SHANNON DALEY
MEMORIAL FUND

The Shannon Daley Memorial Fund is proud to announce its 21st 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 recipients are 12-year old's Julian & Kieran Hydro from West Amwell who are neurodiverse twins who are impacted by multiple neurological disorders and learning disabilities. The second recipient is 15-year-old Owen Apgar from Clinton Township who has Prader Willi Syndrome. The third recipient is 5-year-old Joseph Sensor from Bethlehem Township who has Brain Cancer.

The 21st Annual Shannon Daley Memorial Golf Tournament will be held Monday September 19th, 2022, at the Copper Hill Country Club in Ringoes, New Jersey. There will be a 10 am start time 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 $275 per person, which will include golf, cart, breakfast, lunch, dinner, and 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

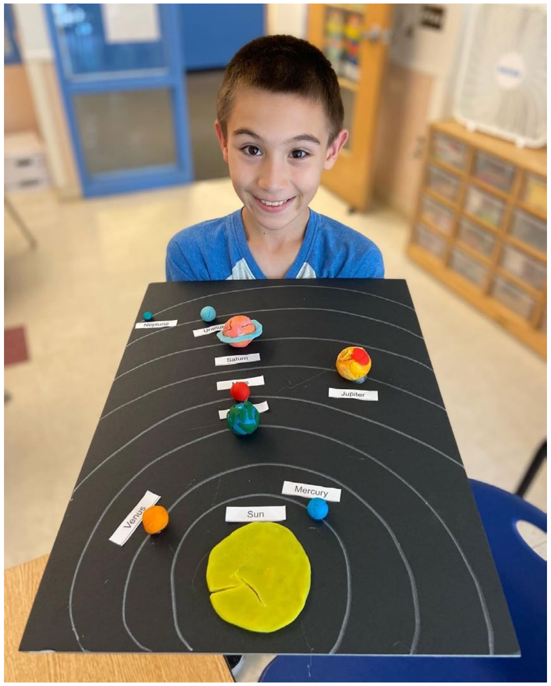
We also have a need for auction items, raffle prizes, and door prizes. Any prizes donated will be clearly marked with the name of the donor. All donations will be listed in the program as well.

If you can assist with any of the above, please notify us. We believe that this is an excellent method to advertise 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

Julian & Kieran Hydro's Story

Julian & Kieran Hydro are twin 12-year-old boys living in Hunterdon County. Over the 12 years of their lives, they have faced many obstacles and adversity. The boys are neurodiverse twins who are impacted by multiple neurological disorders and learning disabilities. The boys have made significant progress through 12 years of multiple therapies with speech therapists, occupational therapists, physical therapists, behavioral therapists, counselors, case managers, and many other supporting staff.



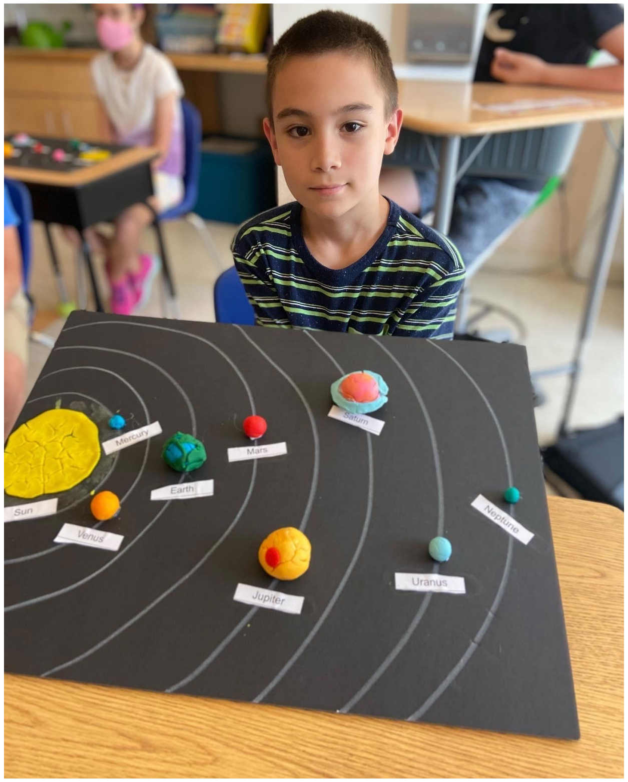
A few weeks before the twins first birthday their father also suddenly passed away leaving his two beautiful & loved boys behind. At the age of 1 Julian and Kieran were referred to early intervention due to apparent developmental delays. Then, at the age of 3 the entered the public school system as children with a disability. At this young age I was told they would never go to college.

However, the twins continue to become the children in their classroom that will work 5 times harder than typical students, just to try to come close to what is expected. The twins are diagnosed with 3 neurological conditions and are also diagnosed with 3 language based learning disabilities. These have also manifested into many mental health needs, due to not having the correct placement and supports and being misunderstood for so long.

