

# STORIES

For friends of Duke Children's // Spring 2022

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COMBINATION  
TRANSPLANT SAVES  
BABY'S LIFE // 2

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PASSIONATE  
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## The Back Story

Two athletes  
power through  
spinal fusion surgery

## An Incredible Journey

A bright future for twins  
born at 23 weeks







## Go Duke!

To celebrate March Madness, all the babies born at Duke in March received Duke Athletics onesies. Duke Children's is proud to partner with Duke Athletics through Birdies for Babies with Men's and Women's Golf, K's for Kids' Cancer with Baseball and Softball, and the

Charity Stripe Challenge with Men's Basketball.

We also want to extend our gratitude to Coach K for all he has done for Duke Children's. We wish him well as he concludes a legendary career as one of the greatest coaches of all time.

Learn more at: [bit.ly/dukeathleticpartnerships](https://bit.ly/dukeathleticpartnerships) and [bit.ly/dukecharitystripechallenge](https://bit.ly/dukecharitystripechallenge).

## letter from the chair

Dear Friend of Duke Children's,

Just a few decades ago, being born at less than 26 weeks was a death sentence. Now babies born incredibly preterm, like twins Amal and Alizay Madni who were born at Duke Children's at 23 weeks, can not only survive but thrive. Read more about their journey and how Duke Children's neonatal care program prepares our most fragile infants and their families for long-term success on [page 6](#).

Duke Children's is also home to the Child Abuse and Neglect Medical Evaluation Clinic, a critical community resource that serves children who are potentially facing sexual or physical abuse or neglect. The providers who have devoted their lives to this population face many challenges, but they are not alone—Steve Felton, a Duke Children's donor, has turned his passion for giving back into crucial support for this important clinic. Read more about the clinic and Felton's generosity on [page 12](#).

Athletic achievements and spinal surgery for scoliosis do not seem like they could coexist, but this is the reality that two remarkable young athletes live every day. Taylor McKinnon and Liza Murtagh are competitive athletes who faced severe scoliosis that could only be treated with spinal fusion surgery. Fortunately, Duke's pediatric spine specialists work with each patient holistically to best treat their short- and long-term needs. Because of this individual patient-focused care, Taylor and Liza are excelling in their athletic and academic goals. See their incredible stories on [page 16](#).

We hope you enjoy reading these Duke Children's stories as well as learning about some additional firsts we have recently celebrated: the first-ever combination heart transplant-thymus procedure in the world, performed last summer on a baby boy, which could change the way that many solid organ transplants are done in the future; the first pediatric patients to move into the new Duke Central Tower; and our first-in-the-nation ranking in National Institutes of Health funding. It's a remarkable time to be a part of Duke Children's, and we thank you for being an important part of the journey.

Because nothing matters more,



*Ann M. Reed MD*

**ANN M. REED, MD**

Chair, Department of Pediatrics  
Physician-in-Chief, Duke Children's

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SPRING 2022

A newsletter for friends of Duke Children's



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National Champion!



# Baby Receives World's First Combination Heart Transplant-Thymus Procedure

## Using processed thymus tissue from the heart donor could lower the risk of organ rejection

A baby believed to be the first person to receive a combination heart transplant and allogeneic processed thymus tissue implantation appears to be gaining the immune cells necessary to reduce or eliminate the need for prolonged use of toxic anti-rejection drugs.

The two procedures—performed at Duke University Hospital in summer 2021 under an expanded access application that was cleared by the FDA—represent a milestone in heart transplantation.

“This has the potential to change the face of solid organ transplantation in the future,” said Joseph W. Turek, MD, PhD, Duke’s chief of pediatric cardiac surgery and a member of the surgical team that performed the landmark procedure.

“If this approach proves successful—and further validation is contemplated—it would mean transplant recipients would not reject the donated organ and they would also not need to undergo treatment with long-term immune-suppression medications, which can be highly toxic, particularly to the kidneys,” Turek said. “This concept of tolerance has always been the holy grail in transplantation, and we are now on the doorstep.”

Currently, transplanted hearts have an average lifespan of about 10 to 15 years. With durability limited by the toxicity of immune-suppression drugs, other options have long been sought.

The idea of using donated and processed thymus tissue during heart transplantation has been under study at Duke and other sites for several years. Because the thymus gland stimulates the development of T-cells, which fight foreign substances in the body, implanting the processed tissue is hoped to establish the donor’s immune system as the recipient’s, so the donated heart is recognized as “self.”

By Sarah Avery

Photographs courtesy of the Sinnamon Family



Easton Sinnamon shares a happy moment with his father, Brandon, at home after his surgery. Easton continues to show positive progress nearly a year after his pioneering transplant procedure.

The approach has shown promise in animal experiments, including in Turek’s lab at Duke, but it had previously not been tried in a living organ recipient.

Duke researchers received permission from the FDA for the investigational procedures after two important factors lined up serendipitously—the youngster, Easton Sinnamon, needed both a heart transplant and processed thymus tissue implantation independent of one another, and he was a patient at Duke, where the processed thymus tissue implantation is solely available.

The processed thymus tissue implantation method, pioneered at Duke by Louise Markert, MD, uses a proprietary technique to culture and administer processed thymus tissue; the process has been licensed to Enzyvant Therapeutics GmbH. The company received FDA approval last fall for allogeneic processed thymus tissue-agdc, indicated for immune reconstitution in pediatric patients with congenital athymia, a rare condition in which children are born without a thymus. Enzyvant provided financial support for processing of the thymus tissue that was used in this research.

“We see tremendous promise in this technology for patients and we are working with urgency to advance research and development for all children in need of cardiac transplants,” said Rachelle Jacques, chief executive officer of Enzyvant.

For Easton, the first-in-human combination of procedures appears to be working.

Tests taken 172 days post-transplant/implantation indicate the processed thymus tissue is functioning, building the critical T-cells that are integral to a well-functioning immune system. Easton’s care team at Duke continues to monitor progress; another milestone is possible in several months when he could be tapered off anti-rejection drugs.

“Cases like this underscore how important new insights emerge when surgery and science are expertly practiced together,” said Allan D. Kirk, MD, PhD, chair of the Department of Surgery at Duke University School of Medicine. “This case has implications for more than just heart transplantation—it could change the way that many solid organ transplants are done in the future.”



