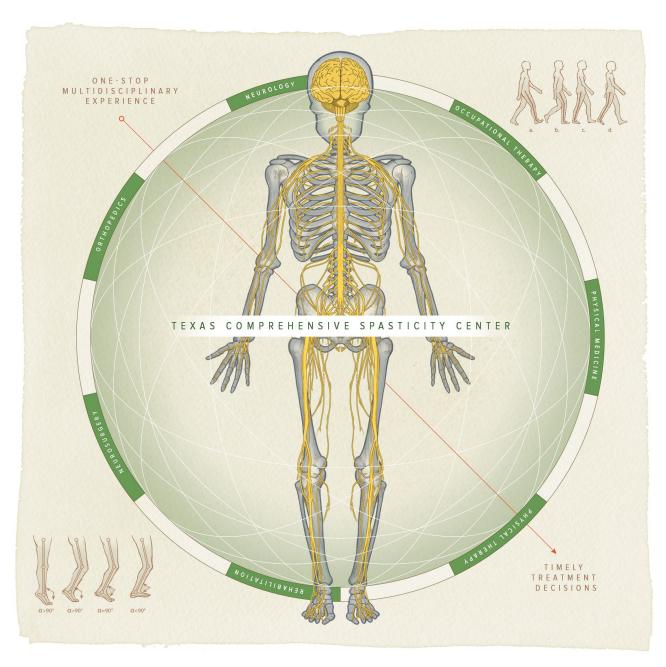
# PEDIATRIC NEUROSCIENCE

- A publication of Children's Memorial Hermann Hospital and McGovern Medical School at UTHealth  $\,-\,$ 







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## It's About Time

Parents of children with spasticity or cerebral palsy usually ask many providers for their opinions before making a treatment decision, and in the process they lose valuable time. The Texas Comprehensive Spasticity Center at UT Physicians takes a different approach. Their multidisciplinary team speeds up the decision-making process by seeing patients together in the same room in a one-to-two-hour visit. Parents hear recommendations for treatment options before they leave, saving them many hours of office visits. Led by Dr. Manish N. Shah and Dr. Nivedita Thakur, both assistant professors at McGovern Medical School at The University of Texas Health Science Center at Houston (UTHealth), the Center has grown in both patient and surgical volumes. Keeping pace with that growth, we're pleased to welcome Dr. Surya Mundluru, assistant professor in the department of Orthopedic Surgery at McGovern Medical School. Dr. Mundluru is fellowship-trained orthopedic surgeon whose primary focus is on cerebral palsy and scoliosis. We also warmly welcome the Center's clinical coordinator, Christy Hill, a highly trained physical therapist with McGovern Medical School whose expertise includes cerebral palsy.

On the basic science and translational front, Rachael Sirianni, PhD, a bioengineer and research scientist, joined McGovern Medical School at UTHealth's Vivian L. Smith Department of Neurosurgery last year. She brought with her a laboratory focused on bringing novel nanomedicine approaches to the clinic to improve outcomes for children affected by malignant brain tumors. Dr. Sirianni and her team encapsulate drugs within biocompatible and biodegradable nanoparticles that serve as carriers to prolong drug action and target specific tissue sites. Her work complements the research we are doing in two single-center trials which investigates the direct administration of chemotherapy into the fourth ventricle to reduce the systemic toxicity of chemotherapy and radiation therapy, which can exact a heavy toll on children.

We are grateful to the Heble family for sharing the story of their 17-year-old son, Garrett, who suffered a brain injury at the age of 15. Our ability to bring children back from the brink of death after neurological injury can depend upon the rapid response of people in the community, the experience of the Memorial Hermann Life Flight® crew and Houston's EMS teams, and the McGovern Medical School physicians affiliated with the Memorial Hermann Red Duke Trauma Institute at Memorial Hermann-Texas Medical Center. Our neurosurgical team is able to move young patients from the Institute's doors to CT angiogram and the OR fast – often in 10 minutes or less.

It is a privilege to work to improve the quality of life of children in developing countries. In this issue we highlight the ongoing work of McGovern Medical School's Gretchen Von Allmen, MD, and Michael Funke, MD, PhD, who are training physicians in Nicaragua. Their onsite work in the country led to a two-month observership at McGovern Medical School for Dr. Yurisa Gómez Zelaya, a Nicaraguan pediatrician who plans to continue her training in pediatric neurology with postgraduate work in Spain. Once again, our team of medical professionals made their annual trip to Port-au-Prince, Haiti, where they spent five days providing care for children with hydrocephalus in conjunction with Project Medishare in Miami.

We hope you find the articles in this issue of the Pediatric Neuroscience Journal thought provoking and useful in your practice. If you have questions about any of our programs, please feel free to contact us directly.

With best wishes.

