



*Photo Provided*

**From left: Bennett Gulyas, Lino Leon and Jackson Bell have formed a unique bond – not to mention quite the fan club – at MUSC.**

## Home is where the heart is: How three boys became fast friends in unlikeliest of settings

BY BRYCE DONOVAN

[donovanb@musc.edu](mailto:donovanb@musc.edu)

From their perspective, it's no big deal.

They're just three neighbors who happen to be best friends. Like most elementary school-age boys, they love joking around, superheroes and video

games – why wouldn't they click? But for their families, their bond is nothing short of extraordinary.

That's because their neighborhood – the place that they have lived for the last three months of their very young lives – is the 3rd Floor of a children's hospital. And though each one of these boys is surrounded by

love, the truth is they're surrounded by even more wires and tubes. Medically speaking, they were all born with hypoplastic left heart syndrome, a birth defect that prevents the left side of their hearts from forming properly. But strip away the science, and the diagnosis is simple:

*See HEART on page 6*

## Number of ranked programs of SC's top children's hospital grows, heart team holds onto top spot

BY HELEN ADAMS

[adamshel@musc.edu](mailto:adamshel@musc.edu)

As the MUSC Shawn Jenkins Children's Hospital maintains its status as the top children's hospital in South Carolina, its heart team ranks among the best in the country. That's according to the 2023-2024 Best Children's Hospital Rankings by U.S. News & World Report.

The Cardiology and Heart Surgery program comes in at No. 4 nationally, and the MUSC Health Pediatric and Congenital Heart Center achieved third in the nation status for outcomes. Outcomes refers to how well patients fare.

Children's heart surgeon Mino Kavarana, M.D., said a culture of mutual respect guides the team's approach. So does its willingness to take on the toughest cases.

"Oftentimes, we'll do things that other centers refuse to do. We will do what we think is best for the patient. An example of that is not shying away from, say, a newborn with a very complicated heart defect or a patient that needs a heart transplantation after having five surgeries."

He said the team strives for high achievement despite being in a state with fewer resources than some other states. "Similar-sized programs have a lot more bed spaces, larger footprint, a lot more resources, a lot more ICU staff, nursing staff,

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3

Prestigious role  
World Lacrosse adds  
expert.

7

New education center  
Beloved educator  
honored.

4 Behavioral health hub

5 Meet Amanda Lilienthal

8 Blue Sky Award

**RANKINGS** *Continued from Page One*

attending staff, more surgeons. And they still can't produce outcomes that we produce, which is a credit to the team that works extra hard, puts in longer hours in order to accomplish that.”

Among the heart team's current patients are three boys who have captured hearts across the Lowcountry and beyond. The three MUSCeteers, as they've become known, are waiting for heart transplants and have become inseparable as they wait in the hospital.

The heart program is one of six at the MUSC Shawn Jenkins Children's Hospital to achieve national rankings from U.S. News & World Report. The others are:

- ❑ Cancer at No. 26.
- ❑ Orthopedics at No. 36.
- ❑ Neonatology at No. 44.
- ❑ Nephrology at No. 48.
- ❑ Gastroenterology and GI surgery at No. 50.

That's two more ranked programs for the MUSC Shawn Jenkins Children's Hospital than last year, said Mark Scheurer, M.D., chief of Children's and Women's Services at MUSC Health. “I was just thrilled to see the number of ranked programs grow and know that there's more that we can do for the people we serve. This is great momentum.”

The hospital's position in the highly competitive regional rankings rose as well. Of the 43 children's hospitals in the Southeast region, the MUSC Shawn

Jenkins Children's Hospital came in at No. 9.

U.S. News reaches its rankings by gathering data from about 200 hospitals. It considers patient safety, infection prevention and the level of nurse staffing. The rankings also factor in the results of a survey of more than 15,000 pediatric specialists that asks where they'd send the sickest children in their area of specialty.

**CANCER**

The MUSC Shawn Jenkins Children's cancer program moved up five spots from last year in the U.S. News & World Report rankings. It's the state's largest and most comprehensive cancer center with the only bone marrow transplant center in South Carolina. It's also the leading referral center for children with cancer in the state and has one of only about 20 comprehensive pediatric research facilities in the country.

Drilling down into the data shows the cancer program ranks No. 14 in the country for outcomes. But the stories behind the numbers paint an even clearer picture of a program known for its collaborative nature.

For example, the children's cancer team recently worked with adult cancer experts to perform a life-changing operation on a 14-year-old boy with a salivary gland type of cancer. Ivan Young is now breathing normally and running and playing like any other kid.



*Photo by Sarah Pack*  
**Boys who became known as the three MUSCeteers, as they bonded while waiting for heart transplants, ride their IV stands in a hospital hallway. Bennett Gulyas, foreground, tries to catch up with his buddies.**



**Dr. Minoo Kavarana says a culture of respect guides the heart team's approach.**

*Photo by Brennan Wesley*

**ORTHOPEDICS**

The leader of the orthopedics team, Robert Murphy, M.D., was thrilled to see his program go from unranked last year to No. 36 this year. “It's a huge deal for our group. It's a really big deal for our group.”

