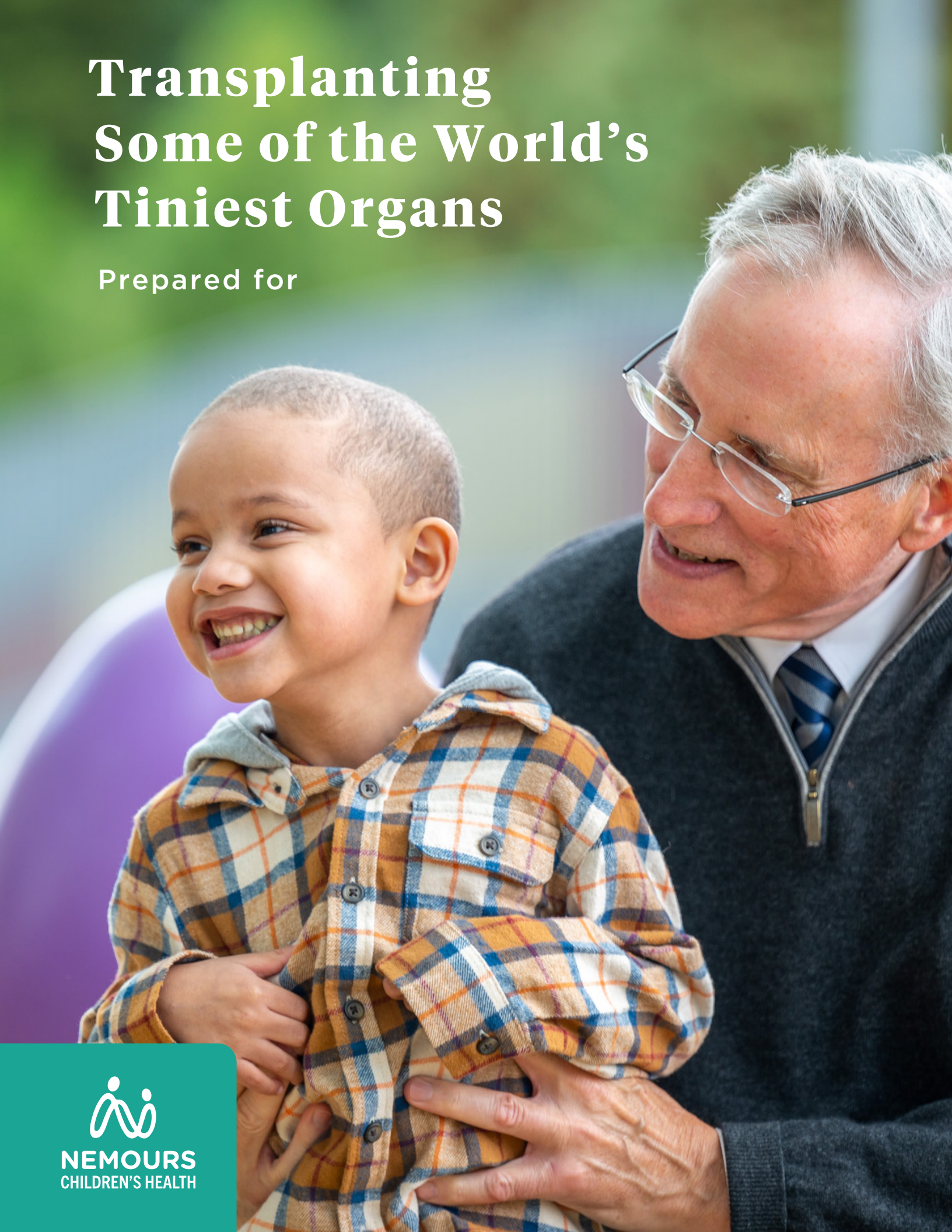


Transplanting Some of the World's Tiniest Organs

Prepared for



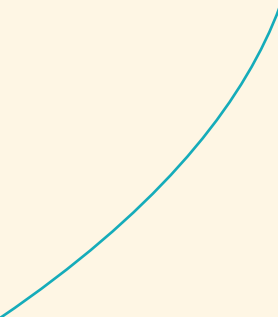
NEMOURS
CHILDREN'S HEALTH



Giving Children the Best Possible Chance at Life

Nemours Children's Health is one of the country's largest integrated pediatric health systems. Everything we do — our medical care, research, education, prevention and advocacy efforts — benefits kids. We also have one of the nation's first pediatric heart, liver and kidney transplant programs. John Noseworthy, MD, established the program during his tenure at Nemours Children's as surgeon-in-chief, which began in the late 1980s. This legacy of excellence has continued through the tenure of Stephen P. Dunn, MD, from 2000 to today. In fact, over the last 29 years, 357 transplants have helped children from more than 14 states, the District of Columbia, El Salvador, Iceland and Jamaica.

