



The Shannon Daley Memorial Fund is proud to announce its 23rd 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 2-year-old Molly Jones from Succasunna who has a rare gene mutation (ZC4H2). Our second recipient is 11-year-old Jabez Manalo from Raritan who had a ruptured AVM (Arteriovenous Malformation) causing a stroke and loss of left side mobility. Our third recipient is 17-year-old Damarion Poulson of Raritan Township who went into cardiac arrest from an asthma attack. Our fourth recipient is 17-year-old Marvin Zepeda Jr. from Flemington who had a ruptured AVM and continues to require neurological procedures.

The event will be held Tuesday March 5th, 2024, 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: Back Page \$2,500 ,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](http://www.shannonfund.org). If you would like to advertise in the program, please call (908) 528 - 2231 or email [Paul.McGill@shannonfund.org](mailto: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

## Molly Jones' Story

On May 29, 2021, Molly Mae Jones was born and completed our family of five including Mom, Dad, big brother Willie (5) and big sister Maxine (7). Shortly after birth, our midwife noticed Molly's breathing was labored and she was sent to the NICU at Morristown Memorial Hospital.

After spending 3 weeks there she was transferred to the Children's Hospital of New York to be consulted by their ENT team. Shortly after transfer, at just 1 month old, Molly underwent her first surgery to help open up her airway. About a month later she had her second surgery to place a feeding tube which was a necessity due to silently aspirating. In August of 2021, Molly was finally released from the hospital and our whole family was together for the first time but without a diagnosis of what was causing Molly's medical complexities. It was not until about 10 months old that we finally received a diagnosis. Molly has ZC4H2 gene mutation (ZARD: Z-finger Adverse Rare Diseases). She is one of only about 166 known cases in the world.

All of the children with ZARD have a wide variety of symptoms.



Molly's individual presentation of ZARD has caused:

Laryngomalacia - a soft airway which required the corrective surgery at 1 month old;  
Hypertrophic Cardiomyopathy - an enlarged left ventricle of the heart which is closely monitored by a cardiologist.  
Seizures - she started having seizures at 8 months old, but they have been managed so far with 3 different medications given twice daily. Cognitive and physical delays such as inability to walk, crawl, speak, and eat. For this she sees Physical Therapy,

Occupational Therapy, and Speech Therapy every week and probably will for her

entire life. Joint Contractures - extreme tightness of her joints, mostly her hips, elbows, and shoulders. She sees a physiatrist for this and gets botox injections to help relax them. A small optic nerve causes poor vision and sensitivity to light. Nystagmus - random and uncontrolled eye movement making it hard for her to focus and visually attend to things.

Molly's biggest hurdle is her silent aspiration of food and liquid when eating or sick. This prevents her from eating or drinking by mouth, so she is completely G-Tube dependent. She gets all her blended meals through syringes and two feeds overnight through a feeding pump. When she gets sick, her aspiration causes her to get frequent pneumonia and collapse of her lungs. She has been hospitalized 13 times in just over 2 years for respiratory illnesses. Her current/latest stay has been over 2 months long and resulted in an additional surgery and Molly needing to be on a BiPAP machine every night while she sleeps. To help manage the severity of her illnesses we complete 3 daily respiratory treatments including a nebulizer albuterol treatment, a percussion vest, a cough assist machine, and steroid inhaler.



have. Molly is unique, complicated, beautiful, energetic, and pure-hearted and we are so grateful to have her in our family.

While all of that information is important to understand Molly's life, the most important thing to know about Molly is that she is incredibly happy and resilient. She has a positive impact on everyone who gets to know her simply from her contagious spirit. Her hardships have caused struggles in our family but have also provided us with perspective, love, and community. With her disease being so rare there is not a lot of information on what to expect in the long term as far as health, development, or quality of life. We just take it one day at a time and give as much love and care as we

## Jabez Manalo's Story

Jabez is a very active 11-year-old who has loved to play basketball and soccer since he was 4 years old. He is a very outgoing, kind, selfless, caring, loving and funny boy. When you meet him, he immediately makes you feel welcomed like you fit right in, and amazing friendships have generated from the many encounters.

