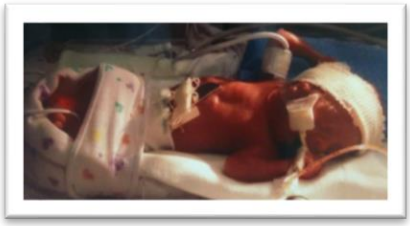
Inspired by Miracles

Meet Addison

Age 9, Lebanon



Addison was born at 25 weeks and spent 87 days in the Neonatal Intensive Care Unit at Penn State Health Children's Hospital. Her mom, Stacy, remembers, "Her skin was almost transparent, thin enough to see her veins beneath her skin. We could see her heart beating in her chest. The cartilage in her ears hadn't formed yet, and her eyes were still fused shut. She was on a ventilator. The sight was both frightening and amazing."

Stacy was on hospital bedrest in 2012 when she watched our Telethon. That year, we purchased NICU incubators. "I knew I was going to have a child that was going to spend time in the NICU and it was very reassuring and comforting."

As a result of Addison's premature birth, she has hypotonia or very low muscle tone. She also has hypermobility syndrome, which causes her joints to be too flexible, which causes fatigue and pain, especially in her lower extremities. Addison attends weekly physical therapy appointments to increase her strength, balance and coordination.

Physical therapists make the workouts fun by incorporating games and toys into the exercises. For example, the Pedalo standing bike helps Addison work on her strength and balance. When Addison leans backward to grab a toy to throw in a basket, she is strengthening her back and core. Her favorite exercise, the barrel roll, helps with sensory issues – plus it makes her giggle non-stop!

"I can't say enough good things about the therapy she receives," says Stacy. "Since starting therapy, Addison can now go up and down stairs without help, she can keep her balance while kicking a ball, and she's able to run without falling." Addison also recently started speech therapy. She JoJo Siwa, shopping and Starbucks!

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Meet Ayden

Age 5, Crawford, Pa.

Nicole felt sick most of her pregnancy. She was used to constant vomiting and frequent trips to the emergency room to receive IV fluids. But on her way home from her 27-week appointment, something felt different. She couldn't stop vomiting. She went to the nearest hospital and ultimately chose to go to Penn State Health Children's Hospital. An ultrasound showed her baby wasn't moving enough, and Nicole started experiencing terrifying hallucinations. She was diagnosed with preeclampsia with abnormal symptoms.

She remembers a doctor coming into her room and saying, "I have about five minutes before I lose them both."

Nicole underwent an emergency C-section and her son Ayden was born. He weighed just 2 lbs. 7 oz. and spent eight weeks in the Neonatal Intensive Care Unit (NICU).

While Nicole and her husband Paul took turns caring for their son, they noticed plaques on equipment like incubators that said *Purchased by Children's Miracle Network*. "It was one of the most humbling experiences I've ever been through," says Nicole. The family was also supported by CMN's patient assistance endowment, which provided gas cards so Paul could travel to Hershey from the home near Erie and still maintain his job.

Ayden is now healthy and happy! He loves baseball, ice skating, hockey, video games and his stuffed Octopus "Octi" which has been with him since he was in the NICU.

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Meet Ben

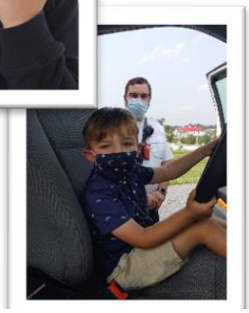
Age 4, Harrisburg

Danielle was eight months pregnant and shopping after church when she thought her water broke. She and her husband, Nathan, headed to Harrisburg Hospital and sure enough, Danielle was prepped for delivery. Since her pregnancy had been healthy, there was no immediate cause for concern.

Benjamin's birth went well, but the medical staff immediately realized he wasn't crying or breathing correctly. Benjamin was quickly whisked away to the Neonatal Intensive Care Unit (NICU). A few days later, his condition worsened. "Everything that could be wrong with his lungs seemed to be wrong," said Danielle. "His entire X-ray was all white. There were no dark spots whatsoever."

A decision came quickly. Benjamin needed to go to Penn State Health Children's Hospital, which had the highest level NICU and a high-oscillating ventilator that could save his life.

He was transported by a pediatric ambulance funded by Children's Miracle Network (CMN) Hershey. "The ambulance team worked seamlessly. They were just amazing. They made sure everything was hooked up properly."



