SHANNON DALEY MEMORIAL FUND

P.O. Box 1271
Whitehouse Station, NJ 08889

The Shannon Daley Memorial Fund is proud to announce its 19th Annual Charity Basketball Event. The Readington Teachers and Readington Men's All-Star Team will once again take on the world-renowned Harlem Wizards.

The Harlem Wizards are one of the greatest basketball show-team organizations to ever "lace it up and let 'em fly." The Harlem Wizards' performance offers a rare combination of individual athleticism, teamwork, and entertainment to delight fans of all ages.

The Shannon Daley Memorial Fund mission is to assist local families facing financial hardship due to a child battling a serious illness. The first recipients are 17-year-old Katie & 15-year-old Liz Moronski from Morristown who both have an allergic mast cell disorder. Our second recipient is 9-year-old Avery Moskowitz of Monroe Township who had Stage 4 neuroblastoma. Our third recipient is 8-month-old Parker Biehl of High Bridge who Pierre Robin Sequence (PRS). The fourth recipient is 7-year-old Tyler Nye of Bridgewater Landau-Kleffner Syndrome (LKS).

The event will be held Tuesday March 10th, 2020 at Hunterdon Central Regional High School Fieldhouse in Flemington, New Jersey. Game time is 7:00 PM. Hunterdon Central Regional High School is located on Route 31 in Flemington. For further directions call (908) 782-5727.

We also have business opportunities for advertisers. More than a thousand spectators attend, and we are anticipating another sellout. Ad rates are as follows: Full-Page $1,000, Half-Page $500, Quarter-Page $250. All donations of $50 or more will be noted in the Program.

Advance tickets for the game are $10 for adults and $5 for children under 12. All tickets are $10 at the door. Donations can also be made directly to the above address at any time.

For ticket information please call (908) 229 - 5460 or go to www.shannonfund.org. If you would like to advertise in the program, please call (908) 528 - 2231 or email Paul.McGill@shannonfund.org . Tickets also are available at:

Darrow's Sporting Edge	(908) 534 - 2838
Sneakers Plus	(908) 788 - 2921
Mr. Clymer	(908) 283 - 6738

Katie & Liz Moronskis' Story

Katie was born on September 28, 2002. Upon her birth, she was promptly whisked away to the neo-natal intensive care unit (NICU). Although mom and Katie were discharged from the hospital, this was the beginning of our special needs journey. Katie has endured severe food allergies, neurological, immune problems and developmental delays that led to multiple doctor visits at first. These challenges led to specialists, speech, physical and occupational therapy appointments, and early intervention services. Multiple food allergies meant we could not eat outside the home, as everything had to be cooked from scratch. The risk of anaphylaxis was ever present if cross-contamination or mistakes were made. There were frequent emergency room (ER) visits for asthma flares and sometimes IV antibiotics. In July 2005, Katie was diagnosed with autism.

Liz was born on May 7, 2004. She also had severe food allergies and immune challenges. In March 2006, Liz was unable to eat and digest food resulting in a 27-day hospital stay where she lost 17 pounds and became unable to walk. Liz was diagnosed with eosinophilic gastroenteritis, duodenitis and esophagitis. The local hospital advised that this was an expensive, long-term problem and that they lacked the expertise to handle such a severe case. They suggested Mount Sinai Hospital (Mt. Sinai) in New York City or Cincinnati Children's Hospital (CCH). Since we had local medical and educational services for Katie, we chose to treat Liz at Mt. Sinai.

All foods were removed from Liz's diet. She drank prescription elemental formula for months. As Liz started to grow again, her ability to drink enough calories became impossible. She required a feeding tube during the night via pump, which we refilled every few hours. Reintroducing of foods in 2007 required an endoscopy after adding six additional foods to keep the eosinophilic disease at bay. Liz was traumatized and became selectively mute, only speaking to family members and not anyone outside the household, especially doctors in white coats. We were referred to a doctor who specialized in medically complicated cases and selective mutism treatment. With treatment, Liz began speaking again and was mainstreamed in kindergarten.

