SHANNON DALEY MEMORIAL FUND

P.O. Box 1271
Whitehouse Station, NJ 08889

The Shannon Daley Memorial Fund is proud to announce its 18th 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. The first recipient is 9 month old Gunnar Bickhardt from Milford who has a Congenital Heart Defect (CHD) called Hypoplastic Left Heart Syndrome (HLHS). The second recipient is 7 year old Benjamin Falcone from Martinsville who has Familial Mediterranean Fever Syndrome. The third recipient is 12 year old Trevor Muller from Jamesburg who has B-ALL Leukemia.

The 18th Annual Shannon Daley Memorial Golf Tournament will be held Monday June 24th, 2019 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 $250 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.

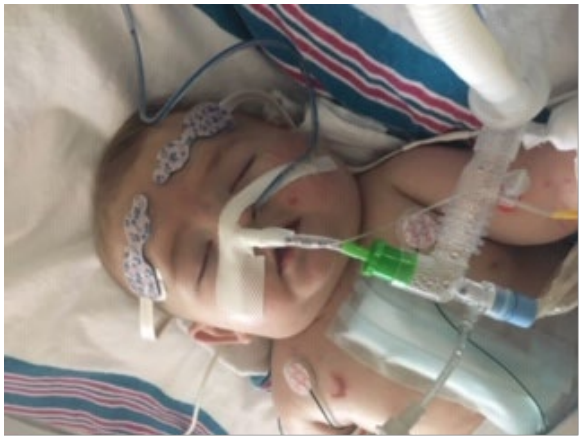
The breakdown is as follows:

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

Gunnar Bickhardt's Story



Gunnar was born on July 29th, 2018 at Hunterdon Medical Center. When he first arrived, the doctors and nurses monitored him closely in the special care unit. His heart rate, blood sugar and oxygen levels were not in the ranges that the doctors were comfortable with and he has a slight heart murmur. After 24 hours, the doctor asked us if we would agree to send Gunnar over to Morristown Memorial Medical Center for some further testing. .

At 9:30 the next morning, Gunnar was transported to Morristown and then New York Presbyterian or CHOP. He arrived at New York Presbyterian that night and the tests were completed. The news of Gunnar's condition was given to us that morning. Gunnar has a Congenital Heart Defect (CHD) called Hypoplastic Left Heart Syndrome (HLHS). The left ventricle did not develop enough to be functional and Gunnar would need a series of three surgeries to correct it. These surgeries were the only way to keep him alive.

His first open heart surgery (OHS), the Norwood Sano, was on August 6th. It was a 10-hour procedure and we waited for him to return to his room. The doctor came out to us and informed us that everything went great and the site looks wonderful. We all prayed for a speedy recovery. The next day, his stats did not improve as much as the doctors had wanted. They had to go in again and find the problem. His Sano shunt needed to be reshaped for better blood flow. Gunnar began to improve as expected from that point on. Slowly, each day, a tube was removed, oxygen support was lowered and we were anticipating bringing our Gunnar home to meet his brother, Bryce, for the first time.

Finally, on August 29th, Gunnar was strong enough to come home. Bryce greeted him with smiles and cheer in the waiting room. We were trained on placing his nasogastric tube (NG tube), administering his medication, and checking all of his stats daily. The first two weeks were overwhelming for everyone. But Gunnar was getting used to seeing his brother and watching his dog roam around the house.

About a month before his second surgery, Gunnar was having a hard time gaining enough weight. The more we fed him, the more he threw up. We were instructed that for the time being, we would continuously feed him via food pump over a 24-hour period. His weight gain picked up again and he was ready for his next procedure. The Bi-Directional Glenn was a success on November 26th. But then again, his oxygen wasn't improving enough and his stats were all over the place. He needed to be brought down to the catheter lab for an exploratory procedure. They removed some extra scar tissue and sent him back to his room. Gunnar was there for 15 days which was much longer than expected. He needed tons of fluid to help his blood pressure and heart rate, but the fluid began collecting in his lungs. However, this time, Gunnar had a blood clot in his native aortic valve and needed blood thinners that needed to be administered by injection. He lost his ability to feel hunger and with that, the motivation to learn how to suck. He visited a feeding therapist every week and soon after that he began physical therapy to strengthen his core.

Gunnar has surprised all of this doctors and therapists. One day, he decided that he was going to master eating not only from a spoon, but from a bottle as well. It was a true miracle. That night, he pulled his tube out, as he always did, but this time my husband and I decided to leave it out and give him another trial off of the tube. He did an amazing job. With some ups and downs, he eventually graduated from his GI specialist and a few weeks after that he graduated from his feeding therapy. He is beginning to crawl and take his brother's toys. He is making so many sounds now and seems to be so much happier tube-free. Pretty soon, Gunnar will be able to get exposure to other children and hopefully be able to handle daycare. We are so lucky to have had such amazing medical professionals, family and friends who have supported him and prayed for him. He is doing amazing and despite his medical history, he is the happiest baby anyone could ask for.

