




2017 Annual Report on Giving

Together we learn. Together we discover. Together we heal.
Together we are changing what's possible.

A close-up photograph of a newborn baby lying in a hospital bed. The baby is wearing a white hospital gown with colorful heart patterns. A hand is gently touching the baby's foot. Medical wires are visible on the baby's chest. The background is blurred, showing other hospital beds.

This is a true story.

HALFWAY TO TERM, NEW PARENTS JENNA AND STEVEN BROWN LEARNED THAT THEIR UNBORN DAUGHTER, HARPER, WOULD BE BORN WITH THE MOST SEVERE FORM OF A SPINAL CORD DEFECT KNOWN AS SPINA BIFIDA. THEY REALIZED THAT SHE MIGHT NEVER WALK, THAT SHE MIGHT NEVER CONTROL HER BLADDER OR BOWELS.

They accepted months of uncertainty to come. They recognized that answers would arrive only after her birth. And they placed their faith in a team of caregivers at the Medical University of South Carolina.

This is a story about a hospital – doctors, nurses, therapists, technicians, midwives, schedulers – building and executing a plan to provide for this family, both medically and emotionally. It's a story about an entire community of caregivers working together, from supporting the parents with genetic counseling to monitoring the baby's tiny heart.

This is Harper's story. It's MUSC's story. And because you're part of our extended family of friends and supporters, it's your story, too. When you see our mantra -- "Changing what's possible" -- this story is what we mean.

We share with you this special Annual Report on Giving as affirmation of the power of philanthropy and a testament not only to the work of our caregivers but also to the generosity of the community that makes their amazing work possible.

Together we learn. Together we discover. Together we heal.

Together we are changing what's possible.



Chapter 1: Waiting for Harper

18 WEEK ULTRASOUND

For the first time in her pregnancy, Jenna Brown showed up for an appointment alone.

She was almost halfway to term at 18 weeks, and she and Stephen had learned that they were having a girl more than a month earlier. Save your time off for when Harper arrives, Jenna told her husband. It's just a regular checkup.

As an ultrasound technician slid her scope across Jenna's belly, Jenna heard the sound of Harper's heartbeat and stared at the black-and-white screen, anxious to see her growing little girl. But the technician stopped and turned off the machine. "Is someone here with you today?" she asked.

Jenna shook her head. She heard the technician say she'd be right back with Jenna's doctor but also the unspoken words: Something is wrong.

They had found a tiny black spot, the doctor explained, possibly an opening in Harper's spine. Jenna would need to see a specialist.

The doctor escorted Jenna to the nurse manager's waiting area, where Jenna tried to whisper into the phone to Stephen without drawing attention. She watched other women rub their own pregnant bellies, pretending not to listen. But Jenna could see it on their faces – pity for her and gratitude that it wasn't them.

Stephen rushed from work to meet Jenna at home. The couple filled the next agonizing hour huddled over a computer at their kitchen table, researching. By the time they left to see a specialist at MUSC, they knew that the tiny black spot on the ultrasound could be a much bigger hole, a chasm that separates their daughter from the chance to ever walk, from the ability to control her own bladder and bowels.

When they arrived at MUSC, an ultrasound technician scanned Jenna's belly once again. This time no one spoke. In that silence, electrified with tension, Jenna felt like she could hear her tears hitting the floor.

The technician escorted the Browns to a genetic counselor, who confirmed that Harper had myelomeningocele spina bifida, the most severe form of the defect in which a portion of the spinal cord protrudes from the baby's back. They wouldn't know the extent of her complications until birth. And even then, they wouldn't know for sure until she started making — or missing — developmental milestones.

For two days, Stephen and Jenna locked themselves in their house, red-eyed and tossing around what-ifs over cold plates of food, unable to eat. They had planned and tried for this baby. And by now, with Jenna's bump beginning to show more and more each day, they'd made the mental transition into parenthood. They were a family of three, and they wanted to make the best choices for their little girl.

She was almost halfway to term at 18 weeks, and she and Stephen had learned that that they were having a girl more than a month earlier. **“Save your time off for when Harper arrives,”** Jenna told her husband. **“It’s just a regular checkup.”**

They had two treatment options: Attempt surgery in utero at a specialty hospital in Philadelphia, or wait until Harper's birth for a spinal repair one day after delivery. Every discussion emphasized the meager time they had to decide. Each conversation woke them from the happy haze of pregnancy and returned them to the daunting reality of Harper's diagnosis and all its unknowns.

At the end of the two days, they called over their family and told them all at once: They were going to Philadelphia.

They packed everything they needed for Jenna to complete her pregnancy in Pennsylvania. They arranged for Jenna's parents to watch their dog and alerted neighbors that they might be gone for a while. Family and friends mapped out schedules so that someone always would be in Philadelphia to help. Jenna, a teacher, filed paperwork to take off the rest of the school year. Her colleagues offered to donate their accrued sick leave to cover the unexpected extra time off that otherwise would go unpaid.

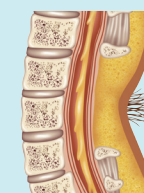
Loaded down with luggage, Stephen and Jenna drove through the worst snowstorm to hit the Northeast that year. Then Jenna underwent 12 hours of testing.

At the end of that long day, five doctors crowded into the room with the Browns and delivered their results in medical speak. Physically and emotionally exhausted, Jenna nodded along, until the doctors wrapped up their report and began talking about incontinence and addressing future problems. Jenna looked at her husband, confused. “Are they saying we can’t do this?”