On 7/6/2023 @ 2:00 AM Jabez's life and our lives changed almost taking his life away. He was rushed to the ER @ RWJ in New Brunswick, NJ with what turned out to be a ruptured AVM causing a stroke and losing his left side mobility. Jabez had his 1st surgery that morning to remove a partial part of his skull to relieve pressure off the brain from the ruptured blood vessel. After a couple of hours, doctors tried to stop the bleeding with a procedure called an angiogram. A CT scan later revealed that the bleeding continued so the next morning he was scheduled to have his 2nd surgery to remove the complicated AVM. Meanwhile, we had no idea how Jabez was affected because he was heavily sedated, intubated, attached with many IV's, a feeding tube, a foley catheter and all the doctors were trying to do, was to save his life. As parents it hurt so much to see our littlest one lying there and



going through it all and we were feeling so helpless but kept praying. The 2nd surgery was a success, and the AVM was removed, a miracle prayer we so longed for, was answered. He stayed in the PICU for 5 days and finally woke up on the 4th day from when "it" all started. As Jabez was waking up, he was in a lot of pain. This is when we sadly found out what the AVM caused; He couldn't move his left hand and left leg. That afternoon he was extubated, and we also found out the stroke affected his speech. We spent the next 2.5 weeks trying to recover and start with PT, OT, Music, and some speech therapies. Jabez had such a hard time here. He was limited to stimulation so we couldn't have many visitors at this point.

We finally headed over to the Children's Specialized Inpatient Hospital. When he first arrived, it was very hard watching him struggle to even try to sit up. There were nights I cried and prayed so hard to help him and give him the strength to face the many challenges that he was facing. He was determined to walk out of the Children's Specialized Inpatient Hospital. Jabez was given a customized wheelchair, as days and weeks, months passed, he was regaining movement on his left leg with the help of an AFO and a sling for his Left shoulder along with a hand splint. Jabez was nicknamed Trooper. We had the love and support of many families, friends, and teachers. He saw how much everyone loved and cared for him and inspired him to keep going. When he was discharged on 9/20/23 his goal of walking (with the assistance of a cane) out during his clap out was accomplished because of his determination and all the inpatient hospital staff.



After coming home, he was home instructed, outpatient therapies continued, and his 3rd surgery (Cranioplasty) took place. Finally in January of 2024 he was able to go back to school in person part-time. Socialization was needed to keep him motivated to continue with his recovery. You can immediately tell the difference in his personality because that sparkle in his eye's illuminated, he socializes more and through his smiles everyone compliments his beautiful dimples. Never take for granted the time with your loved ones is what came out of this experience for our family. Jabez has a long way to recovery, but he didn't earn his nickname "Trooper" for no reason. Milestone after milestone he has proven to overcome what he needs to accomplish. So proud of Jabez! We are genuinely honored to have been selected by The Shannon Daley Memorial Fund. We

are Blessed to add your love and support in Jabez's Recovery Journey.



## Damarion Poulson's Story

The moment you came into this world. I knew that I would do all I could to protect you from everything that would try to harm you. June 4th of 2023 everything changed for me and Damarion on that day. Something happened to my best friend, my son that I had no way of preventing it. I had no way of protecting you from what was to come. Damarion, you had an asthma attack. Your body was receiving oxygen, but your body was not releasing carbon. I was told that your heart stopped and with those words said to me. I lost a huge part of my own heart. My son was a happy sixteen-year-old who played sports, guitar and was a singer/rapper.

