

Coming Full Circle

Mother returns to the fragile world of the NICU

BY DAWN BRAZELL

PHOTOGRAPHY BY SARAH PACK

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One number will always stand out for Charlotte Edwards.

It is 110.

That's the number of steps based on her stride that it takes her to get from the elevator door on the eighth floor of MUSC Children's Hospital to the double doors of the neonatal intensive care unit (NICU). She knows because that is where her son, Legaré, was taken after an emergency cesarean section.

Born extremely preterm at only 25 weeks, Legaré weighed only 1 pound, 11 ounces. He had a 1 in 5 chance of surviving.

That was a number Edwards tried to ignore. Instead she focused on the number of steps it would take to get to the world of the NICU, where she and her husband would be living off and on for almost four months.

"The NICU is pretty much its own little world. It is such a rollercoaster ride. You really don't know what you're in for until you're in the NICU. There are all the beeps and buzzes and highs and lows."

The lows included being called in twice in the middle of the night along with a minister for support because Legaré wasn't doing well. He was not expected to make it.

Edwards would end up living in the surreal world of the NICU for almost four months, steeling herself as she came down the hallway each day for the news she'd receive. One day he would be thriving. The next, close to dying.

"I really had a crash course in nursing for the next 118 days. He received such excellent care and compassion from all of the nurses. It really inspired me to want to go to nursing school. I truly believe my son wouldn't be alive today if it wasn't for the staff. He got sick a lot and they were able to watch his vitals and catch his sickness very quickly."

A former real estate agent, Edwards discovered she had a gift for offering peer support to other families. Nurses noticed her gift and encouraged her to follow her calling to become a nurse.

"I've come full circle," she said in a recent interview as she tended one of two twin girls. She's back on the eighth floor of MUSC Children's Hospital as a nurse now, helping other parents in their journeys. Edwards' son is an active second grader who plays soccer, and she's grateful they have made it this far.

Every year, about 450,000 babies are born too soon in the U.S. Even if a woman does everything "right" during her pregnancy, it can happen. Most women never see it coming. Edwards certainly didn't.

"As a child, I always thought when you grow up it would be easy to have a baby. Until something happens to you, you don't realize how many things can go wrong. Having a baby is a miracle in itself. There is a human being growing inside of you, but you can have a lot of complications."

She found that out on a cool, clear day with bright blue skies on February 17, 2007. Edwards had just entered her third trimester of



A memento of Legaré's growth during his almost four-month stay at MUSC Children's Hospital's NICU.

pregnancy and was celebrating a growth spurt that merited getting some new maternity clothing. She then went to dinner with her family but began experiencing stomach pains. Going to St. Francis Hospital to get it checked out, doctors found her son's heart rate was dropping. Edwards' vitals were unstable.

The next thing she knew she was having an emergency C-section. She later found out that she had severe HELLP syndrome, a life-threatening obstetric complication involving a condition thought to be a variant of pre-eclampsia. ('HELLP' stands for the three major elements of the syndrome: H—hemolysis, EL—elevated liver enzymes and LP—low platelet count.)

"Two days later on my 30th birthday I remember waking up and not knowing what had happened. I just remember bleeding out in the OR. They were trying to let me see the baby before they transported him to MUSC because they weren't sure if he was going to make it or if I was going to make it. That was my last memory until a couple of days later. We're both pretty lucky."

Edwards was on a ventilator for several days while her son was fighting for his life. Her husband, Adam, was going back and forth

between hospitals. When she was able, Edwards was at her son's side.

"I remember thinking he just had to grow, that he was just really tiny and had to be in this incubator. I didn't grasp just how sick he was and all the things that can go wrong. His life was very fragile at that point. It's a delicate balance realizing that and trying to remain positive and hopeful."

Legaré had pneumonia twice, several different blood infections, urinary tract infections, and respiratory issues. Getting him off the ventilator was important. Friends reassured her, telling her not to worry, but Edwards knew what hung in the balance.