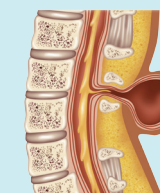
Harper's spinal cord wasn't pulling her brain far enough into the spinal column. Her problem, while severe, just wasn't severe enough to proceed with surgery.

The Browns packed their car. The storm had passed, and bright winter sunshine reflected off the melting snow, as they drove home to Charleston. They called MUSC. They had one option left.

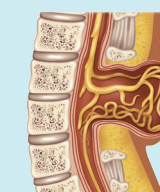
Spina Bifida



Spina bifida occulta: neural tube birth defect, in which structures in the back fail to close properly.



Meningocele



Myelomeningocele (MMC): most severe form of spina bifida, in which a portion of the spinal cord, nerves and their coverings protrude through an opening in the back.



Chapter 2: Best- and Worst-Case Scenarios

ANOTHER WINDOWLESS ROOM with neutral walls and a sheet of stiff white paper stretched across an exam table -- an invitation for poking and prodding and personal conversations.

Jenna and Stephen Brown had been here, or somewhere just like it, too many times in a few short weeks. From their baby's devastating spina bifida diagnosis in Charleston, to hopeful testing at a hospital in Philadelphia and then the crushing news that they didn't qualify for surgery. In these colorless, sterile rooms, they had experienced an emotional spectrum.

Now here they were, back home in Charleston, once again at MUSC in yet another exam room -- this time to see a pediatric neurosurgeon and talk about operating after Harper's birth. Exhausted from weeks of frenzied research that ended in disappointment, they showed up without expectations about Dr. Ramin Eskandari.

He was only a few years older than Jenna and Stephen and a new father himself. He took the time to listen to them, to hear their story. He talked about other surgeries, potential outcomes.

Stephen pressed him for numbers. What are the odds that Harper would need a shunt to route excess fluid away from her brain? What's the chance that she would need multiple surgeries? How likely would she be able to walk or control her own bodily functions?

Dr. Eskandari made no promises. He works in tangibles -- in nerves and skin, in shiny sterile instruments and surgical lighting. Until Harper arrived, he couldn't speak beyond possibilities.

But he also understands the distinct torture of uncertainty. Dr. Eskandari's early childhood took shape against a backdrop of worry during the Islamic Revolution in Iran, where his parents found themselves in danger for dissenting from the rising party. They fled with Ramin and his sister, traveling across the countryside to family members' homes and leaving everything behind.

Dr. Eskandari doesn't remember the noise of protest or gunfire, the way you feel those sounds inside your body like a second, irregular heartbeat, when they aren't in a movie or a newspaper but rather on the other side of your own walls. And he doesn't remember wondering every time his mother and father left whether they would make it home.

When he thinks about Iran, he instead remembers the feeling of water drops in his hair, the smell of mud underfoot and the unburdened happiness of riding on the handlebars of his best friend's bicycle in the rain. A practical clinician, he suspects that he suppressed the rest.

Today he stands out not only for his remarkable abilities but for his genuine compassion. If there's such a thing as a surgeon's surgeon -- a crotchety doctor who manages patients with the same finesse that a short-order cook handles a tomato -- then Dr. Eskandari is the opposite. He's the patient's surgeon who lays a friendly hand on the shoulder of an upset parent, pauses often during tough conversations to assess and never leaves without answering every question.

Now here they were, **back home in Charleston**, once again at MUSC in yet another exam room -- this time to see a pediatric neurosurgeon and talk about operating after Harper's birth. **Exhausted from weeks of frenzied research** that ended in disappointment, they showed up without expectations about **Dr. Ramin Eskandari**.

He decided on this profession soon after his family made it out of the Middle East. His parents landed in Belgium as a stopover on their journey to join family in Michigan. While the Eskandaris waited for green cards, his mother took her children to the park each day.

During the week, the park filled with retirees also passing the time. When young Ramin told his mother how ugly the older people were, she reminded him that she would grow old too. But you can become a plastic surgeon, she challenged, and keep me beautiful.

Ramin failed to see the jest in her suggestion. He refused to consider his mother -- with her long, dark hair and smooth skin -- as one of the people he saw sitting on park benches. For years, whenever anyone asked him what he wanted to do as an adult, he said he would become a plastic surgeon.

His motivation changed as he matured and, rather than preserving his mother's beauty, he wanted to help disfigured children. He credits his interest in pediatric neurosurgery to a seventh grade science teacher in Michigan. The teacher once had animal brains on hand -- Dr. Eskandari suspects she worked out a deal with the taxidermy instructor down the hall -- for her students to dissect.

Dr. Eskandari, straight-faced, calls that the best day of his life -- but it also posed a problem. After class, he told the teacher that the lesson amazed him but didn't quite fit with his plans to help children. You can work on brains, his teacher told him, in a field called neurosurgery -- and you can specialize in pediatric neurosurgery to work with kids.

