SHANNON
DALEY
MEMORIAL FUND
P.O. Box 1271
Whitehouse Station, NJ 08889

The Shannon Daley Memorial Fund is proud to announce its 18th 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 recipient is 7 year old Rebecca Piro from Raritan Township who has Stage 4 Kidney Cancer. The second recipient is 1 year old Domenica Scalzo from Green Brook who has Prader-Willi Syndrome (PWS). The third recipient is 4 year old Trent Powers from Cranbury who is diagnosed with Duchenne Muscular Dystrophy. The fourth recipient is 5 year old Andrew Arias from Hampton who has had a heart transplant and has been diagnosed with cancer from his anti-rejection medicine.

The event will be held Wednesday March 6th, 2019 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

Rebecca Piro's Story

Prior to her diagnosis, Rebecca was an active, fun loving 6 year old who loved to dance, played soccer, and excelled in school. Our lives changed forever on Monday, August 13th, when we took Rebecca to the pediatrician after she complained of some discomfort on her left side and we saw blood in her urine before bed the night before.

Our pediatrician sent us to Hunterdon Medical Center for an ultrasound for an abdominal mass. Once finished, they told us to go directly back to the pediatrician's office. Our pediatrician took us aside and told us what was found and what he believed the diagnosis to be – cancer, specifically Wilms Tumor which occurs in the kidneys. We came home, packed and immediately drove to Goryeb Children's Hospital at Morristown Medical Center.

The following day Rebecca had another ultrasound and a CT scan. The scan revealed that there were also nodules on her lungs, meaning it was stage IV, but only one kidney was affected. The typical course of treatment would be to remove the tumor and kidney immediately, but due to the size of the tumor being approximately as large as two grapefruits, that was not an option.

After 6 weeks of treatment with 3 different chemotherapy drugs, Rebecca was ready for her next evaluation. She had another CT scan and the results had been positive. The main tumor shrunk significantly, but there were still several spots on her lungs. This meant she was ready for surgery, but would also need radiation therapy for the lungs and the treatment would be stretched out an additional 4 weeks due to needing to add 2 additional chemotherapy drugs. During this time of evaluation we also got a second opinion for Children's Hospital of Pennsylvania, and they were in agreement with the treatment plan.

On October 10th, Rebecca underwent her second surgery, this a major one to remove the tumor, kidney and impacted lymph nodes. Other than some additional bleeding, the surgery was successful and the surgeons were able to confirm that they were able to get everything they needed to. She was released from the hospital 6 days later.

Following the surgery, Rebecca had 6 days at home before she would begin the most aggressive part of her treatment. On 10/22 she began her first of 4 weeks of inpatient chemotherapy along with the first 4 radiation treatments. This was a very difficult time due to her still recovering from surgery and due to her age, required to be sedated for every radiation treatment. She was only home for 7 nights from the 4 weeks following surgery and it was definitely a trying time for the whole family.

She had 1 more outpatient chemotherapy treatment before going back into the hospital for her second inpatient week. Following that, several blood transfusions and one more outpatient treatment, Rebecca completed the hardest 6 weeks of her life.

Despite countless trips from Flemington to Morristown and back, surgeries, nights in the hospital and treatments, Rebecca has been a trooper. Her bravery, along with the support of our great community are what help is to get through this extremely difficult time.

Domenica Scalzo's Story

Domenica was born May 3rd, 2017. At a week old she returned to the hospital and was admitted to Morristown's NICU. There they administered a video EEG to rule out seizures and search for the reason why she was not waking up or able to eat. During her two week stay she endured other tests including spinal tap, bloodwork, and genetics testing.

While there we met with neonatologists, geneticists, neurologists, GI doctors, therapists, nurses and counselors to find the cause for her low muscle tone and failure to thrive. Together we made a plan to support her back at home. Before leaving she underwent anesthesia and surgery to have a gastrostomy tube placed in her stomach to ensure she was getting proper nutrition while unable to eat on her own. We brought her home without any clear answers.

Once home, there were unending follow up appointments with doctors and Physical and Feeding therapy sessions started weekly. Our family tried to get a grasp of our new normal. At four weeks old we received the devastating confirmation from genetics testing that Domi has Prader-Willi Syndrome (PWS).

