SHANNON DALEY
MEMORIAL FUND

The Shannon Daley Memorial Fund is proud to announce its 22nd 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. Our first recipient is 1-year old Oliver Powell from Mansfield Township who has Hypoplastic left heart syndrome and Cerebral Palsy. Our second recipients are 14-year-old and 12-year-old Lucas and Lara Marini from Long Valley who both have been diagnosed with Cockayne Syndrome. Our third recipient is 2-year-old Sherwood Bigelow from High Bridge who was diagnosed with Stage 5 Neuroblastoma. Our fourth recipient is 3 year old Tanner Ruggiero from Califon who has been diagnosed with Autism and Global Delays.

The event will be held Tuesday March 7th, 2023, 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 will 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.

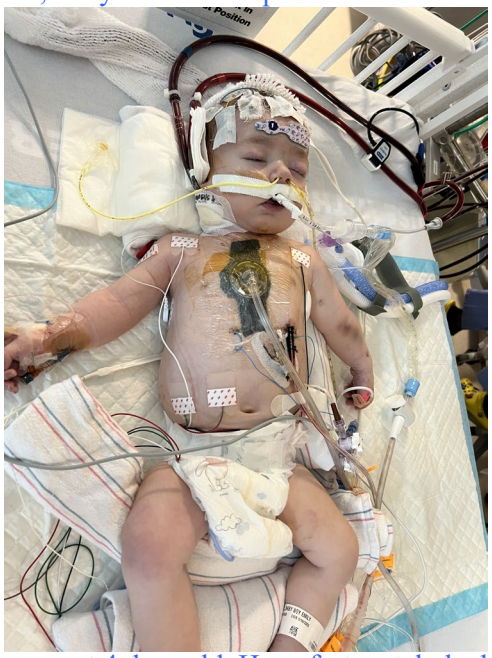
Advance tickets for the game are $10 for adults and $5 for children under 12. All tickets are $10 at the door. Donations can also be made directly to the above address at any time.

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

Oliver Powell's Story

Oliver "Ollie" Powell was born on January 18, 2022, at the Children's Hospital of Philadelphia. Ollie and his mom were closely monitored out of state for most of her pregnancy after he was diagnosed at 13 weeks in utero with a rare congenital heart defect, known as Hypoplastic left heart syndrome or "HLHS". HLHS is a serious and fatal disease in which blood flow is affected in the heart and in Oliver's case, there was no useable left ventricle as it never developed. Essentially, he would be born with "half a heart". Emily and Danny, Oliver's parents, researched hospitals all over the country to find the best care for their son. They were told three options, abort, carry to term and provide comfort care or find him a top cardiac surgeon in the country to perform immediate surgery upon birth. HLHS requires a series of at least three open heart surgeries, one at birth "the Norwood", the second around 4-6 months of age, "The Glenn" and the next "The Fontan" closer to 3 years old. There is still no cure today for HLHS and immediate surgical intervention is required for survival.



Oliver's parents and sister as well as Emily's mom relocated to Philadelphia the day after Christmas 2021. Oliver was born a few weeks later and had his first open heart surgery at 4 days old. He unfortunately had many setbacks in the next few weeks, one which included a major infection in his sternum that caused them to need to reopen his chest and redo the closure. He also had a paralyzed vocal cord from the surgery and could no longer nurse or drink from the bottle like he could at birth. Oliver had another defect, being that his heart is on the wrong side of his chest (the right side) this defect is called dextrocardia. His heart was also rotated in, making the surgeries a lot more complex even for the top cardiac surgeon at CHOP. That surgeon told his parents that the probability of a child with HLHS and dextrocardia was 1 in 100 million.