That was the day 12-year-old Ramin Eskandari began telling people

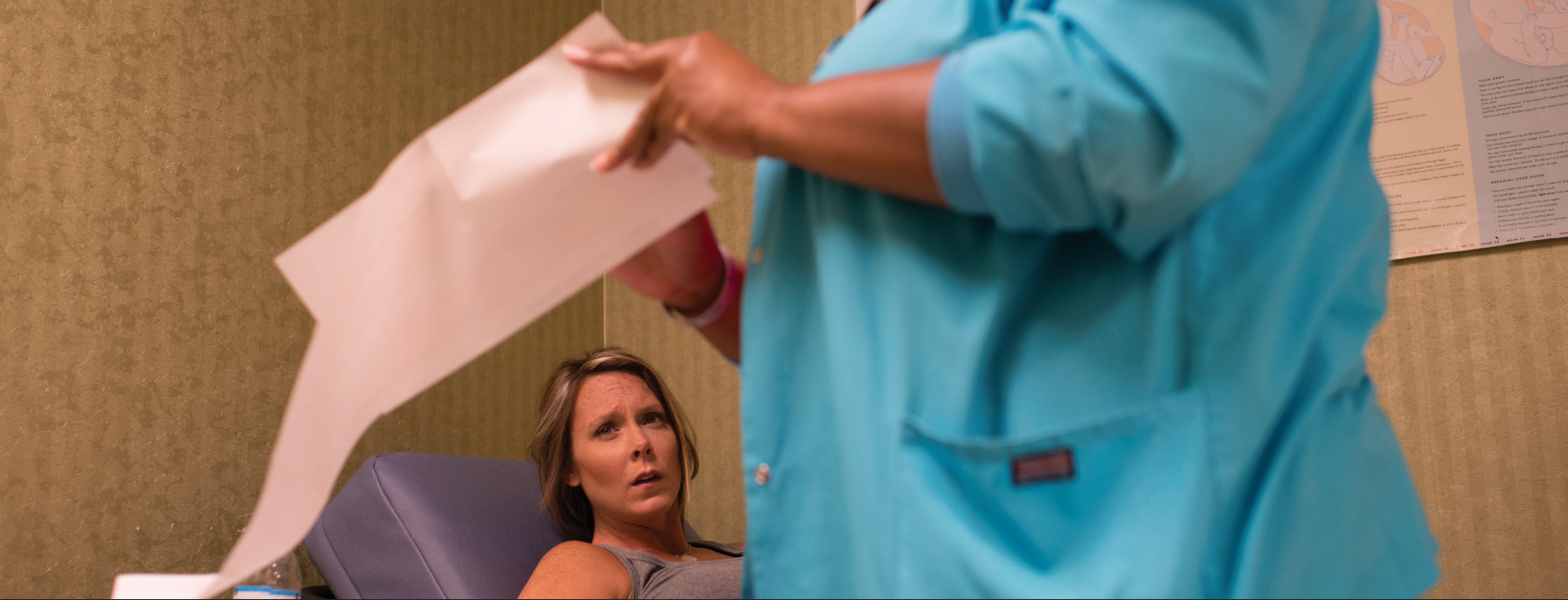
that he would become a pediatric neurosurgeon.

He completed medical school at Wayne State in Detroit and residency at the University of Utah. He landed at MUSC in 2014, following a fellowship at Stanford. When Dr. Sunil Patel, chairman of MUSC's Department of Neurosurgery, talks about Dr. Eskandari, he speaks of MUSC's good fortune. Prestigious children's hospitals across the country had courted Dr. Eskandari, but he chose MUSC as a place where he could provide world-class care and conduct groundbreaking research at the same time.

Jenna and Stephen heard Dr. Eskandari's unsolicited approval from everyone they met. Nurses, doctors and counselors who spotted his name on their chart looked up at the Browns with a congratulatory expression, as they volunteered some praise.

So now, in one more exam room meeting with Dr. Eskandari -- their only remaining option -- Jenna and Stephen had to choose to believe that this time was different.





Chapter 3: Counting Down

JENNA CLUTCHED A WICKER BASKET in the space between her belly and her heart, as a teacher from down the hall explained its contents.

The woman's sixth-grade English class had read *Sadako and the Thousand Paper Cranes*, a fictional account of a young girl who lived a mile from the atomic bomb explosion in Hiroshima, Japan, and developed cancer at age 12. Sadako clung to the legend that someone who folds 1,000 origami cranes would receive a wish. She passed the days in her hospital bed folding cranes and hoping to survive.

After teaching the book, Jenna's coworker had instructed her students to fold birds of their own. And she had encouraged them to find someone to whom they wanted to grant a wish.

The kids had seen teachers wearing yellow Hope for Harper shirts on Fridays. They'd learned a new phrase – spina bifida – attached to Mrs. Brown's pregnancy and the unknowns that came with it. So they'd shaped their own geometric birds with Jenna's unborn daughter in mind.

Presented with the basket and the story behind it, Jenna wiped her eyes, swallowed down the emotion and took a breath. She didn't want to miss a teaching moment.

She thanked the students for their gift and reminded them of the importance of not only compassion but accepting differences.

Harper would be different than other children. And one day she'd be here, in middle school, those toughest of years. Jenna had seen kids tease another student for walking with a limp and tried to imagine life for a little girl in a wheelchair, a little girl whose bathroom breaks involve a trip to the school nurse.

Jenna already knew how tough it was to be different. She taught English to Speakers of Other Languages, students with more stories of hardship behind them than some of their peers would experience in a lifetime. Some rode atop trains from Latin America to find their parents in the United States, facing gang members ready to kill for money, clothing or a thrill. Others lived in fear of deportation and left school when court dates approached, abandoning education in hopes of being forgotten.

Most teachers didn't last long in this job. After six years at Northwoods Middle School in North Charleston, Jenna was considered an old-timer.

Her girls especially confided in her, a young teacher who withheld judgment when they talked about older boyfriends or threats that social workers might remove their baby siblings from bedbug-infested apartments or loving parents who just couldn't afford a highchair or a crib.