"Driving" the ambulance

Because Benjamin's condition was so critical, a doctor explained that he may need a form of life-support called ECMO, a machine that was also purchased by CMN Hershey.

"I remember signing the consent for the ECMO and asking the doctor if we have to go to ECMO, and that doesn't work, is there anything beyond that? And she said no. Knowing that we were at that point was very scary," shared Danielle, while fighting back tears. "But he's a strong little guy. He rallied and did so well."

Benjamin didn't need ECMO after all, and a few weeks later, he was able to go home! Now four, he's surpassing many milestones! He loves baseball, swimming and playing outside. Last year, he even got to visit the new pediatric ambulance purchased by #CMNHershey!

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Meet Bristol

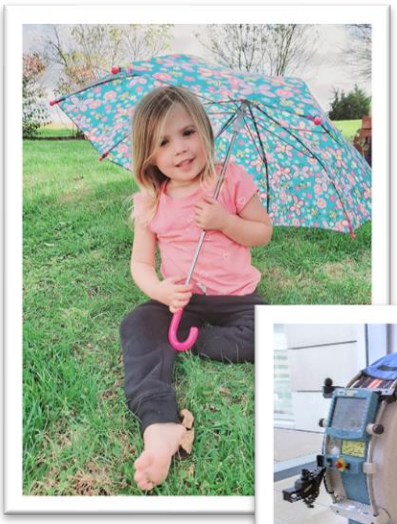
Age 5, Airville

As a paramedic, Josh is used to 9-1-1 calls. But when he saw a page for an emergency at his family's babysitter's house, his heart sank. He instantly knew his daughter, Bristol, was in serious trouble.

14-month-old Bristol had woken up from a nap screaming and then passed out. Bristol's babysitter performed CPR until the paramedics arrived. Turns out, she had experienced a cardiac arrest.

Bristol was flown by Life Lion to Penn State Health Children's Hospital and underwent life-saving surgery. She also suffered a seizure. Because she was so critical, her caregivers decided to use a portable CT scanner that was purchased by CMN Hershey to evaluate seizure activity. The scanner can be wheeled to a patient's bedside so the child doesn't have to be moved. Sometimes it can be too dangerous to move a critically-ill child.

Bristol spent five weeks in the Pediatric Intensive Care Unit and one week in the pediatric rehab unit. During her recovery, she was also helped by Child Life and Music Therapy, two programs funded by CMN Hershey.



Portable CT Scanner

It's not known why Bristol had a cardiac arrest, but her check-ups show her heart is now functioning normally!

Bristol's parents are so grateful for the care their daughter received. They even planned a family fun fest that raised $10,000 for CMN and continue to raise funds through CMN's annual events! What an incredible way to pay it forward!