The twins were also not receiving equal education opportunities at school. At the age of 10 we were finally able to have Julian and Kieran placed into a proper education program. The boys' needs continue to be vast, time consuming, costly, and draining but every time they meet a goal and acquire a new skills, we are so proud of them and very thankful.

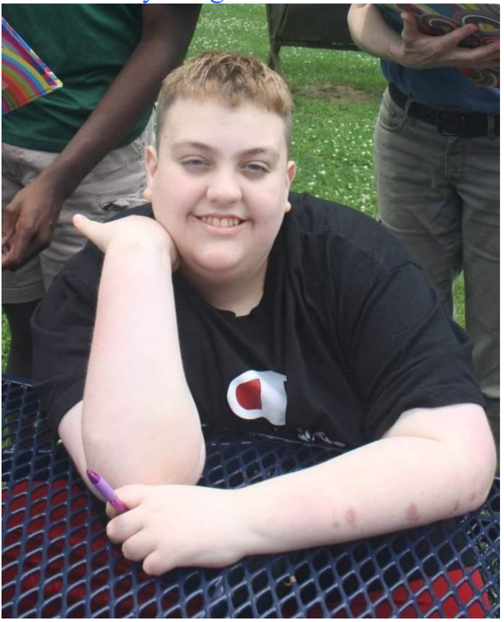
With your support we would like to be able to continue with the twins' multiple therapies, continue with weekly tutoring, give them inclusion opportunities with peers, build back their confidence, and continue to support their mental health needs. We would love to send them to a social skills camp and support their mental health through therapy with animals (which they love). We would also like to correct a dental anomaly that they were born with. The twins are also in need of a complete educational reevaluation soon and we would also like to have that done, to make sure they continue to receive the education they deserve.

Our main goal for our twins is for them to become independent and one day have the opportunity to move on to further education or a career that they enjoy and will be capable of because of all the support we have given them to be successful. We can't wait to see what they will continue to accomplish & know it will be more than we were told to expect.



Owen Apgar's Story

Owen was born Saturday December 2, 2006, via scheduled C-section at Hunterdon Medical Center. Typically, when you deliver your baby, you hear their little cries and get to see them and hold them. This was not the case with Owen. Owen did not cry, and I saw him very briefly before he was whisked away to the special care nursery. The first time I held Owen was about 8pm and only for about 5 minutes before going back to the nursery. Monday morning the Neonatologist came into my room and told me they needed to transfer Owen to St. Peter's Hospital in New Brunswick for additional testing as they were not sure what was wrong with him. At this point the only thing we knew is that Owen was having difficulty feeding and was "floppy". Within hours we were kissing Owen goodbye as he was wheeled out of the nursery.



At St.Peters, Owen was in the main NICU for about 2 days where he received numerous tests, but no real answers. On the third day Owen was sent to the step-down unit where he basically had to eat and grow as we waited for genetic testing. For the next three weeks, I did everything I could to take care of Owen in the unit. The nursing staff was amazing and helped me learn all things I needed in order to take Owen home. Christmas Eve 2006 we received the genetic results, and we were told Owen had Prader-Willi syndrome. The doctors were not able to give us a lot of information but told us we needed to make an appointment with a specialist, and we were cautioned not to go online and research as we would most likely get a worst case scenario. The good news was Owen could come home Christmas day! Best Christmas present ever!

The following weeks and months were challenging. Owen started receiving Physical and Speech therapy at 6 weeks old through early intervention and continued until he turned 3, then he went into Clinton Township Preschool program. The early years were filled with therapies to help Owen get stronger, learn to talk and improve his fine motor skills and many doctor appointments with numerous specialists, surgeries and a few hospital stays.

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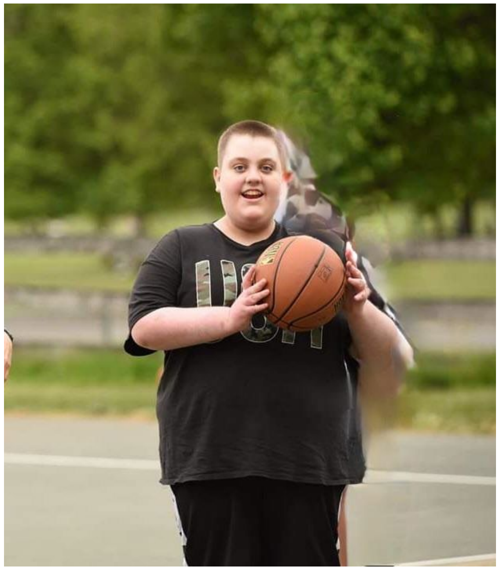
Prader Willi syndrome starts out with babies having failure to thrive but will eventually turn into your child never feeling full, food seeking/stealing, low metabolism and other medical issues. As Owen got older the food obsession got to the point where we needed to put locks on our fridge and cabinets to prevent him from overeating. Children with Prader Willi also have behavioral issues and learning disabilities. Owen's behavioral issues became severe enough that we needed to enroll him in an out of district school when he was in 6th grade. We were lucky to find The Midland School and Owen started there in December 2019.

