Young transplant patient scores big moment on field

All eyes were on 8-year-old who overcame health issues

BY HELEN ADAMS
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This one definitely goes in the win column for Alexander “Xander” Garnsey, a boy more used to being around a team of doctors than a team of baseball players. On May 29, the 8-year-old from Ruffin, South Carolina, threw the first pitch at the Charleston RiverDogs’ game.

His catcher was the CEO of Sharing Hope, the state’s organ procurement organization. Xander, who got a new liver on Christmas day in 2010, wants to spread the word about the need for organ donors. More than 1,000 South Carolinians are waiting for a life-saving organ transplant.

MUSC Health pharmacist and College of Pharmacy faculty member Kathy Chessman, PharmD, who bonded with Xander’s family during his hospital stays, was at the game last night to support him. “He’s an unbelievable little guy who has gone through a lot,” she says.

Xander’s parents knew even before he was born that he would face some serious challenges. “When we found out we were expecting him, we started out at Trident OB-GYN,” his mother, Shannon Garnsey, says.

“When we went in for our 13-week checkup and ultrasound, they discovered his belly just wasn’t as round as it should be. So they referred us to MUSC.”

At MUSC Health, doctors diagnosed Xander with gastrochisis, a problem with the wall of his belly that was pushing his intestines outside of his body. He was born by C-section on February 2, 2010.

“He did well,” his mom says. “Two days later, they pushed back in his bowels, which is the normal procedure. He started doing well. He had some inflammation in his belly, but they said that was normal as well.”

But Xander’s medical problems weren’t over. “By looking at him and even at his labs, you’d have no idea of everything that was going on inside of him,” Garnsey says.

The baby boy developed an infection in his intestines and had to have part of his bowel removed. He also had a fistula, which is an abnormal opening in the digestive tract, and needed an ostomy bag to gather waste from his system. On top of that, he needed an intravenous line and a gastronomy tube to help make sure he got the medicine, fluid and nutrients he needed.

Xander’s parents learned how to use the medical devices and took him home when he was about two-and-a-half months old. But it soon became clear that something was wrong with his liver.

“He’s bilirubin level would jump and go back down,” Garnsey says. “He was very yellow.”

Xander had another operation that November. In December, doctors told the Garnseys that Xander would need a liver transplant. “It was very hard after everything he’d already been through in that first year,” Garnsey says.

He went on the transplant waiting list on Dec. 22, 2010. Two days later, on Christmas Eve, they got a phone call. “They had found a match.”

Xander had transplant surgery earthe next morning at MUSC Children’s Health. “He had his second chance at life,” Garnsey says.

Today, Xander is a second-grader who likes throwing a football with his dad, painting, playing with Legos and trucks and reading. He also collects toys, coloring books, gift cards and blankets to donate to kids at MUSC Children’s Health and the Ronald McDonald House during the winter holidays.

His mother says his family is grateful for the support they’ve received over the years. “The blessings, the prayers from our friends and family. We cannot ever stress enough how thankful we are for MUSC. You don’t feel like your child is one in thousands. You feel like your child matters.”

See XANDER on page 10
PEOPLE

John M. Kaczmar

John M. Kaczmar, M.D., assistant professor, Division of Hematology and Oncology, Department of Medicine, has joined MUSC Health. Kaczmar is a medical oncologist and a specialist treating cancers of the head and neck. He is a graduate of Columbia University Medical School and completed his residency at the University of Pennsylvania and a hematology and oncology fellowship at Fox Chase Cancer Center in Philadelphia prior to joining MUSC.

Steven W. Kubalak

Steven W. Kubalak, Ph.D., associate professor in the Department of Regenerative Medicine and Cell Biology, was named a recipient of the 2018 Distinguished Research Leadership Award presented by the South Carolina Governor’s School for Science and Mathematics in Hartsville. Kubalak has been the coordinator for the College of Graduate Studies placing students in labs across campus for the past five years.

Paul R. Lambert

Paul R. Lambert, M.D., professor and chairman in the Department of Otolaryngology-Head & Neck Surgery, received the 2018 Award of Merit from the American Otological Society at the group’s annual meeting. The award is one of the highest honors in the field of otology and neurotology. Lambert previously served as secretary-treasurer (2007–2012) and president (2013) of this organization.

Brintha Vasagar

Brintha Vasagar, M.D., was named associate program director of the Tidelands Health MUSC Family Medicine Residency Program. Vasagar serves as director of the leadership, advocacy and research programs. She has previously spoken to Congress and the United Nations about international health issues and disaster preparedness. She is a recipient of the Excellence in Graduate Medical Education Award by the American Academy of Family Medicine.