“This case has implications for more than just heart transplantation—it could change the way that many solid organ transplants are done in the future.”

ALLAN D. KIRK, MD, PhD

“The team performed the transplant and implant in a patient who lacked significant thymus function, providing an excellent opportunity to examine how allogeneic processed thymus tissue can shape a person’s immune system to be more receptive to a donor organ,” Kirk said. “If this can be extrapolated to patients who already have a functioning thymus, it could potentially allow them to restructure their immune systems to accept transplanted organs with substantially less dependence on anti-rejection medication. The processing method used for the thymus tissue seems to be critical and is of great interest.”

Born with severe heart defects as well as thymic deficiency from an unknown cause, which severely impaired his immune system, Easton received his transplant on Aug. 6, 2021, when he was 6 months old, followed two weeks later with the implantation of the cultured thymus tissue from his heart donor.

Easton, now one, continues to do well.

“It was one of those things where it could help him, and if it works, it not only helps him, but it could help thousands of other people as well with their children who need transplants,” said Easton’s mom, Kaitlyn. “When we talked about it, it was like ‘Why would we not do it when we can make a difference for all these other people?’”



Watch a video about this historic procedure!



# Duke University Hospital Opens a New Home for Duke Children’s

By Stephanie Lopez

A new bed tower at Duke University Hospital has now fully opened, with pediatric patients and their families moving into new rooms on four floors in mid-December, 2021.

The move-in culminated years of planning and construction of the 11-floor Duke Central Tower, which was designed to provide larger, private patient rooms that accommodate technologically advanced medical equipment, more comfortable overnight family stays with additional space and furniture, and features that enhance staff and patient interactions.

“At Duke University Hospital our children’s team delivers remarkable care for patients from across North Carolina and the Southeast including many complex and medically vulnerable patients and their families,” said Thomas A. Owens, MD, president of Duke University Hospital and senior vice president of Duke University Health System.

“These patients and their parents may spend days, weeks—sometimes even months—with our caregivers,” Owens said. “Our new Duke Central Tower children’s facility is an example of our commitment to not only providing world-class clinical care, but also doing so in an environment which promotes healing and wellbeing for our patients and their families.”

Work on the Duke Central Tower began in late 2017 and cost approximately \$265 million to construct the 350-bed facility.

The building’s first four floors now serve as the new home for Duke Children’s Hospital, and special attention has been focused on accommodating the needs of pediatric patients. Many children require hospital stays of 30 days or more while undergoing treatment for various diseases, and family members often accompany them for the duration.

Features for children and families in the new bed tower include:

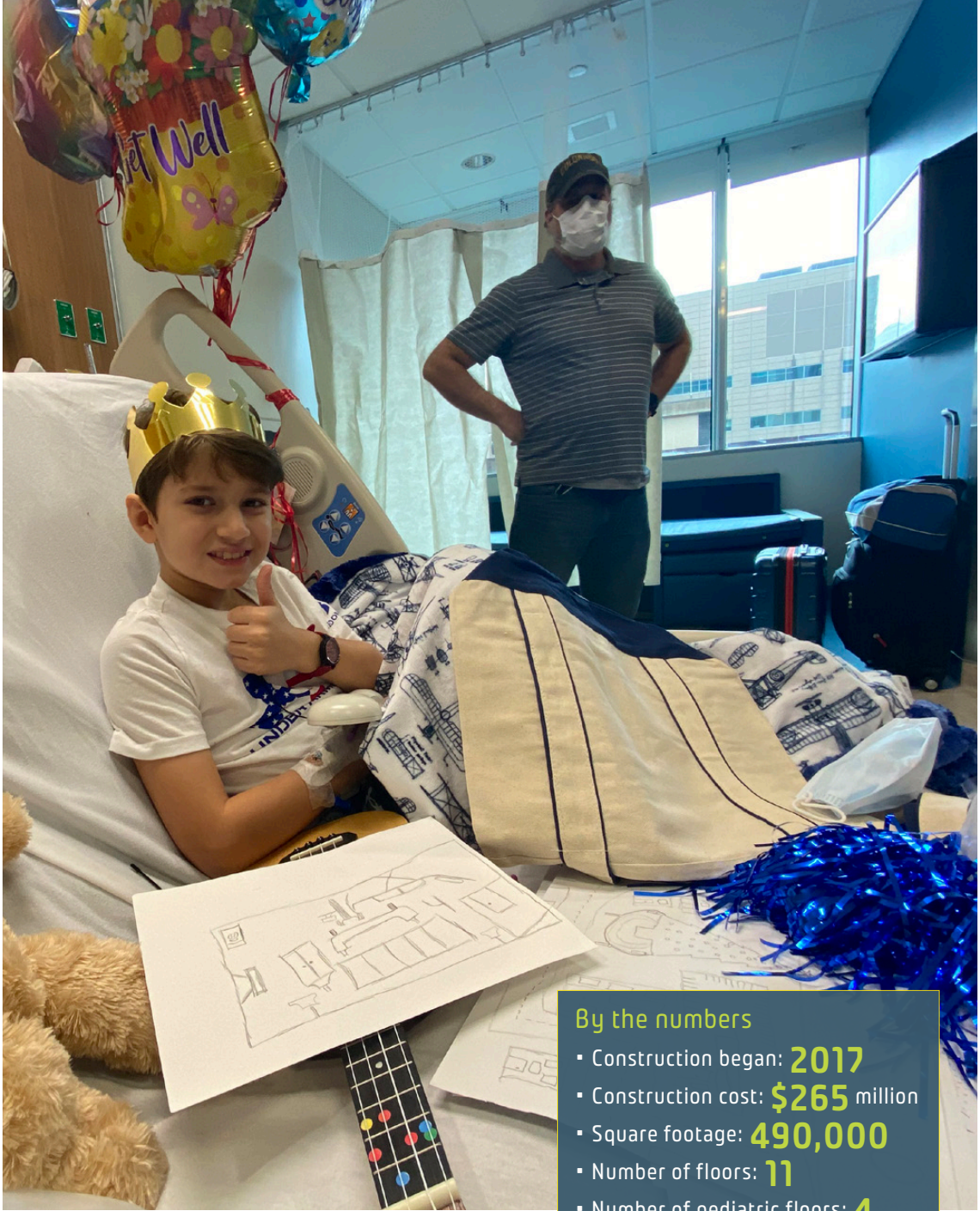
- Patient rooms that average more than twice the size of previous rooms
- Furniture that transitions into beds for family members
- Two pediatric cardiac catheterization labs
- New state-of-the-art pharmacy service
- Designated family zones
- Children’s activity rooms

“The expansion of space for pediatric care in the Duke Central Tower allows our team to provide an enhanced patient experience and for that, we’re grateful,” said Ann M. Reed, MD, chair of the Department of Pediatrics at Duke University School of Medicine. “With the larger rooms, our care teams can provide services and therapies right in the room. We will be delivering our extraordinary care in an extraordinary new space. We hope this helps families feel more comfortable and supported during their time with us.”