She treasured his good days—days when she could do kangaroo care, which meant she got skin-to-skin with Legaré just to cuddle with him. It's a therapeutic practice with wonderful healing benefits for these babies, one she now as a nurse encourages her patient families to do. 'Kangarooing' gave her moments when she could just let the hospital monitors fade away and indulge in feeling like a mom.

"It raises awareness that the NICU just isn't a place to grow. These are sick babies. All of their organs are immature and a lot can happen in the NICU. We had a couple of good weeks and, when

everything looked great, I would kangaroo. Then he got pneumonia and he had IVs coming out of his head, his arms—all over the place. You can tell people it's going to be a rollercoaster ride, but you have no idea what that means until you're on it yourself. You just jump on and hold on. It's a complicated and long road to recovery."

It's a journey that doesn't end at discharge, either.

Legaré faced multiple appointments with health professionals, including occupational and physical therapists and a nutritionist to help him, especially since he was diagnosed as failing to thrive. Edwards sweated over trying to get her 6-month old son to eat a meager 3 ounces—just 100 ccs.

"I can remember at night trying to feed him and crying because I knew if I couldn't get him to eat we'd be going back to the hospital to get a feeding tube. Every week someone would be coming in to do some type of therapy. It was like a revolving door. It was a whirlwind of doctors' visits for the first year of his life."

While other parents were celebrating other types of milestones, Edwards was celebrating that her son at 9 months wouldn't have to get a feeding tube. He would have to have antibody infusions, though, to help fight infections to which he was more susceptible. The first several years were difficult seeing if he was going to have delays and if he was going to get a lot of infections.

After Legaré turned 18 months old, Edwards started a parent partner program to offer bedside support for NICU families and to help them navigate what can be a complicated medical labyrinth.

"You can feel very isolated. I just felt parents needed to meet other parents in the same situation. I started coming back and giving bedside support and just offering resources to them."

That outreach confirmed her calling to go to nursing school and she joined MUSC Health a year and a half ago. She's also on one of the design teams planning the new \$350 million Children's Hospital and Women's Pavilion slated to open in 2019. The teams all have a doctor, nurse, and parent representative on them. (Click here to read more about the new hospital.) Edwards said she's been pleasantly surprised that the parent input is weighed so heavily.

"I think it's wonderful that the new hospital will be based on family-centered care. When your baby is in there, it's still your baby even though you don't feel you have the right to change a diaper or take a temperature. Sometimes you feel you have to ask permission to be part of their care. It's important for the parents to feel like they are part of the care team and to develop the skills they need for when they take their babies home."

Though nurses already practice family-centered care, the new hospital will allow more privacy and space for families to be with their



Charlotte Edwards and Legaré today. Legaré is now an active second grader who plays soccer.

babies. The design will facilitate practicing family-integrated care, a cause dear to her heart.

"We're good at promoting for parents to be patient advocates. We want them to be the voice of their baby. I think that's something we do very well in the NICU. We encourage families to ask questions. They are at the bedside every day. Staff can come and go, but they are the ones who know their baby."

Edwards exudes a sense of calm in the NICU. Obviously, nursing suits her.

"I like being a part of the nursing staff and really enjoy the interactions with the family members. It helps that I can relate to their stories. For example, a mom crying because she has to leave her baby, or when there is a setback regarding their baby's health. The nursing staff really takes pride in the care we give."

Edwards recently spoke to physicians at grand rounds to tell them her story and remind them of the human element that drives all of their work. She shared with them just how long that walk down the eighth floor hallway was for her. And when she finds herself rushing down the eighth floor hallway going task to task, she slows herself down.

"I remind myself that for the people I am walking next to—this could also be the longest hallway of their life."

Interview

MUSC Children's Hospital Welcomes Pediatric Neuroscience Specialists



Dr. Thomas Koch (left) and Dr. Ramin Eskandari (right).

