SHANNON DALEY
MEMORIAL FUND

The Shannon Daley Memorial Fund is proud to announce its 25th Annual Golf Tournament. The Fund was established to help local area families who are suffering financial hardship due to a child battling serious illness or has special needs. Our first recipient is 1-year-old Rowan Cucuzella of Washington who has Cerebral Palsy. Our second recipient is 6-year-old Madison Gransky of Belvidere who has Spastic Quadriplegic Cerebral Palsy. Our third recipient is 1-year-old Leanne Nagy of Holland Township who has VACTERL Association, which is a collection of congenital birth defects that commonly occur together.

The 25th Annual Shannon Daley Memorial Golf Tournament will be held Monday September 21st, 2026, at the Copper Hill Country Club in Ringoes, New Jersey. There will be a 10 am start with sign-ups beginning at 8:30 am. Breakfast will be served at 9 am. For more information on the course, go to www.copperhillcc.com.

The entry fee will be $325 per person, which will include golf, cart, breakfast, lunch, dinner, and an open bar during dinner, awards, and prizes. Individual players and foursomes are invited to play in this charity event. It will be a scramble format.

We have sponsorships ranging from co–sponsoring the event, sponsoring specific contests such as closest to the pin, and individual hole sponsorships starting at $100. Your name will be prominently displayed with whatever type of messaging you choose, and your business will be mentioned in a program given out at the event.

The breakdown is as follows:

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| Event Sponsor | $2,500 |
| Co–Sponsor of the event | $1,000 |
| Dinner Sponsor | $500 |
| Closest to the Pin Sponsor | $250 |
| Hole Sponsorships | $100 |
| Patron | $50 |

We also have a need for auction items, raffle prizes, and door prizes. Any prizes donated will be clearly marked with the name of the donor. All donations will be listed in the program as well.

If you can assist with any of the above, please notify us. We believe that this is an excellent method of advertising your business while also helping a wonderful cause. Please call Paul McGill at 908-528-2231 or email Paul.McGill@shannonfund.org.

For more information on the charity, please go to www.shannonfund.org

# Rowan Cucuzella's Story

Rowan is a 14-month-old boy who had a difficult beginning in life. The pregnancy with Rowan was normal and there were no complications. Labor, however, was very long. After over five hours of pushing, the doctor advised a vacuum attempt was the best option. Numerous failed attempts caused Rowan's heartrate to drop twice, and an emergency c-section was necessary. Rowan was born not breathing and needed to be intubated immediately. Once Rowan was stable enough to breathe on his own, the medical staff noticed that he was having apnea spells. The neonatologist advised it would be best to transfer Rowan to Saint Peter's University NICU. At just 24 hours old, Rowan left Hunterdon Medical Center for answers.


Once at Saint Peter's, the staff quickly set Rowan up with a 48-hour video monitoring EEG where they quickly determined that Rowan was suffering from seizures. An MRI showed that Rowan suffered a significant stroke affecting the left middle cerebral artery, ultimately leading to a diagnosis of hemiplegic cerebral palsy. The neurology team did not have promising words for the outlook on Rowan's life. Rowan would face difficulties with most things that a neurotypical child would not.

After 11 days in the NICU, Rowan was finally stable enough to go home. Life was much more different than first-time parents, Thomas and Dana imagined. Visits at CHOP and Boston Children's were arranged, and Rowan started therapy with Early Intervention at just 8 weeks old. On average, Rowan receives 5 hours of structured therapy weekly, as well as the ongoing therapy at home with his parents.

Rowan is followed by the stroke clinic at Boston Children's Hospital. Rowan visits his doctors every 3-4 months for developmental check-ins. Due to the size of Rowan's stroke; he is at greater risk to develop epilepsy at some point in his life.

For children with neurological disabilities, intensive therapy is highly recommended during the first few years of life while neuroplasticity is at its highest. Through repetition, the brain can create new neural pathways, shifting functions from the damaged part of the brain to an undamaged area. Rowan has participated in Dynamic Movement Intervention (DMI). Each intensive block ranges from 1-3 weeks with 2 therapy sessions per day.

Rowan is currently working on achieving many milestones that he's delayed in like getting into the sitting position on his own, crawling, pulling to stand, walking, etc. While therapy is constant and difficult, Rowan smiles through it all. The next step in Rowan's journey is stem cell therapy. Stem cells have shown amazing progress for those with neurological conditions.

Rowan has faced many challenges in his short life and will continue to do so. With continued traditional therapy and interventions such as stem cell therapy, we are setting Rowan up for the best chance of facing these challenges head on. We are very grateful to the Shannon Daley Memorial Fund for choosing Rowan as a deserving recipient. Your generosity and support mean so much to us. Thank you!

# Madison Gransky's Story

Madison Jane was born on September 1, 2019. Although it was an uncomplicated pregnancy, and she was extremely happy and healthy, Madison's fine and gross motor skills started to fall behind the expected development timeline.

At 6 months old, her pediatrician suggested we connect with Early Intervention (EI). Then Covid struck, so occupational and physical therapies were done through virtual visits. By 11 months old, Maddie was still not achieving expected age-appropriate motor benchmarks, and it was suggested to us then to ask for a referral to a neurologist and physiatrist due to these delays.