He credits a commitment to excellence and quality based on the volume of patients and the complexity of the care they need. “We have really been intentional and thoughtful on investing in the people that engage with each patient through their care journey. So whether that is a surgical scheduler,

whether that is an X-ray tech, whether that's a nurse on the floor, whether that is a nursing assistant. Our program has really tried to educate, empower and engage all of those team members so they really feel like they have ownership and an active part about that patient's care,” Murphy said.

“Everybody that your kid is going to meet really cares about your child and your child's outcome and you having a good experience in it getting done safely.”

Murphy also wants families to know  
**See RANKINGS page 11**

**MUSC** CATALYST news

**Editorial Office**

MUSC Office of Public Affairs & Media Relations, 135 Cannon Street, Suite 403C, Charleston, S.C., 29425

843-792-4107  
 Fax: 843-792-6723

**Editor:** Cindy Abole

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# Chief physician adds new role as chief medical officer for World Lacrosse

By HELEN ADAMS

[adamshel@musc.edu](mailto:adamshel@musc.edu)

Eugene Hong, M.D., chief physician executive for MUSC Physicians and MUSC Health, has scored a prestigious new title: chief medical officer for World Lacrosse. It's a volunteer position, so he'll retain his role at MUSC.

Hong will be put to the test quickly in his new capacity. The World Lacrosse Men's Championship begins June 21 in San Diego. "I'll be advising World Lacrosse on all things related to health, wellness and safety of participants in the community, including policies. For example, what's our concussion policy? How are head injuries handled? How are catastrophic events handled so that there's one uniform standard for the organization? And we organize and are responsible for the medical coverage for all World Lacrosse championship events" he said.

"There are 83 nations involved in World Lacrosse now. We'll have teams from Nigeria, Japan, all over the world next week. Which is very cool, right? Just as a sports medicine doctor, it's wonderful to be involved in giving back to something you love."

It's a role Hong is well-positioned for. "I have been volunteering for USA Lacrosse for 15 years. I have served as the USA national team physician for two different teams: the women's team in 2011, and then the men's team in 2016," he said. He has over 25 years' experience as a sports medicine physician and has served for over two decades as a NCAA team physician; in his clinical practice, he has taken care of high school, college, professional and elite athletes at every level of sport.

"Both years I served as the USA

national team physician, the national lacrosse teams won the world championship, winning the gold. The closest I'll ever get to a world gold medal is having earned one through my national team affiliation.

Hong has also been involved with the Committee of Sports Science and Safety Committee for USA Lacrosse for 10 years, serving as chair for the last four. The committee advises the national governing body for the sport on all things health, wellness, safety and performance related.

Now, he hopes to help lacrosse become an Olympic sport. "The community's very excited because it's actually a many-years process to get into the Olympics, and the International Olympic committees vote in September if they're going to allow it. All signs are that we'll get in as an Olympic sport in 2028."

Hong grew up playing lacrosse and soccer. He still loves being around sports and helping athletes and active people of all ages and abilities. He's proud of what MUSC Health's sports medicine experts have been able to accomplish – including, now, seeing their program represented at the international level.

But Hong said their regional work is important, too. "Our MUSC sports medicine docs are the team doctors at the Citadel and at the College of Charleston. This is the first time ever in the history of the three institutions – MUSC, CofC and The Citadel – that we've partnered in this way, taking care of all their student athletes. I've also been the chief medical officer for Clemson for the last three years. The MUSC sports medicine team also are the team doctors for the Battery and the RiverDogs and the Stingrays. I can't



*Photo by Sarah Pack*

**Dr. Eugene Hong holds a lacrosse helmet in his office at MUSC.**

be more proud of the MUSC sports medicine team" he said, referring to Charleston's soccer, baseball and hockey teams."

Every sport has a risk for injuries. Hong is well aware of the issues specific to lacrosse that he'll face as World Lacrosse's chief medical officer.

"It's a lot of lower extremity injuries: knees, ankles. And then concussions are also a concern for men and women. Rolling ankle injuries, knee injuries, ACLs, MCLs. So it's lower extremity injuries. And then essentially head injuries that we worry about because men's lacrosse has contact within certain parameters. Meaning you have to be near the ball or carrying the ball. We're modifying rules to try and be better and to lower injury rates to make it safer."

Hong said commotio cordis, the condition NFL player Damar Hamlin said stopped his heart, is also a concern for lacrosse players. "Published reports involved college lacrosse players who have been hit by the ball – it's a hard rubber ball and can hit the chest at the wrong time. And we've had sudden cardiac arrest and sudden cardiac death in college lacrosse."

Through his role with the U.S. team, he's been involved in trying to protect

players. "As the national governing body support, we've tried to stay ahead, and we've actually funded research in this area and have engaged some of the leading experts."

Hong has also written a book about mental health for athletes, a subject that has become more commonly discussed, thanks to the openness of superstars such as Simone Biles, Michael Phelps and Naomi Osaka. It covers mood disorders, substance abuse, risky behavior, doping, social media and exercise addiction, among other things.