Those experiences emotionally prepared Jenna for her own challenges, but they also presented a new one. Some of the students who had confided in her – and often relied on her -- understood that

Jenna already knew how tough it was to be different. She taught English to Speakers of Other Languages, students with more stories of hardship behind them than some of their peers would experience in a lifetime.

Harper's arrival might mean their favorite teacher's departure.

Jenna's status at work became another unknown. Just as doctors couldn't answer Jenna and Stephen's questions about Harper's health, Jenna couldn't allay her students' fears of losing her.

She ticked off the days until June 17 – when Harper would arrive, along with answers to all those questions – in two-week increments. Twice a month Jenna went to MUSC for an ultrasound to measure fluid levels on Harper's brain and monitor her development.

She never went alone. Stephen or Jenna's mother accompanied her to every appointment since Harper's diagnosis, holding Jenna's hand in the dark room and watching Harper's silhouette dance on the screen. They guessed about the little, inconsequential things – her eye color, whose nose she'd have – but never the big, nagging questions.

Jenna and Stephen finished the nursery: Harper's white monogram against a fresh coat of gray paint, a sign that said "Fearfully and Wonderfully Made." And they packed a hospital bag: a crossed blessed by a priest, a new headband for their baby to wear each day. They planned the things that they could.

On June 13, Jenna woke up and rolled over to see Stephen lying beside her, quiet and thinking. How are you feeling? she asked.

Scared, he told her. Scared of the unknown.

She told him she was too. Not only did Jenna worry about the severity of Harper's condition but her own capability to provide their baby with everything she would need.

The couple talked it through, like they always did, and broke it down into something more manageable. First, delivery and making sure Harper is healthy. Then, getting her through her first surgery. From there, onto recovery. Only after she healed could they worry about what happens next, let alone the rest of their lives.

They had learned over the past five months that they couldn't control the future any better than they could predict it. And as much as they feared the unknown, they had committed to it.

In three days, they would stop wondering. They would have Harper, and they would have answers.





Chapter 4: Harper's Birth

A PAPER BIRD DECORATED THE DOOR OF HOSPITAL ROOM 592 — not an origami crane, but a stork.

Inside, Donna Pender rubbed her daughter's belly one last time and told Jenna, sleepless and makeup-free, that she looked beautiful. "I'm so proud of you," Donna said. "And I love you."

Stephen's mom stopped by and asked to pray. Stephen, Jenna, Jenna's parents and Stephen's mom clasped hands around Jenna's hospital bed and asked God to watch over Harper's delivery. And as doctors cleared everyone out to take Jenna for her spinal block, Stephen's father gave Jenna a hug and a wink. "Scream loud," he said, "so we can hear you."

Jenna and Stephen had woken up at 4:30 a.m. on June 17, 2015. Or rather, they had gotten out of bed at 4:30 a.m., finally allowing their bodies to catch up to their minds that had been pacing the room since they lay down the night before.

Jenna took a shower, rinsing her skin with an antiseptic solution to prepare for surgery, paying close attention to her abdomen, as the nurse had instructed. She and Stephen arrived at MUSC before sunrise, and Jenna turned off her phone to insulate herself from the barrage of calls, texts and social media notifications that accompany a scheduled C-section.

Anyone she might need to reach was at the hospital anyway, wearing Hope for Harper T-shirts with yellow ribbons for spina bifida awareness.

The operating room moved like a ballet, with each person performing a specific role to complete the surgery with elegance and efficiency. Someone handed Stephen a gown, while another technician scooped Jenna's ponytail into a hairnet. Like backstage during a scene change, everyone pulled on matching pale blue gowns. Someone called out each instrument by name.

From the first moment of incision until Harper's birth took six minutes. Months of wait and worry and hours of meticulous preparation that morning all came down to this – a process that took no longer than brewing a pot of coffee. Against the steady beep of monitors and IV drips, an army of gloved fingers snipped and pried and pulled on Jenna's abdomen, until a pair of hands lifted Harper screaming into the room, and someone shouted, "Happy birthday!"

Jenna heard a voice say, "She's so cute!" but nothing else, as nurses whisked her daughter away to be examined. While the surgeon worked on Jenna's stitches, Stephen followed Harper, listening to the commentary that trailed her bassinet rolling down the hall.

"6 pounds, 15 ounces, and 20 inches."

"Her head doesn't really look that big."

And the facts that would define the rest of Harper, Jenna and Stephen's life:

"She's moving her legs great."

"The defect looks like it's covered with skin, so that's good."

Jenna heard someone say, "She's so cute!" but nothing else, as nurses whisked her daughter away to be examined. While the surgeon worked on Jenna's stitches, **Stephen followed Harper**, listening to the commentary that trailed her bassinet rolling down the hall.

"She has great grasp in both toes, Dad."

A nurse took Harper's footprints upside down, since Harper couldn't lie on her back, and Stephen returned to his wife. He struggled to fashion the words to tell Jenna what he'd learned, while she searched his face to understand his tears.

It's covered with skin, he finally told her. She can move her legs.

A nurse wheeled in the bassinet, lifted the crying baby and placed her on Jenna's chest. In another strange, bright room, Harper quieted when she heard the sound of the heartbeat she'd known so long. The nurse draped a warm white and blue-striped blanket over them, and Jenna studied her daughter.

"There you go," Jenna told Harper. "You're OK, sweet girl."

Harper wanted to nurse, but with surgery the next morning, she had to wait to eat. Barred from fulfilling a natural maternal instinct, Jenna wiped away her own tears when Harper whimpered. The nurse leaned over and touched Jenna's shoulder. "She's going to be fine," the nurse promised and then reminded Jenna, gently, that Harper had to move up to the neonatal intensive care unit now.