He was put in a coma at St.Peters Hospital, June 4th, 2023, due to a cardiac arrest. That is when the heart suddenly stops beating and blood stops flowing to the brain which causes massive brain damage. Damarion, was put on fentanyl so that his body would recover. He had 3 E.K.G'S every month for the first three months. He underwent intense Physical therapy and Occupational therapy. Damarion, was left needing to put a tracheotomy tube in his throat, which connected his larynx to his lungs and to his g-tube. This way he can receive the nutrients needed because of his inability to be able to eat. The tracheotomy was left leaving him needing speech therapy as well going forward. Damarion is nonverbal and non-mobile due to his cardiac arrest from the asthma attack. When he was transferred to children's specialized hospital, he underwent Botox injections in his arms to loosen up his arms because his body had become stiff along with his legs. Damarion had to do intense physical therapy so that he was able to come home. The day they let him

come home was when he was able to get decannulated and with that, was just left with his feeding tube.

The journey home was intense. He has had therapy 3 times a week every week for 4 months. It was hard to get him to his appointments because I have no handicap accessible vehicle. He started school at the beginning of December and is transported to a special needs school in Edison. He now gets his physical therapy, occupational therapy, and speech therapy in school. It's a long recovery and I'm with him through this all the way.

We all miss his silly goofy, silly antics. Every morning he would have talks with your brothers and share laughter together. Him being my oldest he was my shoulder to cry on and someone I could talk to about anything. He would help me protect the family. Now the roles have reversed, and the family protects you. With all that you are going through, we are going to be here for you. We are waiting for you to recover. We miss your voice words of encouragement and your goofy silly self. We can't wait to play football with you. Shoot them hoops. Go on drives to nowhere. Just listening to music in talking about our goals to each other. We love you and miss you.

We want to thank the Shannon Daley Memorial Fund and all those that support to help Damarion and our family. We have not lost hope that he can still recover some more and are thankful to have your support.



## Marvin Zepeda Jr.'s Story

When Marvin was 12 years old, we were a normal family, a single father raising Marvin and his three older sisters. Marvin was a typical boy, a soccer star who loved sports. On October 27, 2018, our lives changed forever. That morning I found him lying on the bathroom floor, he had difficulty standing and could not support himself. I found a neighbor who helped me get him to the emergency room, by the time we got there the situation was dire, he had to be put on a ventilator. The doctors discovered that Marvin was bleeding from his brain. He had an AVM (arteriovenous malformation) that had ruptured causing an intraventricular hemorrhage and an intraparenchymal hemorrhage.



Marvin was immediately flown by helicopter to another hospital where he underwent complex brain surgery, he had two more surgeries before he was sent to an inpatient rehab. Altogether Marvin spent over two months in the hospital; before he could come home, he spent weeks in rehab doing physical therapy, occupational therapy, and speech therapy. After he came home, we had to care for him for another 3 months before he could go back to school. Our prayers were answered- the doctors have said that Marvin's recovery was a miracle. He is able to walk and talk and is still our Marvin.

Marvin's condition will always be there and need to be monitored. Over the last 5 years Marvin has needed intensive follow up, he has been to 6 hospitals, two of them out of state. Most recently we have had to travel to

Philadelphia regularly so that he could undergo a series of neuro radiological procedures.

In spite of everything we have been through, we are very grateful. From the time of his first emergency department admission and throughout his time in the hospital and his recovery, our family received an outpouring of support from the community. It seemed like the whole of Flemington was praying for him: our family, our neighbors, his school, our church, even people from other churches visited Marvin in the hospital. We have felt completely cared for in Flemington.



Marvin is the baby of the family, I could not love him more and I get emotional when I think about everything that happened, it is painful to remember and write about. I work very hard taking care of my family, people often ask me for advice, and I tell them they need to pay attention to their children, if I hadn't been paying attention to Marvin he would have died. Anyone who has had a child who has suffered learns a lot. It taught me to love the people you are with more. People ask what I did to get through it, it wasn't easy. The illness that my son has is nothing small, it is big and requires ongoing treatment, I will always need to take care of him.

We are grateful to the Shannon Daley Memorial Fund for all that they have done for our family and for all of the other families.