Moving the Duke Children’s Hospital units took three days with teams working collaboratively under the direction of a coordinated command center to create a seamless move with as little disruption as possible.

Earlier in 2021, adult patients were moved into the other floors of the new central tower, which has units for oncology, transplant, orthopaedics, and neurosciences, including neuroscience intensive care. With patients now occupying most of the new Duke Central Tower space, the older rooms at Duke University Hospital will undergo renovations and updates.

“At Duke University Hospital, we put the person who needs our care at the center of everything we do,” said Mary Martin, chief operating officer of Duke University Hospital. “The Duke Central Tower is an investment in the actualization of our values, as we care for our patients, their loved ones, and the team members responsible for providing quality care. We are proud of this new building and look forward to sharing it with our community.”



## By the numbers

- Construction began: **2017**
- Construction cost: **\$265** million
- Square footage: **490,000**
- Number of floors: **11**
- Number of pediatric floors: **4**

## Duke Department of Pediatrics ranks first nationwide in NIH funding

The Duke Department of Pediatrics has been ranked first nationally on the list of Blue Ridge NIH research grant funding for pediatrics clinical science departments with a total of \$209,692,204 for 2021. Notably, five of our investigators were ranked among the top 50 for individual research funding, including:

- Daniel K. Benjamin, MD, PhD, MPH, **#1**
- Michael Cohen-Wolkowicz, MD, PhD, **#2**
- P. Brian Smith, MD, PhD, MPH, MHS, **#4**
- Kanecia Zimmerman, MD, **#41**
- Genevieve Giny Fouda, MD, PhD, **#46**

Success in securing NIH funding is considered a strong indicator of the quality of an institution’s research. This strong performance reflects the groundbreaking work of the Department of Pediatrics’ remarkably creative and insightful faculty and dedicated research, grants management, and IRB staff. The number of people contributing to the department’s success in research is commendable, and these contributions extend far beyond NIH funding.



Watch a video about the move!



# An Uncertain Start, AN INCREDIBLE JOURNEY

Comprehensive care charts a bright future for twins born at 23 weeks

Waliya Lari and her husband, Ismail Madni,  
literally have their hands full.

As they share their family's story, they are regularly interrupted by the two squirmy, energetic girls who occupy their laps: twin sisters Amal and Alizay. The girls are typical toddlers, delightful, demanding, and full of life. Lari and Madni wouldn't have it any other way; when the twins were born, their survival, let alone the incredible successes and milestones they have reached during the past three and a half years, was never certain.

## A DIFFICULT BEGINNING

Lari and Madni came to Duke Children's after becoming pregnant with the twins; they lost their first child, a boy born preterm at 22 weeks' gestation, in the fall of 2017. The couple lived in Raleigh, and Lari's maternal-fetal medicine specialist, who was also a Duke physician, told her that Duke was the best hospital in the area for mothers at risk of early labor. Duke Children's 67-bed Intensive Care

Nursery (ICN) is a Level IV Neonatal Intensive Care Unit, meaning that the unit provides the highest level of care for critically ill newborns. It is routinely at 90% or higher patient capacity.

Amal and Alizay were born on November 11, 2018, when Lari was only 23 weeks pregnant. The twins were in the hospital for six months. As micro preemies, both girls had numerous complications. Both were on ventilators to support their breathing. Amal had a bowel perforation two weeks after birth and needed bedside surgery in the ICN as she was too fragile to move to the operating rooms two floors away. At one point Alizay's breathing tube came dislodged and would not reattach—what would happen if it didn't go back in, and she couldn't breathe? Though the situation was critical and frightening, Lari and Madni remember the incredible calm and confidence displayed by everyone involved with their care.

When Amal, left, and Alizay Madni were born incredibly preterm at 23 weeks, their parents could only dream about the girls one day walking, talking, playing, and doting on their new baby brother, Azmi.

By Lindsay Gordon-Faranda | Photography by Matthew Hooker







Being in the ICN can be overwhelming: tiny babies covered in equipment, with various tubes and intravenous lines in place, the beeping of the machines, the close quarters. Madni and Lari soon developed a daily routine in the ICN and came to befriend the providers. “I really appreciated how positive and optimistic everyone was,” Madni recalls. “It helped keep us in a good state of mind. It is bizarre to say that I miss [being in the ICN], but we had a whole little world of people who cared about our daughters as much as we did.”

**“I really appreciated how positive and optimistic everyone was. We had a whole little world of people who cared about our daughters as much as we did.”**  
ISMAIL MADNI

**WHEN WORLD-CLASS CLINICAL CARE MEETS WORLD-CLASS RESEARCH**  
Prognosis for babies born at 23 weeks is a waiting game, though now over half will survive with medical care. Complications are numerous: brain bleeds, infections,

intestinal issues like the bowel perforation Amal faced, and more. This risk drops exponentially as fetal development progresses, especially after 28 weeks. As recently as the late 1980s and early 1990s, 90% of babies born at 23 weeks wouldn’t survive.

Noelle Younge, MD, assistant professor of pediatrics, has written extensively on the improved survival rates of babies born between 22–24 weeks. More importantly, she has noted that these outcomes do not correlate with an increase in neurodevelopmental problems. “The outlook has completely changed for families facing preterm delivery at this time,” Younge states. “It wasn’t that long ago that we didn’t have that many treatment options for them.”