PWS is a rare, lifelong condition which is caused by a malformation on the 15th chromosome. It is a multi-stage spectrum disorder and symptoms may include hypotonia, failure to thrive, developmental delays, learning disabilities, speech issues, short stature, behavioral and mental problems, cognitive impairment, sleep apnea, scoliosis, hormonal issues and hyperphagia. Hyperphagia is the hallmark symptom of PWS that is life threatening and causes those affected to be painfully hungry and never feel full.

There is not a cure for PWS and at this time there is only one drug that is approved for treatment. Human Growth Hormone (HGH) is given every night before bedtime by injection to help both physically and cognitively, but unfortunately it will not help with hyperphagia. We believe that HGH along with a strict, medically supervised diet are Domi's best chance at a hopeful future.

Domi's days are busier than most other children with extra doctors' appointments and scheduled therapies. She currently has eight and a half hours every week she spends in Developmental Intervention, Physical, Occupational, Speech, and Craniosacral Therapies. At two we will be adding in Hippotherapy weekly to help with core and postural strength. We travel as a family to Florida two times a year to visit with the most experienced Endocrinologist who researches and treats PWS, Dr. Jennifer Miller. She is an advocate for our children and a light of hope for our families in the PWS community.

While so many of the things in Domi's life are different like mealtime, playtime and bedtime she is truly a typical toddler, heart and soul. She is pushed and works harder than most but somehow finds the fun in it all. She loves being praised when she does something new. She is sweet, funny and eager to please. She loves music and dancing, baby dolls and fancy jewelry. She gives the very best hugs and has a smile that melts our hearts."

Trent Powers' Story

On September 22, 2015 we sat in a room at Children's Hospital of Philadelphia holding hands and praying that what so many doctors suspected wasn't our reality. Unfortunately, all of our hope, prayers & positivity couldn't change the fact that our 10 month old son, Trent, was about to be diagnosed with Duchenne Muscular Dystrophy. The words came out of the doctor's mouth in what seemed like slow motion and the tears immediately starting flowing along with a feeling (an actual feeling) of our hearts breaking into a million pieces.

To be given this diagnosis is every parent's worst nightmare. You see, Duchenne muscular dystrophy is the most common fatal genetic disorder diagnosed in childhood, affecting approximately 1 in every 3,500 live male births (about 20,000 new cases each year worldwide). Because the Duchenne gene is found on the X-chromosome, it primarily affects boys; however, it occurs across all races and cultures. Duchenne results in progressive loss of strength and is caused by a mutation in the gene that encodes for dystrophin. Because dystrophin is absent, the muscle cells are easily damaged. The progressive muscle weakness leads to serious medical problems, particularly issues relating to the heart and lungs. Young men with Duchenne are usually wheelchair bound by the age of 12 and typically only live into their late twenties. There is no real treatment, no cure and no survival rate

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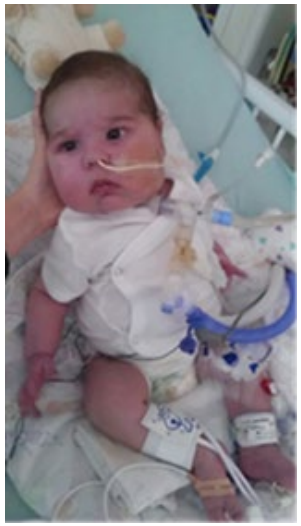
Everything that we hoped, dreamed and envisioned for our son was quickly ripped from us with three words. In seconds we became overwhelmed with medical jargon and the idea of our son having a limit on his life. He has a long journey ahead and a lot to overcome and the diagnosis is grim. As parents your minds start racing and going places no parent's mind should ever have to go and then you stop and look and realize that you have a beautiful, happy and seemingly healthy son. When you look at him these thoughts don't make any sense they seem unreal and impossible but that's the nature of this terrible disease.

Today, over 3 years since diagnosis, Trent is your average four year old who loves animals, all things Disney and his new puppy Luna. He is in his second year of pre-school where he has made many good friends and loves to learn. With his larger than life personality he instantly lights up the room and puts a smile on everyone's face. While he might look and act like a typical four year old there are many things that make Trent's journey unlike most of his peers. Trent's weeks are filled with therapy, days are filled with medications and supplements, months are counted by routine visits to a specialists around the country.

