



The Daddarios

All About Heart

BY JENNA CAPUTO / PHOTOS BY ANGELA MIA PHOTOGRAPHY

Courtney and Matthew Daddario never expected to have to worry about heart health or about losing a child, but February's National Heart Month has taken on a whole new meaning for their family.

Life started out "normally." Courtney was born and raised right here in Niskayuna and loved to play outside as a child. As the youngest in the family with two older brothers, she was often dragged along to many of their games until she began playing sports herself in middle school, running track and cross country until she graduated. After college, she worked as a teaching assistant for both Niskayuna Central Schools and South Colonie Central Schools while still keeping her part time job at Mario's Restaurant on River Road in Niskayuna that she'd had since high school.

Matthew grew up in Schenectady playing hockey, soccer, baseball and golf before graduating from Notre Dame Bishop Gibbons. He is now a Quality Control Technician for Spectrum.

Courtney and Matthew had been friends since middle school but didn't start dating until after college. After marrying, they decided to settle here in Niskayuna to be close to both of their families so all the cousins could grow up together. They had Maddie (now 6), and two years later, were pregnant again for Connor. It was at a routine ultrasound 22 weeks in that they learned life was about to change. Their doctor saw a "blip on the machine" around

Connor's heart and sent them to a high-risk specialist as a precaution. The doctor made it seem like it was probably no big deal, so when Matt couldn't make the appointment, Courtney went with her mother. The day started out frustrating since they had to wait two hours past their scheduled appointment before they even saw the doctor. The technician performed the more in-depth ultrasound, being extra thorough around the heart area.

"She was very sweet and chatted with us the entire time," says Courtney. "I was feeling very optimistic. She finished the ultrasound and stepped out of the room to send the doctor in. I was talking with my mother when the doctor walked in, and he said, 'Well, you're past the window of termination in the state of New York, but you can go to Colorado if you decide to.' I was in shock and disbelief and asked, 'What are you talking about?' thinking maybe he went into the wrong patient's room—I was only there for a 'blip.' He said, 'Oh, you don't know? Your son has a severe heart defect and only a 50% chance of survival.' When you receive news like that about your unborn child, your world crashes around you."

Life changed quickly, and in the following weeks, the Daddarios were put in touch with Dr. Michael Colon, pediatric cardiologist, and Dr. Neil Devejian, pediatric cardiothoracic surgeon at Albany Medical Children's Hospital. Dr. Colon put some of their worries at ease when he said that the survival rate was probably much greater



than 50%. "What we appreciated most about him was his sincerity and the fact that he didn't sugar coat anything, but he also made sure we understood what we were dealing with," says Courtney.

They found out that Connor had three heart defects: Atrial Septal Defect, Ventricular Septal Defect, and a cleft artery off his mitral valve. The rest of Courtney's pregnancy was uneventful and involved bi-weekly appointments with the high risk doctor, monthly appointments with Dr. Colon and a meeting with Dr. Devejian to discuss "the plan" once Connor was born, which happened on July 1st via scheduled c-section at Bellevue Hospital in Niskayuna as originally planned. Connor was an otherwise healthy boy at 6 lb. 15 oz. After initial testing, the original diagnosis remained the same, but the size of the leaks was larger than they originally thought.