But Hong said sports, including lacrosse, bring many benefits as well to players and fans. "Lacrosse combines some of the aspects of soccer, basketball and ice hockey and maybe a little bit of football. The other piece is that it's actually really fun to watch. Typically high scoring, typically fast moving."

And as he prepared to head to San Diego for the world championships, Hong hoped to elevate the profile of MUSC Health's sports medicine expertise and, of course, World Lacrosse. "It's just a super fun sport, which probably explains why it's so popular and is one of the fastest growing sports in the U.S. and the world."

# MUSC part of team bringing badly needed behavioral health hub to Florence

By HELEN ADAMS

[adamshel@musc.edu](mailto:adamshel@musc.edu)

At a time when 1 in 5 U.S. adults deals with mental illness every year, and 1 in 6 kids ages 6 to 17 does the same, the announcement of a new behavioral health hub in Florence, South Carolina, comes as welcome news for a lot of people. MUSC is working with other health care, state and local leaders to make it happen. Construction begins in 2024 on an MUSC-owned site on East Cedar Street.

MUSC President David Cole, M.D., outlined the scope of the problem. “At MUSC, our overarching mission is to preserve and optimize human life in South Carolina. I would say that behavioral health, or lack thereof, intersects with every dimension of our lives. One does not have to look much further than your circle of family or friends to have a story, something horrible, because of a lack of accessible, compassionate, impactful behavioral health.”

The new facility in the heart of the Pee Dee region of the state will address that need. It will include:

- Rapid access triage, which means figuring out what kind of care the patient needs.
- Telepsychiatry, which means using technology to communicate with patients who can't be at the center in person.
- Twenty beds for patients in crisis who need to stay at the clinic to be stabilized.
- A 63-bed psychiatric unit for patients who need more acute care.
- Outpatient services.

“I think this provides basis for us to actually start putting out a fire and then start doing something on a larger scale to allow us to have a healthy society. But today is about more than merely vision. It's about teamwork. It's about core commitment. It's about all the partners putting their needs together for Florence and the Pee Dee region,” Cole said.

Others involved with the June 15 announcement included Gov. Henry McMaster; Robby Kerr, director of the South Carolina Department of Health and Human Services; Rep. Murrell Smith Jr., speaker of the South Carolina House of Representatives; Donna Isgett, president and CEO of McLeod Health;



*Photo by John Russell*

**McCloud Health's Donna Isgett, Dr. David Cole and South Carolina Gov. Henry McMaster speak to interviewers at an event announcing the development of a behavioral health hub in the Pee Dee.**



*Image Provided*

**Rendering of what the facility on East Cedar Street in Florence may look like.**

Teresa Myers Ervin, Florence mayor; and Fred Carter, president of Francis Marion University.

The state is investing up to \$100 million in the project, and the City of Florence has committed to contributing \$5 million. The center will be named after state Sen. Hugh Leatherman, who long promoted the need for such a facility in the Pee Dee. He died in 2021 at the age of 90.

While the current behavioral health system faces multiple challenges, including not enough providers to treat all of the people who need care, the governor

pointed out that South Carolina has shown leadership in this area in the past. “We were the second state to have a state-supported mental institution. Virginia was the first. So we were right there.”

Smith, the House speaker, said the new effort will make history as well. “The Pee Dee area of South Carolina is probably one of areas that has one of the biggest gaps in behavioral health care in the state, and recognizing that, I moved this process forward. That's what we're here for today.”

Carter, of Francis Marion University in Florence, said the Pee Dee region badly needs the new behavioral health hub to help right some wrongs. “In the mid-'90s, we decided to deinstitutionalize mental health care by closing many of our residential centers in South Carolina and establishing regional outpatient and counseling centers across the state,” he said.

In doing so, leaders overestimated the benefits and underestimated the costs, Carter said. “We also didn't allow for the complex problems associated with identifying and educating rural patients and arranging for them to be transported to remote centers. Not treatment but for numerous problems.”

The new behavioral health hub will be part of the solution, Carter said.

Isgett of McLeod Health applauded the collaborative nature of the project. “It took something much bigger

*See HUB on page 11*

MEET AMANDA



**Amanda Lilienthal**

**Department; Years at MUSC**

*MUSC Finance Training and Innovations; almost 17 years*

**How are you changing what's possible at MUSC**

*By collaborating with Revenue Cycle, Supply Chain and Finance verticals to ensure our CTMs have the training they need to do an excellent job*

**Family** *Husband, Ernie (25 years) and daughter, Kathryn*

**Favorite summertime memory** *As a child, my entire family vacationed at White Lake, N.C. My PaPa would buy a roll of tickets for us kids to ride the park rides.*

**Someone special you've met** *Dr. William O'Dell (Parkwood Pediatrics) He encouraged me to reach for the "higher berries" because they were the sweetest.*

**Favorite quote** *"Do unto others as you would have them do unto you." –Luke 6:31*

**MUSC celebrates Pride Month**

*"I feel valued when I see visible support, like seeing people wearing rainbow and ally lanyards and having Safe Zone Ally stickers to identify who staff can go to with LGBTQ+ concerns."*  
- Brandon G., MUSC Health social work

*"We feel supported within our teams through words of encouragement, willingness to grow and change, advocacy and true allyship. We are also grateful for the love and support from the families we have the opportunity to care for every day."*  
- Liz M., M.D., and Nicole M., MUSC Health Palliative Care

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**MUSC Urban Farm transition and celebration**

After more than a decade in its current location on Bee Street near President Street, the Urban Farm is preparing for a transition beginning Oct. 1. Flowers, trees and shrubs are being relocated as the summer crops are being harvested.