In the summer of 2014, two new specialists in pediatric neuroscience arrived at MUSC Children's Hospital. **Thomas K. Koch, M.D.** was appointed to the position of Division Chief for Pediatric Neurology. Previously, he was Division Chief of Pediatric Neurology at Oregon Health and Science University for 16 years. He has also held clinical faculty positions at the University of California, San Francisco and the University of Maryland in Baltimore. **Ramin Eskandari, M.D., MS**, was recruited to be the hospital's pediatric neurosurgeon following his Stanford University fellowship.

PN: What are the pediatric neurological needs in South Carolina?

RE: From a neurosurgery standpoint, hydrocephalus management is the most common need. There is a lot of low or no prenatal care in South Carolina. Babies are born early, have hemorrhages, infections, and undiagnosed anomalies. I'm managing those patients in a different way, using new endoscopic techniques to treat hydrocephalus.

Brain tumors are number two and we're building that program with pediatric oncology. The third highest need is trauma. I'd argue that pediatric head trauma (from concussions or abuse) and spine trauma are underdiagnosed and the ramifications of not catching them early are underappreciated.

TK: In terms of nonsurgical neurological disorders in children, one of the leading diagnoses nationally is primary headache disorder. This is a spectrum, with migraine as the major component. It accounts for missed days of school, parents missing work, and frequent doctor's office and emergency room visits. Another major area of need is epilepsy. The number of children with new-onset

seizures needing a neurological evaluation exceeds the supply of pediatric neurologists nationally. Many of these children have complex needs, and addressing all of them is crucial for the delivery of comprehensive care. Other major areas of need are cerebral palsy and movement disorders, such as tics and Tourette Syndrome.

PN: Dr. Koch, can you give us a sense of your plans for building the division?

TK: I would like to establish within the division areas of specific strength to serve as regional and national referral centers. An academic medical center needs to serve as a health, healing, and discovery resource for the community, including the medical community. My first order of business is to expand our already comprehensive epilepsy program with the recruitment of additional pediatric epileptologists and the expansion of pediatric neurosurgery.

PN: What are your research interests?

TK: My primary area of interest is headache disorders. I was involved in a study at Oregon Health and Science University looking at the Emergency Department (ED) management of severe headache in children. Some of the preliminary work has already been published. I have discussed this work with our pediatric ED staff here and we are looking into re-evaluating our approach and trying to adopt a standardized protocol.

RE: When I came here I was lucky to have a start-up lab funded, which I'm outfitting, in the Darby Children's Research Institute, and the basis for my lab research is neonatal hydrocephalus. I've been doing that for 12 years and have had some small grants from research institutions. We are looking at the

brain and its damage from hydrocephalus. The goal is to predict the point of irreversible damage. At the moment there are few evidence-based and clinical guidelines to guide surgeons as to when to treat pediatric patients with hydrocephalus. In my view, a lot of the deficits that we incur by delaying treatment or not recognizing the failure of treatment occur because we don't know what the damage is and when it happens. My other research is in epilepsy. I'm working with a postdoctoral investigator who has a fellowship to look at the mapping of epilepsy in pediatric patients. We are using a math model to be able to predict seizures.

I'm also working with a Ph.D. scientist in the Department of Neuroscience to examine malignant brain tumors in children. We're working on a tissue bank so we have our own tissue to do our research. The goal is to find new targets for therapeutics for malignant brain tumors.

PN: What is it about MUSC Health that attracted you?

TK: MUSC Health's philosophy to imagine what is possible and to grow and deliver exceptional health care is very exciting. The commitment to build a new Children's Hospital and Women's Pavilion underscores that commitment. It makes a clear statement that health care for children and their families is a priority.

RE: The thing that grabbed my attention was the need for pediatric neurosurgery. I felt that I could come here and help many people. But on top of that I felt I would have the support to grow as a surgeon. It appealed to me that there would be a new head of pediatric neurology. As soon as I got here, I began interacting with clinical faculty and neonatology and meeting with intensive

care unit physicians and anesthesiologists—it's all been very collegial and supportive.

TK: Pediatric neuroscience is a major area for an expansion that will enable us to address the health needs of the children of this state and region. I am very happy to have left the Northwest and to now be a part of MUSC Children's Hospital.

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