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Meet De'Shaun

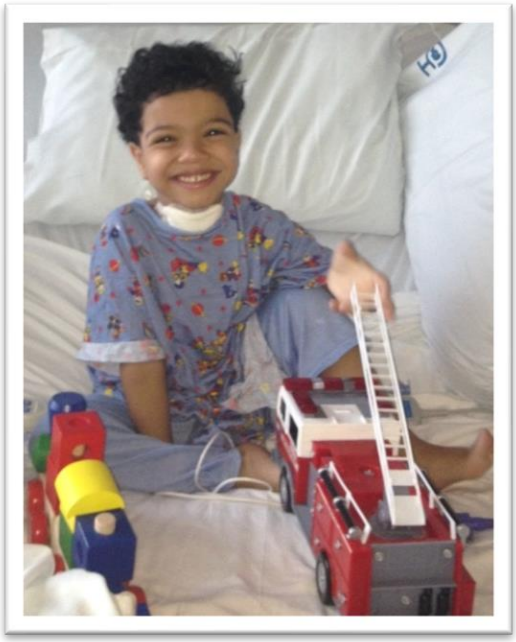
Age 14, Harrisburg

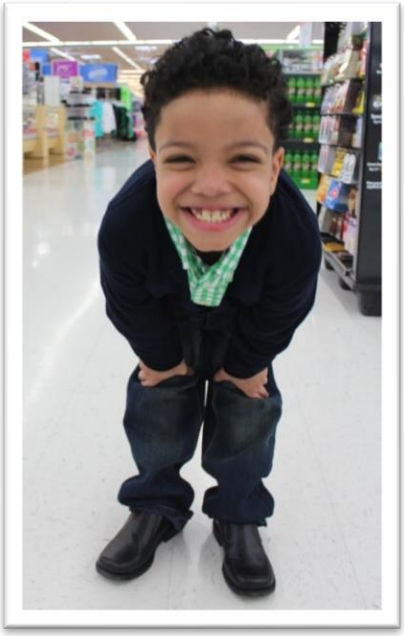
De'Shaun was born in 2007 with just a ten percent chance to survive. He was diagnosed with 13 conditions that affect his heart and lungs. He needed a ventilator to breathe and a feeding tube in his stomach to eat.

Although he will always have medical challenges, De'Shaun has overcome many obstacles. When his ventilator was removed, he got to do something he always dreamed of – swim!

Now a teen, De'Shaun loves to play video games and basketball.

Gifts to Children's Miracle Network support equipment, research, and programs to give kids like De'Shaun the #GiftofGrowingUp. Thank you!





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Inspired by Miracles

Meet Izzy

Age 5, Mechanicsburg

Written by Izzy's mom, Tina

It was my first day going solo with my three-week-old twins, Isaac and Isabella (Izzy) and my other two children. I was nursing and rocking the twins when I heard my two-year-old daughter call for help. She was stuck on the top bunk bed and didn't know how to climb down the ladder. I thought that I could maintain holding the babies while I reached up to grab my daughter's hand to help her off the bed. But as I began to reach out, Izzy fell out of my arms and landed on the floor. SHOCK! PANIC! FEAR! I quickly put Isaac down on the floor and picked Izzy up to calm her and nurse her again. I then called 911, and Izzy was taken by ambulance to the emergency department at Penn State Health Children's Hospital.

My heart broke when a CAT scan showed Izzy's skull was fractured. We were then whisked away to the Pediatric Intensive Care Unit where we faced another devastating blow. Izzy wasn't breathing well and she needed to be intubated. In addition, she had bleeding on the brain that was causing seizures. My husband and I sobbed. We were destroyed, broken and crushed. Her little body was covered with wires and tubes. It's a sight I will never forget. Because of the injuries Izzy sustained, the hospital's Child Protection team investigated. We understood why this was necessary, but it was very difficult to endure. Ultimately, tests showed Izzy's injuries were indeed accidental. The days in the hospital were long and tough, but slowly, Izzy's health began to improve.

Today, Izzy is happy, healthy and full of life! We are very grateful for our experience at Penn State Health Children's Hospital. What impressed me the most was the kind staff who chose to remember that I was a human, a mother, a wife, a daughter, and a friend that had a really bad day on December 6, 2016 and a really great day on December 18, 2016 – the day Izzy came home. Miracles happen!

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Meet Joella

Age 6, Lewisberry

Joella was born at 35 weeks and immediately transported by ambulance to Penn State Health Children's Hospital where she was diagnosed with VACTERL association, a series of birth defects. To save her life, Joella underwent 15 surgeries before she was six months old. Joella's health is now stable, but she continues to need services including physical therapy and speech therapy.

Donations to Children's Miracle Network have purchased the ambulance Joella needed and the Extracorporeal Membrane Oxygenation (ECMO) machine used during one of her open-heart surgeries. Children's Miracle Network also supports the Child Life and Music Therapy programs, which help Joella cope with her hospital appointments and procedures.

Joella enjoys riding her bike, baking and watching NASCAR! She also loves sharing her story and raising money for what she calls her "special network."

Joella also has low vision and introduced us to her friend Truffles! Truffles the cat wears glasses to show that it's okay for kids to wear glasses too. Joella and Truffles have worked together to share CMN's story near and far!

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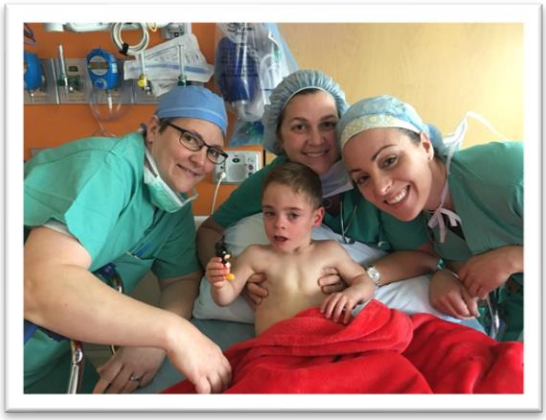
Meet Kai

Age 8, Hummelstown

Kai was born at just 25 weeks gestation and weighed one pound. His mom, Leanne, had given birth early due to preeclampsia. Leanne had lost another son just a few years earlier due to preeclampsia, and she feared she would lose Kai too.

