SHANNON DALEY
MEMORIAL FUND

The Shannon Daley Memorial Fund is proud to announce its 19th 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 recipients are 11-year-old Naomi and 8-year-old Shelby VanNorman from Holland Township who have Congenital Glaucoma and Bethlem/Ullrichs Myopa, respectively. The second recipient is 1-year old Finnegan Loughran from Bridgewater who suffers from Tay Sachs Disease.

The 19th Annual Shannon Daley Memorial Golf Tournament will be held Monday September 28th, 2020 at the Royce Brook Golf Club in Hillsborough, New Jersey. There will be a 9:30 am start time with sign ups beginning at 8 am. Breakfast will be served at 8 am. For more information on the course, go to www.roycebrook.com.

The entry fee will be $250 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

Naomi & Shelby VanNormans' Story

Naomi was born July 14, 2009 to our already little family of three. We had some issues with decreased fetal movement during the pregnancy, but otherwise she came out a big eyed, smiley little elf. We were doing so well post c-section they talked about an early discharge, until the neonatal pediatrician came to talk to us, they believed she had bilateral hip dysplasia and would need leg bracing. Two weeks later she had an ultrasound that she passed with flying colors. We did not know that the first two signs of her disease just went over all our heads.

Shelby completed our family on December 8, 2011, big, beautiful and seemingly healthy. However, when she was a month old, the pediatrician kept going back to her eyes during a visit for what we thought was ear infection. I was born with congenital glaucoma in one eye and consequently lost my vision in that eye due to lens detachment but had been told that it was very rare and that I would not pass it on to my children. We were sent to a specialist at Wills Eye Hospital in Philadelphia, who confirmed our worst fears. He scheduled Shelby for surgery the following week to help relieve the pressure in the affected eye. When he came to talk to us after surgery, he had some bad news. The disease was not in one eye like he thought, it was in both. The Dr. then told us that I should seriously consider leaving my job as a Cardiac Technician. He said that it was going to be a rough time getting Shelby's eye pressures under control and to stay stable, and that he and I were going to become best friends. I never went back after my maternity leave. And he was right, there were times I was in Philadelphia multiple times a week for visits and Evaluations Under Anesthesia (or EUA's). When she was 6 months old, we got more devastating news, that her lenses detached just like mine. Terrified, the Dr. sent both of us for testing for another rare genetic disorder, which not only causes lens detachment, but also sudden death due to heart issues. Thank goodness we were cleared for that, but the Dr began his search for our rare condition. It was not until recently that he finally diagnosed us with a disease that does not even have a name yet, it's called LTBP2. Big eyes and congenital glaucoma, followed by lens detachment are the features. Shelby is closely monitored by three eye Dr's every 3 months to ensure that her pressures remain controlled and that her optic nerves and retinas are healthy and intact. On top of being visually impaired, Shelby has cognitive delays, ADHD and will be undergoing testing for Autism but she could not be a sweeter more loving girl. We always say she is the "Mayor of Shelbyville" and greets everyone she meets with a big Shelby-bear hug.

Things with Shelby had calmed down for the time being, so in July of 2013 I signed Naomi up for ballet. During her recital, we all realized there was something wrong. We had been asking her pediatrician since she started walking about her constant falling and he always told us it was normal for a toddler and that she was just clumsy. Naomi, now 4, was now not only falling all the time, she could not get up off the floor, stairs were hard for her, and she could not hop or skip. We were sent to CHOP to see a Neuromuscular Specialist, a year later, after countless appointments, tests, false leads, a muscle biopsy and finally a full DNA panel she was diagnosed with Bethlem/Ullrichs Myopathy, a rare form of Muscular Dystrophy. It is a progressive disease, and each year we see her strength wane and her abilities become fewer and fewer. Naomi needs a wheelchair to walk longer than a few minutes, stairs are impossible, and she needs help with all the little daily tasks we all take for granted. She wears day and night leg braces, uses a chair lift to access the stairs and has a hospital bed to elevate her at night. Her type of MD affects the lungs, so we have to be vigilant for sleep apnea and anytime she's ill it's all hands on deck with round the clock nebulizer and cough assist treatments that clear her lungs of fluid to keep her out of the hospital. Thank goodness I am able to be Naomi's full-time caretaker. Naomi does not let this get her down though. She has lived up to the nickname "Elf", as she is mischievous and, as one Dr. put it, precocious! She is also very sweet and kindhearted, and no home is dull with her in it.