Owen loves school, his favorite subjects are Science and Social Studies. He enjoys talking to people and I frequently tell him he has never met a stranger. Owen is very compassionate and enjoys helping others. Owen enjoys all sports and participates in Special Olympics Track and Field and is involved with the Hunterdon Outreach Program for about 10 years and has made many friends. Owen has been working with a personal trainer since April 2021 and has been successful in maintaining his weight , and at his latest Doctor's appointment lost 11 pounds. We are so proud of his hard work and look forward to his continued success.



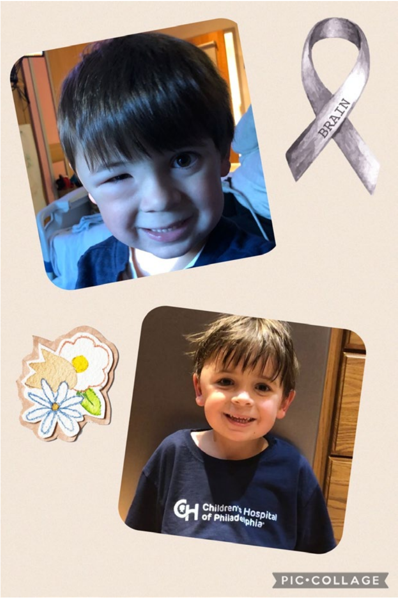
Joseph Sensor’s Story

Joseph was born prematurely at 33 weeks. His true fighting nature and sheer stubbornness had him out of the NICU in under three months. Joseph was a captivating, active and fun baby and around age 3 we noticed that something was amiss. Joseph would have periods of time when he would get a far-away look followed by a period of being very ill. After some investigation we met with the Children’s Hospital of Philadelphia (CHOP) neurology team. Several visits, further testing and an MRI revealed that Joseph was having seizures caused by a brain tumor in his right temporal lobe. We received this devastating news Mother’s Day Weekend, 2021. I used to think that the worst day a parent could have been finding out about a potentially fatal diagnosis for their child, but I was wrong. The worst days are helplessly watching your child battle something you can’t even explain to them. The summer of 2021 brought more time spent at CHOP, more testing and multiple daily seizures and a surgical date was set. One of the most difficult decisions we faced was how aggressive to be with his surgical procedure. His right temporal lobe would need to be removed, but several other areas of his brain were labeled as “concerning.” As a family, we decided that being as aggressive as possible would ultimately be the best course of action over the possibility of multiple surgeries. This meant that there was a chance Joseph would wake up from surgery without any memory of his life before surgery. Because of this, we made a Bucket List with him and were able to complete and document all of Joseph’s items (except for meeting Taylor Swift!) before his surgery.

On September 27, at 6 am, I walked my sweet, tired, and brave boy into the operating room and kissed him as he went to sleep. It took 8 hours for the neurosurgeon to remove Joseph’s right temporal lobe, amygdala, hippocampus, temporal gyrus, and a portion of his white matter. He was brought to the ICU after his surgery, and he made it immediately clear to us that despite all odds his memory was completely intact!

Joseph met the task of recovering from his surgery head on; after a week in the hospital, he was home and playing miniature golf despite the loss of part of his visual field. Joseph has been undergoing physical therapy, occupational therapy and speech therapy since his first surgery along with innumerable appointments at CHOP to monitor his progress and modify interventions. He has experienced left sided weakness as well as several other expected outcomes of surgery but none of this stopped him from going to preschool and playing T ball. Through it all, he has remained the same courageous and loving boy.

In May of 2022 Joseph experienced his first postoperative seizure. This was extremely unexpected even though we were monitoring a cyst and several other findings via monthly MRI. So again, on June 1, 2022, we took another walk into the operating room at CHOP for Joseph’s second surgery. While not as extensive as his first procedure, this was a very intricate procedure. We waited again and after 3 hours the neurosurgeon reported that he had some unexpected findings. A layer covering Joseph’s brain had to be replaced as well as a new route for the fluid around his brain needed to be made. The scarring from his first surgery presented several challenges for the surgeon during this second surgery.



After only 3 days in the hospital, Joseph was home and recovering with his family around him. He is still encountering challenges, but his true fighting nature has him conquering each challenge. We are still monitoring him closely with MRIs and frequent visits to the neurologist and oncologist. Joseph’s sweet spirit and soulful eyes have sustained our hearts on this journey. We know there are still mountains to climb with him, but we also know he will be singing Taylor Swift songs the whole way!