**Come celebrate this chapter with the Urban Farm on July 18, 4:00 to 6:00 p.m., and stay tuned for more information about what comes next.**

**HEART** *Continued from Page One*

These boys are all suffering from broken hearts.

Collectively the trio – Bennett Gulyas (6), Jackson Bell (6) and Marcelino Leon III (9) – have 21 years between them, 10 surgeries and three of the best-decorated hospital rooms you’ve ever seen. The medical staff at the MUSC Health Shawn Jenkins Children’s Hospital dubbed them “The Three MUSCeteers” because they are inseparable.

But if not for a unique statewide approach to pediatric cardiology and a little sprinkle of fate, these three boys wouldn’t be sitting right here, in the game room, unwittingly making what is anything but a normal life seem almost normal.

**BACK TO SCHOOL**

It’s an overcast morning in late May, and Bennett beams as Child Life specialist Bethany Campbell hands him a brand-new Rubik’s cube. In the package, it’s perfect, all six sides solved. The 6-year-old gives a devious smile and in one quick motion, yanks it from the box and makes two quick turns – oranges, yellows and blues now intertwined.

“This is hard,” he says.

Then, two more twists and his face lights up; his shaggy red hair framing his brown eyes as they sparkle with pride.

“I solved the whole thing!” he shouts.

Marcelino looks on, unimpressed. But the 9-year-old doesn’t say a word. No need to burst his pal’s bubble, after all. He turns his attention back to his game of UNO!, hesitates for a second and then plays a “draw 4” card. His opponent frowns.

“Why would you do that to your mother?” Shondrell Leon says, laughing.

Before she can pay her penance, she’s bumped into by an energetic 6-year-old wearing a Paw Patrol fanny pack. Jackson smiles up at her, his blue-framed glasses the centerpiece of his cherub-like face.

“You’re in my way,” he says, too excited to slow down.

To the side, Bennett’s mom, Lindsey Gulyas, laughs and says, “Sometimes I feel like I’m back in college again, stuck at a frat house with a bunch of drunk people. Only now, they’re really little.”

Back at the table, Marcelino asks his mom a question. Suddenly, the room grows unsettlingly quiet, like the eye of a hurricane. There’s a short pause, and then Shondrell nods. At that moment, all three boys simultaneously erupt into cheers, Bennett’s arms shooting up in the air. It’s the MUSCeteers’ favorite time of day: screen time.

After rolling down the hallway like the grand marshals in a parade, they arrive at the elevator, where they will ride up to the 8th Floor Atrium to get the party started.

Campbell, who has worked with hundreds of hospitalized kids in her career, smiles as she says, “Honestly, I’ve never seen anything like this. The bond they have with one another is incredible. And they just run around the unit like they own the place. They’re all so comfortable with staff – and everybody loves them.”

**TRIUMPH OUT OF TRAGEDY**

Though their relationships are still relatively new, the boys’ bond runs deep. Sure, they share an undeniable love of Captain America but more critically, all three are designated 1A – the United Network for Organ Sharing’s top designation for those who are in the greatest need of an organ – on the transplant list. That means that of the roughly 3,400 people in the United States currently waiting for hearts, they are near the very top.

“For sure, it’s great to be one of the first people in line, but ...” Lindsey says, before her voice trails off. She doesn’t need to say the rest. Because it’s hanging there, her words crystal clear for all to see: They are there because their children’s situations are dire.

On paper, it might seem as if the boys are in competition for the same thing, a potentially conflicting situation to be



*Photo by Sarah Pack*

**Marcelino smacks his head as Jackson tells a bad joke, just one of the many signs that indicate the boys are extremely comfortable with one another.**



**Not only do the boys get along famously, it’s also completely obvious they care for one another.**

*Photo Provided*

in for anyone, much less three families who are simultaneously dealing with the biggest fights of their lives. But the determinants for transplant – things like blood type, height, weight – are different enough that it would never mean one of them would take a heart from the other. And though that is a weight off their parents’ shoulders, Marcelino’s mom, Shondrell, knows that if their son’s name is called and a heart becomes available, their family’s fortune is inevitably at the hands of another family’s tragedy.

“You try not to think about that part

of it,” Marcelino’s dad, Tony Leon, says. “Because you’ll just wreck yourself if you do.”