EVENTS

Conversation Cafe

MUSC is very excited to announce the next Conversation Cafe, which will focus on Health and the Environment. On Wednesday, June 6, from 1 p.m. until 2, a panel of three MUSC researchers will discuss the intricate link between human health and the environment, the health effects of climate change, environmental contributors to child health outcomes and the toxicology of obesogens (chemical compounds that can lead to obesity). A discussion and a Q&A will follow. This event is free and open to the public and will be held in Basic Science Building Room 100.

Piccolo Spoleto Festival

Charleston’s Piccolo Spoleto Festival will hold its finale at 5 p.m., Saturday, June 9 in Hampton Park (30 Mary Murray Blvd.) Share the evening with friends, family and neighbors and groove to the sounds of some of Charleston’s finest musicians. For tickets, visit https://web.ovationtix.com/trs/pe/c/10279598 or call 866-811-4111.

Red Cross Blood Drive

Did you know only about 3 percent of the U.S. population donates blood? Please help by donating at the Red Cross IOP Blood Drive, Friday, June 15. There are morning, afternoon and Power Red time slots available. Andolinis Pizza and a gift basket for the 500th overall IOP donor. Call 843-792-6341.
Kids Eat Free at MUSC returns for fourth summer

MUSC is once again partnering with Sodexo to offer Kids Eat Free at MUSC, a program to help reduce food insecurity for children under 18 during the summer months. The program will serve breakfast from 7 a.m. to 10 a.m. and lunch from 11 a.m. to 2 p.m., June 4 through Aug. 19, at the cafeterias in the main hospital, ART and Rutledge Tower. The mission of Kids Eat Free at MUSC is to optimize health by providing adequate nutrition to children when school is out for summer break. This United States Department of Agriculture-sponsored program ensures children have access to nutritious meals when school is not in session by providing breakfast and lunch to children at no cost to the families or the enterprise.

In 2015, Sodexo and MUSC became the first hospital in the Southeast to participate in the USDA’s summer feeding program and is among only a handful of hospitals in the country providing this important program to address food insecurity. Since then, using MUSC’s model as a guide, hospitals in North Carolina, New Mexico, Ohio, Wisconsin and Missouri have started similar programs and collectively served approximately 40,000 meals in the summer of 2017.

MUSC’s program, which has served more than 13,000 meals to children, was designed so no child feels differentiated for receiving free meals. No questions are asked, and children do not need to sign up or show any type of registration, documentation, ID or proof of need to receive their meals. MUSC qualifies as a USDA open site because nearly 90 percent of children who attend nearby public schools qualify for free or reduced-cost meals during the school year.

Food insecurity contributes to the rising cost of health care. Participation in hunger relief programs within health care’s existing infrastructure provides an opportunity to improve population health by increasing access to nutritious meals for those most in need. The USDA funds the much needed program and allows children who receive free or reduced-cost meals during the school year to continue receiving food while school is out. USDA summer meal programs, like Kids Eat Free at MUSC, help bridge the gap for more than 18 million children who lose their most reliable source of nutrition once the school year ends.

Sodexo employees are available to answer questions. For information, contact Sodexo Wellness Dietitian Debbie Petitpain, RDN at petitpa@musc.edu or (843) 792-9644. Printable flyers and information are also available at: www.musc.edu/kids-eat-free.

Program recognizes June 15 as World Elder Abuse Awareness Day

Effort to raise awareness about elder abuse, neglect

BY MARA STEEDLEY

steedlem@musc.edu

The MUSC Elder Abuse Assessment Training and Mental Health Services Program will commemorate World Elder Abuse Awareness Day from 10 a.m. to 2 p.m., Friday, June 15 at the MUSC Horseshoe. Information on elder abuse prevalence, prevention and treatment will be available for faculty, staff, students and the community.

Every year an estimated 5 million people, or 1 in 10 older Americans, are victims of elder abuse, neglect or exploitation. Experts believe that for every reported case of elder abuse or neglect, as many as 23 cases go unreported. World Elder Abuse Awareness Day serves as a call to action for individuals, organizations and communities to raise awareness about abuse, neglect and exploitation of elders. The International Network for the Prevention of Elder Abuse and the World Health Organization launched the first World Elder Abuse Awareness Day on June 15, 2006 in an effort to unite communities around the world to raise awareness about elder abuse.

MUSC’s program was organized under the leadership of program director Melba A. Hernandez-Tejada, DHA, Ph.D. The program trains health care professionals from around the Tri-county area on how to identify and refer cases of elder abuse. The program, based in the MUSC College of Nursing, complements provider training with a telehealth counseling program for elder abuse victims at no cost.

World Elder Abuse Awareness Day is conducted in support of the UN’s International Plan of Action, acknowledging the significance of elder abuse as a public health and human rights issue.