I recently read a beautiful article comparing special needs parenting to an unexpected trip to Holland instead of Italy and I couldn't have agreed more. We didn't plan on going on this special needs path, with having seen over two dozen specialists in three different states between them, but we've seen and learned things we wouldn't have without our "detour". We love our two tour guides more than life itself. We want to give our most heartfelt thanks the Shannon Daley Memorial Fund for their kindness and dedication to special needs families like ours.

Finnegan Loughran's Story

The day the nurse called she asked simply, "Should I tell you now or do you want to pick them up and wait for your husband to come home?" The unmarked envelope sat on the table for the remainder of the day beckoning to be opened. When Michael got home from work, the Loughrans nervously opened it to discover that all the test results were "uneventful".

Uneventful was very good news. The baby did not have a genetic disorder screened by the non-invasive test. So, the Loughran's could take a breath.

Sex: Male

THAT WAS GREAT NEWS! Finnegan's name was chosen years ago when they were pregnant with their first of three daughters. The Loughran's celebrated! Their dream of having a son had come true.

"Finny" Loughran was welcomed into the world by his enthusiastic big sisters, his parents, and his extended family. The joy was so epic that it all but healed a family deeply wounded by the tragedy of losing their first-born daughter Sylvia due to undiagnosed causes when she was 14 months old.

For six months Michael and Jennifer and their daughters Eilish and Serafina were gloriously happy. Finny was not only adorable, but he had soft and tender nature that was drew people in. He had a fan club everywhere he went. Finny was so content to be held, snuggled and cradled that arms reached out begging to hold him. He loved the affection. So did his fans.

In December 2019, Finny was rushed to the hospital in respiratory distress where he tested positive Coronavirus Hku1 (not Covid-19). He was sent home the same day but was sick for weeks. During those weeks he had clearly declined and showed significant signs of low tone.

Low tone was one of the symptoms that his sister Sylvia also had before she passed. Over the next few months, there were many appointments and tests. It was an eye exam and the discovery of "Cherry Red Spots" that indicated he had one of a variety of degenerative lipid storage diseases. The next day a panel of tests were taken by the genetics department and on March 13th, 2020 the Loughran's received the diagnosis of Tay-Sachs disease.

The diagnosis came a week before the New Jersey statewide shutdown causing the shutdown of all developmental services, non-essential medical care, as well as the childcare and education for all the children. Finny lost the open arms of physical contact with friends and family and the Loughran family were plunged into isolation during one of the most devasting times of their lives. Despite the tremendous impediment of the lock down, the local community has shown up for the family in ways that are breathtakingly kind, even if at a distance, and for that the Loughran's are beyond grateful.

Infantile Tay-Sachs disorder is a genetic disease that was at one point believed to primarily affect people of Jewish descent, but the volume of cases among those of Irish descent has been documented over the years has found that 1 in 50 people of Irish decent are carriers.
Tay-Sachs is caused by the absence of an enzyme that helps break down fatty substances called gangliosides which are typically flushed away in healthy developing brains. The buildup causes toxic levels in the child's brain that affect the development and function of nerve cells.

Babies born with Tay-Sachs disease appear normal at birth, and symptoms of the disease do not appear until the infants are about four to six months of age when they begin to lose previously attained skills, such as sitting up or rolling over. Children then gradually lose their sight, hearing and swallowing abilities, and usually die by the age of five.