DAVID I. SANDBERG, MD, FAANS, FACS, FAAP

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## Texas Comprehensive Spasticity Center Expands to Meet the Region's Needs, Offers Families a One-stop Multidisciplinary Experience

hildren with spasticity, movement disorders, or cerebral palsy (CP) have complex care needs and typically see multiple providers for different opinions before parents make a treatment decision. In the process, they lose valuable time and, in many cases, suffer irreversible damage. Specialists affiliated with the Texas Comprehensive Spasticity Center aim to end the cycle of referral from specialist to specialist by providing carefully coordinated multidisciplinary care in a single location.

"WE'RE VERY GOOD AT SAVING TIME AND RESOURCES. WE ALSO INCLUDE EACH PATIENT'S PERSONAL PHYSICAL THERAPIST IN THE EVALUATION PROCESS, WORKING TOGETHER TO OPTIMIZE CARE BY ADDING TO THE FAMILY'S EXISTING COMMUNITY RESOURCES."

- MANISH N. SHAH, MD

A collaboration of Children's Memorial Hermann Hospital, Mischer Neuroscience Institute at Memorial Hermann-Texas Medical Center, UT Physicians and McGovern Medical School at UTHealth, the Texas Comprehensive Spasticity Center is led by Manish N. Shah, MD, an assistant professor in the division of Pediatric Neurosurgery at McGovern Medical School and director of pediatric spasticity and epilepsy surgery at Children's Memorial Hermann Hospital, and pediatric neurologist Nivedita Thakur, MD, an assistant professor in the department of Pediatrics at McGovern Medical School. Fellowship trained in pediatric neurosurgery, Dr. Shah is the leading neurosurgeon in the region



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for selective dorsal rhizotomy, and is also an expert in pediatric epilepsy, craniofacial surgery and craniocervical spine surgery. Dr. Thakur is fellowship trained in adult and pediatric movement disorders and pediatric neurology.

"No other group of specialists in Texas sees spasticity patients together for one to two hours in the same room," Dr. Shah says. "We all work together to determine in one session what the child needs, so that parents know exactly what the treatment options are before they leave the clinic. This approach saves children and parents years of bouncing from provider to provider with no real treatment decision made. Kids with spasticity often need to be seen by three or four specialists. By the time they see all of these providers - and many have long scheduling wait times - contractures may have caused irreversible damage to their joints and muscles. Even in multidisciplinary clinics, one specialist visit follows another, so that parents and kids spend a full day, or more, seeing providers."

Only a few centers in the country gather all the disciplines – neurology, neurosurgery, physical medicine and rehabilitation, physical therapy and occupational therapy –

Dr. Manish N. Shah (standing) and Dr. Nivedita Thakur (left) work closely with other multidisciplinary team members to let parents know exactly what their child's treatment options are before leaving the exam room.



at the same time in one room for a more efficient visit. "Patients and families see us all together in a clinic visit, which results in a streamlined multidisciplinary evaluation," Dr. Thakur says. "Then we review our observations, imaging studies and videos of the child as a team. Because there are multiple variables that go in to managing spasticity, the discussion is extensive and unique for each child. We are able to synthesize one

plan based on our discussions and present this to the patient and family."

Parents may also send videos of their child for triage in advance, a service the team provides at no cost. "We're very good at saving time and resources," Dr. Shah says. "We also include each patient's personal physical therapist in the evaluation process, working together to optimize care by adding to the family's existing community resources."

#### Management of Spasticity Comes First, Before Orthopedic Surgery

"One thing our team agrees on, as do many national experts at centers around the country, is that spasticity should be managed first before orthopedic interventions when at all possible," says Christine "Christy" Hill, a UTHealth physical therapist who is coordinator of the Texas Comprehensive Spasticity Center. As a physical therapist with 21 years of experience, she is uniquely qualified to coordinate the care of children with spasticity and movement disorders resulting from cerebral palsy.

available to co-manage care. Dr. Mundluru began his career in medicine in the department of Internal Medicine and department of Pediatrics at the Hospital of the University of Pennsylvania and Children's Hospital of Philadelphia training programs. During his time in Philadelphia, he developed a love for pediatric orthopedic care and pursued further training in orthopedic surgery at New York University Langone Orthopedic Hospital for Joint Diseases. He completed the prestigious Dorothy and Bryant Edwards Fellowship in Pediatric Orthopedics and Scoliosis at Texas Scottish Rite Hospital for Children in Dallas, Texas. Dr. Mundluru



At the Texas Comprehensive Spasticity Center at UT Physicians, Dr. Manish Shah (left) and physical therapist Christy Hill (middle) evaluate a young patient with cerebral palsy during his visit with the multi-disciplinary team.