As a member of the United Network for Organ Sharing, the private, non-profit organization that serves as the nation's organ transplant system, our program has been active since our first kidney transplant in 1993. Our liver transplant program began in 2000 when Nemours Children's completed the first-ever pediatric or adult liver transplant in Delaware. Our heart transplant program began three years later with the state's first-ever heart transplant. We are one of 45 pediatric hospitals for liver and kidney transplantation in the U.S. and have the only heart transplant program in Delaware. Transplantation is one of the most heavily regulated areas of medicine.



Our highly experienced transplant team in the Delaware Valley includes surgeons; pediatricians; specialists in heart, liver and kidney disease; nurses; therapists; social workers; dieticians and child life specialists from all areas of expertise. Top-rated therapy services help post-transplant children get better faster to return home as quickly as possible. In addition, our team works with Nemours Children's pediatric gastroenterology and gastroenterology programs, consistently ranked among the nation's best by U.S. News & World Report. We treat children with the most severe and complex conditions and participate in research to improve transplant outcomes for kids everywhere.

Last year, more than 1,900 children were on the national waiting list for lifesaving organs. Over 500 of them were between the ages of 1 and 5. The need for new kidneys and livers is far greater than the number donated yearly. In addition, a wide range of illnesses results in the need for transplantation, including cancers, numerous metabolic diseases, congenital conditions like biliary atresia and chronic kidney disease. When left untreated, these disorders can lead to death.

At Nemours Children's, recent efforts have focused on providing transplants for the smallest and youngest children with organ failure. Combined organ donation and transplantation techniques have created strong outcomes for these children. In addition, we work with world-renowned Thomas Jefferson University's Transplant Institute for our adult living donors to ensure the latest, most-advanced care available. This collaboration of providers is time intense. Endowed funds will allow ongoing participation by vital team members.



More Than Two Decades of Visionary Leadership:

Stephen P. Dunn, MD

Chair, Department of Surgery and Chief,
Division of Solid Organ Transplantation

“When I was young, the physicians I first heard about were medical missionaries, and I always thought that what they were doing was really important. It seemed to me that helping sick people was one of the best things I could do with my life. I made that decision early — while in middle school. Over time, I knew I wanted to help children.”

— Stephen P. Dunn, MD

Little did young Stephen Dunn know that these decisions made during his formative years would result in a distinguished career as a widely renowned pediatric transplant surgeon. His combined liver and kidney experience totals more than 700 transplants. An international presenter, Dr. Dunn is also an author of well over 100 peer-reviewed articles, book chapters and abstracts and editor of one of the first comprehensive books on transplants in children.

Notably, Dr. Dunn was the first transplant surgeon in the Philadelphia region to use living liver donors and divide adult-sized livers in two to serve more children when there were not enough organs to keep up with the demand for pediatric transplants. Dr. Dunn also established a research immunology laboratory in 2000, putting Nemours Children’s at the forefront of infectious disease diagnosis. At the outset of the pandemic, we efficiently and swiftly transformed the laboratory into a site to complete COVID-19 PCR tests based on our ability to perform highly sophisticated testing.

In addition to his clinical and surgical obligations, research efforts and teaching responsibilities, Dr. Dunn has been Chair of the Department of Surgery beginning in 2013 and Chief of the Division of Solid Organ Transplantation since June 2000. As such, he is responsible for financial stewardship and budget, day-to-day operations, research oversight, educational initiatives, quality and safety objectives and management of medical staff matters, including the recruitment and retention of faculty.

Dr. Dunn feels a primary responsibility is to ensure all children in the region needing a transplant have access to this complex and costly care. He has done significant work identifying kids in need and points out that even getting primary care is difficult for some children and families.

His passion for providing access extends beyond the Nemours Children's service area. Dr. Dunn has spent decades making liver transplantation available for children in under-resourced countries. He started liver transplant programs in Bolivia, India and Jamaica. Over the last 24 years, nearly 100 children have received their liver transplants through the programs Dr. Dunn established abroad, where no access to care in these countries previously existed.