Extremely preterm infants have higher success rates at Duke Children’s than at comparable hospitals, in measurements involving both survival and recovery from complications. Michael Cotten, MD, professor of pediatrics and chief of the Division of Pediatric Neonatology, says the reasons why are largely due to Duke’s involvement in multiple collaborative programs.

Duke is a member of the National Institutes of Health-supported Eunice Kennedy Shriver

Neonatal Research Network, a consortium of 14 sites across the country that shares information about clinical treatments and research discoveries and participates in clinical studies. Duke is also part of the Vermont Oxford Network, a collaboration of more than 1,000 neonatal care centers worldwide that shares data on clinical outcomes and works to establish benchmarks for clinical care by conducting mass efforts on quality improvement studies. Additionally, Duke is involved with local networks, including the Perinatal Quality Collaborative of North Carolina.



“Duke has an open-minded approach to what we do well and what we don’t do well,” Cotten adds. “Being part of [these networks] allows us to participate in studies and to ask and answer questions to improve care for all babies in our ICN.”

Jennifer Peterson, MD, who was medical director of the ICN when the Madni twins were inpatients, also credits every member of the multidisciplinary team. “We are a collaborative unit that takes everyone’s piece of expertise and utilizes it to its fullest which is why our ICN has the amazing outcomes that people marvel at.” Cotten, Younge, and Peterson also acknowledge simple interventions, improved maternal care, and increased parental involvement as improving long-term success rates.

Lari and Madni were aware of the unique opportunity that being at an academic hospital provided, not just for the care given to the twins, but also for how their experience could help other families. They enrolled the twins in every research study available. “Past research enabled them to survive,” Lari says, “and we wanted to pay that forward.”

Younge is grateful to all the families who participate in research because there is much to learn, especially now that viability

for babies born at 22-24 weeks is so new. “There is still so much to be learned about how to best care for these infants.”

**CONTINUING SUPPORT**  
Amal and Alizay’s Duke Children’s journey wasn’t over after they were discharged. They were followed for several years by the Special Infant Care Program. The program, which is overseen by William Malcolm, MD, professor of pediatrics, provides comprehensive care to families who are taking their babies home after long hospital stays. Babies are monitored for a variety of developmental milestones and receive outpatient clinical care from a multidisciplinary team of providers, including physicians; a child psychologist; physical, occupational, and speech therapists; a dietician; a social worker; and others. The program also has an infant complex care fellowship program, the only fellowship of its kind in the nation, which trains pediatricians in how to care for high-risk infants after they are discharged from the hospital.

Special Infant Care also includes the Transitions Program, which provides the parents of the highest-risk infants, such as those born at 26 weeks or less or



infants going home with medical equipment, comprehensive and full-time outpatient support. This includes a pager that the parents and primary care physicians can use 24 hours a day, seven days a week, should there be an issue at home, enabling the medical team to provide immediate support and problem-solving. The Transitions team also teaches parents how to care for their medically complex children at home, including operating the medical equipment many of these babies need.

The twins and their family recently moved to Austin, Texas, to be closer to relatives. However, they waited until Amal and Alizay graduated from the Duke Children’s Special Infant Care Program, an outpatient clinical and support program for families taking their babies home after long hospital stays, before making the move.

Malcolm sees Special Infant Care as the bridge between intensive and primary care. “When you look at the roller coaster ride of having a baby in intensive care, you don’t realize how stressful it is taking them home,” he says. “Having this sort of program is





so important because it supports the family and hopefully alleviates some of the stress of taking home a fragile baby.”

Madni and Lari were grateful for this added safety net when they were finally able to take their girls home from Duke. They say they used the pager system quite often, noting that it was an enormous support system that helped them through worrisome moments. The twins were only readmitted for planned surgical procedures. “What stood out for

the twins is that while they had their challenges, they both did incredibly well,” Malcolm recalls. “After they went home, they stayed home, and that’s because the parents knew their kids, learned how to care for them properly, and alerted Duke when something wasn’t going well.”

### NOT JUST SURVIVING, BUT THRIVING

Guiding an incredibly preterm baby to a full and healthy life takes an entire village, and the providers

“Every time we visit a new doctor, they are amazed the twins were born at 23 weeks. It speaks volumes about where they were, how far they have come, and the fruit of all the work Duke has done.”

WALIYA LARI

at Duke who care for these babies do not take their responsibility lightly. Ronald Goldberg, MD, professor of pediatrics, directed

the ICN from 1996 until 2017, and witnessed enormous improvements and changes in neonatal care. He recognizes all the achievements around research and clinical care, but to him, what has always stood out about the Duke Intensive Care Nursery is a passion that cannot be quantified. “When I first came to Duke, I remember an extremely preterm baby died, and the nurses held the child as it died,” he recalls. “And I felt the one thing that the unit had is a heart. It still has that heart. It’s a moment I’ll never forget.”

“Parents trust Duke to take care of their most prized possession,” Peterson adds. “It is a privilege to be a part of the patient’s care and the family’s journey.”

Amal and Alizay’s journey to a bright future is just beginning. They both graduated from Special Infant Care when they were around two and a half years old. Shortly after, the family left the Triangle to move to Austin, Texas, to be closer to extended family—their primary reason for remaining in the Triangle was to ensure both girls completed

their follow-up clinics at Duke.

The girls, who turned three in November 2021, are flourishing in their new home. They have both been discharged from all outpatient therapies and are healthy toddlers: attending preschool, making friends, and achieving milestones such as walking and talking and having their feeding tubes removed—milestones that were distant dreams when the girls were first born. Amal and Alizay have also recently become big sisters, welcoming a little brother, Azmi, to the family in December

2021. Their parents report that the twins are doting big sisters to their newest family member, who was born full-term at 39 weeks.

Despite the twins’ difficult start, Madni and Lari look at their time at Duke with nothing but positivity, expressing gratitude to every physician, nurse, and therapist who played an integral role in helping their daughters not just survive, but thrive. “Every time we visit a new doctor, they are amazed the twins were born at 23 weeks,” Lari says. “It speaks volumes about where

they were, how far they have come, and the fruit of all the work Duke has done. They are healthy. It’s amazing.”

### YOU CAN HELP

support breakthrough pediatric research that will save lives. Go to [bit.ly/springstories22](https://bit.ly/springstories22) or use the enclosed envelope.