Liz had a flare up of her eosinophilic disease which stumped Mount Sinai Hospital in 2011. They referred us to CCH, which we visited three times for treatment. CCH suggested that Katie might have eosinophilic disease and that they also treat Katie's food allergies. However, they were soon stumped and referred our family to the National Institutes of Health (NIH) Allergy and Infectious Disease division for further review in 2012.

The NIH was intrigued and offered to help. We spent a week at the NIH from 8am to 5pm daily being evaluated by specialists from dental to genetics. The NIH advised that both girls have an allergic mast-cell disorder that is a single disease with multiple manifestations, including chronic skin flushing, itching, eczema and hives, bee sting allergies, skeletal abnormalities, and GI disturbances including heartburn, as well as numerous food and drug reactions.

As adolescence kicked in, Katie became increasingly unstable. She was hospitalized for two weeks in 2014. Finally, in 2016, she had a 30-day inpatient stay at a specialized hospital unit for developmental delays and psychiatric disorders. Multiple physicians from Columbia to Albert Einstein were consulted. Katie was diagnosed with bipolar disorder, which will require lifetime treatment and frequent monitoring, on top of the autism and other medical problems already at play. Multiple hospitals, medical specialists and our local physicians coordinate to maintain continuity of care. Every day Katie requires multiple medications and monitoring.

The best advice we received in 2005 was to continue to be a part of the community and to participate as much as possible without isolating ourselves at home. Our family and our professionals have worked diligently to keep our children safe, happy, healthy, and growing, but the girls' challenges have affected everyone involved. We are grateful for help of the Shannon Daley Memorial Fund.

Avery Moskowitz's Story

Avery was diagnosed with cancer on August 8, 2013. She was three years of age. Avery enjoyed going to the library, Gymboree, crafts, playing with friends etc. Avery was taken to her pediatrician because for the prior month she was not feeling well. I finally asked the doctor to do some blood work on her. He sent us for an ultrasound. Then they asked us to return to his office, and he informed us that Avery had cancer, and to take her to the hospital right away.

The doctors told us they believe it was Wilms tumor. So, we were told that she would be losing a kidney and that hopefully they can remove all the cancer. Avery was prepped for surgery, and an hour and a half later into a five-hour procedure the surgeon came out of the operating room to inform us that after opening Avery up, they realize that Avery did not have Wilms tumor. Avery had stage 4 neuroblastoma. They closed her up, and immediately started chemotherapy. At this time the only inserted a double lumen Broviac into her chest. Over the next five months Avery endured many hospital stays, fever, sour belly, shots, allergic reactions, blood draws, blood and platelets transfusions, Broviac dressing changes, daily cleanings /flushes of her port, medications and five rounds of chemotherapy.

One of the hospitals we were at, gave us a diagnosis that Avery was a NED which means no evidence of disease. This meant my daughter was in full remission. We were so happy it was the first time I was able to breathe a sigh of relief. And I thought after five rounds of chemotherapy we had a true miracle. Unfortunately, that only lasted three days. This is when my world started crumbling once again. My oncologist called me with such sorrow in her voice I knew something was not right. We got our second results from a different hospital back. A secondary hospital the Children's Hospital of Philadelphia, known as chop, called us to inform us that Avery was not NED. She had full body cancer in her skull, entire spine, shoulder blades, upper arms, full pelvis, thighs, and in her bone marrow.

The long-term side effects thus far from her cancer treatments are organ damage, infertility, stunted growth, spinal wedging, cataracts in both eyes, breakdown of her teeth (chemotherapy eats right through the enamel leaving your teeth gray and black), permanent hearing loss. As I mentioned before her teeth wound up with an eminence amount of work. She had 7 root canals, 8 stainless steel caps, 4 white caps, 12 cavities and 1 removal. She has tiny tattoos all over her body, that a permanent from where they had to do the laser proton radiation therapy. Avery must now wear hearing aids in both ears that she gripes wearing every day. She has permanent kidney damage. One shrunk to 25% and the other one is 85%. They believe that to smaller one will continue to shrink and will result in removal in the future.