For more information, contact me at 843-792-0796 or steedlem@musc.edu or Gabrielle Mooneyham, treatment coordinator, at 843-792-2910 or mooneyhg@musc.edu.
**Physician, sickle cell specialist challenges Class of 2018 to show compassion, empathy to patients**

**Editor’s Note: Dr. John F. Tisdale is a clinical scientist working at the National Heart, Lung and Blood Institute in Bethesda, Maryland. He was the speaker at MUSC’s 189th Commencement on May 19. Below is the full text of his speech.**

Good morning. I would first like to thank the leadership of MUSC for inviting me to address this 2018 graduating class. It is truly an honor for me to be here today and to share in this momentous occasion.

Nearly 30 years ago, I was sitting where you are now. I’m a native Charlestonian. I was born just a block from here, and my family has lived here for many generations. In fact, I may be the only family member to ever leave the surrounds of this wonderful city. I attended public schools West of the Ashley and lived and worked just a few blocks away from here at McAlister Funeral Home while attending the College of Charleston. During that time, I also played music in many downtown venues to earn extra money to support myself.

I entered the School of Medicine in 1986, and it was here that I acquired the knowledge and experience that set me on the course that I continue on today. In May of 1990, on a day just like today, I was preparing to walk and, in my mind, move to Nashville, Tennessee, to begin my residency training in internal medicine at Vanderbilt University.

At Vanderbilt, I learned the importance of the caliber of the education I received here at MUSC. My first rotation as an intern was in the Medical Intensive Care Unit at the prestigious Vanderbilt University Hospital, which is known for its cutting-edge experience in critical care. Helicopters were bringing in severely ill patients that would become my responsibility during the ‘every other night’ call rotation. I was petrified, at first. But my comprehensive education and intense hands-on clinical experience here at MUSC gave me the tools to rapidly adapt to this and the many coming challenges.

It was clear to me right away that I was far better prepared than my fellow interns at Vanderbilt for these challenges. I know that there are always butterflies when new challenges lie ahead. But I can tell you firsthand that your MUSC education has prepared you well for these challenges. I went on to complete my residency and served as chief resident before moving to the National Institutes of Health for further training in hematology and transplantation. After a post-doctoral fellowship in hematopoiesis, I finally established my own laboratory and clinical program.

I know how important this day is in your journey. You are here today to celebrate a major accomplishment. And as I am saying this, I am sure you are already thinking about all those long nights studying, the enormous effort you put into preparing for exams, the countless hours spent going over books and notes — for many of you, the time spent on clinical rotations developing your clinical skills and for others, the time spent in the lab late at night and on weekends developing your skills in biomedical research.

I am sure you remember feeling incredibly exhausted, and despite that exhaustion, having to study even more or having to run just one more gel. I still remember that myself. You are celebrating all of the hard work that you did over the years that has led to your graduation today. You should feel very proud of that hard work and I’m sure your family and loved ones feel the same way too. Congratulations to all of you on your achievements. Congratulations also to the Golden Graduates, celebrating their graduation 50 years ago in 1968.

Today I want to also bring something else to your attention. I want you to reflect for a moment about those things that did not depend on your hard work but have also made it possible for you to be where you are now. You may think it is an awkward topic to bring up in a graduation. But I want you to think about it today, because an awareness about the many things that do not depend on our own hard work is crucial for the work we do as health care professionals and biomedical researchers. Even more, I would say that this awareness is essential so that we not only provide the best care for every individual patient, but that we also contribute to improving the options for patients, enhancing the health and well-being of our communities and our society as a whole.

Many things are indeed just a matter of luck. You all should bask in the praise and recognition for all of your hard work these past years. You should also be thankful that you had the good luck to be healthy, to be smart and to have or be able to garner the financial resources to pursue higher education at MUSC — and the good luck to have the support in this journey that is gathered here today to celebrate with you.

Life is a natural lottery, and all of you had at least reasonably good luck in this one. We also know with certainty that our actions — diet, exercise and adherence to medical regimens for example — have a remarkable impact on our health. But evidence still shows that most of what constitutes our health is socially determined. It depends on where in the socioeconomic spectrum we were born. On how much money the families we were born to have. On our parents’ level of education. On our race and ethnicity. And all of that is dictated by luck: the natural lottery.

Awareness about this natural lottery, which in the context of health care often implies multiple layers of bad luck, is crucial for the health professions and is absolutely essential for the practice of medicine. Many of the patients you will encounter, either directly or through your work, have the misfortune of being born with genetic illnesses or they develop illnesses later in life, and we have the moral duty to respond to that misfortune by treating them with kindness, compassion and care. And when we advise them to adapt healthy behaviors and adhere to medical treatments, we must be aware that our same words will mean something different to different patients. It is very different to instruct a patient with new onset Type 2 diabetes on an exercise program if they work on a 9-to-5 schedule and can afford the gym fees and the help to look after their kids while they...
THE CATALYST, June 1, 2018

MEET KELLY

Kelly Perritt, Ph.D.