The nurse rolled Harper out to the hallway crowded with family and close friends clutching coffee cups and waiting for this moment. They peered into the bassinet, smiling and cooing and snapping photos on their phones. Stephen, following behind, paused to talk with his mother-in-law – about the birth, Harper's lesion, their next

steps. But as he opened his mouth to speak, after five months of uncertainty, he leaned in to her shoulder and cried.

He went back to get Jenna and pushed her up to the neonatal intensive care unit in a wheelchair. They brought a pink and gray headband that they'd packed and slipped it onto Harper's head.

Dr. Eskandari walked in and smiled. His wife insists on putting the same hair accessories on their daughter, too, he told them.

Watching the new baby, he said, "Hey, look at those feet going!"

He still couldn't give Jenna and Stephen answers about Harper's bowel and bladder function, but the layer of skin over her lesion had protected her from paralysis. He explained to the Browns that hydrocephalus, or fluid buildup on Harper's brain, would spike after surgery. He would monitor her head growth to see if Harper needed a shunt.

Jenna and Stephen listened and nodded, as he outlined the nearly five-hour surgery awaiting their daughter in the morning, alternating glances between their new baby and the man who would hold her future – and theirs – in his hands.

"You're so beautiful," Jenna whispered to Harper, stroking her arm. "You're perfect."



Chapter 5: Repairing Harper’s Spine

STEPHEN ASKED THE QUESTION: “WHEN ARE THEY COMING TO GET HER?”

He and Jenna held Harper in the dim blue light of the neonatal intensive care unit. Hums and beeps charted vital signs of the hospital’s tiniest patients and counted out loud the Browns’ every second together.

Some parents crowd around plastic bassinets in this unit for months, marking each day – sometimes every hour -- as a victory for their babies born too soon or too weak. But Harper was just passing through.

Swaddled in a pink-striped blanket embroidered with a yellow spina bifida awareness ribbon, she wore a flapper-style headband with a pale pink blossom. A nurse answered Stephen’s questions without words, as she lifted Harper from his chest and placed her into a bassinet for transport to the operating room.

Jenna and Stephen said nothing. Jenna gripped the edge of the plastic box that held her daughter and reached in to stroke Harper’s head, while Stephen rubbed his wife’s shoulders – both of them unsure what to do with their empty hands that moments before had held their little girl.

After months of waiting, Harper was here. That black dot on an ultrasound – an anatomical question mark – now had an answer. But the relief lasted only a day. With the first sunrise since Harper’s birth came a new anticipation.

The nurse slipped a black mask over Harper’s eyes to protect them from the harsh white operating room lights and rolled her out. Stephen pushed Jenna out of the neonatal intensive unit in a wheelchair, and Dr. Eskandari met them in the hallway. He knelt beside Jenna.

“It’s going to be fine,” he told her. “We’re going to take care of her.”

Harper’s diagnosis, myelomeningocele spina bifida, means her spinal cord had herniated from her back without the protective layers of membrane, bone and muscle that normally insulate a person’s bundle of nervous tissue from the world.

Surgery doesn’t repair nerves or improve a patient’s ability to move. Rather, it prevents infection. And the procedure should take place within three days of birth – the sooner, the better.

Dr. Eskandari trained under four pediatric neurosurgeons while in residency at the University of Utah, three during a fellowship at Stanford and two more working in Uganda before his seventh and final year as a resident. There, poor nutrition in mothers translates to more babies with neural tube defects. Dr. Eskandari saw 11 myelomeningocele spina bifida cases in the two months he spent in Uganda, the same number he treats annually at MUSC.

He trained in settings that varied from a world-class teaching hospital with Ivy League pedigree to a medical facility in East Africa, where the power went out as often as 25 times each day, interrupting procedures until someone could rouse the single maintenance man who held a key to the generator tucked into a shed outside. On

nights or overcast days, staff members would hold flashlights and cell phones over patients while waiting for the generator so that Dr. Eskandari could continue his procedures.

For seven years he observed and asked questions. He practiced every aspect of surgery hundreds of times alongside mentors, mentally filing away techniques he liked and some he didn’t. One neurosurgeon taught him always to review the case before beginning – to perform the surgery in his mind before ever touching an instrument to bare skin.

Dr. Eskandari likes to wash his patients himself, a task often left to support staff. He uses that time to position the patient, to review the exact location of the surgery and to ensure that everything is as sterile as possible to prevent infection later.

He plays reggae in his operating room. Its characteristic rhythm, with guitar chops on the offbeat, keeps his mind moving through the paces and neither stresses nor lulls him. He figures none of his patients would object; after all, he doesn’t know anyone who doesn’t like reggae.

When he arrived in the operating room on June 18, two 3-inch pink feet poked out from under white surgical linens. Dr. Eskandari began Harper’s case by scrubbing her back with an alcohol-based antiseptic.

Then he drew an ellipse on her back, a thin curve of black marker to indicate where the healthy skin stopped and where he would close her incision after repairing the defect. After that, he washed her again, this time with iodine that left a brown-red stain on her skin.

He walked out to continue his mental preparation over a deep metal sink, where he washed each finger on both sides and both arms up past his elbows – a thorough, practiced routine -- while his team draped Harper under pale blue cloth, refining the workspace to a single rectangle of one-day-old skin.