When that bittersweet day finally does arrive, MUSC Health pediatric cardiologist Heather Henderson, M.D., will be the first one to know. As the three boys’ primary heart doctor, she’s the one who will get the call if one of them becomes what she refers to as “the primary” – the top name on the secretive list seen only by UNOS. After she hangs up, she will quickly huddle with the other doctors and transplant

**See HEART on page 10**

# Neurology pays tribute to beloved educator, clinician with named education center

BY CINDY ABOLE  
 aboleca@musc.edu

A little more than a month after his passing, MUSC leadership, colleagues and family members gathered to honor the memory and career of clinician, educator, mentor and friend Paul B. Pritchard III, M.D., with the opening and ceremonial naming of the Dr. Paul B. Pritchard III Neurology Education Center. The unit is located in Suite 429 of the MUSC Clinical Science Building.

Dr. Pritchard was remembered for his many contributions to the Department of Neurology. For 52 years, he was

a dedicated clinician, educator and mentor, preparing the next generation of physicians and neurology specialists in the areas of physical diagnosis, clinical neurology and careers in medicine. He was also recognized for many leadership roles in his career from neurology clerkship director and course director of the neurology section to chairman of the neurology residency



**Pritchard**



*Photo by Zheng Chia*

**Becky Pritchard, center, joins Neurology's Dr. Jonathan Edwards, left, colleagues, staff and family on June 9 for the opening and dedication of the Dr. Paul B. Pritchard III Neurology Education Center.**

committee. He also served as the program's longest-serving neurology

residency program director until 2010.

See **TRIBUTE** on page 9

# Tackling a connective tissue disorder using nerve stimulation

By RYN THORN

[mcgheek@musc.edu](mailto:mcgheek@musc.edu)

An MUSC research team has received the 2023 Blue Sky Award to further the understanding and treatment of an often mischaracterized and dismissed disease, hypermobile Ehlers-Danlos syndrome (hEDS), using vagus nerve stimulation (VNS).

The team is led by stroke rehabilitation researcher Steven Kautz, Ph.D., chair of the Department of Health Sciences and Research in the College of Health Professions, and Russell “Chip” Norris, Ph.D., professor in the Department of Regenerative Medicine and Cell Biology in the College of Medicine. Other team members include Heather Boger, Ph.D., professor in the Department of Neuroscience, and Bashar Badran, Ph.D., professor in the Department of Psychiatry and Behavioral Sciences.

The Blue Sky Award is granted to an interdisciplinary team to assess the utility and value of a creative, daring idea that is unlikely to receive traditional funding due to its high-risk, high-reward nature.

This type of intrepid research can bring clinical breakthroughs. A breakthrough is urgently needed for hEDS, which is not well-understood but is devastating for many.

Members of the MUSC research team know this devastation firsthand.

“I have two children, both of whom have Ehlers-Danlos syndrome,” said Kautz. He detailed that his children, both in their 20s, have been significantly affected by EDS. “My daughter is bedridden and has had her life completely disrupted from the time she became a teenager.”

Likewise, the Norris lab has a personal investment in improving the lives of those with hEDS. It was Cortney Gensemer, Ph.D., an hEDS

patient herself, who joined the Norris lab as a graduate student and led the team to study the disease.

“As a patient-scientist, I have a unique perspective in the lab,” said Gensemer. “Combining my scientific background, personal experience and connection to the patient community allows me to contribute to knowledge in the field and push the boundaries of what we know about hEDS.”

The lab now has many other members, from volunteers to interns to coordinators, who either have been diagnosed with hEDS or are close to someone who has been.

## UNDERESTIMATING HEDS

Often incorrectly believed to be a rare, non-serious condition, hEDS affects the entire body in significant ways. At least 1 in 500 people have the disease, well above the 1 in 3,000 threshold at which a disease is considered rare.

hEDS is a connective tissue disorder that causes joint and muscle pain, joint dislocation, gastrointestinal discomfort, sleep disturbances, tingling or other unpleasant sensations on the skin and a whole host of other symptoms. People with hEDS often experience these symptoms at varying levels of severity at different times, making the disease unpredictable. Managing the disease is estimated to cost patients more than \$100,000 per year, with some having costs of over \$1 million in that time frame. It is anything but benign, said Kautz.

Troublingly, half of all people with hEDS report considering suicide due to both the physical effects of the disease and the failure of care providers to recognize the disease, resulting in a lack of proper care to address pain, comorbidities and/or hEDS’ myriad, often debilitating conditions.



*Photo Provided*

**From left, Dr. Jesse Goodwin, Dr. Lori McMahon, Blue Sky Award recipients Dr. Steven Kautz, Dr. Cortney Gensemer and Dr. Bashar Badran at the awards ceremony.**

*See AWARD on page 12*



**TRIBUTE** *Continued from Page Seven*

MUSC President David Cole, M.D., FACS, honored Dr. Pritchard for his dedication, enthusiasm and passion for his patients and advancing neurology education at MUSC. For some, according to Cole, Dr. Pritchard was considered a founding father of modern neurology and evidence-based epilepsy patient care in South Carolina.

"Paul dedicated his career and service to MUSC, the state of South Carolina and the MUSC family for almost five decades. It's rare that someone believed in and stayed with an organization for that amount of time, and I think it says a lot about his passion for patient care and our mission," Cole said.