If the path had been linear for Oliver, he would have been home hopefully in a month in a half, but the next 4 months Oliver proved to be very unstable and would require hospitalization and monitoring during the "interstage period" before the next open-heart surgery. He spent more than three months on a ventilator. He met his sister for the first time at 3 months of age due to covid restrictions. He did not get to go outside (with nurses) until he was 4 months of age. The next surgery was his ticket home as many doctors had painted a rosy picture of a normal life with a stable child. After his next surgery, lightning struck. Oliver had a completely unexpected and sudden cardiac arrest. During this time, he received 35 minutes of CPR and was surgically placed on ECMO life support. ECMO is a blood circulation technology that oxygenates your blood and preserves your organs, most importantly, your brain. During this time, you are fully paralyzed, and a ventilator is breathing for you. Oliver was given less than a 10% chance of survival. Not only that, but his parents were told based on the portable MRI, he had suffered a profound brain injury and "may never be able to take care of himself". His right side of the brain was completely dead. Those next 50 days, Oliver beat all the odds. He was finally able to come home in July of 2022.

Ollie was recently diagnosed with cerebral palsy. He just turned a year old! He's not yet rolling or sitting up but he's getting there! His right eye has nerve damage and he's lost some vision. He's currently on a feeding tube but starting to eat some purees by mouth. As the family could never find nursing care due to the shortage, Emily had to leave her job to care for her son. Oliver is an incredibly loved and happy kid and never starts or ends the day without a heart melting smile. He's touched so many lives around him and given his parents an entire new perspective and appreciation on life. The family is in such awe of the support and kindness they have received through this time from friends, family, and complete strangers. It truly takes a village.

Lucas & Lara Marini's Story

When you have children, you open the door to a new chapter of your life. With each birth comes excitement, hope, dreams, and more and more love. But when your child/ren begin to have delays, these focuses start to shift, and you begin to take on new wishes with sprinkles of worry. When Lucas was born, we knew that there may be some concerns ahead because of a traumatic birth. However, he was a social baby, engaging and happy. But he struggled with meeting his developmental milestones. 26 months later, Lara arrived. Our hearts grew larger, our dreams expanded. But she also started to show some developmental delays and the search began. After 2.5 years of searching with attending countless doctor appointments and performing numerous tests, on January 22, 2015, both Lucas and Lara were diagnosed with Cockayne Syndrome, an extremely rare genetic progressive terminal disease. Our worlds were rocked, why us, why our children?

But after we digested the disease and the dust settled, we chose to look for the positives. Always looking for things they could do, instead of the countless things they needed help with or couldn't do. Taking cognitive impairments, extreme sun sensitivities, speech delays, mobility challenges, hearing aids/cochlear implants, gastrostomy tubes all in stride to help them develop and grow to be the best that they could be. It's been 8 years since our diagnosis and the children have grown and changed since that day back in 2015, but the one thing remains- They give the best hugs, they know how to thaw the coldest heart, they see no boundaries in themselves, or others and they are full of pure love. They always work hard and are relentless with their perseverance.

We have taken this diagnosis of Cockayne Syndrome and embraced it. We can't change it, no matter how much we would like, so we take it in stride. Our family has grown one more with the addition of their brother Leyton, who completes our family.

We have taken this diagnosis to help spread awareness for both Cockayne Syndrome, and also for abilities of people with unique needs. We created a public Facebook page called Marini Bucket List, to highlight all the things that the children can do and experience. So that one day we will look back and know that we lived a full life, not one of fear and sadness but rather one of hope and adventure.

We are humbled to have been selected by the Shannon Daley Memorial Fund and are excited to continue to let our light shine during such an amazing event.

Sherwood Bigelow's Story

Hi, my name is Sherwood. I was 10 months old when I was diagnosed with Stage 5 Neuroblastoma. The doctors say that I was a high risk. I went through 6 sessions of Chemotherapy to reduce my tumor from being big to being small so that the doctor would be able to remove it from my adrenal gland. I then got my scans to see how much progress was made after the chemotherapy drugs and the doctors were happy to say that it had been reduced drastically.

