



Davidsonville family raises more than \$500,000 for medical research

By MITCHELLE STEPHENSON
For The Capital

When Ida Heck of Davidsonville gave birth to her fourth child, Jenna, she and her husband Ed were not overly concerned about the port-wine stain birthmark covering half of her face, and didn't have time to consider that this mark on their new baby could be a sign of a potentially serious medical condition.

Within hours upon arriving home with the new addition to the family, the couple got the kind of phone call every parent dreads. It was their pediatrician, who had done some research on port-wine stain birthmarks. He wasn't sure, and they'd need to do tests, but he thought that they should be aware of the dangers of Sturge Weber Syndrome.

Of course the Hecks had never heard of this condition. It is very rare, affecting about one in 50,000 children.

While the hallmark of the syndrome is the pink-to-purple birthmark on the face, the complications include vision problems like glaucoma and blindness, and brain involvement including cognitive learning disabilities, headaches and seizures. While the problems may not surface right away, as the child ages, the birthmark changes in character, thickening and potentially causing more severe damage.

Within days of her birth, the Hecks took Jenna to Children's Medical Center in Washington, D.C., for an MRI. While the doctors at Children's told the family that the MRI showed no brain involvement, Dr. Ann Comi, a neurologist at the Kennedy Krieger Institute's Hunter Nelson Sturge Weber Center, told them that she couldn't rule it out.

It didn't take long for them to learn that their little girl had a very serious condition. She already had increased pressure in her eyes, and would need eye drops and surgery. They searched for information and research, but Comi informed them that the condition is so rare that there weren't many studies.

Ida Heck comes from a large local family, and has a sizeable network of friends. She decided that if there weren't any studies, she could do something about helping to find funding. While dealing with three older children, and a little daughter with a serious medical condition, she took on the task of hosting a fundraiser.

To make matters worse, during this time, her uncle, Gaeton DeCesaris, was suffering from lung cancer, and was undergoing treatment.

"He'd come back from his chemotherapy sessions, and come to my house to pray with me for Jenna," Heck said.

Her uncle, who passed away two years ago, is the benefactor for the DeCesaris Cancer Institute at Anne Arundel Medical Center, so helping the larger community is in her blood.

While brainstorming for ideas for a fundraiser, Heck and her brother, Al DeCesaris, came up with the idea to do



Jenna Heck, 4, is pictured with her mother, Ida Heck, of Davidsonville. While the tally for this year's Bands on the Bay fundraiser is not yet complete, estimates are that they will be able to contribute an additional \$100,000 to the Kennedy Krieger Institute's Hunter Nelson Sturge Weber Center.

an adult party with live bands and an auction. They secured a beautiful spot on the Chesapeake Bay at Herrington Harbour South, and they contacted friends and family members to help.

In the three years that followed, they managed to deliver more than \$500,000 to the Kennedy Krieger Institute's Sturge Weber Center.

Along the way, they managed to pick up some additional help with the event. Alan Faneca, who plays for the New York Jets, has a daughter with SWS. Faneca, along with his wife Julie, have signed on as co-chairs of the event.

This year, the fundraiser took place at the same beautiful spot under a spacious tent overlooking the Bay. Former Gov. Bob Ehrlich and his wife Kendell attended and addressed the crowd, as did former heavyweight world champion boxer Riddick Bowe.

There were hundreds of silent auction items, and the live auction featured tickets to a Jonas Brothers concert and a signed guitar from the band Led Zeppelin.

Three bands played: Orlando Phillips, Doug Segree and The Sacchetti Band. Jenna's older sister, Kaitlyn, 13, confidently and beautifully sang after the live auction was finished. The event drew about 500 people, and will likely deliver at least another \$100,000 to the center — "even in this economy," Ida Heck said.

Unfortunately, at this year's event, little Jenna, now 4½, couldn't attend. She and her mom Ida stayed home because Jenna had a fever, which sometimes leads to

severe headaches and grand mal seizures. They've ended up in the hospital before, and Jenna's mother didn't want to chance an emergency room visit.

Otherwise, Jenna is doing well. She'll start kindergarten next year, and she has two years of preschool under her belt. The county helps with occupational therapy because Jenna is legally blind in her right eye.

Despite surgery and eye drops, the port wine stain has taken its toll on her vision.

Luckily, Jenna was able to avoid seizures until after she turned two, which makes it less likely she'll have developmental disabilities as a result of her condition.

Ida Heck was a little concerned about how the kids might treat Jenna, and what they might say about her birthmark. "They're very accepting. In the beginning, I sent a letter home explaining the port-wine stain, and the red mark on her face, and told them about the laser treatments she gets that leave brown spots, and they've been great," she said.

But what makes her most optimistic about Jenna is her own courage. "She is a very headstrong child. A few weeks ago, a lady at Chick Fil-A gasped, and Jenna said, 'that's my spots, it's a port-wine stain!'"

To help the research at the Hunter Nelson Sturge Weber Center at Kennedy Krieger Institute, visit sturgeweber.kennedykrieger.org.

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