Department; How long at MUSC
Brand Strategy & Enterprise Marketing; six months

How are you changing what’s possible at MUSC
By working with the brand team to deliver messages that elevate our brand with key audiences

Family and pets
Husband, Michael; daughters, Meagan and Tabitha; son, Garrett; and a Rottweiler dog, Brock “Tootsie Bear”

Last book read
“The Power of Habit” by Charles Duhigg

How would you spend $1 million
I’d start a nonprofit to help women develop their entrepreneurial and business skill sets

Favorite baseball team
St. Louis Cardinals

Words of advice
Great things are not done by impulse, but by a series of small things brought together. — Vincent Van Gogh

Conversation Cafe
6.6.18

HEALTH AND THE ENVIRONMENT
Exploring the link between human health and environmental health

MUSC Panel Featuring
Demetri D. Spyropoulos, PhD
“Obesogen Toxicology: What doesn’t kill you makes you fatter”
Mark T. Hamann, PhD
“How Climate Change will Impact our Health”
John E. Vena, PhD
“Cultivating a Healthier Tomorrow for SC Children: Environmental Contributors to Child Health Outcomes”

1:00 pm - 2:00 pm
Wednesday, June 6th
Basic Science Rm. 100

Hosted by MUSC Sustainability & Recycling
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Teaching Excellence awards honor distinguished faculty

Four exceptional faculty members will be honored for their contributions to teaching excellence at MUSC’s annual faculty convocation on Aug. 21, the beginning of the 2018-19 academic year. The MUSC Foundation’s Teaching Awards were established in 1994 as part of MUSC’s educational strategic plan and continue to recognize the outstanding contributions of the recipients. The event will be held in the Drug Discovery Building auditorium.

The faculty members are:

- Cynthia B. Dodds, Ph.D., assistant professor, College of Health Professions, Educator–Mentor/Clinical–Professional.
- Gretchen A. Seif, DPT, associate professor, College of Health Professions, Educator–Lecturer.
- David W. Shirley, PharmD, assistant professor, College of Pharmacy, Developing Teacher.
- Patrick M. Woster, Ph.D., professor, chair and SmartState endowed chair in drug discovery, College of Pharmacy, Educator-Mentor/Scholarship–Academic.

Patrick M. Woster, Ph.D.
College of Pharmacy

Educator-Mentor/Scholarship-Academic

Woster joined the MUSC faculty in 2011 as professor and the SmartState endowed chair in drug discovery, coming from Wayne State University. He received his doctorate in medicinal chemistry from the University of Nebraska and did postdoctoral training at Rensselaer Polytechnic Institute and the University of Michigan.

“Dr. Woster has an uncanny ability to balance grant funding, publications, business ownership, departmental leadership, teaching and guiding individualized research projects,” stated several students in a letter of nomination. “We can all confidently say that we have been provided an excellent role model for our future careers in science.”

Throughout his career, he has won several teaching awards and has served in leadership positions in national organizations, including the American Chemical Society and the American Association of Colleges of Pharmacy.

David W. Shirley, PharmD
College of Pharmacy

Developing Teacher

Shirley received his doctorate from the MUSC College of Pharmacy in 2002 and joined the faculty in 2015, following a career in community pharmacy where he served as a preceptor for many MUSC students on fourth-year experiential rotations.

“We were very fortunate to recruit Dr. Shirley to our institution as an assistant professor in 2015,” stated Kelly Ragucci, Pharm.D., professor and chairwoman of Clinical Pharmacy and Outcomes Sciences, in a nomination letter. “David has been ranked the No. 1 lecturer (out of 25 faculty members in the department) for the past two years...His courses also rank in the top 3 or 4 of all courses in the curriculum.”

He has received several awards both in community and academic settings including the Gordon-Merkel Professionalism Award, Professor of the Year by the class of 2019 and Teacher of the Year by the class of 2021.

Gretchen A. Seif, DPT
College of Health Professions

Educator-Lecturer

Seif earned her doctorate in 2009 from Regis University and joined the MUSC faculty in 2008 as an instructor.

Her nomination generated several letters of support from students, former students and colleagues. Common themes found throughout the correspondence involved her engaging teaching style, her commitment to her profession through participation in professional organizations and her involvement with the student-run CARES clinic for underinsured and underserved patients. “She is one of the most energetic, passionate people you will ever meet,” states Karen Wager, DBA, professor and associate dean for student affairs in the College of Health Professions. “To be honest, it is hard for me to imagine a more talented and deserving candidate for this award. In my 30 plus years of experience in higher education, I would place Dr. Seif among the best educators I have ever known.”