"Maximizing the rehabilitation potential of children with spasticity is key to the management of the condition," Hill says. "If spasticity is well managed, it decreases the likelihood that children will need repeat orthopedic procedures. If a child is a candidate for selective dorsal rhizotomy, Dr. Shah will schedule the surgery and we'll arrange a transfer to Shriners Hospital for Children for inpatient rehabilitation after discharge from acute care. I coordinate care between the two facilities." Follow-up visits occur at UT Physicians Pediatric Surgery Clinic.

If a child needs to see an orthopedic surgeon at Children's Memorial Hermann Hospital, Surya N. Mundluru, MD, is joined the department of Orthopedic Surgery at McGovern Medical School at UTHealth in Houston, and the Texas Comprehensive Spasticity Center in October 2018 as the point person for children with cerebral palsy (CP).

"Kids with CP have multiple musculoskeletal problems that create neuromuscular-based conditions of the hip, knees and upper extremities, including the hands," says Dr. Mundluru, an assistant professor of orthopedics at McGovern Medical School. "It has a somewhat common presentation, with spasticity, spasms and rigidity. Some children can walk, some can't, and others walk with assistive devices. Those with very



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severe CP can develop scoliosis. We treat them collectively because no one specialty can treat these kids alone. If a patient is a candidate for selective dorsal rhizotomy, Dr. Shah does the procedure first, which allows me to be more minimally invasive in the orthopedic approach, avoiding muscle contracture releases and osteotomies to shorten bones, or change their alignment."

A key strength of the pediatric spasticity program is the ability to admit patients to the Shriners Hospital for Children for inpatient rehabilitation after surgery. "Their quality is incredibly high, with eight hours of activity a day," Dr. Shah says. "It's not uncommon to have four or five therapists working with one child, and the children can do spectacularly."

With its national reputation and good outcomes, Texas Comprehensive Spasticity Center has grown substantially in both patient and surgical volumes, specifically for selective dorsal rhizotomy. The Center offers a comprehensive plan that makes it easy for the patient to arrange surgery and either three or six weeks of outpatient therapy at TIRR Memorial Hermann Outpatient Rehabilitation-Kirby Glen.

"The process we've created fills an enormous care gap in the community and illustrates how much of a challenge it is for parents of children with spasticity to coordinate care for their kids," Dr. Shah says. "We all work very well together to ensure that patients are appropriately diagnosed and receive treatment in a timely fashion. Parents of these children tend to be very involved. It's amazing to see how many people work together for these kids and how inspiring they can be."

## Coordinating the Many Moving Parts of Care for Children with Spasticity

Cerebral palsy (CP) remains one of the most common neurological complications of birth, affecting about 1 in 500 infants. The end result is often rigidity and spasticity with disabling contractures and pain.

"Cerebral palsy describes a continuum of motor dysfunction from very mild impairment to spasticity so severe that movement is almost impossible," says Christy Hill, McGovern Medical School physical therapist and coordinator of the Texas Comprehensive Spasticity Center, a collaboration of Children's Memorial Hermann Hospital, Mischer Neuroscience Institute at Memorial Hermann-Texas Medical Center, UT Physicians and McGovern Medical School at UTHealth. "Even mild untreated spasticity in a child who can run and jump, and doesn't appear to have a disability, can cause premature aging in the joints, which can lead to pain and muscle contractures - deformative forces on the joints most commonly seen in the hips and feet. Sometimes we see mild leg length discrepancies if only one side has mild spasticity and the other doesn't. Many times these children are undertreated until young adulthood when spasticity really starts to affect their quality of life. The bottom line is that all manifestations of spasticity should be treated before they lead to muscle contractures."

Hill is responsible for coordinating the multidisciplinary spasticity clinic, which is part of UT Physicians Pediatric Surgery Clinic, and provides care for pediatric to adult patients. Hill is research coordinator for the McGovern Medical School site of the national Cerebral Palsy Research Network; Manish N. Shah, MD, assistant professor of pediatric surgery at McGovern Medical School, is lead investigator.

Hill, a physical therapist with 21 years of experience, met Shah, the Texas Comprehensive Spasticity Center director when they worked together to help a mutual patient. "I was impressed and when the coordinator position was posted, I applied. The rest is history," she says. "I joined an already dynamic team to coordinate the many moving parts of managing children with complex medical needs, including spasticity. My personal goal is to provide care coordination so that each child who comes to

us maximizes his or her future potential."

Hill earned her bachelor's degree in physical therapy in 1997 at Daemen College in Williamsville, New York, and completed certification by the Neuro-Development Treatment Association in 2012. She began her career in inpatient rehabilitation for children and adults with brain injury, and has worked in outpatient rehabilitation, acute care and early childhood intervention. After moving to Texas in 2010 with her husband and three children, Hill went into private practice, treating adults and children while also working part time at TIRR Memorial Hermann Outpatient Rehabilitation-Kirby Glen, and later at ECI-Project GROW. She joined McGovern Medical

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- CHRISTY HILL,
PHYSICAL THERAPIST

School at UTHealth and the Texas Comprehensive Spasticity Center in February 2018.

