



The Shannon Daley Memorial Fund is proud to announce its 20th 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. Our first recipient is 16-year-old Morgan Hewitt from Franklin Township who has Acute Myeloid Leukemia. Our second recipient is 3-year-old Hunter Ehnstrom from Martinsville who has Myelomeningocele Spina Bifida, Hydrocephalus, and Arnold Chiari Malformation II. Our third recipients are 8-month-old Penelope & Charlotte Jacobs from Hackettstown who were both born prematurely and weighing under 2 lbs. each. Our fourth recipient is 9-year-old Jacquelyn Hendershot from Easton who has Trisomy 21 (Down Syndrome).

The 20th Annual Shannon Daley Memorial Golf Tournament will be held Monday September 27th, 2021, 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

Morgan Hewitt's Story

Like many school children in 2020, Morgan was navigating her freshman year at North Hunterdon High School amid a pandemic, where she found school being shut down in March and going virtual. Her hope was that her sophomore year would be back to normal however that was not to be the case. On September 9, 2020 Morgan was having toothaches common with wisdom teeth coming in. She developed a 102.4 fever while on the antibiotics so on September 19, 2020, her mother took her to St. Peter's Hospital in New Brunswick, NJ. The next day Morgan and her mother were given devastating news that Morgan had some form of Leukemia and was



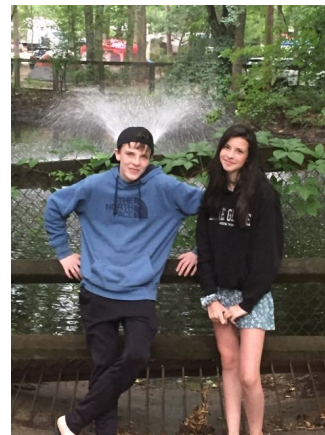
was admitted to Robert Wood Johnson's Children's Hospital in New Brunswick where further testing showed she had Acute Myeloid Leukemia. At the age of 15 she had the adult form of AML; not the pediatric form. The chances of survival from this form of Leukemia were grim. While at RWJ Hospital, Morgan received Chemotherapy treatment which did come with side effects. She lost her hair for the very first time, which for a teenager, that is a traumatic experience. On top of all of the treatment and side effects, Morgan was isolated on a hospital room floor with other kids battling cancer due to Covid

19 restrictions. Her parents were the only ones who could come into her room and be with her.

Morgan was able to come home right before Christmas to spend time with her family and she received a warm welcome from her community. Morgan was later transferred to Children's Hospital of Philadelphia and was scheduled for Transplant in April of 2021, but that came with major setbacks. She had contracted Covid-19 while at home, which pushed her transplant to May 12, 2021. It was during this time that the wonderful doctors at CHoP found a secondary form of Leukemia. This required an alteration in her treatment plan. All five of her siblings got tested to be donors and the family was stunned to find out that all five siblings were a perfect match to be her donor! The chances of finding one sibling to match was 25%! Just prior to transplant, Morgan had to undergo a very intense chemotherapy treatment and radiation. Morgan received countless blood and platelet donations, she experienced the loss of appetite, loss of taste and smell, and she endured countless headaches.

With the transplant date approaching, it was decided that her next oldest sibling, Ian, would be her bone marrow donor. Ian would be the one to give his little sister the greatest gift of all, the gift of LIFE! Ian was willing to sacrifice his wrestling career so that he could give his sister what she needed to survive. May 12, 2021, he started the transplant procedure and ended it with taking his bone marrow donation and personally bringing it to Morgan, who was waiting in her hospital room. At that moment, Ian and Morgan shared a period of time together that they will always remember for the rest of their lives. Morgan went through a period of time where her liver was not functioning properly and a drain was inserted and the liver function was corrected. Morgan went through testing to see how her brother, Ian's bone marrow was taking. Within a month's time, his bone marrow had engrafted 100%! Usually that number is at 80%. Morgan continues to show no trace of both forms of Leukemia and is now residing at Ronald McDonald House of Philadelphia. She returns to the hospital weekly for testing and eventually the doctor visits will be less and less. Currently, Morgan is hoping to return home to Franklin Township, Hunterdon County between the end of July to mid-August. What most people do not realize is the aftercare that takes place once Morgan returns home. The Hewitt home will be transformed into a medical environment where Morgan will be isolated for an extended period of time.