“It’s a gift you can’t imagine the ultimate outcome to, but it will be profoundly impactful and appreciated.”

PAM AND GERY ANDERSON  
DUKE CHILDREN’S DONORS

## Leave a Legacy for Duke Children’s

Planned gifts can be a powerful way to plan for your future. We’ll work with you and your financial advisor to create the appropriate plan that will make a difference for Duke Children’s.

Learn more about different types of tax-saving planned gifts at [bit.ly/dukegiftplanning22](https://bit.ly/dukegiftplanning22).





# A Team of Passionate Hearts

A Duke Children's clinic finds the perfect match in a supporter with a passion for helping those who need it most

A way from the main Duke University medical campus is a specialty clinic on North Duke Street—you may not have heard of it. In a building with other pediatricians, the Duke Child Abuse and Neglect Medical Evaluation Clinic (CANMEC) is a world unto itself behind frosted windows to protect the privacy of the vulnerable population who accesses medical care there.

This small clinic with a big heart serves approximately 700-800 children a year for whom there is concern for sexual or physical abuse or neglect. Children referred to the clinic may have been taken to the emergency room, their primary care provider, a mental health provider, or they may have been reported to Child Protective Services or to law enforcement. These agencies then rely on CANMEC to provide expert medical evaluation of the child's health related to possible abuse or neglect and to guide case decisions, including how best to support families.

By Miriam Sauls  
Photography by Les Todd

## A SMALL CLINIC, AN ENORMOUS NEED

The clinic has been operating since the mid-1980s and is currently directed by Aditee Narayan, MD, MPH, professor of pediatrics and associate dean for curricular affairs at the Duke University School of Medicine. "I first became exposed to the field of child abuse pediatrics when I was a resident at Duke," says Narayan. "I didn't even know it was a field or a career path, but I actually went into medical school with the goal of serving this population that I serve now, which is vulnerable children and adults in crisis."

Evaluations at the clinic include comprehensive exams for injuries, visual documentation, interviews, testing and treatment for sexually transmitted infections, mental health and development needs assessments, and screening for other adverse childhood experiences. After these assessments, the clinic helps coordinate additional services such as mental health treatment and referrals to other medical subspecialties.

While the clinic is one of five in North Carolina doing this comprehensive work, it is the only program that offers a child abuse pediatric fellowship. The first recipient of the accredited fellowship was Lindsay Terrell, MD, assistant

professor of pediatrics. Like Narayan, Terrell was similarly driven by a long-time passion to work with this vulnerable population.

During her residency at Duke from 2011 to 2014, Terrell found herself spending more and more time in the Child Abuse and Neglect Clinic. She was trained in general pediatrics and wished for a career that allowed her to impact the health of vulnerable children, specifically those in foster care. At the same time, Narayan was trying to create and fund a three-year child abuse and neglect fellowship. Fortuitously, Terrell's strong passion coincided with the beginning of the fellowship program.

But funding is always a challenge for new programs.

## AN INCREDIBLE PASSION FOR DUKE CHILDREN'S

Enter Steve Felton. Felton, a financial advisor from Rocky Mount, spent time at Duke Children's with his son who was battling a staph infection. Felton vividly recalls the day they were leaving the hospital more than ten years ago. "I said 'Lord, I know we're going home today and I'm very thankful, but I just have to do something for this hospital. I don't know what

Duke Children's donor Steve Felton with one of his paintings.



it's going to be, but when you put it on my heart, I promise I'll act on it."

Felton's desire to help Duke Children's remained until one day he had the idea to host an auction and wine tasting to benefit the hospital. He reached out to his friends, and they got to work. "I made a promise I'm not breaking," Felton says. "We raised \$27,000 that first event, and we did it again and have raised over \$100,000."

Felton was eventually contacted by a gift officer from Duke Children's Development and was invited to join the Duke Children's Board of Advisors. "I turned white as a sheet and went outside in the hall and said 'somebody get me some water.' I felt like I was going to pass out. But then I joined the board."

As a financial adviser, Felton is in a perfect position to advise clients who want to donate to local causes. His enthusiasm for Duke Children's is no doubt palpable to his clients, many of whom are now Duke Children's donors, thanks to his tireless advocacy. And that passion is also evident when he volunteers for fundraising events like the annual MIX 101.5 Radiothon for Duke Children's.

After raising money for several different programs at the hospital, Felton was introduced to CANMEC, which was looking for funding for its fledgling fellowship program. Learning about the work at the clinic was all it took to convince Felton it was a perfect place to direct his energy. Thus, the clinic got its fellowship funded, and Terrell's dream job became a reality.

But Felton didn't just raise money for the fellowship. On a visit to CANMEC, he noticed the walls were bare. So he fixed that too by



**"You never know what a gift is going to do, and one little gift can turn into another gift and another gift."**

STEVE FELTON

providing objects of his other passion—painting. Besides donating his paintings to liven up the walls at the clinic, he encourages donating to the clinic on his website, [sfeltondesigns.com](http://sfeltondesigns.com) and shares proceeds from his art sales to the clinic and other local charities.

"Steve Felton not only asked how he could help, but he actually listened and made it happen," says Narayan. "He is completely real and the ripple effects from his partnership with us have been amazing."

To Terrell, Felton was this guy in the sky who brought life-changing opportunities to her life.

She has since gotten to know him and says he couldn't have a bigger heart. "To see that his generosity has allowed us to transform the care for children in just a few years is incredible, and we are excited to see the long-term impact."

#### A CONTINUING NEED

Terrell went on to be the first director of the Foster Care Clinic within the Child Abuse and Neglect Clinic, making it the only clinic in the state that combines the two programs in one space. Terrell considers it a privilege to work with children in foster care, their foster parents, social workers, and biological parents. "During clinic days, it is only children in foster care and their caregivers who are in our waiting room." Terrell is moved by children who realize they are not the only ones in their situation. "They often express feeling sad or worried about the recent changes in their lives," Terrell says. "I get to tell them that every other child that comes in here feels the same way. And, I believe, that it is important for them to hear they are not alone."

Herself a foster parent, Terrell says, "Research shows you just need one person who cares about you, shows you respect, and how to love to improve resiliency and have a long-term impact. I often think it could be one of our interactions in here that gives children some hope for their future."