A spinal cord begins as a flat plate and rolls into a tube during fetal development. But in spina bifida cases, the cord stays flat. Dr. Eskandari would pull unhealthy tissue away from the raw spinal cord and fold the cord into the proper tube shape. He then would restore the layers of dura, muscle, fat and skin that protect a spinal cord and prevent fluid from leaking out.

When he finished scrubbing in, Dr. Eskandari pressed his hands together at his fingertips to avoid touching anything and opened the door to the operating room with his back.

Bob Marley’s “No Woman, No Cry” played, as he made the first incision.

One floor up, 15 relatives and close friends crowded into Jenna’s postpartum hospital room. Unsure of what to say, they looked at Stephen and Jenna. Their silent pity made the walls feel tighter, the air almost too heavy to breathe.

The men left to get lunch and to give Jenna some privacy to try to pump milk for Harper. When a nurse suggested that the women do the same, no one budged.

Jenna produced a few meager drops. Her sister, Lauren, saw the overwhelming frustration on Jenna’s face and asked her to take a walk. As they stepped away from the confines of the room and into the natural light of the hallway, Jenna felt her shoulders relax beneath her hospital gown. Lauren cracked a joke about everyone crammed into the room, and Jenna laughed for the first time.

When Lauren spotted Stephen returning from lunch, she excused herself. Jenna and Stephen decided to stay in the hallway, just the two of them, until Dr. Eskandari returned. The couple waited in silence, their eyes trained on the swinging doors to the children’s hospital.

In the operating room just beyond those doors and down the hall, Dr. Eskandari understood why doctors in Philadelphia had disqualified Harper for in utero surgery. Only the tip of her spinal cord had adhered to the abnormal tissue, so the cord didn’t pull her brain down as significantly as expected.

Harper’s case, while still the most severe form of spina bifida, was one of the mildest examples Dr. Eskdandari had seen. He spent an hour and a half removing skin, repairing her spinal cord and then closing her incision with stitches as fine as hair.

He stepped through the doors leaving the children’s hospital and stopped when he found Jenna and Stephen leaning against the wall, waiting for him. Still wearing his surgical cap, he hugged Jenna and smiled.

“It went well,” he said. “It went really well.”





Chapter 6: ‘Miracle Baby’

DURING HER FIRST FEEDING, HARPER HUNGRILY SWALLOWED TOO MUCH MILK TOO FAST. Jenna and Stephen watched, horrified, as their daughter — who made it through a high-risk birth and delicate surgery on her spine the next day -- turned blue.

A nurse whisked Harper away and left her parents cradling doubt. Were they ready for challenges at home, when no one could swoop in?

Jenna took a CPR class in Harper’s room and watched everything the nurses did. She and Stephen wanted to change diapers, provide bottles and meet Harper’s every need as if they were on their own.

The Browns planned for Harper’s hospital stay to last a month. Her care team at MUSC told them to prepare for weeks of sleeping on couches and commuting to and from the hospital, but Harper recovered and thrived faster than anyone anticipated.

When a nurse came in on Harper’s due date – a week after her birth – she carried discharge papers. Jenna called Stephen at work. “It’s time to come take your wife and baby girl home,” she said. But she worried.

Jenna dressed Harper in a white ruffled dress, and she and Stephen loaded her into a brand-new car seat in the back of their white Infiniti sedan. Doctors gave Harper clearance to ride home but otherwise wanted no pressure on her back.

Stephen drove slowly, carefully. Every wheel turn seemed suspended in time, and the 15-mile trip home to Hanahan felt like another

unnerving test of patience for the new parents. Harper slept the entire way, and Jenna watched her tiny chest rise and fall from the seat beside her.

Three weeks later, Jenna’s friend – a labor and delivery nurse – stopped by to meet Harper. The friend noticed that Harper struggled to breathe at times.

Jenna and Stephen brought her to see their pediatrician a day before their scheduled one-month appointment. The doctor watched Harper’s breathing – nothing to worry about, he said – and completed her scheduled checkup while they were there.

He discovered that Harper’s head circumference had spiked 2 centimeters since birth. Dr. Eskandari was in Atlanta with his wife and baby daughter, so the pediatrician referred Harper to the MUSC Children’s Hospital emergency room.

An imaging scan confirmed the Browns’ fears: The ventricles in Harper’s brain had grown.

Spina bifida patients often develop hydrocephalus, or fluid buildup on the brain. A Chiari II malformation, part of Harper’s diagnosis, pulls the cerebellum and brain stem down and can obstruct fluid flow, causing rapid head growth.

Jenna and Stephen drove home expecting to schedule a surgery to install a shunt that would divert fluid from Harper’s brain. But the next morning Dr. Eskandari called from his cell phone. He’d had the images sent over to him on his trip, and he told them not to worry just yet. So far, Harper still fell within the target numbers in his mind.

A few days before Harper turned 2 months old, Jenna tickled the spot on Harper’s thigh where her paralysis would have begun. **Harper giggled for the first time.**

The Browns bought a flexible measuring tape to check Harper’s head at home and track her growth between appointments, even though Dr. Eskandari warned that they’d only drive themselves crazy. But after so many months of unknowns, they needed that scrap of control.

They always knew the possibility that Harper would need a shunt, along with all the other possibilities that now seemed so much worse. Harper might not have been able to move her feet. In fact, she could have been paralyzed from her inner thigh down. And yet their baby girl seemed to elude each frightening possibility that emerged.

A few days before Harper turned 2 months old, Jenna tickled the spot on Harper’s thigh where her paralysis would have begun. Harper giggled for the first time.