"And although he formally retired from MUSC in 2019, I find it a testament to his fine character and commitment to the education of future neurologists that when asked, he couldn't quite stay away and agreed to continue imparting his vast knowledge and expertise with students, residents, fellows and APP fellows. On behalf of the MUSC senior leadership team, we thank Paul for his incredible and critical service and hope he and his loved ones know how grateful we and the citizens of our state have been blessed by his presence and warm heart."

The MUSC Department of Neurology is the only program in the state that offers a comprehensive stroke center and Level 4 epilepsy center with surgical capabilities for specialized patient care. The new neurology education center is part of a dedicated space designed to be modern, inviting and open in concept. It is composed of common and separate spaces – a large open concept teaching room; imaging and diagnostic room; common learning spaces for students, residents and fellows; as well as a student lounge, staff offices, quiet spaces, plus a central referral hub to manage clinical neurological services offered throughout the adult and pediatric hospitals.

At the June 9 dedication, Jonathan Edwards, M.D., professor and chairman

of the Department of Neurology, welcomed guests and unveiled a plaque with an engraved portrait of Dr. Pritchard on it. Edwards also presented a duplicate plaque to Dr. Pritchard's widow, Becky Pritchard, and the family, who also attended the midday event before officially opening the facility to guests.

"This new center for neurology education will serve as a central hub for the education of medical students, residents and fellows in neurology. For Dr. Pritchard's devotion and commitment to patient care and research, we're so proud to name the center after our friend, colleague and role model in neurology education," said Edwards.

South Carolina Advocates for Epilepsy, SAFE founder Karen St. Marie and her son, Erick, spoke about the new center's impact for physicians and clinical teams on behalf of patients and families who received care under Dr. Pritchard.

The dedication plaque hangs near the entrance of the new center. It features an image of the center's namesake.

"Erick has been a patient of Dr. Pritchard after suffering from epileptic seizures in March 2007 up until his retirement," said St. Marie. "What a gift Dr. Pritchard was to us. He was someone who was truly passionate about what he did and was dedicated to helping his patients. He supported us in every way. It was he, Dr. Edwards and others who encouraged me to restart the SAFE program, the only statewide nonprofit group devoted to education and advocacy for people living with epilepsy. Dr. Pritchard was always supporting this group through his presence at events, advocacy and donations. We will always treasure him, thanks to the many fond memories we shared together."

Becky Pritchard also shared her sentiments with the crowd. "Thank you to all of you. Paul loved MUSC – he truly loved it. He loved the people he worked with, his patients and



*Photo by Zheng Chia*

**Dr. Edwards shows members of the Pritchard family around the new facility, which includes a large teaching room, offices and dedicated learning spaces for students, residents and fellows.**

everything he did here. That's why he couldn't give up the fight until the end. We were blessed that he had friends, physicians, colleagues and staff and so many who wrote a note, called or have done many things for us and especially his granddaughters. There are not enough words to express how much this means to me and our family. Thank you again," she said.

College of Medicine Dean Emeritus Jerry Reves, M.D., was a medical school classmate of Dr. Pritchard's at MUSC in 1965. "Paul has always been the consummate gentleman and scholar. His family, patients, friends and colleagues knew they could always count on him for anything. I especially depended on his willingness to see any patient who needed to be seen and receive his compassionate expert care. It's fitting that the education space is named for him – he never tired of teaching the next generation with his characteristic enthusiasm, patience and unfailing concern."

Neurology colleague and friend Jerome Kurent, M.D., also emphasized the importance of the new education center to future physicians and students. "This new educational facility is an outstanding tribute to our

esteemed late friend and colleague. It will provide a superb learning environment and state-of-the-art facility for neurology residents, fellows and medical students for many years into the future. It is also a reflection of successful MUSC collaborations and vision into the future of neurology education which made this landmark event possible."

A native of Augusta, Georgia, Dr. Pritchard grew up in Ware Shoals, South Carolina, and received his medical degree from MUSC in 1969. After completing his neurology residency at the University of Virginia, and fellowship training at Harvard University, he returned to MUSC in 1975. Board certified in clinical neurology and clinical neurophysiology, Dr. Pritchard was promoted to professor of neurology in 1992. He was a fellow of the American Academy of Neurology, director of Continuing Medical Education for the American Epilepsy Society and a member of the professional advisory board of the Epilepsy Foundation of America. He was the first recipient of the Leonard Tow Humanism in Medicine Award,

*See TRIBUTE on page 11*

## HEART *Continued from Page Six*

surgeons.

“If we think it’s a good match, things move very quickly at that point,” Henderson said. “Time is so critical with transplant. The less time the heart isn’t beating, the better.”

As for the procedure itself, what these surgeons do is incredibly complex, a skill that takes decades to perfect. To think that they can transfer a surviving heart, and it will remember to beat and pump blood perfectly for an entirely new human almost feels like science fiction. That wonder isn’t lost on the woman who sees it happen on a weekly basis.

“The whole process is magic,” Henderson said. “Sure, it’s not a cure but to think that there’s a possibility of getting more time with the people you love, I mean, this is why I do what I do.”

### THE HEART OF THE MATTER

There is nothing magical about waiting, however.

