

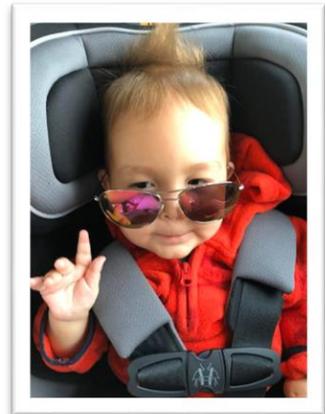
# Inspired By Miracles

## Meet Lucas

19 months, 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 Children's Hospital, one of four state-designated SMA treatment care centers in Pennsylvania.

SMA is a neuromuscular disorder which 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! Now 19-months-old, he undergoes occupational and physical therapy and is working hard on improving his leg strength. His parents hope he'll be crawling soon. Cognitively, he's right on track.

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

Meet more Miracle Children at [CMNHershey.org](https://www.CMNHershey.org)

**Thank you for giving the #GiftofGrowingUp!**



# Inspired By Miracles

## Meet Tallulah

Age 3, 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 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 are 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 heartache, worry, 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 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 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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# Inspired By Miracles

## Meet Bristol

Age 3, 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 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.



It's not known why Bristol had a cardiac arrest, but her check-ups every three months show her heart is functioning normally! Now 3-years-old, Bristol is on the move! She loves Mickey Mouse, trains, coloring and playing with her younger sister, Kasen.

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 at Penn State Children's Hospital! What an incredible way to pay it forward!

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# Inspired By Miracles

## Meet Ayden

Age 2, Meadville

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 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.



Ayden is now two-and-a-half-years old and was recently discharged from the NICU follow-up clinic. He's still tiny, but doing well. He needs nutritional supplements, but is excelling cognitively and developmentally.

Ayden loves his little sister Hailey, watching Mickey Mouse Clubhouse and riding his bike. Even though Ayden and his family live near Erie, PA, they continue to drive to Hershey for his care.

Nicole says, "We traveled over 300 miles to ensure we received the best care possible. The staff at Hershey is the best!"

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# Inspired By Miracles

## Meet Stella

Age 2, Reading

If you see Stella coming your way, watch out! She recently got her 1<sup>st</sup> wheelchair and she's been on the move ever since.

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 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 facility dog Becky. 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 is currently a patient at the Penn State Children's Hospital feeding clinic to learn to eat more foods. Funnily enough, her favorite food is meat! She also loves coloring, swimming and doting on her new baby brother, Joey.

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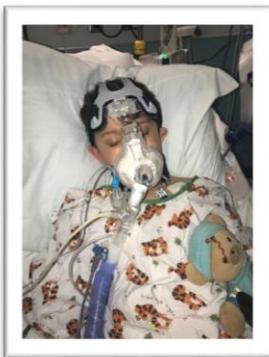
## Meet Kyle

Age 10, Middletown

“Your child has a major cardiac anomaly.”

When Miracle Mom Mona heard these words from her doctor during a pre-natal 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. The tube was just removed last summer. 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.

And now that his g-tube is out, Kyle and his family are hoping to plan a vacation to Disney World!



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# Inspired By Miracles

## Meet Ramiah

Age 1, Harrisburg

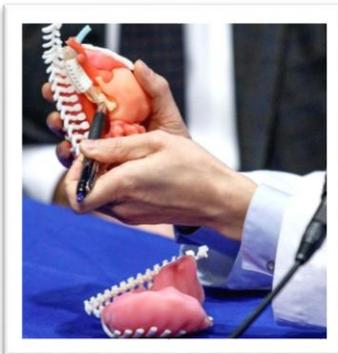
When Leanne Martin found out she was expecting her fourth daughter, Ramiah, she hoped her pregnancy would be routine like her others. But this pregnancy turned out to be drastically different.

A prenatal ultrasound revealed something was wrong with Ramiah's heart. Leanne was able to carry Ramiah to full-term and gave birth at a hospital in Lancaster.



"But when she was born, she looked blue and wasn't crying," Leanne recalls.

Doctors soon realized Ramiah's situation was far more complicated, and she was transferred to Penn State Children's Hospital. Shortly after her arrival, it became clear that Ramiah had an extremely rare developmental abnormality called tracheal agenesis: she didn't have a trachea, or windpipe.



*Photo from PennLive*

Most children with this condition do not survive. To give Ramiah a fighting chance, she needed immediate surgery, and her medical team had to develop a way to essentially build a trachea.

Using the expertise of multiple specialists at Penn State Children's Hospital and other medical centers, including engineers and radiologists, a 3D-printed device was surgically implanted as a scaffold to help Ramiah's esophagus serve as a replacement for her missing trachea. She also underwent surgery for a congenital heart defect. This

case marks the first time that 3D printing technology was used to "build" such a device and successfully implant it in a patient with tracheal agenesis. The device is bioabsorbable and designed to provide a durable tracheal replacement. The replacement of Ramiah's trachea was just one of several surgeries the infant underwent in her first few months of life.

Despite her challenges, Ramiah has made significant developmental progress. For example, she loves to interact with her big sisters and can communicate a few words through sign language. On Jan. 30, 2019, she went home from the hospital for the first time.

