



Heart-to-Heart

August 11, 2019

Nonprofit with Bergen County roots improves the quality of life for children, adults born with heart defects

Oftentimes in life, it is the smallest gestures that leave the greatest impact – a simple smile, a handwritten note, a visit from an old friend. During times of hardship, these heartfelt efforts are what, in the end, make all the difference. For Bergen County resident Rachel Oldenburger, this comfort was hand-delivered to her in the form of a “goodie bag” just days after welcoming her beloved son, born with a Congenital Heart Defect (CHD), into the world.

“There really is nothing like the loneliness and heartbreak you feel when you sit for hours on hours, day after day next to your child in a hospital bed,” recalls Rachel, as she explains her son Shea’s need for open heart surgery at just 4 days old. “One day, our social worker entered the room with a bag filled with a notebook and pen, fluffy socks, information on CHD and a bunch of other items that a mom and family could use while staying in the hospital.”

Also inside the bag, was a brochure for the Congenital Heart Defect Coalition (CHD Coalition), a non-profit organization with a network of CHD families working together to improve the lives of children and adults with CHD, as well as that of their family members.

The idea for the CHD Coalition started in 2006 when two Bergen County mothers, both of whom had a child with a complex congenital heart defect called Hypoplastic Left Heart Syndrome (HLHS), realized that a local support system for affected families simply did not exist. Determined to make a change, the mothers teamed up with their pediatric

cardiology nurse to form the organization, which has now grown tremendously, reaching beyond its Northern New Jersey roots to directly impact over 240 families. Their vision – to create a community of “heart families” that offers peer support during times of uncertainty – most certainly came true. Today, the Coalition continues to spread hope for the future of those affected by CHD, providing the simple comfort in knowing that no one is alone.

The three main pillars of the CHD Coalition’s mission are focused on uniting and supporting the CHD **community**, increasing public **awareness** and raising money for lifesaving medical **research**.

“A significant differentiator between the CHD Coalition and similar organizations is our commitment to research,” explains Executive Director Mike Laub. “Innovative research and emerging medical technologies offer an enormous impact on the survival and long-term care of affected individuals. Unfortunately, research specific to CHD has been seriously underfunded due to a lack of widespread national awareness. While research offers the huge potential for improvement and prevention of CHDs, programs that support the community and hospitals deliver an immediate benefit to the families and children. For this reason, the CHD Coalition is a very unique organization that understands the importance of contributing to both.”

Nearly one of every 100 babies is born with a congenital heart defect, which is approximately 40,000 babies in the United States per year. About 25 percent of these children will need heart surgery or other interventions to survive. With advancements due to medical research, 85 percent of affected newborns now live to at least the age of 18, thanks to organizations like the Coalition, dedicated to reducing the impact of CHD through various fundraising events and awareness programs.

The CHD Coalition holds two large fundraisers every year – a tricky tray dinner at The Venetian in Garfield and, in September, its annual CHD Awareness Walk and Family Fun Day at Darlington County Park in Mahwah. Last year’s walk had nearly 2,000 people in attendance from across the Tri-State area. More and more people are discovering this truly unique experience, which celebrates the lives of “Angels” lost and those who continue to fight the battle – those whom the Coalition like to call their “CHD Warriors.”



“We don’t like to use the word ‘survivor,’ since these amazing children are truly warriors,” says Laub. “While surgery may fix their life-threatening heart defect, chronic heart disease will forever affect their long-term quality of life.”

At the walk, participants enjoy several activities, food, games, music and so much more. Over the past 11 years, this event has raised over half a million dollars to fund innovative research. But the Coalition’s fundraising efforts don’t stop there – other significant initiatives include multiple smaller social events, which are free for families of the CHD Warrior, allowing both the parents and children to gain peer support from other families who have undergone similar experiences. In addition, the Coalition awards scholarships to CHD Warriors advancing to college, and delivers over 500 heart bag care packages to families admitted into the cardiac care unit at eight surgical hospitals within New York and New Jersey – a simple, yet, in cases like that of Rachel and her son, life-changing act of kindness.



Since that day she received the care package, like many others, Rachel was instantly intrigued with the Coalition and its efforts, becoming a member soon after.

“I had never sat at a table with any other CHD parents before,” she explains. “As soon as I showed up at my first meeting and met everyone at the CHD Coalition, I knew they were people with whom I’d make lasting relationships.”

That was the start of Rachel’s journey with the CHD Coalition. She now gives back to the non-profit that gave her so much, serving as its social media coordinator to promote events and raise awareness on a daily basis. Rachel is also in charge of honoring all the CHD Angels and families at the CHD Awareness Walk, a responsibility for which she is eternally grateful.

“A big part of my job with running the Facebook page is to talk with the families who send messages asking for support. When my son was diagnosed with CHD, I was determined to find the silver lining. I’ve now discovered that this silver lining is to use our experiences and knowledge to help other families on their CHD journey.”

Rachel goes on to describe this as the greatest benefit of being part of the CHD Coalition – simply being able to talk to a family that needs a positive outlet, as well as having someone to lean on during tough times.

Bergen County businesses and families have become critical to the many achievements of the CHD Coalition. Both of the organization’s largest fundraising events are held in the area, offering an excellent sponsorship opportunity for local businesses to gain greater exposure. However, the Coalition has limitless boundaries, with plans to continue delivering its message of hope to families outside of the New York/New Jersey area through the creation of additional chapters, which means additional funding for research to ensure a long-term quality of life for those affected by congenital heart disease.

“Every year, we welcome new people at our events, meet new families, and learn about new CHD Warriors,” says Rachel. “And every year, we also add someone to our Angel table at the walk. CHD isn’t going away, and until it does, it’s important for all CHD families to know that there are people out there who know exactly what you are going through, exactly how you feel, and can tell you that you are not alone in this journey.”

To learn more about the CHD Coalition and how to become involved, visit <http://chdcoalition.org>.

By Megan Montemarano