Kai needed a ventilator, bowel surgery, and battled serious infections. He spent 204 days in the Neonatal Intensive Care Unit (NICU) at Penn State Health Children's Hospital. Over the years, Kai has continued to face challenges. He needed oxygen and steroid therapy for his chronic lung disease and physical therapy to help with his developmental milestones.



Leanne says Kai is a true message of hope in a time of darkness. The Parke family is grateful for Children's Miracle Network for providing the incubators and other equipment that Kai used during this NICU hospitalization and for the ongoing family support CMN provides through Child Life and other programs. Kai continues to experience hospitalizations and surgeries as needed and gets his thyroid checked every few weeks. But overall, he's doing well!

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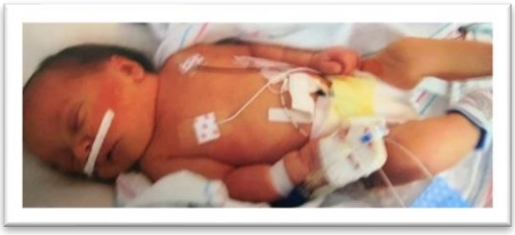
Meet Kyle

Age 12, Middletown

"Your child has a major cardiac anomaly."

When Miracle Mom Mona heard these words from her doctor during a prenatal ultrasound, her own heart began to race.



Mona's son, Kyle, had a rare condition – tetralogy of fallot – a combination of four heart defects that affect the structure of the heart. As a nurse, she knew the diagnosis was life-threatening.

"I was balling. There were so many things going through my head, but ultimately we decided that whatever God gives us, we will handle."

In addition to the heart defect, Kyle was growing at a slow rate and did not have enough amniotic fluid. Mona was put on bed rest for several weeks until Kyle was ultimately born at 34 weeks gestation.

"I heard him cry and that's when I cried because I knew that meant he was breathing. I knew he was going to be okay," Mona recalls.

Kyle needed his first open-heart surgery when he was eight months old, a second surgery at 14 months and the third surgery when he was three. He also needed a g-tube in his belly for nutrition due to severe reflux. He also receives therapy for attention deficit hyperactivity disorder and Asperger's.

CMM Hershey has supported Kyle's journey in several ways from the Child Life team that helped him and his big sister Jazmyn cope with hospital stays to the neonatal and heart equipment Kyle needed when he was born.

Today, Kyle is a busy young man! On any given day, you might find him at karate or gymnastics practice, playing flag football or video games, or cheering on his favorite sports teams - the Philadelphia Phillies and Dallas Cowboys.

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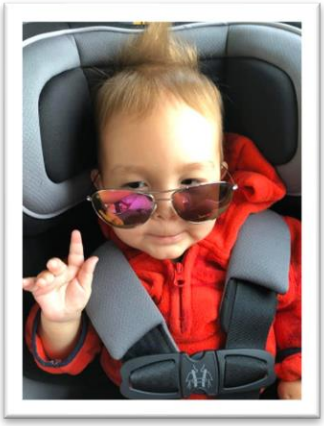
Inspired by Miracles

Meet Lucas

3, Grantville



Miracle Child Lucas is already making history! He was the first patient with spinal muscular atrophy (SMA) to receive a new gene therapy treatment at Penn State Health Children's Hospital, one of four state-designated SMA treatment care centers in Pennsylvania.

SMA is a neuromuscular disorder that affects motor nerve cells in the spinal cord and hinders and eventually takes away a child's ability to walk, eat or in some cases breathe. In severe cases, infants who appear normal at birth, never sit, roll or crawl and often need full-time mechanical breathing support by a year of age. This disorder is the number one genetic cause of death for infants and affects 1 in 10,000 children.

In 2019, Lucas received a new gene therapy called Zolgensma that targets the genetic root cause of SMA by delivering the survival motor neuron gene, which is missing or mutated in SMA. This treatment allows affected children to achieve and maintain motor milestones like sitting, crawling, standing or walking without support, and in most cases, the child will never need mechanical breathing support again.