We also donated her to tumor to science. Thankfully, we did this, because in their research they found out that she had the colon cancer gene. Her body mutated itself before she was born. Neither my husband or I have this gene thank God. So, at age 12 to 13 we will be going for preventative treatment of care for colon cancer. There are 10 types of colon cancer. Ten is the worst, she has number nine. Avery will have several thousand polyps that will have to be removed over a lifetime. We will yet again overcome!!! Avery is an amazing little fighter.

Despite all she has gone through, Avery is an amazing loving and giving child. If she saw, or heard another child upset or crying, she would say, "mommy can we please give them one of my toys or stickers to make them happier." The funny thing is she gave all her brand-new toys that she just got a way to make them happier. She was known on the floors as the sticker and toy girl because she always gives out stickers to everybody every day and toys.

My daughter, Avery is a gift from God, to us, and everyone she meets. She always brings a smile to the face of anyone who meets her. She has taught me so much. How to persevere, live in the moment, and love on a deeper level. Fortunately, through an unfortunate circumstance, this experience with my daughter has renewed my faith in humanity. There are so many selfless people out there in this world, that love to just give, and not ask anything in return.

Parker Biehl's Story

Parker was born June 12, 2019, weighing just 3 pounds 13 ounces at Hunterdon Medical Center. He had to be under close watch due to complications during pregnancy and giving birth. Once he was born the complications changed from just being premature and possible sugar issues to learning he had a cleft palate. After 5 days in the NICU at Hunterdon Parker was transported to Saint Peter's to meet their craniofacial team for discussion of what his cleft palate meant and to learn how we would be able to feed him.

During his stay at Saint Peter's, Doctors came to the conclusion that Parker had Pierre Robin Sequence (PRS), in which the infant has a smaller than normal lower jaw (micrognathia), a tongue that is placed further back than normal (glossoptosis), and an opening in the roof of the mouth (cleft palate). This combination of features can lead to difficulty breathing and problems with eating early in life. After Parker's tongue tie was cut to help with feeding his desaturation of oxygen episodes had gotten worse to which he had to stay on his belly or side with CPAP 24/7. Parker had become a candidate for a Mandibular Jaw Distraction (JD) surgery, which would move his small jaw forward and open his airways to improve his breathing. Saint Peter's could not get their teams to do the surgery which led to the need to be transferred to the third hospital after 10 days in their NICU.

June 28th, Parker was transported to Children's Hospital of Philadelphia, CHOP. It was at CHOP that a sleep study was performed, and we learned just how bad Parker's breathing and desaturation of oxygen was. We learned he was desaturating 90 times an hour and that the JD surgery was needed as soon as Parker could put on enough weight and until then had to be on high pressure CPAP 24/7 and was extremely positional. Since he was on CPAP, he was not allowed to work with a feeding therapist and had to be fed by nasogastric tube (NG tube). After the JD surgery was complete it took a few weeks for his jaw to be moved forward enough that he could breathe on his own. At that point we then worked on trying to get him to take a specialty bottle for cleft palates and to start weaning him from his pain medication from his surgery. After 81 days in 3 different hospitals Parker finally was able to come home with CPAP for when sleeping, a pulse oxygen machine, and feeding bags for his NG tube as he didn't quite master the bottle yet.

Since coming home though things haven't slowed down Parker still had to follow up with many specialist for both his PRS issues and other premature minor development issues including a Pulmonologist, Craniofacial Plastic Surgeon, Urologist, ENT, Audiologist, Ophthalmologist, Gastrologist, Genetics, a feeding therapist and a nutritionist. Parker was diagnosed with torticollis and plagiocephaly since being home which has him working with a physical therapist once a week, has him in early childhood intervention due to being delayed from his time in the hospital and now is causing him to need a helmet. He started getting severe reflux shortly after we got home which caused him to get an aversion to nipples and prevented him from learning how to use a bottle so we are still working with a feeding therapist to try to get him to eat orally. He's also had to go back into the hospital for his second surgery to have the metal hardware from his JD removed and still has more surgeries to come like his palate repair and ear tubes in June.