"Some children come to us undiagnosed, and our model of evaluating spasticity patients as a multidisciplinary team in one visit is especially helpful for them," she says. "The parents have the opportunity to interact with all team members together, and the specialists benefit from the observations of experts in related disciplines. A plan of care is presented to parents quickly, which saves children and parents years of seeing provider after provider without a definitive treatment decision."

If additional testing is needed after the initial evaluation, Hill follows up. "It is so important to have the commitment of parents and the input of the child's therapist," she says. "The therapists who have followed these children long term know them best, and our goal is to have a symbiotic relationship with them. As parents who have

children with complex medical needs know, coordination of care can be a full-time job. Our program is comprehensive in the sense that the option that works best for one patient might not be the right choice for the next. If parents are unable to commit to rehabilitation, the child's spasticity management options change. One patient might need bracing and therapy, another an intrathecal baclofen pump, another Botox<sup>®</sup>, another selective dorsal rhizotomy, another an orthopedic intervention after tone management such as lengthening or reconstructive surgeries. Our team always addresses the least-invasive options first, which means optimizing physical therapy, occupational therapy and speech therapy. Early mobility is important for cognitive development, and we provide equipment recommendations to get the child to maximize exploration of their environment."

Hill works directly in the UT Physicians clinic with Dr. Shah, assisting in evaluation and coordinating care for patients and families. She also works with pediatric neurologist Nivedita Thakur, MD, an assistant professor in the department of Pediatrics, and pediatric physiatrists Stacey Hall, DO, an assistant professor in the department of Physical Medicine and Rehabilitation, and Glendaliz Bosques, MD, an associate professor in the same department.

"These physicians are responsive and accessible," she says. "Dr. Shah gives therapists and other providers his personal cell phone number, and is a great example of the kind of care we provide. I have taken that example of accessibility from him, and provide that same level of access to our families traveling this complex care road with their children.

"We want physicians to know that they can always reach out to discuss management of their patients' care, and our goal is to integrate our unique approach with the child's current care team," she adds. "This goes for physicians and also for physical, occupational and speech therapists who would like to send patients and families to us for a comprehensive team evaluation. We are not a one-size-fits-all facility. Every patient has different needs, so we give patient-specific recommendations. We take the time to understand the family's expectations as well as their goals. Developing realistic expectations, commitment to optimizing function for the child and long-term management is an important aspect of our clinic something I had not seen before in my career."

## Nanotechnology for Drug Delivery: The Science of Moving Chemotherapeutic Drugs Directly to Brain Tumors

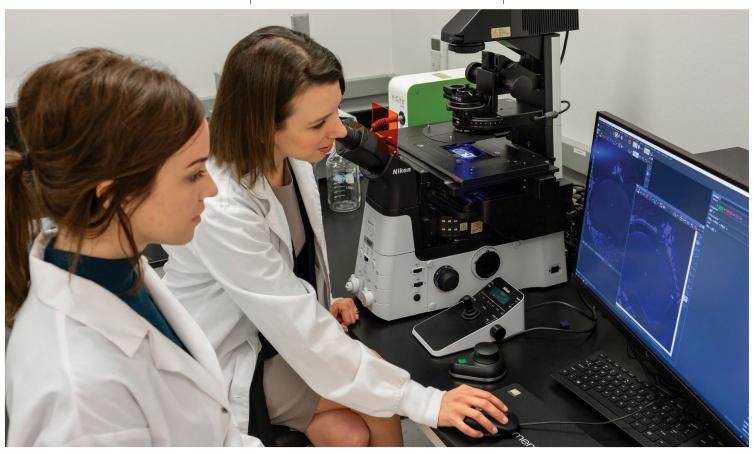
nly a very small amount of the chemotherapeutic drugs given systemically for the treatment of pediatric brain tumors actually reach the brain, due to the blood-brain barrier's efficiency at excluding the entry of most agents that circulate in the blood. As a result, the current outlook for children with recurrent malignant brain tumors is extremely poor. Most clinical trials offer systemic chemotherapy or radiation therapy, both of which have side effects, and often fail in children with recurrent tumors. Bioengineer and research scientist Rachael Sirianni, PhD, aims to change this approach. When she joined the faculty of McGovern Medical School's Vivian L. Smith Department of Neurosurgery at UTHealth in June

2018, she brought with her a laboratory focused on bringing novel nanomedicine approaches to the clinic to improve outcomes for children affected by malignant brain tumors.