For those with 1A status, it can be as long as a year before that elusive phone call comes – Henderson said six to nine months is a reasonable expectation, but it really can vary – which means that for the foreseeable future, “home” for these three families from Spartanburg, Mauldin and Lexington – is now this hospital in Charleston, South Carolina.

Just for a moment, think about what that would be like for a parent. Your house is hundreds of miles away. You’re sleeping on a fold-out couch. You’re eating Subway two meals a day. Meanwhile, outside the hospital walls, life goes on. Bills need to be paid. Other kids need to be driven to soccer practice. How



*Photo by Sarah Pack*

**Not only are the boys close with each other, they have effectively gained two extra sets of parents as well.**

on earth do you make all of that work?

“You know, you just find a way, I guess,” says Jackson’s mom, Kristin Bell. She and her husband, Trent, often trade off – she does weeks, and he does weekends.

“This whole process is so disruptive to these families,” Henderson said. “As if things aren’t tough enough dealing with a child who is very sick. These people have to uproot their entire lives. Put everything on hold. Most of us are lucky enough that we’ll never have to deal with anything like this. I can’t imagine what they’re going through.”

Though it might be a nice consolation prize to live in the city where your child’s hospital is located, several studies have found that the way states like South Carolina – which are few and far between in the U.S. – handle pediatric cardiovascular surgery is leading to better outcomes.

“What makes what we do special is the system of care we’ve developed with our statewide partners: delivering excellent continuity of care close to home and a single site where advanced procedures are offered,” said Mark Scheurer, M.D., chief of Children’s and Women’s Services for MUSC Health.

Often referred to as “regionalization of health care,” the idea of putting most of your resources into one place, versus watering them down at multiple locations, has several upsides. The most obvious of which is if you put all of your best surgeons in one place, you’re bound to have better results. It’s a basic tenet of life: The more times you do something, the better you tend to get at it. Medicine is no different.

“Don’t get me wrong, whenever possible, we want kids to get care close to home. But when you’re talking about some of the more complex procedures, it just makes sense to have one surgical center,” Scheurer said. “That allows us to build a team that can deliver the most advanced therapies because we’re not trying to do it all over the state. Leaders around our state were very intentional in creating the collaborative environment we have today. In the end, it puts the patient and their family as the focus.”

### THE BEST MEDICINE

Henderson, the boys’ cardiologist, remembers coming into work one weekend, and the 3rd Floor was oddly quiet. For the briefest of moments, she was concerned. But then she went by the boys’ rooms, one by one, and saw each of them sound asleep. One of the nurses explained that there had been a glow stick party the night before. “Apparently, it was a late night,” Henderson said, the smile evident in her voice.

That’s because she gets it. She knows that their special bond and these shared experiences matter. That they give these three little guys something extra. Something tangible.

Each other.

“This thing they have? It’s real,” Henderson said. “There is no doubt in my mind that they have an advantage that other patients don’t. They keep each other company, make each other laugh. And seeing that happiness – look, it’s hard to live in a hospital when you’re a kid – but these lighter moments, these normal moments, when they just get to be regular kids? These. These are going to be what gets them through.”

## Farewell to the Urban Farm!

Join us July 18, 4:00 to 6:00 p.m., for a special celebration!





Photo by Kristen Lee

**Pediatric oncologist Dr. Michelle Hudspeth checks in with Ivan Young two years after he underwent robotic surgery for a rare cancer.**

## RANKINGS *Continued from Page Two*

that his team is ready to tackle anything. “I would want people not only in our neighborhood, but people in our region to know that we take a lot of pride in being able to care for any and every pediatric orthopedic condition, whether that’s your neighbor’s child that had a fall off the monkey bars to the most complex multispecialty interdisciplinary care.”

### NEONATOLOGY

The neonatology program, which involves the care of newborn babies, jumped 36 spots from last year’s ranking to reach No. 44 this year, Scheurer said.

“They were kind of like the little engine that could. They were just persistent. It was important and they wanted to substantively improve their care and they wanted to bring recognition to the team, which was well-deserved. If they continue on that trajectory, they will go great places.”

About 3,000 babies are born in the MUSC Shawn Jenkins Children’s Hospital every year. It has a neonatal intensive care unit that draws families

with sick or otherwise fragile babies from around the region. It’s the only Level 4 NICU in the state, which means it offers the highest level of neonatal care.

Cutting-edge research is also part of the program’s focus. For example, pediatrician Julie Ross, M.D., is part of a large national clinical trial helping babies born with neonatal opioid withdrawal syndrome get healthy and home more quickly than in the past.

### NEPHROLOGY

The hospital’s nephrology, or kidney care, program maintained its spot in the top 50 nationwide. It has the largest pediatric nephrology program in South Carolina and the state’s only multidisciplinary children’s kidney transplant program.

The ranking shows that the program stands out when it comes to the survival rate of kids who have kidney transplants, the management of dialysis and infection prevention. It treats everything from urinary tract infections to chronic kidney disease to kidney failure.

In 2022, the nephrology team captured a lot of attention when it transplanted a kidney to a little girl

named Natalynn Mann from her aunt, who lost more than 100 pounds to become her niece’s donor.

