



How You Helped Families with CHD's This Year



Eleanor the Heart Warrior!

This year we helped 4 children with CHD's with medical expenses, travel and meals. We sent two children to Camp Meridian, and we donated to a scholarship fund in memory of Katie (12) who died of a sudden heart event. Following, is a letter of thanks to the Stronghearts family from one of our beneficiaries describing the powerful story of "Eleanor the Heart Warrior".

Ellie is our first child. At 19 weeks pregnant in June 2015, we found out we were expecting a little girl, but also found out that she had multiple congenital heart defects. She had a narrowed aortic arch, VSD, malfunctioning valve and a small left ventricle. She was given a 50% chance of improving before birth while still most likely needing surgical repairs of the defects, and 50% chance of not improving and being diagnosed with HLHS. We were prepared for her to have open heart surgery at birth to repair just the narrowed aortic arch at Maine Medical Center and then she would need another surgery when she had grown at around 3 months old to repair the holes.

Ellie was born Halloween evening and was closely monitored with echoes every day for a week in Maine Medical Center's NICU. Doctors were pleasantly surprised to see her aorta did not actually narrow more as predicted, and her surgery was cancelled. Then they discovered she had Persistent Pulmonary Hypertension and CHF, and her ventricles had a very weak squeeze as her body tried to stabilize. She did not respond well to medications or treatments, and was transferred to Boston Children's Hospital at 9 days old. She had a cardiac catheterization the next day and became a challenging case for the Heart Failure Team.

Although she never looked or acted sick on the outside we were told Ellie was very sick on the inside. Even the most specialized Heart Team in New England, perhaps even the country, could not explain her weak ventricles. She developed Ventricular Tachycardia and was monitored for another 4 weeks on IV medicines. We were told if she was unable to wean successfully from the IV medicines, she would need a heart transplant.

Ellie was transferred 6 times during her 6 week stay at BCH, between NICU, CICU and the Cardiac step-down unit. She finally weaned from the IV medicines after one failed attempt, and was discharged at 52 days old on December 21st with uncertain prognosis. She still had a very weak squeeze in her ventricles, and the Heart team hoped she only needed time to grow and get stronger for her ventricles to function better or her heart could give out on her.

Ellie was closely monitored at home with a Visiting Nurse and Cardiology appointments every week in Maine or Boston. She was restricted from daycare and most of the public to keep her extra healthy. In February at 3 months old, with severe ventricular dysfunction still, were told to prepare for possibly listing her for a heart transplant, and scheduled another cardiac cath in Boston to biopsy her heart and start the listing process. A few weeks later, just days before her cardiac cath, her echo showed some improvement finally, and the surgery was postponed indefinitely. A month later, she improved more, and at 6 months old her ventricles were functioning almost at what is considered normal. Just at the doctors had hoped, she just needed time to grow and get stronger and healthier.

At 9 months old, Ellie's heart was functioning as a normal heart should, and she discontinued 3 of her 5 heart medicines. She was discharged from the Heart Failure Team in Boston, and had checkups with her Maine cardiologist. On the week of her 1 year anniversary of her open heart surgery in November, she weaned successfully from her last heart medicine and hasn't been on any since. She does have a slight narrowing of her aortic arch, but doesn't need a stent placed as of yet. Ellie had genetic testing back when hospitalized to help the Heart Team find the root of her troubles and months later the results showed she had a chromosomal mutation that caused the defects. Knowing this made the Heart Team extremely relieved the medicine worked to keep her stable at home while she grew and got stronger and healthier. It also helped them predict how to treat her in the future, as this specific mutation sometimes shows some relapsed trouble in the teenage years.

Today Ellie is a very healthy and happy 14 month-old with no developmental setbacks. We believe our daughter was able to thrive to health not only from the medicines, but due to the outpouring love and support from our family, friends, coworkers and people like you who have helped relieve some stresses so we could focus more on loving, caring and nurturing our sick infant. The smallest gestures made the biggest difference for us, and we are so grateful. Another Heart Mom once said when there was ever a financial burden, there came along a helping hand in some form, just in time to get her through. That is exactly what you did for us with your extremely generous bond gift. Thank you Stronghearts for being so giving and caring, and for being that helping hand for us throughout Ellie's journey to health. You have helped make our daughter's heart strong!

With much appreciation and gratitude from the bottom of our hearts to yours, Michelle and Jake Waterhouse

Memorial Heart Gardens at the Pottle Tree Farm

Madeline's Heart-shaped tulip garden bloomed! Imagine these tulips in brilliant red! It is always a wonderful surprise when a bulb bursts into color. We decided to plant memorial gardens each year at our Around the Lake for Stronghearts event. Drive by the Pottle Tree Farm in May and you will see an ever expanding collection of heart-shaped tulip gardens in memory of loved ones affected by congenital heart defects.

Next spring, in addition to these red tulips, you will see purple tulips in memory of Katie. Katie died suddenly from a heart event at age 12. Her family shared that she loved the color purple.



15 Years for Stronghearts!

This year marks our 15th year! It's hard to believe Seamus would be 15-year-old in a couple of months and that it has been 12 years since Jim Pottle from the Pottle Tree Farm passed. They are both so present, still. Last year we raised \$4,248.89 between our two fundraising events— Winter Sports and Fun and Around the Lake for Stronghearts. Deep felt thanks to the Pottle Tree Farm, Jon and Claudia Carroll for another year of t-shirts, business donations, volunteers, family, friends, participants, and supporters big and small. You are making a difference. Listen to this TED-Talk by one of our Camp Meridian campers: <https://www.youtube.com/watch?v=pKrQIHbeqW4>

Small Grant Application for Families

Please send families caring for a child with CHD's and in need of support, our way! Stronghearts@roadrunner.com www.Stronghearts.org

Memorial Donations in Loving Memory of:

Nancy Jane Carroll Butler, Sandy Bull, Katie Fugel, Anna Auditore, Chris Guida, Gina Patterson, Madeline Schaafsma, Mike Duffy, Patricia McDonald, Millie Gomez, Kip Gormley, Ginnie and Leanard Ritchie, Scott and Mary Metcalf, Evan Jewell Weston, Paula Louise Weston, Jim Pottle, Seamus Carroll Duffy, Diane Bassett, Lewis Bassett, Elizabeth Matera, Dale Sherrard, Elliot Fishbein, Bob Dolan, Caroline Dopyera, Lee and Irene Carroll, Judy McDonald, T.Way McDonald, Dana Bowen, Jr., Philip Clement, Sid and Hazel Bahrt, Dr. James Bates, Leiana Howarth, Moses Holbrook Walker, Jim Neal, John Benvenuti