A Career Spent Leading the Field

Dr. Dunn's extensive experience has kept him in high demand as transplant science and therapies have evolved. For example, he was deeply involved in the initial studies of early immunosuppressants, including the absorption and metabolism of various drugs. With the benefit of high-performance liquid chromatography — a platform to expedite the development and understanding of pharmaceutical reaction processes — Dr. Dunn's experience positioned Nemours Children's as a leading center using medications used to prevent acute and chronic organ rejection.

In addition, Dr. Dunn helped develop and validate a real-time PCR test for Epstein-Barr virus diagnostics that aids medical management. He is also an author of a study regarding liver transplantation for children with unresectable hepatoblastoma requiring liver transplantation, published in the journal *Frontiers in Bioscience*.

In the Children's Oncology Group's AHEP 0731 study for imaging liver cancer, Dr. Dunn was a member of the central review committee and was one of several co-authors in the subsequent publications of those study results. He has also served on safety monitoring boards for the immunosuppressant sirolimus, which helps prevent rejection following liver and bone marrow transplants.



Pediatric Transplant: On the Horizon

Dr. Dunn's vision for improvements in clinical care includes making significant progress in supporting children with liver failure with new and evolving technologies before transplant. Further, he envisions refinements in techniques that will allow even the smallest children to access care globally. Finally, Dr. Dunn will work on advancements in immunosuppressive treatment that will enable children to live longer, healthier lives.

Well Beyond Medicine: Our Request for Support and Partnership

To support the next chief of the Division of Solid Organ Transplantation's critical role in the continued development of our world-class transplant program and advance vital research and pilot initiatives of resolute physician-scientists, we respectfully request your participation in a \$3 million fundraising effort to establish the Stephen P. Dunn, MD, Endowed Chair of Transplant.

Endowed funding is the most influential form of philanthropy. The Nemours Foundation permanently invests the corpus of the donation, so the fund's value and ability to impact lives grow perpetually. Our Board of Trustees allows for annual spending of 5% of the fund's market value for use each year at the chairholder's discretion to advance the work of programs, research, talent recruitment and other priorities.

As the fund's value grows through market investment and potentially other gifts, so does the annual discretionary pool available to its chairholder. In this case, Dr. Dunn would have the funds to ensure that the most pressing needs of the coming years will have a sustainable, permanent funding source to positively impact children and their families.

Successive chairholders will have the same opportunity 25, 50 and 100 years from now. When Dr. Dunn steps down from the Chief, Division of Solid Organ Transplantation position, this endowed chair would allow us to recruit a similarly renowned academic chief with a substantial record of leadership, research and accomplishments in transplant expertise.

Funding for recruitment is crucial and helps ensure that the physician-scientists considering joining the Nemours Children's transplant team will have the resources necessary to reach their full potential. Support for a promising recruit and adequate investment in their priorities can fundamentally change how we understand a problem and envision a treatment, alleviating the suffering and enhancing the quality of a child's life while leading the way toward creating cures.

Establishing perpetual funds dedicated to innovation and excellence gives Nemours Children's the ability to incubate the next great idea in transplant medicine, expedite breakthroughs in the lab and at the bedside and undertake projects that better the lives of the most vulnerable children we serve. In addition, the perpetual annual funding stream derived from this endowed chair will fuel innovation far into the future and help attract additional funders to consider investing in our work.



Children ‘Reborn’ Thanks to Transplantation at Nemours Children’s: Meet Riley

In mid-August 2021, as Melissa took her second-born daughter, Riley, to her four-month check-up near their southern Delaware home, her infant seemed fine. Looking back, Riley’s dad, Brad, said she might have been slightly jaundiced and had a little “Buddha” belly, but there were no other signs that anything was wrong. However, during her exam, their pediatrician recognized that Riley’s spleen was enlarged. Their doctor was alarmed and recommended Melissa and Riley drive straight to the Nemours Children’s Hospital Emergency Department for blood work and tests.

Following a two-hour drive north and many examinations, Melissa and Brad learned that Riley had biliary atresia. In this rare pediatric liver disease, damaged or absent bile ducts outside the liver trap bile and bile acids inside the liver. The situation may result in cirrhosis and even liver failure. Their only option for Riley was a liver transplant.

“We felt very comfortable with Dr. Dunn immediately,” said Brad. “Within a few days, we met Riley’s transplant team and knew we were in the right place.”