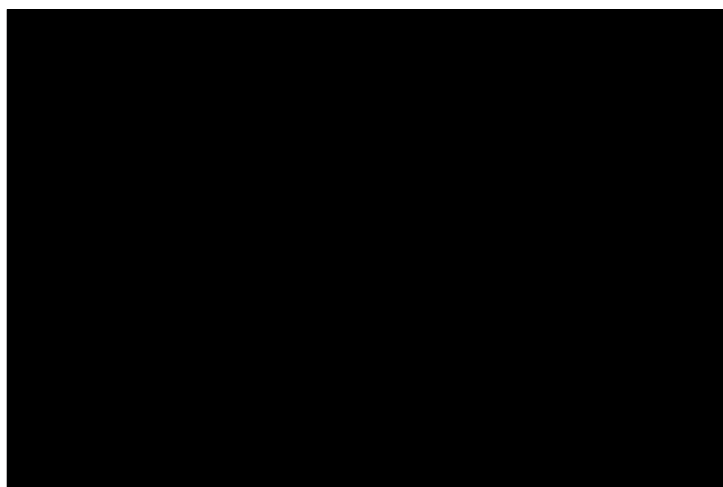
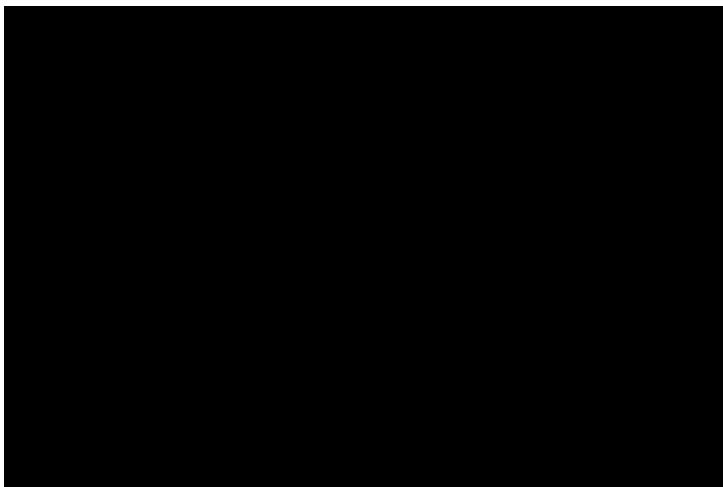
The initial plan was to do Connor's repair surgery within the first three months, but he had to be a certain size prior to surgery, and like most heart kids, Connor had a hard time gaining weight. In addition to acid reflux issues and his weight gain problems, he also had a couple of scary hospital visits when his heart began to go into failure. "We knew the signs and symptoms because his coloring

would be off and his chest would show a 'pulling' of sorts," says Courtney. "This could happen from him catching a common cold. His breathing would become labored and would result in us having to get some high flow oxygen and monitor him for a few days."

Finally, at his six-month appointment, he seemed to be stabilizing and steadily gaining weight. They scheduled his surgery for when he would turn one. On July 13, 2017, Connor underwent his first open-heart surgery.

"It was by far the longest and scariest day of our lives," says Courtney. "We were confident in Dr. Devejian and his ability to help our son, but there's always a 'what if' that runs through the back of your mind. Knowing our one-year-old son was undergoing such a massive surgery, was going to be under anesthesia for eight plus hours and on by-pass had me a jumble of nerves. I think, for me, I just had to trust in God and in everything else that Connor was going to be okay, because in my mind, there were no other options."

After the surgery was over, the doctor came out to tell them that everything went well, but what they thought was a larger hole in the center of his heart actually ended up being a series of very small pin holes, making it more





challenging to close them all. They closed the larger holes that they were able to and were going to monitor to see if the smaller holes closed on their own as the heart grew. They repaired the mitral valve as well, and for the first time, his heart function was considered “normal.”

Now they were a “heart family,” and the Daddarios weren’t really sure what that meant. Amy Galvin, an acquaintance from Courtney’s Niskayuna school days, also had a heart kid, and her family introduced the Daddarios to the American Heart Association’s (AHA) Cardiac Kids program. The first event they tried was a breakfast with Santa when Connor was five months old and Maddie was two and a half. The experience was instantly something that would become a fixture for their family.