This diagnosis was, and still is, devastating to everyone who knows and loves Trent. The idea of watching our sweet boy slowly lose all of his abilities and independence is unsettling and never sits well. But we know what the future is supposed to hold for us which is why we choose joy. Our love is our strength and we do everything in our power to provide our son with the best that life has to offer. We travel to see specialists and give him access to the best therapies to help ensure that we are giving him the best chances at life. Our journey is a marathon and one that we plan on running with everything we've got.

Andrew Arias' Story



Andrew was born on July 22, 2013. When I was 14 weeks pregnant, an ultrasound showed Andrew's heart was not forming properly, so we were referred from Hunterdon Medical Center to Children's Hospital of Philadelphia (CHOP). Then he was diagnosed with Hypoplastic Left Heart Syndrome (HLHS). This is a birth defect that affects normal blood flow through the heart. As the baby develops during pregnancy, the left side of the heart does not form correctly.

The day Andrew was born started his first battle in life, when he was born his umbilical cord was around his neck 4 times, but he was ok! Within 30 minutes of his birth, they placed a central catheter to keep him alive, then was transferred to the CICU. He needed to stay with oxygen 24 hours a day and be fed through a nasogastric feeding tube. A week later he got his first heart open surgery and a pick line placed on his left leg. We thought he was going to have just a couple of reconstruction heart surgeries, but his heart got worse. Soon we got the heartbreaking news, he needed a new heart and he was placed on the waiting list. We didn't have any idea how long we were going to wait, all this time he had to be in the CICU. When he was two months old, we had been offered a new heart, but that day around 6pm we got a call and they said that the heart was not as good as expected. Days later Andrew got a tracheostomy and after that Andrew felt happier of having something less that bothered his face. At 3 months old, I remember that I was sitting next to my baby's crib and noticed his heart rate went from 100 to 200 beats per minute with the nurse changing his feeding tube for fluids, everything seemed very strange, I thought "something is not right", then minutes later a doctor came to me and told me in a soft voice, I think there is a possibility for a new heart but please don't get too excited until we make sure it is the right one for your son, but we are going to be ready for it. Minutes later I received a call and that person said to me, we got a heart for your son and it is not a good one, it is an excellent heart. At that moment I knew that the heart came from God through our prayers. We can't describe the feeling of happiness for our son and at the same time the sadness knowing that another child and how that family could be feeling.

Hours later Andrew went for surgery for around 4 hours. It was a success! I never felt so happy to see him with so many cables and tubes in his body after surgery. He started having beautiful rosy cheeks, and pink nails, it was not purplish any more, and in total we stayed 5 months in the hospital. Two days before Christmas Andrew was sent home for the first time, with around 12 different medicines and depending on a respiratory ventilator. That was the most lonely and exciting Christmas ever in our lives. He started getting stronger and by the age of 9 months, he was removed from the respiratory ventilator. Over the next couple of years he got at different times painful mouth ulcers, ear infections and a lot of hospitalization due to his lower immune system and had a couple of eye surgeries.. "No matter what he had been through he continues to be happy and sweet", when everything seems to be going better.

Andrew got some mouth sores as he had happened before and we had to go to (CHOP) hospital and stayed about a week for recovery, the Doctors did couple of biopsies to find out the reason why Andrew was having the mouth sores, but the team at the hospital could not find an answer, they said Andrew was like a puzzle. One of the doctors from oncology felt Andrews belly because she thought the ulcer may be relater with the liver, then she order a ultrasound of his belly, and result shows some dark spots in his belly, and because of that, they did an colonoscopy and the result were shocking to us. Andrew showed signs of Post- Transplant Lymphoproliferative Disorder (PTLD) cancer, but to confirm those result, they did an endoscopy and the result were same, Andrew was diagnosed in 2018 with cancer (PTLD) cancer , and that was caused from one of his heart medicines that he still needs. We drove 1 ½ hours to go to (CHOP) so Andrew could receive his chemotherapy. On February 6th, Andrew completed his 9 cycles of chemo and now we are waiting for positives results from Andrew's (PET) scan. During all this time Andrew didn't feel any pain, and that make us feel very blessed because in a lot of cases kids with (PTLD) experience some pain in their belly.

Thank you to the Shannon Daley Memorial Found for give us the opportunity to share our brave boy story and that way show that in life nothing is impossible when we believe in God and put all our faith in his hands.