RACHAEL SIRIANNI, PHD
Director, Pediatric Neuro-Oncology
Research; Assistant Professor,
Department of Neurosurgery
McGovern Medical School at UTHealth

In her lab, Dr. Rachael Sirianni focuses on bringing novel nanomedicine approaches to the clinic to improve outcomes for children with malignant brain tumors. "We encapsulate drugs within biocompatible and biodegradable nanoparticles, which serve as carriers to prolong drug action and target specific tissue sites," says Dr. Sirianni, an assistant professor of neurosurgery at McGovern Medical School at UTHealth. "In the past, we developed a number of novel approaches



for engineering nanoparticle composition and surface properties to enable central nervous system drug delivery in adults with brain cancer, and in other disease applications, such as neurodegeneration. Now we're focused on developing these systems for intrathecal and intraventricular drug delivery to treat brain tumors in children."

Dr. Sirianni entered undergraduate school at Arizona State University intent on going to medical school. She quickly found bioengineering was an interesting way to merge her love of math and science, and was excited by the opportunity to use the principles of engineering to solve complex medical problems. She went on to earn her doctorate in biomedical engineering at Yale University, where she developed models of drug delivery from polymeric biomaterials. She also completed a postdoctoral fellowship in diagnostic radiology at the Yale School of Medicine, where she developed novel imaging techniques to track the distribution of polymers in the central nervous system. Her doctoral and postdoctoral work, supported by interdisciplinary training grants from the National Institutes of Health, bridged topics that included polymeric drug delivery, transport modeling, neurobiology and imaging. She accepted her first faculty position in 2011 at the Barrow Neurological Institute in Phoenix where her laboratory researched drug delivery and tissue engineering for the treatment of central nervous system disorders.

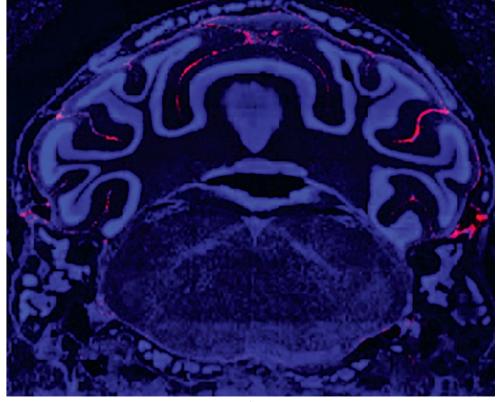
"I got invested in a scientific problem, and it took off from there," she says. "There are many drugs available to treat disease, but most don't go directly to the site where they provide the most benefit. This is especially true of the brain, with its carefully regulated barriers. My science is the science of drug delivery and understanding ways to circumvent these barriers."

Her laboratory uses polymers to encapsulate drugs, which can improve drug bioavailability, prolong drug presence in tissue and decrease drug toxicity. Nanoparticles can be engineered to target specific cells and tissues in the body. This can improve the potency of a drug without introducing additional toxicity to other organs. When the nanoparticle is suspended in fluid and is within the body, drugs that have been encapsulated inside are released slowly, in a controlled and localized fashion.

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DRUG DELIVERY AND UNDERSTANDING WAYS TO CIRCUMVENT THESE
BARRIERS." – RACHAEL SIRIANNI, PHD

"Early on scientists discovered that nanoparticles have the capability to slide in between the spaces of the tumor's vasculature, such that they selectively accumulate within the tumor," she says. "We call this enhanced permeation retention, and it enables nanoparticles to deliver encapsulated drugs preferentially to large tumors that are highly vascularized. However, there are some kinds of tumors and parts of tumors that do not receive a good blood supply. Delivery to these kinds of tumors remains a major challenge."

To address this challenge, Dr. Sirianni and her team are working on different approaches. "Pediatric brain tumors have a tendency to metastasize along the surfaces of the brain and spinal cord. Called leptomeningeal metastasis, it remains very difficult to treat," she says. "We figured that instead of delivering nanoparticles intravenously, we should administer them directly to the cerebrospinal fluid that moves across these lesions to get more drug to the parts of the tumor that are exposed to cerebrospinal fluid, with less overall toxicity. Currently, we're focused on engineering nanoparticles to possess the right properties to accumulate selectively within these metastatic lesions."



Nanoparticles moving across the surfaces of the cerebellum, which is where medulloblastoma arises.

Dr. Sirianni has chosen drug-delivery methods with an eye toward clinical translation. Because the polymers her laboratory produces are nontoxic, degrade over weeks to months, and are readily cleared by the body, there is potential to design new, safer chemotherapy for patients.

#### Basic Science and Clinical Research Converge at the 2017 Ian's Friends Foundation Awards

At UTHealth, Dr. Sirianni works closely with David I. Sandberg, MD, FAANS, FACS, FAAP, professor at McGovern Medical School at UTHealth and director of pediatric neurosurgery at Children's Memorial Hermann Hospital and Mischer Neuroscience Institute at Memorial Hermann-Texas Medical Center. The two met in Atlanta in September 2017 when they independently received two of the three \$125,000 WhatIFF grants awarded by Ian's Friends Foundation, a nonprofit organization that provides support for innovative research designed to find a cure for pediatric brain tumors.