Outsiders marvel at how the clinic doctors and case workers manage coping with this intense work day after day. "It's incredibly difficult work," says Narayan. "We are sitting with people for some of the worst moments of their lives. What keeps us going is knowing that we can give care with kindness and compassion."

Narayan remembers being told multiple times that her team are the only people who have given families hope that their child is going to be okay. The team is there for families in their darkest moments, but they never claim to fix everything. "Nobody has that power," Narayan adds. "But we can help them feel that things aren't hopeless, and we can share with them what we know to help their children."

Narayan credits her incredible team as a daily motivator. The team shares the same values and supports each other through positive and negative times. She also stresses that no one on the team is impervious to the sadness they witness every day; they simply determine how to

manage it and know to rely on each other.

And that coping skill is necessary, because the need for spaces like this—not just in North Carolina, but also around the whole nation—isn't going away. "Our Foster Care Clinic has received national recognition and we're receiving questions and referrals from across North Carolina," says Terrell. "We have great opportunities to grow but figuring out how we gain support is challenging."

"This work with the clinic has far exceeded anything I ever imagined," says Felton. "And there are a lot of people in this world who have a heart to give, but they don't think their little bit matters. But I tell them you never know what a

gift is going to do, and one little gift can turn into another gift and another gift—there's no telling what it can turn into.

"I'm never too busy for anything Duke Children's needs," Felton adds. "And I say if I can do it, others can do it. I'm just a regular father with a passionate heart."

And he found his match when he joined the team at CANMEC, all with equally passionate hearts.

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Join this special group of annual donors committed to the Duke Children's mission. Members of the Duke Children's Society receive the following benefits:

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- Subscription to *Stories* magazine and *The Bounce* e-newsletter

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# The BACK Story

## Two Exceptional Athletes Power Through Spinal Fusion Surgery to Reach Their Dreams

Most young athletes would expect spinal surgery to be a career-ender, dashing their hopes for long-term competitiveness in most sports. But that doesn't have to be true.

Thanks to the pediatric spine specialists at Duke Children's, two young athletes were able to overcome severe scoliosis and get back in the competition. Taylor McKinnon, a high school hurdler, and Liza Murtagh, a collegiate swimmer, persevered through difficult surgeries and recoveries. They not only regained, but exceeded, the athletic heights they had achieved before they underwent their difficult surgeries. Both are now pursuing their athletic and academic goals.

### SCOLIOSIS IN CHILDREN

Scoliosis is an abnormal curvature of the spine usually diagnosed during childhood or early adolescence. It affects six to nine million Americans, according to the American Association of Neurological Surgeons. Although mild scoliosis usually is not serious, problems with posture, pain, or respiratory issues can develop over time if untreated. Early

intervention is key because scoliosis may get worse as children grow.

Duke pediatric spine specialists offer the full range of nonsurgical options such as casting (for younger children and infants), bracing, and specialized physical therapy, as well as advanced spine surgeries and procedures. Treatment recommendations are tailored to each child's unique anatomy and needs.

### OVERCOMING OBSTACLES

Taylor McKinnon, of Durham, began running competitively at a young age. When she was diagnosed with scoliosis as an 8-year-old, she hoped the hours spent wearing a thoracic brace—which she nicknamed “The Horrible”—would straighten the curve in her back.

Though Taylor wore the brace nearly 23 hours a day, even sleeping in it, her curve continued to progress. At age 13, the summer before her freshman year in high school, Taylor underwent spinal fusion surgery to correct the curve.

By the time of Taylor's surgery, the curve in her thoracic spine had progressed to nearly 60 degrees. Though concerned that her daughter

would have to undergo back surgery, Taylor's mom, Shawna McKinnon, says her main concern was how it would impact her running ability and her quality of life, especially her ability to bear a child in the future.

“Taylor absolutely loves to run, and she has been successful at it,” Shawna McKinnon says. “We wanted to ensure that for as long as she wanted, she would still be able to run.”

### ROUGH WATERS

A nine-time state high school swimming champion who began swimming competitively at a young age, Liza Murtagh was diagnosed at age 13 with scoliosis. Though her family knew she'd likely need surgery, they wanted to try other treatments first. The family lived in Wilmington and their pediatrician initially referred them to a scoliosis clinic in Raleigh. When that clinic proved to not be the right fit, her mother, Jean Murtagh, did additional research, and ultimately found Robert Lark, MD, MS, professor of orthopaedic surgery at Duke. After meeting him and his team, the family knew they had found the right place for Liza's care and began to regularly make the

Liza Murtagh, left, and Taylor McKinnon did not let a scoliosis diagnosis and difficult surgery and recovery slow them down in the water or on the track.



By Karen Doss Bowman

Photography by Brian Smith and Les Todd



“Aside from Dr. Lark’s experience and skills, he invests time and care in each individual patient to determine the right surgical plan.”

JEAN MURTAGH

long drive from Wilmington to Durham.

“We felt so lucky that we had found a physician who listened,” Murtagh says. “Aside from Dr. Lark’s experience and skills, he invests time and care in each individual patient to determine the right surgical plan.” Lark told Liza and her family that she would need surgery but wanted to wait until Liza was ready.

Swimming was an enormous part of Liza’s life and losing that was unthinkable. Murtagh says that Dr. Lark never pushed Liza into surgery until she was prepared and ensured that Liza remained an active part of her treatment process and the decisions around it.

After bracing for nearly two years, Liza’s curve continued progressing to over 50 degrees. It was time and, more importantly, Liza was ready to consider surgical options.

### SPINAL FUSION FOR SCOLIOSIS

Lark performed Taylor’s and Liza’s surgeries. Taylor underwent posterior spinal fusion surgery in June 2017. This procedure involves correcting and stabilizing the spine with rods and screws. Next, surgeons fuse together the vertebrae to prevent the curve from progressing. Taylor’s spine was accessed from her back, called a posterior approach.

