

A Mother's Determination and a Daughter's Strength

# Finding a Cure for *Hydrocephalus*

By Candice Graham



Cooper (7), Ema (5), Hunter, Chara, and Ethan (7)

**Chara McLaughen** was 36 weeks pregnant with her daughter **Ema** when she and her husband, Hunter, learned that Ema would be born with a condition called hydrocephalus. Hydrocephalus, commonly known as “water on the brain,” is a condition that causes cerebrospinal fluid to accumulate in the brain. While the exact cause of hydrocephalus is unknown, it is known that it can affect individuals at any point in life – from the time they’re in the womb, into adulthood.

Because of the excess fluid in the brain, a ventriculoperitoneal or ventriculoatrial shunt must be surgically inserted into the brain to divert fluid to another area of the body where it can be absorbed as part of the normal circulatory process. In Ema’s case, a shunt was inserted to route the fluid to her stomach when she was just 5 months old. Since her first surgery, Ema has had to undergo eight more for a total of nine brain surgeries in the five years since she was born.

Why so many? Shunt treatment fails or malfunctions in 50% of children in the first two years after surgery. In fact, Ema’s seventh shunt surgery only worked for four weeks before an infection caused her to need her eighth and ninth operations.

“The worst part about this is that we never know when or if Ema’s shunt will malfunction,” Chara says. “This is a never ending thing that Ema will have to deal with until there is a cure or a better treatment.”

Since there was no group or organization for hydrocephalus in Chattanooga yet, Chara connected with a national group, the Hydrocephalus Association, for support. She then set out to create her own local group to bring awareness of the condition to the area and to raise money to find a cure. Four years ago, Chara started and currently chairs the Greater Chattanooga Hydrocephalus Association WALK, which brings together friends, family, and community supporters. It raised \$27,000 last year.

“It’s great to have the support of other moms who have children with this condition. Being able to ask them questions and get their input on things is a big help. I found national support and wanted to bring it home,” Chara says.

While there’s no cure for hydrocephalus yet, Ema has surpassed the expectations of her first doctor, who, when she was born, gave only bleak hope for her future mental, physical, and physiological health. Today, Ema frequently sees her pediatrician Dr. Stephanie Stegall at Spring Creek Pediatrics. “There’s not a day I’ve regretted choosing her as our pediatrician,” says Chara, noting that Dr. Stegall has been a huge support system throughout Ema’s journey, even calling to check on them when they made the nearly three-hour trek to Nashville for surgery at Vanderbilt.

For a child with hydrocephalus, things like headaches can’t be soothed with baby aspirin, and a trip or fall doesn’t just mean it’s time for a nap – they’re subtle indicators that it may be time for another brain surgery and shunt replacement.



Ema and her mom Chara



Ema with Miss Tennessee 2013, Shelby Thompson

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Because of a fall she suffered on her fifth birthday, Ema’s shunt became infected, resulting in near blindness in her left eye. Her pediatric ophthalmologist, Dr. Ed Peterson at Pediatric Eye Specialists, helped to diagnose her blind eye and prescribed her with extra-strength glasses.

Today, Ema lives with the challenges of her condition, but never loses her sense of humor. “Because of the infection, Ema had to get her current shunt on the opposite side of her brain than her other shunts, so she had to have all of her hair shaved. At first she was sad and wouldn’t look in the mirror, but now she just tells everyone that her neurologist is a really bad hair stylist,” Chara says. In the fall, Ema will begin Kindergarten at Silverdale Baptist Academy, and she has her two big brothers, twins Ethan and Cooper, age 7, there to look after her. Last year, the school decided to support Ema and raised a whopping \$13,000 for hydrocephalus research.

Ema’s current shunt has advanced programmable functions, which indicates that with research and time, positive treatment improvements for this condition can be found. And Chara doesn’t intend to stop bringing awareness of this condition anytime soon. “I’m a mom with a small voice, but I will definitely be as loud as I can so that others don’t have to go through what Ema and our family has gone through,” Chara says. “It’s been a long five years, and she is the strongest child I have ever seen. She has endured so much in such a short time. She’s unlike any child you’ll ever meet.” **HS**

This year, the 4th annual **Greater Chattanooga Hydrocephalus Association WALK** will be held in Coolidge Park on **October 25**. For more information, visit [hawalk.kintera.org/chattanooga](http://hawalk.kintera.org/chattanooga).