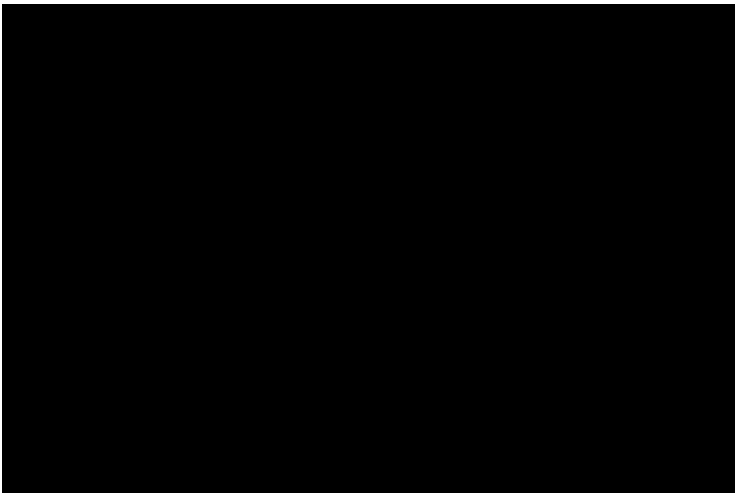
“Walking into a room full of kids that all have various heart defects and being surrounded by other parents and siblings who get what you’re going through is a very overwhelming feeling, but in the best possible way,” says Courtney. “That day in December was the first time since Connor had been born that I felt like our situation was understood. I remember leaving there and getting tears in my eyes because I finally felt like we could do this. I knew we would have support from this group and that both Connor and Maddie would have lifelong friendships from that group.”

Since then, the Daddarios have attended many of the Heart Kids gatherings, including the Heart Walk 518 for TeamConnorMan, Keeler Auto Group’s Trunk or Treat, the Tri-City Valley Cats’ Superhero Night, as well as the AHA Heart Ball and Cycle Nation.

This amazing group is a part of the AHA, which has always been a part of Congenital Heart Defect (CHD) research. CHD is drastically underfunded compared to many other childhood diseases, even though it is the leading cause of death among children. If anyone in the community wants to help by volunteering or by other means, they should reach out to Amy Young, the director of the local AHA chapter. Community members can also join or make a team for the Heart Walk, and there are ways for local businesses to be involved as well.

Connor is now in preschool and loves to golf and is hoping to play baseball in the spring. Maddie is in first grade and enjoys gymnastics and soccer. Matt is also a golfer and is hoping he’ll be able to get out more this year than last. Courtney is now a stay-at-home-mom, but still works a couple of nights a week as a bartender at Mario’s Restaurant and is looking forward to helping out at the kids’ school again once it is safe to do so. The Daddarios also have a 13-year-old Rat Terrier named Lulu.

As a family, they are homebodies, just enjoying life



together watching movies, playing games or being outside. They love home projects and entertaining friends and family. In the summer, they like to get out to all of the local parks and playgrounds as well as visit the Saratoga Racetrack and family homes on Sacandaga Lake. Usually, every spring they also go on a vacation to Hilton Head, South Carolina, but their trip last year was cancelled due to COVID. They're hoping to be able to do it this year.

Moving forward, they plan to help others in a similar situation as much as possible. Since Connor's diagnosis, Courtney has researched and educated herself as much as possible and wants to be there for other families. "I have met some other amazing heart parents and it's

nice to be able to have someone else in your corner that understands what you're going through," she says. It is her hope that someday research and funding for CHD will be sufficient enough for other parents to never have to hear this devastating news. Until then, she knows that there is still much hope and life for these cardiac kids. "I hope that Connor always knows that he can do anything that other kids can do, and that although he has a pretty extensive scar, that scar tells a pretty incredible story!"

For more information about the local chapter of the American Heart Association, visit www.heart.org/en/affiliates/new-york/capital-region.

HISTORY

Substitute Teacher & Substitute President

BY DENIS BRENNAN,
NISKAYUNA TOWN HISTORIAN



"Substitute President" may be bit disingenuous, but Chester A. Arthur did replace James

Garfield as President of the United States in September 1881 after Garfield's assassination. Years earlier, Arthur also substituted in a Niskayuna elementary school. He had graduated from Union College in 1848 and spent several years in the region studying law and teaching at local schools. One school where he taught as a substitute for a brief time was the one-room Rexford School at the corner of Balltown and Riverview Roads—the current site of a Stewart's shop. In 1956, the Rexford School joined with the Alplaus school to become the Glencliff Elementary School in the newly consolidated Niskayuna School District.