Benjamin Falcone's Story

At 5 months old Ben had a 106 fever, it was the night of Hurricane Sandy, and every month since suffers from a high fever and difficulty breathing. By the time he was 4 years old, Ben had experienced a high fever of over 107 on 14 different occasions in the hospital, unable to eat as he aspirated into his lungs due to the airway defect, and had undergone multiple procedures to help alleviate his illness and was diagnosed with failure to thrive. He also suffers from severe stomach and joint pain from the Familial Mediterranean Fever Syndrome and he now shows symptoms of neurological/cognitive dysfunction which includes involuntary hand and finger movements. Ben is now 7 years old with about half of his life consisting of trips to his medical team from CHOP to Hackensack Hospital including a GI, Infectious Disease, Immunologist, Rheumatology, Neuropsychologist, Neurologist, Pain management, Pulmonologist, Feeding Therapy and frequent visits to the Pediatrician almost weekly. In addition, securing care takers and tutors for when he is sick and falls behind in school (another challenge that we now face). As you can imagine he was extremely developmentally delayed due to his first 4 years of life being so ill.

When you have a child nothing quite prepares you for coping with an illness in which there is no cure that is extremely unpredictable. To explain what he experiences as simply as possible, his brain each month sends a signal out to his body every 30 days that there is an infection. His body responds by secreting a tremendous amount of mucus and an inflammatory response occurs throughout his body. His joints and muscles ache and he gets fevers ranging from 102 to 108 and large sores in his mouth and nose. During this time he cannot eat, throws up continuously and is at very high risk for dehydration, seizure, etc. Each month is different as sometimes he can walk and sometimes he is bed ridden for multiple days and in constant pain. We have had over 65 hospital trips with him unable to breathe because of the weakened airway; the inflammation impacts his airway and with the mucus it is very difficult for him to breathe. Ben's body is tired and he sleeps often, and gets tired easily. His body has a hard time regulating and he overheats so summer months are vulnerable for him and during cold and flu season any illness triggers the flare up and his fevers are higher during the episode. If Ben continues to have fevers over 105 he faces a threat of kidney failure and then heart failure. There is no cure and the only medicine that may help which is colchicine he cannot tolerate; it causes his stomach to bleed as it is not for pediatrics.

We are working to balance Ben's happiness when he is in a healthy span and then keeping his fevers under control by giving him the most supportive environment possible. We were once waiting for the light at the end of the tunnel and now just accept the new normal for us. Ben now faces a new challenge, now that he is of school age the additional challenges are education – being able to learn and process. Ben began having involuntary movements of his fingers, hands and reflexes. He is still too young for an official diagnosis but based on these behaviors it is likely that he has Bachet's Syndrome which is a manifestation from the fevers. We are faced with finding the proper education environment at this point and getting him in an appropriate place where he can thrive and support the management of his disease. Life is different. Ben however knows nothing different, but now is beginning to realize that other children are not like him and asks why Daddy doesn't get the fevers or his friends. He has been diagnosed now with anxiety and depression as he is becoming more aware of his condition. We cannot reiterate how important it is for Ben to be in a suitable learning environment with the appropriate resources to keep him physically and mentally healthy and strong.

Raising a family is extremely challenging and nothing can ever prepare a family for having a child diagnosed with a chronic condition, but knowing there is a support system and others out there praying means so much! We have so much gratitude and thank everyone for your support.

Trevor Muller's Story

Trevor is one of the most fun-loving, brave, inspirational 12 year old boys that I know. The reason I say one of is because during Trevor's Journey we have met too many Brave and inspirational boys and girls just like him.

Trevor's Journey started one Unforgettable Day on June 16th 2016. That is the day that forever changed us. That is the day we found out that our son had cancer, B-ALL Leukemia to be exact and that he would be going through three and a half years of grueling chemo treatments. I don't think it ever really fully sinks in when you hear your child has cancer. My heart broke that day, and it continued breaking through the first two and a half years of endlessly living in the hospital. Watching my son sometimes fight so hard for his life. His body being so beat down that he couldn't even sit up on Christmas morning to open his own presents. Spending every holiday and birthday in the hospital. Then add the grueling chemo treatments. Oh boy are they rough.

Trevor happens to be a child whose body hates the chemo drugs. Not that any child's body should like those harmful drugs but Trevor happens to experience many bad side effects. Things I wish I never had to see my child struggle to go through. Things no human should ever have to go through. Twice he experienced something called mucositis. The second time was so bad it ran through his entire digestive system. It was like his entire insides were burned with a blowtorch. That was when he slept through three full weeks on a morphine drip just to give his poor little body the healing time it need it. And let's not mention the chemo drug that gave Trevor blood clots in his sinus cavity. The endless painful two needles a night for over a year until the blood clots dissolved.

I think the absolute worst for Trevor are the endless spinal taps with chemo that lay him up for about 2 weeks at a time and come with excruciating migraines. Thank God we now only have to experience those every 3 months, but there was a time they were weekly.

The one true Miracle out of all of it though is that no matter how bad things have gotten Trevor has always kept his smile and his laughter I am forever grateful to all the new friends and family that we have made along the way that have helped to keep that smile on Trevor's face