Gastroenterology and GI Surgery

The gastroenterology and gastrointestinal surgery team’s high ranking comes as a new leader settles in. Benjamin Kuhn, D.O., MUSC Children’s Health division chief, is pleased to join a program with a strong track record.

“Technically I was only here for four months before the rankings package was due to submit. So I can’t take much credit for this year, but I really look forward to having a lot of momentum moving forward. Part of my hire was

crafting a new trajectory for building out our program. So I’m happy to have a running start,” Kuhn said.

This marks the eighth year that U.S. News has ranked the program, which has been growing. “Our program over the past couple years has been in a phase of expanding new specialty programs. If there is a niche subspecialty condition out there, we aim to service that need. As a division chief, I’m strategically making investments in those areas so that people don’t need to travel out of state to receive nationally recognized care.”

## HUB *Continued from Page Four*

than McCloud Health. It took this state. It took the Department of Mental Health. It took the support of the legislature, and it took us getting out of our own way to do something that’s better for the people of this community.”

Florence’s mayor thanked her fellow leaders for coming together as well. “I think one of the key things that you can see about Florence right now is how well we’re working together. Now, collectively, we can take care of the total mental health of all our citizens – but not just here in

the Pee Dee – but beyond today.”

Cole of MUSC said Florence and the Pee Dee are promoting innovative approaches to help families dealing with severe mental illness, substance abuse, abuse and other behavioral health concerns. “I’m willing to predict this hub will serve as a model that we can emulate and continue to build across different regions with partners across the state. This is something that every region, from my belief, is going to have to step up with its health care and its community – we serve the patients, the families, the citizens of South Carolina.”

## TRIBUTE *Continued from Page Nine*

awarded in 2000, and served in numerous community leadership roles in the Tri-county area. He retired from MUSC in June 2019, but continued to work with students and contribute to the department until recent years. He is survived by his wife, children, grandchildren and other family.

In lieu of flowers, donations can be made to the Paul B. Pritchard III, M.D., Endowed Epilepsy Lectureship and Education Support Fund, via the MUSC Foundation.

## Worksite screenings available for MUSC, MUHA and MUSC-P employees via Doctors Care

MUSC presents the Know Your Numbers Worksite Wellness Biometric Screenings via Doctors Care. The first basic screening for MUSC PEBA Health Plan members is free. Additional tests are also offered.

- Aug. 2: MUSC South Park, 1 South Park Circle, West Ashley.

- Aug. 4: MUSC Wellness Center Auditorium, 45 Courtenay Drive.

Schedule your appointment at <https://booknow.appointment-plus.com/y7smevc6/>.

**AWARD** *Continued from Page Eight*

“The vast majority of patients have a terrible time managing their care because physicians simply don't believe hEDS is real, and they think it's all in their head,” said Norris.

One of the Blue Sky Award recipients' goals is to change damaging medical misconceptions about hEDS by elucidating the biological mechanisms underlying the disease. They also hope to assess the potential of VNS as a treatment for hEDS.

**A NEW APPROACH**

VNS is already used to treat stroke, which brought it to Kautz's attention. It's also used to treat everything from depression to Parkinson's disease. However, the MUSC team is one of the first to test it in hEDS.

The vagus nerve is one of the longest nerves in the body, starting in the brain and traveling to the abdomen. When

stimulated, it can affect a variety of body systems and processes.

For this project, the team will use a novel technique for stimulating the vagus nerve to target a variety of symptoms in volunteers from their database of 7,000 hEDS patients.

“We're using an electrical form of brain stimulation that'll be applied to your ear,” said Badran. “Our work over the last decade has suggested that stimulating that nerve in the ear activates parts of the brain that are influenced by activation of the vagus nerve.”

The team will also monitor patients' hEDS symptoms to see which ones are lessened by VNS.

To learn more about how hEDS symptoms develop and how VNS is affecting those symptoms, Boger will use VNS on mice with hEDS symptoms.

“My goal is to make some small contribution to helping hEDS patients by understanding the mechanisms that

lead to this disease,” said Boger.

In addition to understanding what is happening in the body during hEDS, the team also wants to understand why and how VNS helps to ease hEDS symptoms.

“We also need to understand why VNS could provide relief for these patients,” Norris said. “When you start understanding treatment mechanisms, you have a lot more options for understanding the disease, which we know very little about.”

**BLUE SKIES AHEAD**

The dark days when hEDS was



**Norris**

downplayed and misunderstood may soon give way to blue skies, thanks to this team's cutting-edge interdisciplinary research.

“It's really only at places like MUSC where you can bring together clinicians and researchers and basic scientists to put together a team that will start to lay the fundamental scientific groundwork for studies that can make a big impact in people's lives across the world,” said Badran.

Several members of the team are already on the forefront of hEDS research, continuing to examine the genetic components of the disease. And there is much more on the horizon beyond the study funded by the Blue Sky Award.

“My hope is that this is the start of a bigger research program that would be able to look at hEDS from the animal model molecular level up to trials for improving quality of life for people with hEDS,” said Kautz.