“For people in the central Pennsylvania area, [Penn State Children’s Hospital] has great staff and so many wonderful things happening here. You don’t have to travel far for good help,” Leanne Martin said at a news conference, moments after her daughter was discharged from the hospital.



*Ramiah with her mother Leanne*



*Ramiah with her sister Rebekah*

Ramiah is now among the very few children worldwide to survive this condition. Medical publications report only one other in the United States. Nonetheless, her prognosis is uncertain. She still depends on a ventilator to assist with her breathing and is fed by a tube in her stomach. She will face additional surgeries as she grows.

“We never lose sight of the fact that the focus of our work is a patient and her family,” said Dr. Robert Cilley, surgeon-in-chief at Penn State Children’s Hospital. “Nevertheless, it is a remarkable accomplishment to bring so many experts together to create a unique solution for a patient with such a serious problem.”

Donations to Children’s Miracle Network make possible investments in state-of-the-art treatments and research to give children like Ramiah a fighting chance. Children’s Miracle Network also supports the programs that have helped Ramiah’s siblings and parents cope with her complex condition. Child Life uses play therapy to interact with Ramiah and her siblings, and the Hummingbird Team helps to coordinate her complicated care and support the family’s emotional and social needs.

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# Inspired By Miracles

## Meet Benjamin

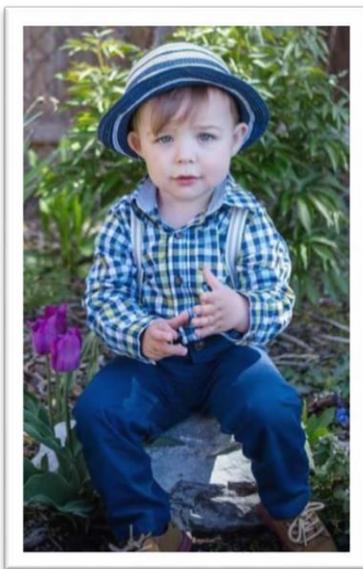
Age 2, Harrisburg

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 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."



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 two, he's surpassing many milestones! He's obsessed with the TV show Daniel Tiger's Neighborhood and loves playing what he calls "bat ball" (baseball) with his family!

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# Inspired By Miracles

## Meet Izzy

Age 2, 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 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 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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# Inspired By Miracles

## Meet Jake

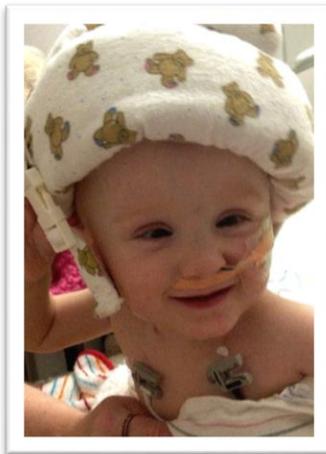
Age 6, Palmyra

Like many expectant parents, Kari and John were excited about growing their family. But then their son, John Eric Petrone, III, known as “Jake,” was born at 24 weeks and 4 days. Born 16 weeks early, he was considered a micro-preemie on the cusp of survivability.

At birth, Jake weighed just 1lb 8oz, the same weight as six sticks of butter. Jake had no heart rate at delivery. The neonatal team at Penn State Children’s Hospital was able to resuscitate him, but they were not confident he would survive his first night. At the family’s request, Jake was baptized in the Neonatal Intensive Care Unit (NICU). The family was told to expect the worst.



*Jake in the NICU photographed beside his dad’s PA State Police badge*



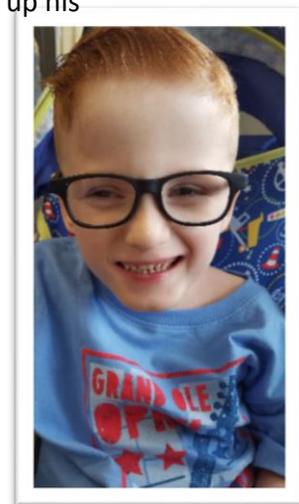
*Jake after brain surgery*

Overnight, a miracle happened. Not only was Jake alive, his condition had stabilized. John and Kari remember Jake’s doctor saying, “He’s here, and he’s not going anywhere.” At almost the exact moment, Jake raised his little arm and shook his fist in defiance!

Jake faced many obstacles during his 148-day NICU stay. “I’ve watched him die a dozen times,” says John. Jake experienced a Grade IV (the worst) brain bleed, which caused cerebral palsy. He also needed tube feedings and a ventilator. He was so small, Kari could fit her ring up his arm.

When Jake finally came home, he battled new challenges including eye surgery and brain surgery due to hydrocephalus (a build-up of fluid on the brain). He participates in speech, physical and occupational therapies to help tackle mobility issues from cerebral palsy.

Jake is a very inquisitive boy who loves to sing, dance, read and watch Daniel Tiger’s Neighborhood and American Idol. For a child who wasn’t supposed to survive his first day of life, every step of his journey has been miraculous. Your support continues to give Jake every chance to live his healthiest life.



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