Jenna returned to work when Harper turned three months old, leaving her mom and sister-in-law with detailed notes on the baby’s routine and warning signs of trouble. Jenna maintained her composure for her students but ticked off the minutes between each break from class when she could check her phone for photos and updates. She filed for family medical leave every Friday to attend appointments with an early interventionist who monitored Harper’s progress toward developmental milestones.

Harper met them all – lifting her head, kicking her legs, rolling over. She started eating solid food at four months old, devouring peas, carrots and squash.

When the Browns returned to see Dr. Eskandari in December, just before Harper turned 6 months old, he marveled at Harper. Her

blue eyes sparkled beneath a white and gold polka dot bow, and she smiled at her neurosurgeon.

Not only had she hit every developmental milestone -- as if her diagnosis a year earlier never had happened -- but her skull growth remained within his safe parameters. Dr. Eskandari told Jenna and Stephen that they could wait until she turns 1 for her next brain scan.



He reminded the Browns of the rarity of their daughter’s outcome. As he sat on the other side of the exam room, listening, Stephen wiped tears from his face. One year earlier he had stared at a black dot on an ultrasound screen, a hole filled with questions. And now – finally – were the answers he’d spent every day hoping to hear.

“You’ve got yourself a little—” Dr. Eskandari began.

Jenna answered for him. “Miracle.”

Dr. Eskandari nodded. “Miracle kid.”



About this story

IN MAY OF 2015, WE WERE GRANTED AN UNEXPECTED GIFT.

I was in my third trimester when we were contacted by a videographer with the MUSC marketing team. He reached out to our obstetrician's office in search of a family whose unborn child had received a multifaceted diagnosis in utero. His office was looking to document and travel along with a family from pregnancy to birth and beyond, with the purpose of advocating for the new MUSC Shawn Jenkins Children's Hospital.

I agreed to meet with him. We wanted to hear him lay out MUSC's vision to ensure it would coincide with ours. I returned home that evening to relay everything to Stephen.

At first, we were reluctant. We were very open about Harper's diagnosis, but were we ready to put our most intimate moments on display, moments of weakness we didn't portray in public? As we continued the conversation, we weighed the pros and cons.

Initially, we were taken back to a particular memory, five minutes in time that would impact our outlook forever. We sat in a conference room with five physicians, as they explained the expectations for Harper's life. One doctor spoke out about the feelings spina bifida children, specifically teenagers, face as they discover their differences. He talked to us about the possibility of depression. This was the first time we stopped to think about Harper's emotions in all of this. From that moment, we vowed to hold on to every keepsake,

letter and picture for Harper to reflect on her beginnings. She would be able to see the inspiration her life had on others, before ever entering this world. What better way to fulfill this promise than to accept MUSC's offer?

We pressed on. We decided we wouldn't let Harper's suffering go in vain. We would fight to bring awareness for her, for the families who shared their beautiful children and brought us back from our darkest times, and for the future families who we could pay it forward to. This documentary would bring that opportunity to light. We could educate the public about spina bifida and the many conditions which follow, all while honoring every family before us and to come.

Thus, filming began.

Never in a million years would I have thought we would gain so much more -- a new family, our MUSC family. After almost two and a half years, we've built lasting relationships we will cherish for a lifetime: a midwife who held my hand through pregnancy and continues to follow Harper's story; NICU nurses who still check in on her and are blown away by her development; pediatric nurses who know Harper by name; a devoted development team that endlessly supplies us with opportunities to share Harper to benefit fundraising efforts; a professor who allowed us to use her PT lab and performed assessments to get Harper the best therapist; and a videographer who has been by our side since Harper's worldly debut.

Our closest relationships to stem from all of this are rooted in two

Together we learn. Together we discover.

Together we heal.

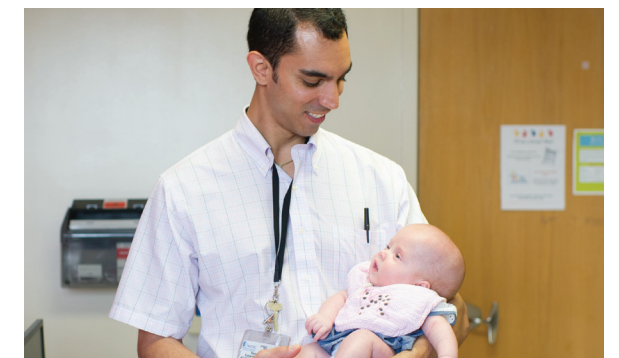
Together we are changing what's possible.

visionaries with very different backgrounds but the same ideals about Harper -- a journalist and a neurosurgeon who believed our story could create a major impact. They have bestowed upon us some of life's greatest wisdom, trust and memories. And being able to watch our children grow, laugh, play and love together has been the most rewarding of it all.

In closing, I would like to tell you about a mother. This mother is pregnant. She recently found out the gender of her baby and heard the baby's heartbeat for the first time. In a total stranger's office, she just received the news of her unborn child's diagnosis. With her soaked face hidden in her clenched hands, these immediate thoughts pop into her head: Why me? How will I deal with this? Can I afford this? Am I strong enough to handle this?

That's her. That's the mother we hope to reach in the waiting room, as she scans a hard copy of Harper's story, or as she frantically returns home to scour the internet and comes across Harper's documentary. She finds hope. She finds reason. She finds her will. She and her unborn child are one of our many reasons WHY.

- Jenna Brown





Epilogue

HARPER LANE BROWN TOOK HER FIRST SOLO STEPS ON AUG. 15, 2016.