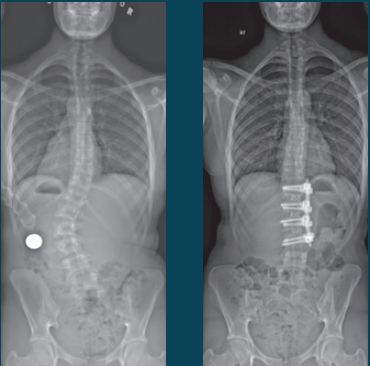
“All of our vertebrae have four separate joints,” explains Lark. “When you do a fusion, you lose the mobility of those vertebra. That’s scary for people, especially people who are as active as Taylor. They think they’re not going to be able to get back to doing sports or dancing or other activities that we assume require a lot of spine mobility. Taylor’s a good testament that some of those myths aren’t necessarily true. With proper surgical technique and recovery, kids can get back to doing what they love.”

Liza’s surgery was performed in June 2019. She had an anterior spinal fusion, which involves accessing the spine from the front of the body—behind the abdomen or chest wall. “We didn’t want to disrupt the muscles in her back because she needed those for the breaststroke and other swim strokes,” Lark says. “This approach helps preserve mobility in her upper back, shoulders, and hips.”

Murtagh recalls that right before Liza went into surgery, Lark asked her if she wanted to be perfectly straight or should he try to preserve mobility. Without any hesitation, Liza requested that her mobility be preserved.

## The BACK Story

### Before and After

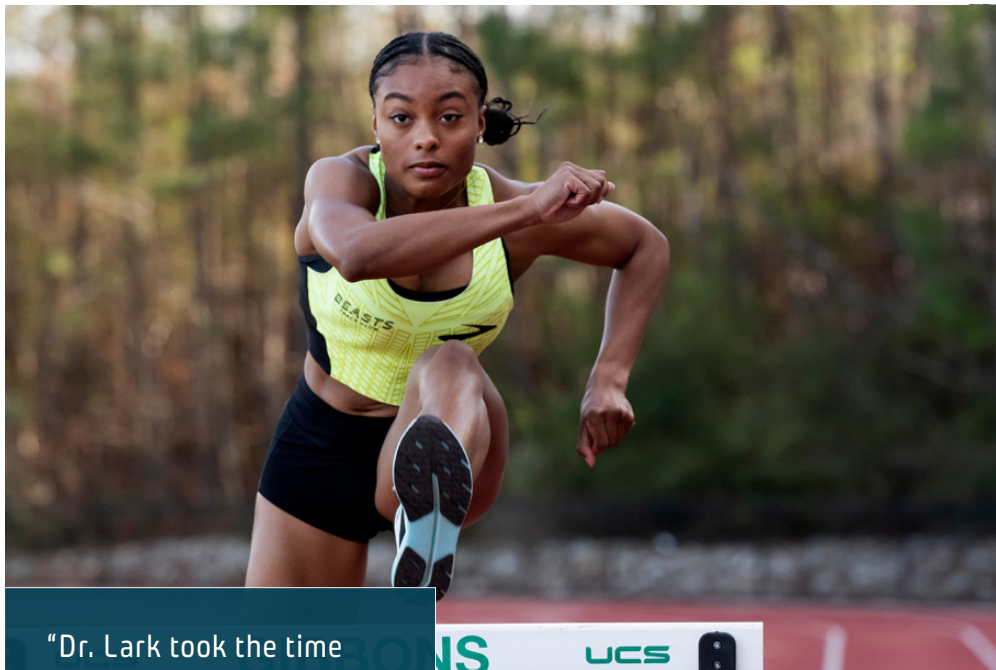


Duke’s pediatric spinal specialists will work with each family to find the best treatment option for their needs. For Taylor and Liza, spinal fusion surgery was the best option. These before-and-after radiographs demonstrate the curvature and correction of their spines. Taylor McKinnon is shown above, and Liza Murtagh is shown below.



Despite their difficult surgeries and recoveries, Taylor and Liza are excelling athletically and achieving new competitive milestones.





“Dr. Lark took the time to look at how a hurdler jumps and runs, and what muscles they use. He took time to understand her goals and her dreams of running in college or in the Olympics someday.”

TIM MCKINNON

Though the original surgical plan for Liza involved six vertebrae, Lark was able to straighten her curve and preserve mobility by fusing only four vertebrae.

#### ACHIEVING INCREDIBLE HEIGHTS

After surgery, patients stay in the hospital for a few days and then recuperate at home with limited movement for six weeks.



Taylor, seen here with her parents, will attend Vanderbilt University in the fall and compete on their track and field team.

wasn't going to have any problems after surgery,” says Taylor, now a senior at Cardinal Gibbons High School in Raleigh. “I was going to be as fast as ever. But crossing the finish line after winning that race was crazy. It was a full circle moment of just understanding that hard work and persistence really do pay off.”

Taylor will graduate from high school this spring and plans to attend Vanderbilt University where she will continue running track and field. She aspires to become a U.S. Diplomat in the Foreign Service.

“Surgery has definitely changed everything about my body, and I'm more comfortable in my own body now,” says Taylor, who won the

“The recovery piece was absolutely hard for Taylor, and it was hard for us,” Shawna McKinnon says. “But we persevered, and we did everything that Dr. Lark and the team encouraged us to do just to make sure that she healed properly. She was a true champion through it all.”

Taylor's dad, Tim McKinnon, knew she was tough enough to get through it.

“I really felt like Taylor was in good hands,” he says. “Dr. Lark took the time to look at how a hurdler jumps and runs, and what muscles they use. He took time to understand her goals and her dreams of running in college or in the Olympics someday. And he wanted to make sure that she still could pursue those dreams.”

Nine months after her surgery, Taylor took first place in 100-meter hurdles at the North Carolina 4A State Championship.

“I was really hungry to prove to myself that I



Liza currently swims for Boston College. Lark, her surgeon, cheered her on at a meet when her team came to Duke University for a swimming competition.

MileSplit National Girls Performer of the Week for Indoor Track and Field in January and received the N.C. High School Athletic Association 4A Female Track & Field Sportsmanship Award last year. “It's just opened so many doors for me.”

#### JUST KEEP SWIMMING

Liza was given strict postoperative recovery orders: no swimming, only walking for three months. Once she was cleared to swim, she still had to limit her stroke styles and what maneuvers she could do in the pool. Liza's goal from the time she scheduled the surgery was to be able to fully participate in her club and high school swim seasons. Thanks to the surgery, the guidance from Lark's team, and to Liza's work in the pool, she achieved that goal and so much more.