The Next step was to have surgery to take out the remaining tumor that was left on my adrenal gland and they removed 95% of it. They said that the tumor was the size of a lemon. The next step in my treatment was to have proton therapy. This is also known as Radiation Therapy. This was used to take away the rest of the tumor that they couldn't remove during the surgery. I went through 2 weeks of proton therapy and the doctors declared it a success.

The next step in my treatment was stem cell therapy. I had to have 2 sessions of stem cells transplanted to wipe out all of cancer cells in my body and to replace them with non-cancerous cells in my body. This took two months of intensive therapy to complete. When that was done, I was back at home to rest up for the final step of my treatment course.

The final treatment needed was immunotherapy which I had six sessions of that. After that, it was back at home to rest my body after all the treatments I have been through. My next checkup was with the doctor, and we repeated the scans to see what the results were from all of my treatments. The Doctors were very excited after looking through the scans to tell us that I am cancer free. My side effects were that I now have a loss of hearing because of the intense chemotherapy that I been through. The Audiologist says that I will need hearing aids as well as speech therapy.

I am a typical boy who is wild little man and loves to play hot wheels and play pillow fights and loves to cuddle with mommy and daddy and love to help out as well. I'm a very awesome little man and am grateful to the doctors to who got me to where I am today.

Tanner Ruggiero's Story

Hi, Tanner is a 3-year-old ball of energy, happiness, and joy. He spends most of his days flipping through books, swinging on swings, and outlasting any kangaroo in a jumping competition. The energy level he has is infectious. His genuine excitement for the simplest of life's wonders is a constant reminder for us to pause and enjoy it with him. He's only been in our lives for 3 years, but he has already taught us many life lessons.

When Tanner was 2, he was diagnosed with autism, global delay, and sensory processing disorder. We spent a large amount of the last year setting up a variety of services for Tanner which has made him the busiest little toddler. Research suggests that years 2-5 is the most effective time to treat and apply some of the therapies he partakes in because of how the brain is developing. As a family we decided to try to do the most we can to foster this brain development and are constantly trying to find new and creative ways to effectively further this process.

Tanner attends occupational and speech therapy once a week and attends Moving Mountains ABA clinic as his "school." There he spends 23 hours a week doing most of his therapy and learning. He also goes to a chiropractor and is attending open house sessions at the YMCA geared for sensory kids.

Because of this desire to meet the higher threshold of these needs, we struggle as a family in three main areas: sleep, safety, and communication. We as a collective unit are very sleep deprived. Tanner goes through cycles where his sensory needs aren't met despite being very busy. It makes it hard for him to sleep and can often be found jumping in his bed for hours between the hours of 1-5am. It's normal for us to see only 20-25 hours of sleep in a week. Sleep deprivation is something we wouldn't wish on anyone. Tanner's learning and mood changes, we as his parents struggle to meet the demands of our full-time jobs and worst of all, our health plummets.

The answer to getting more sleep means high activity all day! We were prescribed by his developmental pediatrician, mandatory, rain or shine outdoor time doing high energy activities like running, climbing, and jumping beyond what he would normally do in a day.

The hardest part of Tanner's medical diagnosis is the lack of communication we have with him. He is working hard and has developed more language through his therapies, but he still isn't able to communicate his needs effectively. He also isn't able to fully understand what we say to him. Simple things that a parent takes for granted are a real struggle in our home. At the end of a long day of sensory seeking on no sleep and guessing then second guessing every small task, we tuck him in and say good night and don't get that "I love you," that melts the hard parts of the day away. And despite knowing he loves us, it's hard to not know what he is thinking and feeling every day.

We have a great team of support from family, friends, therapists and now the supporters and families of the Shannon Daley Memorial Fund. While the autistic community is moving away from the puzzle piece as it's accepted symbol, I feel that in Tanner's journey we have collected and pieced together some of his most important puzzle pieces and our job as his parents is to continue to seek out the rest to give Tanner his best life, as he would want it, even if he can't convey it himself- yet!