Among her several honors are the foundation’s Developing Teacher Award for 2011-12, the College of Health Professions’ Service Award for 2014, the South Carolina Commission on Higher Education’s Service Learning Award for 2015 and the South Carolina Chapter of the American Physical Therapy Association’s 2016 Emily Cate Service Award.

See Awards on page 8
Inspire, innovate, influence – MUSC Health’s Nurse of the Year is an expert at all

By Mikie Hayes
hayesmi@musc.edu

MUSC Health’s 2018 Nurse of the Year, Maggie Dillehay, is known for teamwork. Heralded by her colleagues for leading by example and always going above and beyond, Dillehay is a Medical Surgical ICU team member. For the many special attributes she brings to the job each day and her numerous accomplishments, she was recognized at the Nurse of the Year ceremony May 7.

National Nurses Week begins every year on May 6 and ends on May 12 – Florence Nightingale’s birthday. The week is promoted through the American Nurses Association and features a variety of events across the nation designed to honor nurses for the work they do and educate the public about nurses’ unique roles in health care.

MUSC’s special recognition event kicked off National Nurses Week on campus and reinforced MUSC’s commitment to recognizing its nurses publicly for the outstanding care and compassion they continually provide to patients and families at the bedside and beyond and the positive impact they make on health care.

In keeping with this year’s national theme – Inspire, Innovate, Influence – colleagues nominated Dillehay for the prestigious recognition because of the many ways she accomplishes each of these important actions.

“Maggie has been our nighttime clinical staff leader since June and a member of our team since July of 2015. Maggie has never been afraid to jump in, and get involved. As many know, this unit has been going through multiple transitions, many of which caused this unit’s morale to take a large hit. Maggie has been the light for this unit. She reminds us that this change is temporary, and that what makes our unit great is our teamwork. She brings us back to what is important, the patients.”

Dillehay inspires others, her teammates say, and she continually finds ways to innovate the type of new approaches that will have a lasting influence on her unit.

“Maggie is open and welcoming, she embraces every new staff member with an open mind and focuses on helping them build the skills necessary to become a thriving ICU nurse. Maggie is always willing to go to bat for her staff members to ensure that they are in the best environment to succeed. She leads by example and works so hard to make our unit the best place to work. We are so lucky to have her in our unit, and look forward to seeing all the wonderful things yet to come.”

Mia Lombardelli, RN, an MSICU teammate, shared an example of the lengths Dillehay went to meet the needs of a patient and his family, her commitment a hallmark of the character she exhibits on a regular basis.

“Maggie has gone above and beyond in caring for her patients. An example that comes to mind is a long-term patient who had made the decision to withdraw care. Our nurses had set up a special moment where the patient was able to see his dogs, make paw and handprints. Unfortunately, after a series of unfortunate events, it ended up in the trash. Maggie coordinated with Environmental Services, the house supervisor coordinator and 1West to get the appropriate gear and access to the dumpster and then ended up getting in the dumpster and eventually finding the

See Nurse on page 11

MSICU nurse Maggie Dillehay was named the 2018 MUSC Health Nurse of the Year on May 7 during the annual ceremony held at St. Luke’s Chapel. Colleagues nominated her for all the many things she does to make the unit a wonderful place to work and receive care.
MUSC Center for Telehealth Physician Receives National Recognition

MUSC Center for Telehealth Medical Director Dr. S. David McSwain, left, receives the 2018 Telehealth Champion Award presented by a member of the American Telemedicine Association at the organization’s annual meeting in early May. McSwain was recognized for his contributions and advocacy to advance telehealth services at MUSC and across South Carolina. Right photo: McSwain, third from left, with MUSC’s Drs. Jimmy McElligott, from left, Kathryn Cristaldi, David McSwain, Dee Ford, Brooke Yeagar (S.C. Children’s Hospital Collaborative), Sabrina Smith (ATA Chief Operating Officer), Shawn Valenta and Dr. Ragan DuBose-Morris.

Awards

Continued from Page Six

Cynthia B. Dodds, Ph.D.
Educator-Mentor/Clinical-Professional

Dodds has been associated with MUSC since 2004, first as an adjunct faculty member and since 2013, as a full-time faculty member. Dodds began her career with the South Carolina Department of Health and Environmental Control as a physical therapy team leader. She eventually went into private practice and was a co-founder of the acclaimed Pattison’s Academy, a charter school in Charleston County for special needs children.