In the end though, Morgan can count herself as a warrior who battled and beat two forms of Leukemia! She is a survivor, and she was given that fighting chance by her brother, Ian. Morgan and her family have endured so much over this past year and hopefully when Morgan's journey is finished, they can be together as a family and spend quality time loving, laughing and living. There will be ongoing medical expenses and challenges for them as a family, but they have weathered the worst of the storm. Nothing can keep them down!



Hunter Ehnstrom's Story

Hunter was born on September 13, 2018. He is our happy, second rainbow baby and younger brother to our amazing Austin. During my 16-week check-in with our OB, I had discussed some pains I was having. Out of precaution due to my already high-risk state, they did an unplanned ultrasound. The nurse was quiet during the ultrasound, which was unusual and as she finished up, she said, "ok I'll go get the doctor for you". We knew this was not good. The doctor came in and said, "So the good news is that the pains are just a pulled muscle from how quickly you're growing. The bad news is this area." As she pointed to the screen, she began to explain that the



baby was showing severe signs of Spina Bifida. She explained that we would be referred over to St. Peter's University Hospital for additional testing and diagnosis. In that moment our world crashed, we had no idea what to expect or which direction to go in. Within the next few days, we had genetic testing done, more ultrasounds, and an amniocentesis to confirm diagnosis. Hunter was fully diagnosed with Myelomeningocele Spina Bifida and Arnold Chiari Malformation II. They said from their scans it looked like his open lesion was from about L3 or 4 down to S1. With these diagnoses came along his

additional diagnosis of Hydrocephalus, along with having a neurogenic bladder and bowel. Over the next few weeks, we had many phone calls with CHOP and spent two days there going through evaluations to determine if Hunter and I were eligible for open fetal surgery. At the end of the second day of testing we got the exciting yet scary news that we were eligible, but we only had a 2-week window left to have the surgery. On Friday June 15, 2018, Hunter and I underwent open fetal surgery at CHOP to close Hunter's back. Hunter officially became a "Twice Born Baby". His neurosurgeon explained that the lesion was much bigger than expected and was L1-S3. After a 3-month strict bed rest, Hunter was born and spent 13 days in the CHOP NICU for breathing complications. While in the NICU his neurosurgeon said he was a medical miracle and a true warrior. We were told without surgery he would be completely paralyzed from the waist down and with surgery the hope would be to have some movement and feeling from the

waist to the knees. Hunter was already showing positive movement below the knees, although very minimal, it was still more than expected.

At 6 months old Hunter had a VP shunt placed as his hydrocephalus was causing concern. In November 2019 at just a little over a year old, Hunter underwent tethered cord surgery. In October of 2020 Hunter had an exploratory shunt revision to see why he was having severe fluid buildup along his spine. In the following weeks Hunter was experiencing severe pain in the back and head and vomiting. After several ER visits and additional cat scans, ultrasounds, and MRI's, Hunter had another shunt revision in February of 2021 where a blood clot was found in the valve of his shunt. The valve and part of his tubing was replaced and since then pain in the back is random. Hunter undergoes repeat MRI's every 6 months to monitor his shunt, fluid buildup on his spine, and signs of retethering. In addition to all of this, Hunter needs routine check-ups with his allergist for his severe dairy and latex allergies, his urologist to monitor for his neurogenic bladder and bowel, his ophthalmologist for growing pressure from hydrocephalus and his current astigmatism, and his Spina Bifida clinic doctors to monitor any changes and progress on a whole.

Hunter is our little stubborn fighter who tries so desperately to keep up with his big brother. Hunter wears AFOs and uses a posterior walker to get around. He loves his physical therapy sessions weekly and will be starting the preschool disabled program in our school district for the first time this September. Although he has gone through a lot since his birth, Hunter is as resilient as they come and goes through life with a constant smile on his face. He is an inspiration to all those who know and love him.



Penelope & Charlotte Jacobs' Story

My name is Ashley, I delivered twin girls December 22nd emergently due to a placenta abruption. Penelope and Charlotte were born at 23.6 weeks gestation weighing only 1.8 lbs. and 1.10 lbs. thankfully both girls were born fighting. When I woke up from my emergency surgery, I was grateful they were alive and fighting in the NICU. Both girls have been through multiple medical procedures. Penelope (baby A) had her left lung collapse before she was even 24 hours old, by day two, she had a bowel perforation and had to have her first minor surgery. A Penrose tube was put into her stomach to drain fluid, but they said she was so small they basically put it in blindly and to hope for the best, but she was too small to do exploratory surgery at a couple days old. On day 6 of life both girls had head



ultrasounds and Penelope had grade 3&4 brain bleeds detected. The neonatologist offered comfort care for Penelope, and I refused. I was going to fight with her as long as she wanted to fight. (Penelope later had 2 separate surgeries for a temporary shunt and then a permanent shunt due to the brain bleeds causing a block of spinal

fluid, she will have a shunt forever and also was diagnosed with hydrocephalus). Everything in the NICU moved slowly... yet things were moving quickly.