Madison was then diagnosed with Spastic Quadriplegic Cerebral Palsy at one year old. She began taking an oral medication to help mitigate her spasticity, as well as receiving Botox shots every 3 months in her legs. She got her first pair of AFOs (ankle foot orthotics) and soon received her first stander and walker (providing her first opportunity to move independently). Before she was 2, we had both a brain MRI and genetic testing done. The genetic testing revealed two mutated genes that Mom shared with Maddie, and therefore they were deemed unlikely to be the cause of her tightness, since Mom shared no similar traits. The MRI revealed no evidence of any brain injury, and only a tiny spot of atypical development. We were told that this spot was most likely what was causing her spasticity. Doctors and therapists were always impressed by how well she moved, though her body felt so tight. Maddie always amazed us with her strength, perseverance, and incredible gains.

In February 2023, after meeting with a team of doctors at a spasticity clinic and completing a trial spinal injection of medication to confirm spasticity, we made the decision to undergo a Selective Dorsal Rhizotomy (SDR). Our little 3-year-old strong one came through like a champion! She spent about a month at Children's Specialized Hospital recovering and regaining strength, and by the end of her stay, Madison was walking in her walker again! We could not have hoped for better results, and saw our girl become more comfortable and move more freely.

Unfortunately, our excitement was cut short, and Maddie's tightness had fully returned by her 6-month follow-up with the surgeon and spasticity team. As SDR is supposed to be a permanent fix for spasticity, the surgeon believed that it might be another underlying cause and sent us to a new movement disorder specialist. This neurologist thought it appeared to be spasticity, but questioned causation, and sent us for further genetic testing.

At this follow-up testing we were advised that there was new research on one of the genes previously identified, and that this, instead of the atypical spot in her brain, was what was causing all of Maddie's tightness. Findings on this gene were limited, and Maddie's neurologist still wanted us to explore other possibilities, so she connected us with another top movement disorder specialist at Boston Children's Hospital. He is conducting a study on genes that cause Hereditary Spastic Paraplegia, and in October of 2025, Maddie was deemed a good candidate and enrolled in the study.

In April 2026, we began a trial of a new medication, and for the first time since SDR, we saw some lasting reduction in the tightness in Maddie's legs. This improvement was also accompanied by episodes of weakness, where her legs would give out unexpectedly. The Boston team advised us that both the reaction to the medicine and the unexpected weakness could indicate that we are seeing underlying dystonia as opposed to spasticity. So now the team will be looking for genes causing both, and we will be returning to Boston in August for further evaluation.

It's been a 6-year whirlwind of different causational diagnoses, treatments that do not work the way they are expected to, and thousands of hours of therapy work. Through it all, our daughter has remained happy, outgoing, and has a desire to do every possible daredevil activity that she can do in life.

We are incredibly grateful for the honor of being chosen to be a recipient of the Shannon Daley Memorial Fund. Our family thanks everyone who helps to make this organization and these events possible!

# Leanne Nagy's Story

Leanne was born January 25, 2025. At birth it was discovered she had Tracheoesophageal fistula with an Esophageal Atresia (TEF-EA) Type C, which means that the upper part of her esophagus ended in a closed pouch and the lower part connected to her trachea. Literally, born unable to swallow. At 2 days old Leanne had surgery to sever the esophagus/trachea connection and reattach the two sections of esophagus. The surgery went well, and she left the NICU after 17 days. However, at 6m old when she began to eat solids, Leanne spit up everything she ate. An esophagogram showed a narrowing of her esophagus at the surgical site, allowing only fluid to pass. She had a series of 3 dilations to re-open her esophagus. By the 3rd dilation, her eating had improved but she still couldn't eat like a typical baby her age. A swallow study showed dysmotility in her lower esophagus, which affected how food moves down to her stomach. Even now, at 18m, her food still needs to be modified in order for her to eat. If it's not or if she eats too fast, it sometimes will get stuck and she'll spit it up. This may happen a few minutes after eating but at times has taken hours-to-days to dislodge.

Her TEF/EA is part of VACTERL Association, which is a collection of congenital birth defects that commonly occur together: Vertebral, Anal, Cardiac, Trachea, Esophageal, Renal and Limb. To be diagnosed as VACTERL, one needs to have a defect in at least 3 of the 7 systems. Leanne was found to have a hole in her heart, possible spinal issues, the trachea/esophagus connection and is polydactyl. These issues will affect her for life, so she has a wide team of doctors keeping an eye on her with periodic checkups. During her first year, Leanne also had flattening on the right side of her head. She wore a helmet between 3-9m and had physical therapy for a year to try to correct the issue, with minimal improvement. Finally at 13.5m she was diagnosed with craniosynostosis, a premature fusion of her right lambdoid suture (the rarest form of craniosynostosis.) At 15.5m she had Cranial Vault Remodeling Surgery, which consisted of removing the plates in the back of her head and un-fusing the suture, to prevent any intercranial pressure from forming. She is still healing but doing great

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Through all of this, she is the happiest little girl, always smiling. She loves her 4-year-old sister (who was just diagnosed with Lyme) and her 7-year-old brother. A true water baby, she LOVES the outdoors and anything to do with water and sand. And ironically, she loves to eat, which is improving as she is learning to chew better. Hopefully with age that will continue to improve. She currently has surgery scheduled for Oct 2026, another scheduled for Jan 2027, and time will tell what else she may need. But we know she'll be smiling through it all!

Thank you so much for taking the time to learn about Leanne. We feel honored to be selected by the Shannon Daley Memorial Fund and are touched that others care about our little warrior as much as we do. From the bottom of our hearts, thank you to all the volunteers, sponsors, guests and everyone in between who make this event possible!