"Dr. Sirianni's presentation was the single best one at the conference. As I

listened to her, I was so excited about the great things we could accomplish together," recalls Dr. Sandberg, whose major research interests focus on novel means of delivering therapeutic agents into the brain for the treatment of child-hood brain tumors. "We shared a cab to the airport, and I asked her to consider moving her family to Houston so that we could work together."

Dr. Sirianni was not seeking other opportunities. "My first thought was that I live in Arizona, not Texas, and that's not changing. But the opportunity was not something that would come along every day," she says. "Dr. Sandberg is incredibly driven to change the therapeutic outcomes of kids with brain tumors in his lifetime, and he is tackling this problem from the clinical side. I was using similar approaches to develop novel therapeutics on the preclinical side. This collaboration enables us to concentrate our efforts on a problem that we have both dedicated our careers to solving. In the end, it was impossible to say no to that opportunity."

Dr. Sirianni joined the faculty at McGovern Medical School in the summer of 2018. Her vision is straightforward: to

bring new therapeutics to clinical trials with the hope of changing treatment of childhood brain tumors in ways that will also improve quality of life.

She was recently awarded a five-year, \$2.7 million R01 grant by the National Institute of Neurological Disorders and Stroke to tackle exactly this problem: designing nanoparticles that can target drug delivery to leptomeningeal metastasis in pediatric medulloblastoma. Her laboratory will evaluate the safety and efficacy of these new approaches, as well as test whether delivery of drugs from nanoparticles can reduce the radiation dose needed to treat metastases. Dr. Sandberg is a co-investigator on the grant, and they hope their work will eventually lead to new options for the treatment of malignant brain tumors in children.

"You have to explore the unknown before you can envision how it will change patient care," Dr. Sirianni says. "In academic medical centers everyone is doing his or her best to choose important problems to study at the basic science level. We all want to pick problems where we can make a difference. My interest is on the translational aspects of developing new therapies, taking new drugs and new approaches from bench to bedside. In the laboratory, we're designing nanoparticles that can improve drug delivery. On the translational, side we're beginning to do work that will directly augment Dr. Sandberg's clinical trials.

"Systemic chemotherapy and radiation exact a heavy toll on children," she says. "It's poorly understood why children develop brain tumors, and there is currently no optimal treatment approach. Early on in my career, I interacted with families whose children had received these diagnoses. These interactions made me realize how few options exist for children with malignant brain tumors, and how difficult these burdens are for the families affected. I began thinking about what tools we need, and how to fill the gap in knowledge. It felt like a niche in which I could make a major impact."

### Pediatric Brain Tumor Trials at Children's Memorial Hermann Hospital Approved by Sandberg

Two single-center trials under way at McGovern Medical School at UTHealth, are investigating novel therapies with the potential to improve outcomes for children with fourth ventricular brain tumors while avoiding systemic toxicity.

The first trial, "A Combination Intraventricular Chemotherapy Pilot Study," is investigating methotrexate and etoposide infusions into the fourth ventricle or resection cavity in children with recurrent posterior fossa brain tumors. It is conducted at Children's Memorial Hermann Hospital by David Sandberg, MD, FAANS, FACS, FAAP, professor at McGovern Medical School at UTHealth and director of pediatric neurosurgery at Children's Memorial Hermann Hospital and Mischer Neuroscience Institute at Memorial Hermann-Texas Medical Center. The trial is open to patients age 1 to 80 years old with recurrent medulloblastoma, recurrent ependymoma and recurrent atypical teratoid/rhabdoid tumors involving the brain and/or spine.

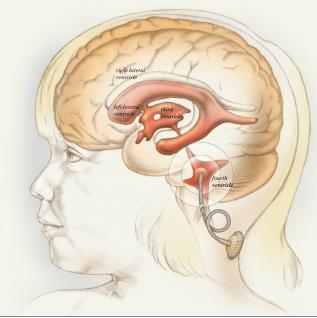
"The study employs a novel means of treating malignant tumors that originate from the fourth ventricle: infusion of two chemotherapy agents directly into the fourth ventricle rather than systemic intravenous delivery," says Dr. Sandberg, who holds the Dr. Marnie Rose Professorship in Pediatric Neurosurgery at UTHealth. "Our primary objective is to determine if combination intraventricular infusions of two agents are safe and can be infused without neurological toxicity. The secondary objective is to assess the antitumor activity of these infusions in the hope that

they will yield even more robust treatment responses than those observed in the previous single-agent trials." The study is listed at clinicaltrials.gov, NCT #02905110, under "Brain Tumor Recurrent."

