIE REILLY, WHO lives in the City of Fairfax, said her 20-week standard sonogram was also fine. Since she had her first child via Cesarean section, the doctors recommended she deliver her second baby that way too. But Reilly was hesitant because of her recovery experience the first time, and she wanted a late-term sonogram to determine if her baby's weight was low enough to deliver naturally.

"It was a 37-week sonogram, where all the radiology group had to do was tell me my baby's weight, but they kept going back to the baby's heart," said Reilly.

When she delivered her son, Collin, in Fairfax, he was immediately transferred to the Children's Hospital of Philadelphia — one of three hospitals in the country that performs the complicated pediatric CHD open-heart surgeries. Because of the type of CHD Collin had, if it wasn't detected until a week into his life, as Alexandra's was, he might not have lived. The entire left side of his heart was underdeveloped, so he would not have picked up any oxygen, said Reilly.

"The organs are still developing at 20 weeks, so it's hard to detect," she said. "Maybe it is that everyone gets the sonogram later [in the pregnancy]."

Alexandra also underwent her first heart surgery at the Children's Hospital of Philadelphia. Her second surgery will take place sometime in the next four to five weeks, and a third surgery will be necessary when she is about 2-years-old. She is currently doing fine, said Lisa, after gaining a little weight and getting lots of rest.

Grabb said the American Heart Association dedicates most of its research money to adult research, so the priorities for childhood CHDs aren't there. Maybe it's the ultrasound technicians who need extra training, or perhaps more standard tests are needed to check for the problem, she said. "Checking oxygen levels; that's free."

The Greenfields were home with Alexandra for nearly a week before her heart murmur was detected in an office visit. She should have never been released from the hospital because of her CHD.

"We thought everything was fine with her," said Lisa Greenfield.

"It was really very much a surprise," said Jeff Greenfield.

IN THE MEANTIME, the Fairfax-area families have a support group through INOVA Fairfax Hospital. Tender Hearts is an organization that brings families together to help each other cope. Since there are about 35 different types of CHD, when two children have the same type, the organization tries to connect them so the more experienced family can give their advice and support, said Reilly. Tender Hearts is what connected the Greenfields to both the Reilly and Grabb families.

"Some of the families are just so supportive of each other," said Lisa Greenfield.

The organization conducts fund raisers, family picnics and seminars for CHD families. They also make care packages and meals for families that have to stay in the hospital for such long periods of time, which is common.

The organization is conducting a doughnut and pizza sale at INOVA Fairfax Hospital on Valentine's Day to raise money for its families.

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