Two recent CHP graduates, Allison Blackburn and Caitlin Keller, nominated Dodds, citing her innovative education methods, which are evidence-based, service-connected and “fun,” according to their letter of support. She recruited 14 children for MUSC’s first “Baby Day,” in which physical therapy students could observe and assess infant motor development. She also obtained funding and equipment for students to make “Go Baby Go” cars, modified toy cars for children who experience delays in mobility. Her community outreach projects include regular mission trips to Uganda, taking students to treat patients. “Dr. Dodds’ welcoming demeanor, inventive teaching techniques, and commitment to public service make her an invaluable asset to rehabilitative students and the entire MUSC community,” they wrote.

Her honors include the 2015 Gold Foundation Scholar, 2015 Harvard Macy Scholar and 2015 CHP Educator of the Year. She was also nominated for the foundation’s 2015 mentor-educator award and CHP’s 2014 Educator of the Year.
implement that exercise program, than if they are a single parent working two long shifts and barely making ends meet.

Health care professionals must be aware of these differences and persist in being kind, compassionate and caring with the patients that are struggling not just with illness, but also with other unfortunate situations. Perhaps a patient could not make an appointment because her job doesn’t allow her to take sick days, and she’s afraid of losing it and both her health insurance and her ability to feed her kids. Or perhaps she just couldn’t afford the copayment.

A caring attitude in health care professionals should not be taken for granted. I work on sickle cell disease, a genetic disease that arises from inheriting from both parents a single misspelled letter in the DNA that provides the instructions for hemoglobin in the blood. The molecular basis for the disease was described more than half a century ago by Linus Pauling and his colleagues where he referred to sickle cell disease as a “molecular disease.” It was the first disease to be characterized at the molecular level. Pauling went on to receive the Nobel Prize in Chemistry in 1954 for his groundbreaking work.

The genetics were soon worked out. The gene mutation arose as an evolutionary adaptation to malaria. The good luck in the natural lottery of inheriting only one copy of this misspelled gene from either mom or dad protects individuals from the lethal consequences of malaria. This protection has led to its natural selection in areas where malaria is endemic, including sub-Saharan Africa and Southeast Asia. However, inheriting two copies of this misspelled gene — one from mom and one from dad — results in sickle cell disease, and this bad luck in the natural lottery has serious consequences.

The World Health Organization estimates there are more than 300,000 born with sickle cell disease in Africa every year. The vast majority, perhaps greater than 90 percent, do not live beyond 5 years of age. Here in North America, where the disease affects predominantly those of African descent, public health interventions such as universal newborn screening, along with penicillin prophylaxis against overwhelming infection and other supportive care measures, have been implemented and virtually all children now survive to adulthood. This has been a major victory in the management of this disease here.

Unfortunately, the disease still takes its toll. Patients experience frequent severe pain from blockage of blood vessels by the abnormal, sickle–shaped red blood cells that characterize the disease. This pain is often so severe that patients require repeated and prolonged hospitalizations for pain management with multimodality therapy, including high dose narcotics, that can last days to weeks. The blockage of blood flow in vital organs takes its toll as well. Patients experience complications in all major organ systems.

Stroke is one of the devastating complications of the disorder and affects young children with sickle cell disease at a high rate. A colleague I met some years ago has a child with sickle cell disease who is a child prodigy. He was playing and performing violin at the age of 5 at a level exceeding that of many adults. A sudden stroke at 5 left him unable to walk or even speak.

The accumulated damage from the disease results in a markedly shortened lifespan that remains at a median in the 40s here in the U.S.

In my training, I was perplexed as to why we had no specific therapies for sickle cell disease, especially since this is the first disease for which the molecular defect was identified. Pauling and others were excited by the knowledge of the molecular basis and predicted that therapies would soon be pursued based upon this new knowledge in the late 1940s. But as I started my residency training in the 1990s, we had no such specific therapies. There were no FDA-approved drugs, and we could only provide pain medicines and fluids to alleviate the suffering.

I was also perplexed by the stark contrast in support and research funding that other genetic diseases like hemophilia or cystic fibrosis receive that affect a different demographic. And I was perplexed to see the stigma associated with the disease. The notion held by many that patients with sickle cell disease were coming to the emergency room seeking narcotic medications not to control their pain, but rather, to get high.