We worried constantly of infections, or moving PICC lines, getting enough nutrients, checking blood constantly to make sure their bodies had the right amount of oxygen. Both girls required laser eye surgery for ROP (retinopathy of prematurity). They needed to be transported at different times

to another hospital for each of their surgeries. Charlotte & Penelope both were intubated for almost 100 days due to the severity of their chronic lung disease. Charlotte also had a Granuloma in her throat that caused breathing issues, later the Granuloma disappeared but left significant inflammation in its place. When it came time to bottle feed, Charlotte was unable to do that fully due to the inflammation in her throat causing breathing issues. She currently has a g tube, that she is fed through. Just recently she has been cleared to drink more by bottle. Charlotte and Penelope are on oxygen completely at night and periodically during the day as tolerated. Penelope spent 141 days in the NICU and Charlotte spent 162 days in the NICU, both girls have many specialist and therapies to follow up on for the next several years and for some specialists they will need to see for life.

We are grateful they fought at 23 weeks to be here today. They are 8 months old now! We look forward to them continuing to grow and look forward to every milestone they reach as they continue their fight.



Jacquelyn Hendershot's Story

On October 13, 2011, Jacquelyn K. Hendershot was born, and my life was to change forever. After 10 years of infertility and 5 pregnancy losses I was finally a mom. The pregnancy was rough, and I was hospitalized from 26 weeks fighting for my and my daughter's life. During my high-risk pregnancy, I opted to take the prenatal testing because of my age, and I will never forget that phone call. I was at work when the nurse called to tell me the results which predicted that my baby was high risk for Trisomy 18. I never did any other testing after that one. As soon as Jackie was delivered, via c-section, she was rushed immediately to the NICU



because she was premature at 33 weeks. It wasn't until the second night that a doctor came into my room and basically stated they suspected she has Down Syndrome, they took blood, and the results would take about a week and just walked out of the room. All of my doctors visited with Jackie in the NICU because everyone was so vested in my care and were so shocked by this diagnosis that no one believed this to be true. But I will never forget the day we were called into the NICU, and all these nurses and doctors surrounded my daughter and at this time the doctor confirmed that Jacquelyn was born

with Trisomy 21. I was more freaked out with being surrounded by everyone than the diagnosis itself and one of the doctors came over to us and said how he felt sorry for us with dealing with infertility for so long and then having a disabled child. From day one I never focused on my daughter's disability to me she was my baby, my child, my daughter and that is how I was going to raise her as.

Jackie is a happy child and always has been, she is very social, outgoing, compassionate and just loves life. People seem attracted to her spirit and she always ends up the center of attention. Life has been challenging and not easy for my daughter, since birth she has undergone

surgical procedures every year of her life. We have been making monthly visits to the Children's Hospital locations for doctor appointments, therapies, testing and surgical procedures. Trisomy 21 or Down Syndrome is a lifelong disability that affects a person mentally, physically, behaviorally, and health wise with no cure but constant treatments, medications, bloodwork, therapies, schedules, and procedures. Jackie has had biopsies done to test for Hirsh Brung disease, several ear tubes inserted, several removal surgeries of the ear tubes, tonsils and adenoids removed (twice), an audio brain stem test done, and dental work. Jackie has also been wearing some form of orthotics in her shoes since she started walking and she can only wear good sneakers for support. In 2019 Jackie was hospitalized with pneumonia for 10 days and prior to that there was many middle of the night trips to the ER for croup/strider episodes. We also deal with several sinus infections throughout the year due to her small nose and when she was an infant I was always dealing with her runny nose and rosy cheeks.

Jackie is a very active child, so I need to keep her busy and occupied so she is involved in a variety of activities which include baseball, soccer, swimming, horseback riding, summer camp, bike camp, and cheerleading. Jackie enjoys going for walks with her dog Edy and the two of them play for hours. Jackie is a superstar; she has had her picture in the local papers many times and even was on the local news station when they did a story about her and visiting with Santa Claus. This year Jackie and Edy's picture was chosen out of thousands that were submitted to be displayed on September 18th on the two adjacent Clear Channel Jumbotron screens in Times Square and be live streamed online. The sky is the limit for my Jacquelyn!