The second study, "Infusion of 5-Azacytidine (5-AZA) into the Fourth Ventricle or Resection Cavity in Children with Recurrent Posterior Fossa Ependymoma," is also open for enrollment to patients age 1 to 80 at Children's Memorial Hermann Hospital.

"5-AZA is a DNA methylation inhibitor that has been infused in non-human primates with no neurological toxicity, while achieving substantial and sustained cerebrospinal fluid levels," Dr. Sandberg says. "Recent studies have demonstrated that DNA methylation inhibitors are logical therapeutic candidates for ependymomas originating in the posterior fossa. Our goals are to establish the safety of direct administration of 5-AZA into the fourth ventricle and also hopefully demonstrate the clinical efficacy of these infusions." The study is listed at clinicaltrials.gov, NCT #03572530, under "Brain Tumor Recurrent." "Despite advances in pediatric neuro-oncology, we're still seeing too many children die of malignant brain tumors, and the treatments currently available are not satisfactory for children," he says. "Many suffer extreme toxicity from chemotherapy and radiation, and we believe we can do better. We hope that these novel approaches to drug delivery will improve treatment outcomes."

FOR ADDITIONAL INFORMATION ABOUT BOTH CLINICAL TRIALS, PLEASE CONTACT BANGNING YU, MD, PHD, AT BANGNING. YU@UTH.TMC.EDU OR CALL 713.500.7363.



# 10 Minutes to the Operating Table: Children's Memorial Hermann Delivers Incredible Speed for Pediatric Neuroscience Trauma

fter a severe traumatic brain injury, when the brain is under pressure, every minute counts. Within 10 minutes of his arrival at the Red Duke Trauma Institute at Memorial Hermann-Texas Medical Center, Garrett Heble was in the operating room being prepped for surgery, with pediatric neurosurgeon David Sandberg, MD, FAANS, FACS, FAAP, by his side.

"Garrett was very close to death when he arrived, and today he's a happy kid with a bright future ahead," says Dr. Sandberg, professor at McGovern Medical School at UTHealth and director of pediatric neuro-

"WE ARE ONE OF THE BUSIEST PEDIATRIC TRAUMA CENTERS IN
THE COUNTRY, AND THESE CASES ARE ROUTINE FOR US. MOST
IMPORTANTLY, WE HAVE AN AMAZING TEAM. EVERY TEAM MEMBER
TREATS EVERY PATIENT LIKE THEIR OWN SON OR DAUGHTER."

- DAVID SANDBERG, MD

surgery at Children's Memorial Hermann Hospital and Mischer Neuroscience Institute at Memorial Hermann-Texas Medical Center. "The speed of getting a brain trauma patient to surgery makes the difference between life and death. Had Garrett arrived at the hospital even a half hour later, or if there had been a delay in getting him to the OR, the outcome would have been different."

Garrett's eyes were fixed and dilated when he arrived at the Level I Pediatric Trauma Center, where time from the front door into the OR is on average 10 minutes or less, and time from the front door to incision is an average of 39 minutes.

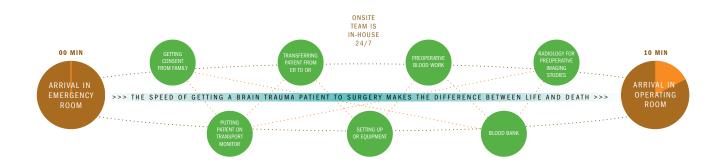


DAVID SANDBERG, MD, FAANS, FACS, FAAP
Director, Pediatric Neurosurgery; Professor
and Chief, Division of Pediatric
Neurosurgery; Dr. Marnie Rose Professorship
in Pediatric Neurosurgery
McGovern Medical School at UTHealth

"These are very fast timeframes for the amount of preparation required for this type of case," says Julie Zurek, MSN, RN, CFRN, clinical director of perioperative services, imaging, procedure and ECMO services at Children's Memorial Hermann Hospital. "It takes a huge collaboration of services that start in the emergency department - teamwork between the laboratory for preoperative blood work, the blood bank and radiology for scans, including x-ray and CT. If we do not complete the needed minimum preparation in the ED, we are always ready for seamless transition to the OR, where we can also complete lab work and obtain x-rays and blood. Our onsite team is in house 24/7, with an OR room always ready and equipped with supplies personally selected by each neurosurgeon for all trauma cases that come through our doors."

About an hour before his arrival at the Red Duke Trauma Institute, Garrett, who was 15 at the time, was riding on the back of a friend's four-wheeler in a gated community located about 50 miles south of Houston. He fell off, his head hit the asphalt and lost consciousness. He regained it briefly, but by the time his mother, Holly Heble, arrived a few minutes later, he had slipped back into unconsciousness.