This led some to withhold the only treatment we had at the time: pain medications. In fact, patients with sickle cell disease uniformly tell me that when they have a severe pain crisis, they do their best to handle it at home, but if forced to seek medical attention before heading to the emergency room, they put on their nicest outfit — their ‘Sunday best,’ because they have all at some point experienced situations in which health care professionals have treated them as if they were drug addicts, faking a medical need, leading to an encounter in which they were denied the medical care they urgently needed. Their severe sickle cell pain thus compounded by the indescribable pain of being misjudged and mistreated by the same health care professionals that were supposed to provide them with

See ALUMNUS on page 11
The MUSC and Medical University Hospital Authority (MUHA) Board of Trustees held its regularly scheduled meeting to hear reports on the university’s academic and research initiatives, as well as the operations of its health system. The Friday meeting coincided with the 189th MUSC Commencement exercises, held the following day, Saturday, May 19, at McAlister Field House on The Citadel campus. The inclement weather forecast caused the graduation ceremonies to be moved indoors rather than remaining outdoors on MUSC campus.

This year, MUSC graduated 626 new health care professionals from its six colleges: Dental Medicine, Graduate Studies, Health Professions, Medicine, Nursing and Pharmacy. Visit http://academicdepartments.musc.edu/pr/pressrelease/2018/2018_commencement.htm.

Attending his first meeting as an MUSC/MUHA board member was W. Melvin Brown III, M.D., appointed to the MUSC Board of Trustees effective May 2. Brown represents the 6th Congressional District of South Carolina, which includes all of Allendale, Bamberg, Barnwell, Clarendon, Colleton, Hampton and Williamsburg counties and parts of Beaufort, Berkeley, Calhoun, Charleston, Dorchester, Georgetown, Orangeburg, Richland and Sumter counties. To read more, visit http://academicdepartments.musc.edu/pr/pressrelease/2018/2018_commencement.htm.

During the session, MUSC board Chairman Donald R. Johnson II, M.D., read a resolution in appreciation of William W. "Bill" Peagler III, Berkeley County supervisor and council chairman. An entrepreneur and business leader, Peagler was cited for his vision, hard work, countless contributions to public service and for being “a tremendous champion for the Medical University of South Carolina by spearheading efforts of primary and specialized rural health care coverage to citizens of his county and region.”

As it closed, the resolution stated, “MUSC looks forward to working with Mr. Peagler and the citizens of Berkeley County in the years ahead on providing accessible and innovative health care...The MUSC Board of Trustees commends William W. "Bill" Peagler III, for his service to this institution and the citizens of South Carolina.”

“I’ve met Dr. Cole [MUSC President] many times, and we’ve discussed the needs of people in the rural areas where they don’t have the care that we have here in Charleston County,” Peagler said. “We’ll do everything we can to help expand the quality of life services provided by the Medical University.”

In December, MUSC announced plans to seek approval to construct a 128-bed hospital in Berkeley County at an estimated cost of $325 million. MUSC has filed for a certificate of need from the South Carolina Department of Health and Environmental Control (DHEC). DHEC must issue a CON before certain types of health care acquisitions, expansions and creation of new facilities are allowed.

In other business, the board voted unanimously to:

- Approve the MUSC Certificate in Clinical Research (CCR), a new post-baccalaureate and/or post-master’s certificate program to be implemented on July 1. Previously approved by the South Carolina Commission on Higher Education, the CCR is a 100 percent online distance education program in the College of Graduate Studies. By obtaining a CCR, clinicians such as M.D.s, Pharm.D.s, post-MSN nurses, RNs, physical therapists, clinical study coordinators and other health care professionals will accrue competencies to perform clinical research. This certificate aligns with the MUSC goal to Advance New Knowledge and Scientific Discoveries, as it will equip more clinical providers to participate in biomedical research.
- Rescind the honorary degree (Doctor of Humane Letters) bestowed on William “Bill” H. Cosby on May 21, 1999, due to his recent conviction.

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ALUMNUS  Continued from Page Nine

care.

I decided to focus on sickle cell disease, motivated by these injustices and inspired to develop specific therapies where none existed. I chose a research path, because doing research would allow me to improve the lives not only of the limited number of patients that I could take care of as a physician, but also of the many more in need of treatment across the globe that I would never have the opportunity to meet.

There is now considerable optimism for sickle cell disease. Though the pace of progress was initially slow and frustrating, we have now amassed the tools to begin contemplating a cure that is available to all patients, at least in the developed world, and we are already considering ways to make these therapies available in resource-poor environments.

Since the cause of all of the complications of sickle cell disease rests in the abnormal sickle-shaped red blood cell, we reasoned that going to the factory where these red blood cells are produced would be a viable strategy for treatment. Indeed, our efforts to develop bone marrow transplantation strategies over the last two decades for adults with sickle cell disease have been effective. Over 90 percent of patients can now be cured after receiving a bone marrow transplant from a tissue-matched brother or sister without the disease.