Now a freshman at Boston College, Liza competes in the Atlantic Coast Conference and



made the school's Top 10 All-Time Performers list in swimming. Liza had to undergo an additional sports medicine physical to be cleared for competition; the physician at Boston College said that hers was the best post-fusion mobility he had ever seen. After college, Liza plans to become a pediatric dentist.

“Dr. Lark is so good about getting to know his patients and learning about us personally. He learns about your family and your goals to decide what's going to best suit you,” says Liza, who was the 2021 NCISSA Division II State Champion in the 100 Breast and 200 Individual Medley competitions and anchored both winning 200 and 400 free-relay teams. “When we were at Duke, all

the nurses provided such a calming presence and were so supportive. The whole team just made it so much easier to recover.”

“We found the surgeon who saw that Liza's scoliosis was more a bump in the road, not the end of her journey, but a part of it,” her mother adds. “Words cannot express our gratitude to Dr. Lark for his ability to listen and to look at each individual and come up with the right game plan for them.

We appreciate his efforts and willingness to help Liza get back to competing at a high level.”

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# BOUNCING ALONG

Our community supporters put the FUN in fundraising!

## Duke Children's Charity Stripe Challenge

The first-ever Duke Children's Charity Stripe Challenge in partnership with Duke Men's Basketball concluded the weekend of the Final Four. While the tournament outcome was disappointing for Blue Devil fans everywhere, the Charity Stripe Challenge ran the entirety of the 2021–2022 season and resulted in \$107,836.30 raised for Duke Children's! Go Duke!

Prior to tipoff at every men's basketball home game during the season, a different Duke personality or celebrity guest walked out on the court with the game host, stepped up to the "charity stripe" and attempted a foul shot to help raise money for Duke Children's. A made shot earned \$1,000 and a missed shot was worth \$500. Celebrity shooters this season included Duke Men's Basketball greats such as Grayson Allen, Steve Wojciechowski, Marshall Plumlee, Danny Ferry, JJ Redick, Mike Dunleavy, and more!

Fans who couldn't be at Cameron Indoor Stadium during the season were also able to join the Charity Stripe Challenge Fan Pledge. Fans could choose a fixed amount to pledge for every free throw made by the Blue Devils during the season or could choose to make a one-time pledge to show their support. This year, the Blue Devils made 498 free throws.

Thank you to Duke Men's Basketball and all our Charity Stripe Challenge supporters!

Learn more at: [bit.ly/dukecharitystripechallenge](https://bit.ly/dukecharitystripechallenge)



Duke Men's Basketball greats, Duke Children's providers and patients, and Duke Children's supporters were all a part of the Charity Stripe Challenge, including:

1. Marshall Plumlee, Duke Children's patient Creed Kolasa, and game host Clay Glidewell
2. Viviana Martinez-Bianchi, MD, and Gabriela Maradiaga Panayotti, MD, with Gene Banks
3. Sarah Armstrong, MD, and family with JJ Redick
4. Grayson Allen with game host Rich Kirshner
5. Mike Dunleavy
6. Jen Peterson, MD, and family with the Duke Blue Devil





# MAKING MIRACLES

## Children's Miracle Network Hospitals®

Children's Miracle Network Hospitals is an alliance of 170 premier children's hospitals in North America, which collectively treat more than 17 million sick and injured children each year. Children's Miracle Network Hospitals creates strategic partnerships with businesses and organizations whose individual locations then raise money for their local hospital.

Since 1984, Duke Children's has raised funds through various Children's Miracle Network Hospitals partnerships.



## Dance Marathon is back!

Every spring, hundreds of college students on campuses from the Piedmont to the coast come together to dance the day away for an important cause—our patients! Dance Marathon is a Children's Miracle Network Hospitals student-led program on college campuses in which local students come together to fundraise throughout the year, culminating in a day-long dance marathon event. All proceeds go directly to their local Children's Miracle Network Hospital. Five campuses hosted Dance Marathon events for Duke Children's in 2022, including one high school. Together, these amazing students collectively raised \$212,721.24!

Thank you to our Dance Marathon students! We are incredibly proud of and grateful for their efforts!



## This year's Dance Marathons raised \$212,721 and included:

- N.C. State University - \$50,526.09
- Saint Mary's School - \$5,000.00
- UNC-Wilmington - \$21,282.93
- High Point University - \$6,543.00
- Elon University - \$134,364.22

## Thank you for a Season of Hope to remember!

The first-ever Season of Hope fundraising campaign for Duke Children's was an enormous success, raising \$642,990.90 for clinical care, provider education, and pediatric research. The Season of Hope launched November 1 and culminated December 14-15 with the 27th annual MIX 101.5 Radiothon for Duke Children's. Community support in the form of individual donations, business sponsorships, and project crowdfunding culminated in this remarkable philanthropic achievement, which will help support the children and families who come to Duke Children's for hope and healing. Thank you to everyone who helped to make the first Season of Hope so successful! Information about the 2022 Season of Hope for Duke Children's will be shared soon.



## An Update on Our Champion!

During April 11-16, Duke Children's patient Benjamin Pappas and his family attended Children's Hospitals Week, the Children's Miracle Network Hospitals meetings that take place annually in Orlando, Florida. Benjamin is one of eleven CMN Hospitals patients currently serving as national champions and ambassadors for CMN Hospitals and for children's health. Benjamin and the other champion families enjoyed a whirlwind week of programming, including events hosted by CMN Hospitals corporate partners such as Ace Hardware and speaking engagements at several "Meet the Champions" panel sessions. He was also the featured speaker at a session attended by representatives from top fundraising Walmart and Sam's Club locations around the country and at the Corporate Partner Summit, attended by representatives from CMN Hospitals' corporate partners. In addition to his champion duties, Benjamin and his family enjoyed a day at the Disney parks before traveling home to Raleigh. Thank you, Benjamin, for beautifully representing not only Duke Children's, but pediatric patients around the country!







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3. Call us at **919-385-3137**



## CELEBRATE and DONATE

Celebrate a birthday or anniversary by giving back. Create an online fundraiser to support the cause you care about at Duke Children's!

Start fundraising at  
[bit.ly/strongertogether22](http://bit.ly/strongertogether22).