



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. The first recipient is 1 year old Rowan Cucuzella of Washington who has Cerebral Palsy. The second recipient is 6 year old Madison Gransky of Belvidere who has Spastic Quadriplegic Cerebral Palsy. This year's other recipients have yet to be identified.

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:

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 heart rate 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!