And this is really encouraging, but only around 10 percent of patients have a tissue matching donor in the family. So, we turned to targeting the patients’ own bone marrow and have developed strategies that allow us to repair their bone marrow. We can do this by either adding a copy of the correctly spelled gene to their bone marrow cells using engineered viruses such as HIV or we can do this with new tools that allow us to cut and repair the misspelled gene in the DNA of their bone marrow cells with surgical precision.

We now have trials testing these new approaches underway. On one, we are collaborating with Dr. Julie Kanter here at MUSC, where patients with sickle cell disease get top notch, comprehensive care while contributing to advancing new therapies. These trials are now bearing fruit. We have accrued over 100 patients with sickle cell disease at the NIH Clinical Center on these various trials, the majority of whom, are now living free of this devastating disease.

These new opportunities have led to intense interest in academia and industry in further developing and refining curative therapies for sickle cell disease. These trials have also allowed us to dispel the notion that patients with this disease have ulterior motives in seeking pain medications. After a successful transplant, our patients no longer require narcotic pain medications. They no longer return to the hospital and can finally work and participate in life.

I therefore urge you today, that in every single medical encounter, you pause to be aware of the many misfortunes that nobody did anything to deserve. For example, my patients who did nothing to deserve to be born with sickle cell disease. Nobody did anything to deserve to be born rich or poor, or black or white, or from educated or uneducated parents.

I urge you to be thoughtful and not rush to assumptions that are more often wrong than right. To question and challenge assumptions. To be bold and push boundaries. To use your degree for the greatest benefit of those you encounter. To be always compassionate towards patients’ suffering and to be mindful that some choices that you have as an individual, may not be among the real choices that your patients have. That is what health care is about.

Health care professionals do not operate in a vacuum. We are part of health care systems that have their own set of rules that we often take for granted. In our health care system, health insurance depends upon one’s work, and in almost all cases, we get health insurance through our jobs. That means that access to health care is jeopardized when one’s ability to work is jeopardized.

As a health care provider who treats patients with sickle cell disease, I reflect often about our health care system. My patients with sickle cell disease, because of the frequent, unpredictable and severe pain crises that affect them throughout their lives, have great difficulty in maintaining their jobs. When they lose their jobs, they also lose their health insurance. They lose access to health care precisely when they need it the most: when they’re having a severe health crisis.

I invite you to reflect about that scenario for a minute. You have bad luck because you were born with a genetic condition like sickle cell disease, and you have bad luck because health care professionals at times misjudge. You have bad luck because, until only recently, no specific therapies were available. Then, you have bad luck because you are part of a health care system where your access to health care is in frequent jeopardy every time you have a serious health need.

As a health care professional, I cannot reconcile our health system with the care, kindness and compassion that I strive for in every interaction with my patients.

I long for an improved health care system that is embedded with those same values; it would be better for my patients and for all the patients that struggle with health problems, for their families and loved ones, for the health of our communities and for society as a whole. I invite you to reflect today in what I consider a crucial moment in your educational, professional and personal journey about the natural lottery. The natural lottery is neither just nor unjust. It’s a plain fact. What is just or unjust is what we do in response to it.

I want to encourage you to respond to it by treating all patients — be they patients with mental illness, cancer or addiction — with care, kindness and compassion, advancing knowledge in the health sciences to improve the care we can provide and the public health interventions we can implement and also striving for a health care system that advances everybody’s health.

I hope that the commitment to excellence in the health care professions that you make today includes the commitment to forge a better world with better care, better treatment options and a better health care system.

And I hope that whatever path you may take from this strong foundation you have received here at MUSC that this message stays with you during your entire career and you, in the future, pass it to younger generations.

Thank you and congratulations once again.

NURSE  Continued from Page Seven

family’s last memento.”

Dave Dolan, RN, nurse manager of the MSICU, said Dillehay is the quintessential nurse.

“Maggie is really compassionate and empathetic. She goes above and beyond constantly for her patients and families. She also makes sure the staff always has what they need. In fact, if you saw the term nurse in the dictionary, Maggie’s picture would be there.”

Recently, he said, she was on a plane bound for the National Teaching Institute and Critical Care Exposition, when she was called upon to serve.

“Someone on her flight was having a stroke, and she stepped up to provide medical care. Here she is on her way to a medical conference, and she provides lifesaving measures on the plane. And while the plane had to be diverted to Georgia, Maggie saved her life. That’s just the type of nurse she is.”

Dillehay, a member of the American Association of Critical-Care Nurses, has served on Team A during multiple weather disasters, which at times affected day-to-day clinical operations. She contributes her expertise widely at MUSC as a member of the MSICU leadership team and MUSC Health Nursing Shared Governance. She sat on the Exemplary Professional Practice committee. She precepts new nurses, teaching them how to become effective ICU nurses. She was also recognized as a CRRT (continuous renal replacement therapies) super user.
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