This has caused mom to have to quit her job and be Parker's full-time caregiver with all his appointments, therapies, and medical needs on a daily basis. Through all these constant appointments and medical battles Parker is still one of the happiest babies you will ever meet. Nothing seems to stop him, and he is such a strong fighter, he's his family's hero. No matter what, he always has a smile on his face.

Tyler Nye's Story

Tyler was born on June 22, 2012, a 30-week preemie. He and his twin sister were taken to save his life. Tyler weighed 880 grams at birth. He was as small as a barbie. Tyler was born with polydactyly, pectus carinatum, and suffered an IVH grade 1 at 9 days old. Even though he was born early and started with delays in grasping things and so on. Once he had surgery to remove his extra webbed digit, he was able to meet every single milestone and blossomed into a healthy neuro-typical child.

At 2 years old in 2014 Tyler suffered a grand-mal seizure. He was rushed to the hospital where we were told that it was not a seizure and he passed his neuro-focal exam. We followed up as we were told and did many tests where it was ruled that he was completely fine and had no long-lasting effects of being a preemie. Years later it would become known to us that this seizure was the beginning of what we never saw coming.

In August 2017 Tyler developed a relatively mild stutter. Within a few weeks that stutter became a greater concern and while at his 5-year checkup before Labor Day we decided it was best that we get a speech evaluation done. On Labor Day evening we put a Neuro-typical 5-year-old to bed and the following morning we woke up to a 1.5-year-old baby. He lost his ability to communicate and lost cognitive and overall functioning. I rushed to the hospital where it was found that Tyler had CSWS, Continuous spikes and waves during sleep is a rare epileptic encephalopathy of childhood characterized by seizures, an electroencephalographic (EEG) pattern of electrical status epilepticus in sleep (ESES) and neurocognitive regression in at least 2 domains of development. At first the doctors at the ER did not believe that he only had a stutter the previous day. They truly believed that he was like this for his whole life. He started seizure medication and went home after three days. We would begin the task of many tests being done to see how severe the regression was. The regression would continue but not at the rapid pace it was. The medication helped give him some speech back. For the next year we continued with tests, doctors and more hospital visits to determine how undiagnosed epilepsy can do this to someone. I automatically thought back to 2014 when I rushed him to the hospital for having had a seizure and they thought I was wrong.

In 2018 Tyler was diagnosed with Landau-Kleffner Syndrome. Landau Kleffner syndrome (LKS) is a rare childhood disorder characterized by the loss of language comprehension (auditory verbal agnosia) and verbal expression (aphasia) in association with severely abnormal electroencephalographic (EEG) findings during sleep and clinical seizures in most patients. Tyler would go into the hospital every 4 to 6 weeks for the next year for IV-SoluMedrol to attempt to slow down the regression and stall it. His EEG's were becoming worse but his cognitive functioning was improving, We were able to see one of two doctors in the country who studies LKS in Boston in the fall to help us determine what to do from here as the solumedrol did help but it maxed out Tyler's progress. Tyler could not count to 5 in October 2017 and now he can count to 15 again, something he could not do since around the time he turned 5. We will return to Boston in April to go over the genetic testing done to see what genes may be more prominent for his rare epilepsy. Every year he has his neuro-psychological exams done to see how he is doing.

Tyler has defied all the odds against him since the day he was born and will continue forever. We will never stop believing! God gives special needs children to special parents for a reason. While it has not been easy, we will continue to strive for the best in him, his healthcare and his education. We have two special needs boys and one very neuro-typical daughter. God has graced us with so many blessings and we are very thankful to have our children with us every day. "Remember not all disabilities come with an outward appearance, remember a disability does not define the person and above all be kind and courteous for tomorrow is never promised"