While it’s ideal to wait until a child has celebrated her first birthday before transplantation, Riley wasn’t processing food and needed a feeding tube by Halloween. She was very sick. In mid-November, Riley had the first of several blood transfusions. Dehydration and high ammonia levels landed her in the pediatric intensive care unit, and on the Tuesday before Thanksgiving, Riley was intubated.

The transplant team felt that plasma exchange was the next step as they waited for a donor liver. However, during the procedure, Riley coded. “Her team brought her back — twice that day,” said Brad. However, she would remain intubated until her transplant surgery.

The weekend following Thanksgiving, Riley began to accept the plasma exchanges better, and she went through dialysis daily. That Monday, the team experienced their first “false alarm” when a donor liver was available but was too big for Riley. The next false alarm came when a donor liver was too fatty. Riley had been intubated for 10 days, and her parents began to lose hope. Melissa and Brad went back to the Ronald McDonald house that night, and within an hour, they learned they had a 6:30 a.m. operation scheduled. When the time got pushed to 7:30 a.m., Brad said, “We thought, ‘here we go again.’”

However, that was Riley’s transplant day. She was back in her room that night by 5:00 p.m. with a new liver.

“We could see Dr. Dunn’s smile through his mask,” said Brad. “This post-transplant year, we’ve had our ups and downs. There have been a lot of tears through a problematic case of RSV, delays in getting Riley to sit on her own, mobility and eating. We have physical therapy coming weekly to help her with steps.”

“But now she’s an ornery pre-toddler, terrorizing her sister, Caelyn, who is nearly two years older than Riley,” said Brad. “The sisters can’t get enough of each other. Riley gets into everything she can and is doing very well. My wife and I know that we can’t control everything because people will get sick. It is what it is. But we try to control what we can and support each other and our girls.

“We know Riley wouldn’t be alive without Dr. Dunn, the transplant team and the PICU team that kept her alive,” Brad said. “The liver donor and her Nemours team gave someone as small as Riley a fighting chance to have a life. So, our hearts jump off the charts when we see her crawling around in a diaper with a big smile. We are so grateful.”



Children ‘Reborn’ Thanks to Transplantation at Nemours Children’s: Meet Amari

Alagille syndrome is a rare, multi-system life-threatening condition in which a child’s bile ducts are abnormally narrow, malformed and reduced in number. A genetic mutation causes the incurable illness and leads to a toxic accumulation of bile acids and progressive liver disease. Last year, just 2,500 kids in the U.S. were living with Alagille syndrome. Amari was one of them.

Amari’s mom, Ruth, remembers telling his pediatrician about her son’s severe and unrelenting itch that led to bleeding. Following emergency blood work, Ruth got a call the next morning to rush him to Nemours Children’s Hospital.

In Wilmington, the single mother of two met clinicians who created a plan to manage her 5-month-old’s symptoms with medications. For the next 2.5 years, Amari’s Nemours team monitored his blood every three months, and he did well. By March 2021, though, the internal itching was causing scarring. “He couldn’t reach the itch,” Ruth said. “We changed his medication to manage the itching and began to discuss a transplant.

“That September, we had a routine visit with all the usual tests. The next day, I got a call to rush him back to the hospital because there were abnormalities in his blood work,” said Ruth. “Following an MRI and CT scan, Amari was admitted to the hospital. He had a lesion on his liver and two spots on his lungs. His doctors told me that it was hepatocellular carcinoma.”

Fortunately, the lung spots were not cancerous. However, the lesion in his liver was growing at a rapid pace.

“I understood that we needed to get the liver out of Amari to cure his cancer and organ disease,” said Ruth. “Up until that point, I had been working full-time, fighting to keep my job while caring for my son. So, it was a lot of information all at once.”

The next step for Amari's transplant team was to create a compelling case citing his cancer to get him onto the top of the organ waiting list. Fortunately, the plan worked.

"If Amari didn't have the lesion, he might not have made it to the waiting list," Ruth said.

Time passed, and Dr. Dunn and the transplant team were concerned. Finally, they got a call notifying them that a liver was available. However, there was a mass on it that rendered it unusable. When they received a second call from his transplant team, Amari had a fever which meant he could not safely go through a major surgery.

"We had many people praying for Amari at that point. But the cancer was growing so fast that the transplant team and Dr. Dunn felt they might have to treat him with chemotherapy before his transplant surgery," said Ruth. "The team explained that another option was to cut off the blood supply to the lesion. It would mean an additional major surgery, but I knew it was the best for Amari and would buy him some time.

