Meet Elyse

MECHANICSBURG, PA

Elyse was born with a rare genetic disorder known as Pyruvate Dehydrogenase Complex Deficiency, or PDCD, which causes significant developmental delays and muscular differences.

AFTER HAVING AN UNUSUAL REACTION to a standard hearing test after she was born and missing some expected milestones, doctors initially diagnosed Elyse with cerebral palsy, but the diagnosis just didn't feel quite right to Elyse's family. However, they were still grateful that Elyse was getting the care she needed, including tests, doctor visits, therapy, and equipment.

The summer before Elyse turned two, the results from her genetic tests came back, showing the cause of all her delays – PDCD. As the family learned, cerebral palsy is just one feature of this condition, which helped everything to fall into place and finally make sense.

Elyse has needed hearing aids, glasses, and special equipment such as a gait trainer to help her walk, but she has continued to thrive despite the challenges she faces. She attends multiple therapy sessions every week, including speech therapy, physical therapy, occupational therapy, and music, but music is Elyse's best motivator! For Elyse, it provides healing and improves her self-expression, communication, and attention.

Around the same time as her diagnosis, Elyse's family discovered that her left hip was dislocated, requiring her to undergo muscle-lengthening surgery and wear a hip spica cast for three months. Elyse's mom, Amanda, says that they were so worried about the surgery going well that when it came time to leave, they realized they didn't have a way to get Elyse home safely without calling an ambulance. Thanks to the Patient Assistance Fund supported by CMN, Elyse's family was provided with an adaptive car seat that is specially designed for pediatric patients who are in hip spica casts.

"Just knowing that I had a piece of equipment to keep her safe, to keep the cast safe, to keep everything safe, meant the world to me," says Amanda.

Elyse and her family continue to give back and support other families like theirs. Miracle Mom Amanda co-leads the Healthy Kids Running Series and helped to create the Challenger Division so that children with different abilities can enjoy the same activities as their peers. CMN provides scholarships so that other Miracle Families can participate.

In addition to funding the special equipment that helps to keep Elyse safe and thriving, your gift helps kids like her by supporting programs like Child Life, art therapy, and much more.

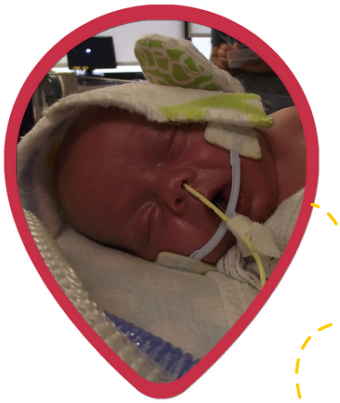
Meet Gannon

YORK HAVEN, PA

Known to many as Warrior Gannon, Jr., this kid is a fighter who brings a smile to the face of everyone around him with his positive, creative spirit.

EVER HOLD A SODA CAN?

That's about how big Gannon was at birth – just 13 ounces. After he arrived 12 weeks early, Gannon was transported by pediatric ambulance to Penn State Health Children's Hospital, where he spent 225 days battling to survive. Gannon was so small that his dad could slide his wedding ring all the way up his son's arm.



Gannon quickly earned the name "Warrior Gannon" as he battled many health challenges. He needed a ventilator and G-tube feedings and has faced seizures, chronic lung disease, and many other conditions.

Gannon was diagnosed with very early onset IBD and undergoes regular Remicade infusions, which he wrote about in his first-ever published book to benefit CMN! He attends physical therapy to build muscle strength and balance. He also went to the Penn State Hershey Feeding Clinic to learn how to eat solid food, starting with bites the size of a grain of rice. A few years ago, Gannon experienced another amazing milestone – he was able to have his breathing tube removed and now breathes on his own!

Doctors believe that Gannon broke his femur while he was a preemie. His weakened bones have resulted in that femur breaking two more times - most recently, just as he was learning how to run! Gannon had been enjoying participating in the Healthy Kids Running Series, thanks to a CMN scholarship, but not even a broken leg could stop this warrior. While in his wheelchair, Gannon still participated and enjoyed spending time with his friends.

Despite his many challenges, Gannon always has a smile for everyone he meets! He loves to wear his signature bow ties and tap dance. He is always working on his next book, he loves to draw, and his amazing artwork has even been auctioned off to raise money for CMN!

Gannon is a huge fan of the Philadelphia Eagles and the Phillies and hopes to go to the games one day. Gannon loves to make other children smile and help them feel at ease if they are scared at doctors' appointments or infusions.

In addition to funding the pediatric ambulance and neonatal incubator that kept Gannon alive, your gift helps by supporting programs like Child Life, medical camps, music therapy, and much more.

Meet Rylan

ETTERS, PA

Rylan's official diagnosis is still uncertain, but he continues to need regular care from specialists at Penn State Health Children's Hospital and is making great progress!

JESSICA'S FIRST PREGNANCY went completely as expected, so it came as a surprise when doctors told her that she would need to be hospitalized during her pregnancy with Rylan. Scans showed that Rylan was not growing the way that doctors hoped, also known as Intrauterine Growth Restriction (IUGR). Jessica spent two months in the hospital while doctors tried everything they could to give Rylan a chance to get bigger on his own. However, when scans continued to show that the left ventricle of Ryan's heart was not growing, Jessica was induced 2 months prematurely.

Since leaving the NICU, Rylan has needed ongoing care and continues to see many specialists. He has consistently been in the lowest percentile for weight for his age. Eating and gaining weight has been a struggle, requiring him to have a G-tube for feedings when he was younger. He also had surgery on his adenoids when he was 9 years old to help correct his sleep apnea. Rylan still attends physical therapy regularly, and although he has permanently low muscle tone, he has made huge strides in his muscle strength! In addition, Rylan is missing a muscle in his lip, has some speech delays, and has a special device in his mouth. He continues to see the cardiologist for regular check-ups, but today, his heart is healthy!

One of the most challenging things for Rylan and his family is that doctors believe that a genetic disorder is responsible for his ongoing medical issues, but so far, they have been unable to identify exactly what that might be. The uncertainty and all the testing can be draining. Still, they are grateful for the care that Rylan receives at Penn State Health Children's Hospital! His mom was able to benefit from food vouchers provided by CMN when she was an inpatient at the hospital, and Child Life has helped to keep Rylan calm and distracted during procedures.

Rylan loves music (classic rock is his favorite) and he is learning how to play the guitar. He participates in gymnastics and loves ninja warrior activities! His mom calls him "an old man in a kid's body" who is thoughtful, fun, and gets along with everyone. Rylan wants to give back and hopes to someday write a book so that other kids with low muscle tone will be able to see that they are not alone.

In addition to funding the neonatal incubator that helped Rylan grow, your gift to CMN helps kids like him by supporting programs like the Patient Assistance Fund and much more.