Lucas received the therapy through a one-hour infusion. Child Life distraction toys were used to help hold him still during his IV insertion and therapy. Child Life staff also met with Lucas and his family to give them a tour of the unit.

Today, Lucas is doing well! He undergoes occupational and physical therapy and is working hard on improving his leg strength.

When you support Children's Miracle Network, you support programs like Child Life and research to help make new therapies possible. Thank you!

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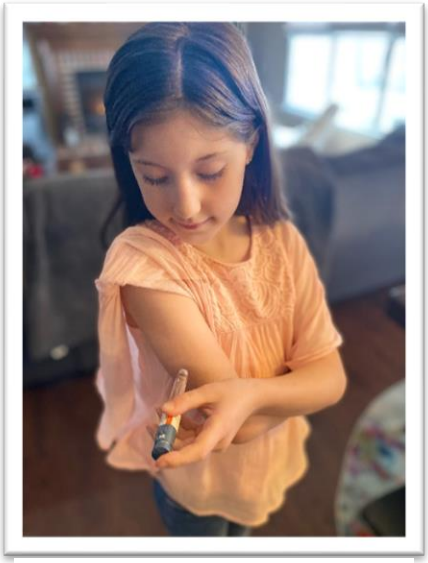
Meet Lucia

Age 9, Hershey

Just by looking at Lucia, you wouldn't know that sometimes she needs to give herself six shots a day! Underneath her bright smile, she is one tough girl.



Lucia giving herself insulin

When Lucia was six, she started losing weight and was thirsty all the time. Lucia's pediatrician discovered her blood sugar level was dangerously high, and she was immediately sent to the emergency department at Penn State Health Children's Hospital. Lucia says, "I thought that something really bad was going to happen. I was super scared."

Lucia was diagnosed with type 1 diabetes, which means her pancreas does not produce the cells that break down sugars. It's a chronic, life-long disease that Lucia manages 24/7. Her parents went through hours of training to learn about diabetes and the experience was overwhelming. It was tough on Lucia too. "I never imagined being a kid with diabetes," she says.

Lucia is insulin-dependent and wears a continuous glucose monitor called Dexcom G6 that she can check at school or wherever she is. Her parents can monitor it remotely through an app too! Now 8, Lucia can even give herself insulin shots. "It was a little hard at first, but you get the hang of it," she says. Lucia's family has also learned which types of carbohydrates can alter her glucose levels. "I thought it was horrible at first, but you can still eat lots of things. Sometimes I get sad when I see my friends eat sweets, but it's better to be healthy and eat sweets in moderation and take good care of my diabetes." Lucia stays active too. She loves to act, dance, play tennis, jump on her trampoline and play with her Barbies.

Lucia has a Dexcom device on her arm to continuously measure glucose levels.

Children's Miracle Network provides Lucia and families like hers with financial support for initial supplies, medication and education materials, which are not always 100% covered by insurance. Children's Miracle Network also funds the KDKC and Setebaid medical camps for kids with type 1 and type 2 diabetes so kids can enjoy summer activities while learning about diabetes with the help of trained counselors, medical personnel, and dietitians. Thanks for giving kids with diabetes the #GiftofGrowingUp!

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Meet Molly

Age 16, Lancaster

Molly's journey with Penn State Health Children's Hospital began just after she turned two and had trouble walking. She was diagnosed with Juvenile Idiopathic Arthritis, which was eventually controlled with oral medications.

After several years of good health, Molly began to feel ill in December 2015. She would say she had to vomit, but never would. She started to feel like food was going to make her sick. She was refusing to eat and rapidly losing weight. After seeing various specialists, Molly was diagnosed with Avoidant Restrictive Food Intake Disorder. Molly had a fear of vomiting and she thought food was the culprit.

She immediately began a partial hospitalization program with Penn State Health Children's Hospital's Teen and Adolescent Eating Disorder Clinic. Molly and the other patients took part in daily sessions to learn about nutrition and healthy eating habits. Treatment also included music, art and pet therapy and support groups for parents.

Molly completed the 8-week program and now receives follow-up care as an outpatient. She also sees a therapist to cope with anxiety, which can trigger her eating disorder. Best of all, she's back to doing the things she loves including hanging out with friends and singing! Molly has sung the national anthem at several Lancaster Barnstormers and Harrisburg Senators games. She takes several dance classes a week and is training her own service dog!