She is now 2 years old and runs, dances and swims. She loves Mickey Mouse and shooting hoops. She speaks in complex sentences and knows how to spell her name. Harper never required additional surgery.

Jenna and Stephen Brown, along with Harper, now represent MUSC as the campaign family for the Pediatric Neuroscience Research Fund. Jenna remained a middle-school teacher for a year and a half after Harper’s birth before becoming a full-time volunteer, advocate and spokeswoman for pediatric neuroscience awareness and children’s health in general.

Dr. Ramin Eskandari sees an estimated 1,000 patients per year at the MUSC Children’s Hospital and performs about 200 surgeries annually. Some of his most notable recent cases include replicating a pediatric brain tumor cell line that now can be used in research internationally, and successfully treating a baby whose skull fused prematurely due to a disfiguring birth defect.

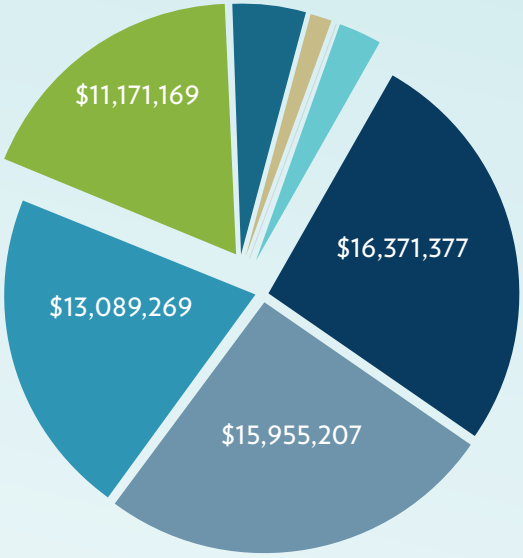
Dr. Eskandari’s daughter, Kiara, is Harper’s age. Kiara and Harper have become close friends, just like their parents.

Read more and see the videos from this story on www.musc.edu/giving/harper

At a Glance

Number of gifts:

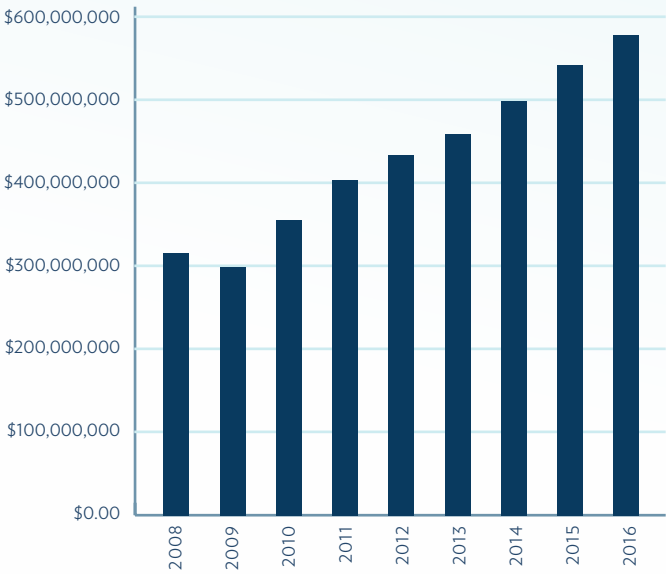
ALUMNI:	14,453
FACULTY AND STAFF:	\$3,037,200
STUDENTS:	\$862,072
VOLUNTEER BOARDS	\$14,458
OTHER INDIVIDUALS:	\$1,740,420
CORPORATIONS:	\$16,371,377
FOUNDATIONS:	\$15,955,207
NONPROFIT ORGANIZATIONS:	\$13,089,269



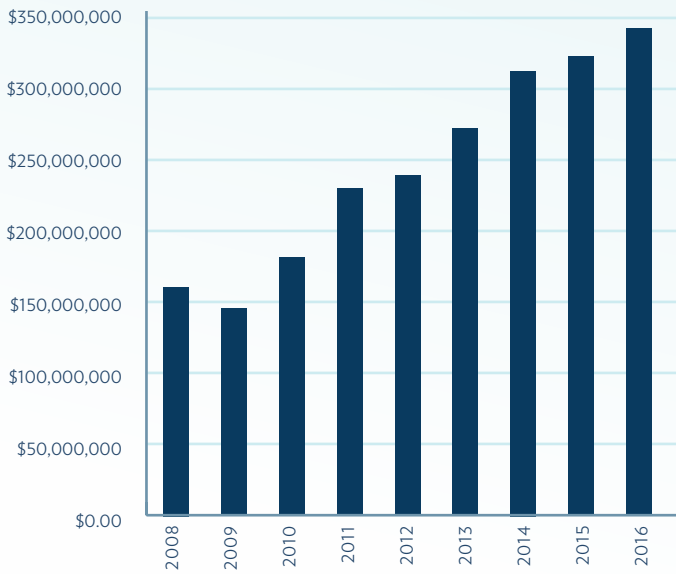
TOTAL GIFTS AND PLEDGES: \$62,241,172

Trends

MUSC Foundation Total Assets (in millions)



MUSC Foundation Total Endowment (in millions)



Published by the MUSC Office of Development and Alumni Affairs
268 Calhoun Street • MSC 182 • Charleston, SC 29425

Concept: Allyson Crowell, Brennan Wesley

Design: Emily Stooksberry

Writing : Allyson Crowell,

Editing: John Nash

Photography: Brennan Wesley

Question Call 843-792-4275 or toll-free 800-810-6872 or visit muscd.edu/giving



Changing What's Possible®