SHANNON DALEY
MEMORIAL FUND

The Shannon Daley Memorial Fund is proud to announce its 22nd 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 5-year-old Konrad Skwirz from Readington who has a rare genetic disorder PIGN-CDG. Our second recipient is 9-year-old Aerilyn Colon from Stewartsville who has a rare genetic condition Trisomy 13.

The 22nd Annual Shannon Daley Memorial Golf Tournament will be held Monday September 18th, 2023, 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 $300 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

Konrad Skwirz's Story

Hi, my name is Konrad Skwirz, I'm a 5-year-old boy. I have an older brother Dominick 12 and a sister Angelica 8. I was born in August 2018 as a healthy boy, however when I was only a few months old my parents noticed that I wasn't holding my head up and turning around. When I was 5 months old, I was at my first Neurologist visit where I had my first confirmed set of seizures. That day I was admitted to the hospital and had multiple tests done. After 4 long months of waiting for genetic results, I was diagnosed with an extremely rare genetic disorder known as PIGN-CDG, a type of inherited metabolic disease called Congenital Disorders of Glycosylation (CDG). This disease is also known as MCAHS1, Multiple Congenital Anomalies, Hypotonia, and Seizures Syndrome Type 1. As of 2022, globally there are fewer than 110 known children affected with this disease. As genetic testing is becoming increasingly widespread, more and more cases are being identified each year. Unfortunately, there is not a lot of research about this disease that would provide any interventions or protocols to improve or enhance the daily lives of children with this disease. The population of children affected with this disease experience neurological and developmental delays, severe muscle tone disorders, and seizures.

Ever since then, I went through multiple testing, hospital visits, and doctor's appointments to get help to control these ongoing seizures, overcome my hypotonia, and to help me meet milestones that I'm very behind at. Currently, I'm a very popular kid with a big smile that all my nurses and doctors love at multiple hospitals and doctors' offices in NJ and PA. I have been battling these seizures almost every day. These seizure episodes drastically overwhelm my physical strength. As a result, I have difficulty functioning and carrying on my daily activities. Although I'm nonverbal, I can express my needs and emotions physically with facial expressions such as being hungry or not feeling well. When I'm hungry – you are in trouble. To alleviate these symptoms, almost every day I have physical, occupational, and speech therapies at school. My family has meticulously and routinely been helping me with my daily activities as well. Currently, I'm working on developing my neck and trunk strength which is very hard work for me (30 minutes at a time).

During the long pandemic time I had very little help and my parents had to learn how to become therapists and specialized caregivers to overcome difficult times. Finally, when everything got better, I went to school. Like many kids, I enjoy my bus ride to school. I go to a very special school in Edison NJ. The school I attend is called Lakeview School New Jersey Institute For Disabilities. Every day I set milestones for myself to overcome the obstacles I'm facing through this disease. Despite these obstacles, I'm always optimistic, happy, and so kind. My smile is so contagious that it lights up any room. I want to gain the strength to overcome the barriers of this disease.

Aerilyn Colon's Story

Hi, Meet Little Miss Aerilyn! She is 9yr old, hair bow loving Diva, living with a very rare genetic condition called Trisomy 13 also known as Patau syndrome. Trisomy 13 is a genetic disorder in which a person has an extra 13th chromosome. This rare genotype anomaly causes severe birth defects and global developmental delays. Only 10% of the children diagnosed with Trisomy 13 make it to birth -while 2% live through the first year of life before succumbing to the severity of illness. Because each chromosome contains hundreds of genes, the "addition' (Aerilyn's extra 13th chromosome) -or- "Loss" of even a single chromosome disrupts the existing equilibrium in her cells -therefore this genetic disorder was labeled "Not Compatible with Life." "Imagine receiving that type of diagnosis during a 28- week ultrasound of your child in utero?" As her parents we were absolutely crushed under the weight of this devastating news. The medical literature painted a very daunting and dismal outcome for our daughter Aerilyn. Against the advice of many physicians, we decided to push through and fight for our child Aerilyn.

Despite the overwhelming challenges and uncertainty presented by this life changing diagnosis, the only option we had was to anchor ourselves in our faith and our love for God. "And that is the honest truth!" -God and Aerilyn had the blueprints "for her life's purpose" and this glorious medical journey ready-to-go as soon as she landed on soil. Like a force of nature! Aerilyn tackled through some heavy hitting challenges involving countless procedures, severe illness, and life-threatening medical issues. Even physical limitations have not stopped Aerilyn from achieving major life goals (didn't think it could be possible). Like "Walking" with a robotic gate training system and "Riding a tricycle" just to name a few. Aerilyn is an absolute joy and a hilarious character! With her Iconic resting "facial expressions" of disapproval. She has inspired so many people around the world who follow her journey to believe all things are possible! Even the collection of 200 hair bows! March 29th, 2024, Aerilyn will be celebrating her GREATEST milestone, "Aerilyn's 10th Birthday!!"

The Shannon Daley Memorial Fund has been an absolute blessing in our life! With the help and support of their fundraising event, our dream to build an accessible bathroom for Aerilyn is coming TRUE! THANK YOU, SHANNON DALEY MEMORIAL FUND we are incredibly excited, to be a recipient of your kindness & wonderful cause.