Donations to Children's Miracle Network fund research, equipment and programs like the Eating Disorder Clinic which treats more than 12,000 patients annually. From group therapy supplies to toys and games for patients, CMNH donations give these Penn State Health Children's Hospital patients every chance for a healthier future. And with the new Lancaster Pediatric Center opening in 2022, Molly will have access to behavioral health specialists close to her home.

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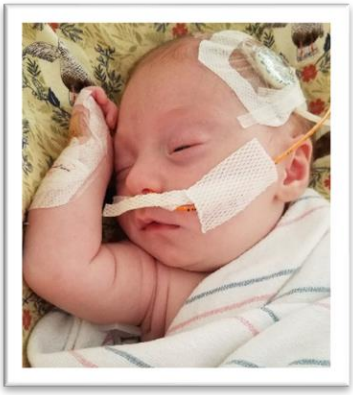
Meet Stella

Age 4, Reading

Stella's miracle journey began when she was born in 2017. Her mom, Sophie, had a normal pregnancy, but immediately after Stella was born at a hospital in Reading, a nurse spotted a defect on Stella's back – a symptom of spina bifida, which occurs when a baby's spinal cord does not develop or close properly in the womb.

She was transported by Life Lion pediatric ambulance to Penn State Health Children's Hospital for surgery. Soon after she went home, she was readmitted to place a shunt in her brain to drain fluid.



While shunts save lives, they can become infected or clogged, and little Stella has had more than ten surgeries in just her first two years of life. She also needed a laminectomy (spinal surgery) to remove additional fluid and scar tissue.

CMN Hershey has helped Stella throughout her many hospitalizations. Child Life used toys to distract Stella from uncomfortable procedures, and she LOVES Becky the facility dog. She has also enjoyed many music therapy sessions and benefited from equipment in the Neonatal Intensive Care Unit. In addition, CMN funded the pediatric ambulance that transported Stella and an isolette she needed in the Life Lion helicopter.

Stella loves coloring, swimming and doting on her baby brothers. For Doctor's Day, she honored her surgeon, Dr. Rizk!

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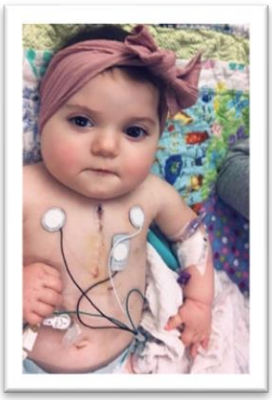
Miracle Family

Inspired by Miracles

Meet Tallulah

Age 4, Carlisle

Just a few minutes after she was born, Tallulah turned blue. X-rays showed she had esophageal atresia – her esophagus was not attached to her stomach. When she was placed in an incubator to be transported to Penn State Health Children's Hospital, it would be the last time her family would see Tallulah without tubes on her face for nearly three months.



Her mom Brenna shares, "After 7 hours in surgery, our girl came back to the Neonatal Intensive Care Unit (NICU). She came back intubated. She came back fragile. She came back with a chest tube."

Tallulah fought through many milestones and setbacks over the next 12 weeks until she finally came home. In the past three years, Tallulah has needed heart surgery, feeding tubes and therapies, but she has faced each battle with pure determination.

Brenna adds, "She is a fighter, and she sure fought her way home."

Brenna shared these numbers – a reflection of their miracle journey.

1 *in 4,000 babies is born with esophageal atresia.*
2 *cases of aspiration pneumonia.*
3 *months we lived away from home while our daughter lived in the hospital.*
4 *major surgeries in her first two months of life.*
5 *holidays we celebrated in the NICU.*
12 *weeks of a lot of heartaches, worry, and unanswered questions but also answered prayers, progress, and healing.*
84 *days we spent in the hospital with our daughter.*
Countless *prayers, phone calls, texts, visits, words of encouragement, labs, heel sticks, tears, and hearing about how my strong, beautiful baby girl was one amazing little human.*

Children's Miracle Network provides equipment like incubators and care items for NICU babies. In 2020, Penn State Health Children's Hospital added three new floors including a bigger NICU with 56 beds. Gifts to CMN Hershey helped to fund cameras for each incubator so parents can keep a close watch on their little ones even when they can't be in the hospital. Thank you for giving our tiniest patients the #GiftofGrowingUp.

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