"That night I cried, prayed and pleaded to God because I couldn't watch my son suffer anymore. It was the first time I let it all pour out. Until then, I knew I had to stay strong for Amari. The next morning, we heard from the team, and I felt in my heart that this was the liver for my son — it was his time. And it was."

Amari and his family are approaching his "transplant-a-versary," which they will celebrate with enormous gratitude.

"While we have endured obstacles since he received his new liver, Amari can finally be a normal kid," said Ruth. "Dr. Dunn, the transplant team and the nurses at Nemours Children's provided amazing care to our family. They kept me completely informed at every step, and their warmth and compassion let me know that I was not alone. Of course, I am still not alone. They are fighting for Amari as hard as I am."



Children ‘Reborn’ Thanks to Transplantation at Nemours Children’s: Meet Ariana

Six-year-old Ariana recently began cyber school, and she loves it. Her mother, Maria, was not sure she’d ever reach this milestone. Ariana spent the first week of life in the NICU of a Philadelphia hospital. Maria was sick when she gave birth and couldn’t see her daughter for four days. When she did, Maria found Ariana severely jaundiced. Ariana was seeing specialists from a pediatric Philadelphia hospital to help determine what was wrong.

Maria had Ariana transferred to the pediatric hospital, where she was in the NICU for additional testing and care that lasted nearly a month.

Ariana was soon diagnosed with juvenile nephronophthisis. Her kidneys were not working, and she needed dialysis. Her care team placed a central line in Ariana to facilitate lab work, shaved her head to place IVs, performed a bone marrow biopsy, and put a peritoneal dialysis port in her belly for home dialysis. That day, Ariana went into cardiac arrest. She was two months old.

“I thought I was going to lose my child,” said Maria.

Ariana was on a ventilator for two weeks and in the PICU for nearly two months. Finally, Maria began learning how to perform dialysis at home so her daughter could be discharged. But numerous complications led to Ariana spending her first year of life in the hospital.

“I kept questioning myself — why Ariana? I took good care of myself while I was pregnant; I didn’t drink or smoke. So why was my daughter suffering like this?” asked Maria.

For the next two years, Ariana received her care at the same hospital. Then, Maria noticed that Ariana developed a heavy cough in the middle of the night.

“I put my hand on her back, and she threw up large blood clots,” Maria said. “Our local pediatric hospital didn’t have a liver specialist, so

they sent me to a second children's hospital for testing. There, I was informed that Ariana needed a new kidney and would require a liver transplant when she was older. But something didn't feel right to me. My gut told me I needed to take her somewhere else."

Ariana was 3 years old, still on dialysis, and had developed an intense itch. So her doctor started Ariana on a new medication to combat high phosphate levels. Just a few afternoons after taking the prescription, the family was in their living room, and Ariana asked her mother why she had turned the lights off. She told Maria that she could not see. They returned to their hospital, where an eye specialist examined Ariana and informed Maria that her daughter had gone blind due to kidney disease.

"I was devastated and still didn't have a clear answer as to why my daughter was throwing up blood," said Maria. "One of Ariana's nurses — an angel, really — took me aside and told me to do my research but to take her to Nemours Children's in the meantime. The same nurse called Nemours Children's and told them about Ariana's case. The next day, I got a call from Nemours asking me to bring Ariana to Dr. Dunn immediately."

"When we got to Nemours, Dr. Dunn touched Ariana's belly and said, 'Oh, yes — Ariana needs a liver transplant.' Then, he left the room and returned with kidney and liver transplant papers for my husband and me to review. I burst into tears and hugged my daughter while my husband signed the papers."

After her transplant surgeries, Ariana's skin color normalized, her eyes were no longer neon yellow, and her itching ceased. Maria calls it a complete U-turn.

"Now she eats everything, loves to ride her bike, play dress up and LEGOs, jumps on the trampoline — these are all activities she couldn't do before the transplants," said Maria. "Ariana loves to socialize with people and asks them questions about everything. She is a brand-new child! We can't thank Dr. Dunn and the transplant team enough."





Thank You!

We truly appreciate the opportunity to present this significant investment for your review. Nemours Children's stands at the precipice of an exciting new era in our mission to transform pediatric health by providing care, conducting impactful research and educating the next generations of care providers — all to create the healthiest generation of children in our country's history. Thank you for considering our request to join us as a partner in this crucial work.

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