"He was bleeding from the nose, and we could rouse him slightly but he was not



verbal," Heble recalls. "EMS arrived and called Memorial Hermann Life Flight<sup>®</sup>."

Heble's husband, Kurt, was closer to Houston and arrived at the Red Duke Trauma Institute before the helicopter carrying Garrett landed. Dr. Sandberg was at the Institute when they arrived.

"We had to move quickly, which we do as well as or better than any hospital in the country," says Dr. Sandberg, who holds the Dr. Marnie Rose Professorship in Pediatric Neurosurgery at UTHealth. "We are one of the busiest pediatric trauma centers in the country, and these cases are routine for us. Most importantly, we have an amazing team. Every team member treats every patient like their own son or daughter."

When Holly Heble arrived at the Institute, her husband told her things didn't look good for their son. "All indications pointed to no brain activity – fixed pupils, no reaction to pinch tests and the CT scan results," she says. "Dr. Sandberg said that if he was going to operate, he needed to do it now and we said, 'Yes, yes, yes!' He took off running. Garrett was in surgery for a few hours, and afterwards Dr. Sandberg sat with us and described the surgery, and said that all we could do is wait to see how he responded."

In the space of a few hours, Garrett had been transported by air ambulance, had surgery and had begun moving his right side in the Pediatric Intensive Care Unit. "It was a tough decision to operate because of his poor neurological condition," Dr. Sandberg says. "We never know how young people will respond, and we wanted to give Garrett a chance.



High school junior Garrett Heble is back on the golf course thanks to the quick response of the neurosurgery team at the Red Duke Trauma Institute and Children's Memorial Hermann Hospital.

So much has to happen before the patient goes to the OR - triage, consent to operate, imaging and the OR has to be set up. They move so fast. By working with a skilled team, we were able to save his life."

Garrett remained in the Pediatric ICU for five days and spent another five on the neurosurgery floor. "Gradually he regained the ability to do things," Heble says. "He recognized everyone and as soon as they took the breathing tube out, he started talking. He was transferred to Shriners Hospital for Children for rehabilitation, where he had physical therapy,

occupational therapy and speech therapy every day for eight days."

Today Garrett is a junior in high school taking all honors courses. He's on the varsity golf team and works part time at a local golf course. In February he began his college visits, with the ultimate goal of going to dental school.

"We owe everything to Dr. Sandberg, and we'll never be able to repay him for going ahead with the surgery," Heble says. "A lot of doctors might not have gone forward with it, given Garrett's condition, but Dr. Sandberg took a chance and it was very much worth it."

## BEYOND BORDERS: PHYSICIANS WORK TOGETHER to Improve Epilepsy Care in Nicaragua

n May 2016, Gretchen Von Allmen, MD, and Michael Funke, MD, PhD, made their first joint visit to Nicaragua, where they met with physician leaders at the Universidad de Managua and local hospitals to begin planning the development of a collaborative pediatric epilepsy training program. The need is great: only two pediatric neurologists serve the country's 2.15 million children, and epilepsy is the fourth most common chronic disorder based on data from the Nicaraguan Ministry of Health.

"THERE IS NO SURGERY FOR EPILEPSY AVAILABLE IN NICARAGUA, **BUT THERE ARE MEDICATIONS THAT CAN BE DELIVERED** AT THE PRIMARY CARE LEVEL. ENABLING THE MAJORITY OF PEOPLE TO LIVE NORMAL LIVES WITHOUT THE STIGMATIZATION AND **EXCLUSION THAT CAN ACCOMPANY THE DISEASE."** - GRETCHEN VON ALLMEN. MD

> During that visit, the two physicians met third-year resident Yurisa Gómez Zelaya, MD, who served as their translator, and examined pediatric epilepsy patients with them in clinic. At the time, Dr. Gómez was writing her thesis on the clinical and epidemiological aspects of febrile seizures, a topic of great relevance to Nicaragua.

> Of the country's more than 6 million inhabitants, 1 in 26 will develop epilepsy in his or her lifetime, a statistic based on worldwide prevalence. "That adds up to 250,000 people with epilepsy, about a third of whom are children," says Dr. Von Allmen, associate professor of pediatrics, chief of pediatric epilepsy and director of the pediatric epilepsy program at McGovern Medical School at UTHealth and an attending physician at Children's Memorial Hermann Hospital. "There is no surgery for epilepsy available in



#### **GRETCHEN VON ALLMEN, MD**

Director, Pediatric Epilepsy Program; Medical Director, Memorial Hermann Pediatric Epilepsy Monitoring Unit; Associate Professor, Division of Pediatric Neurology McGovern Medical School at UTHealth



#### MICHAEL FUNKE, MD, PHD

Medical Director, Memorial Hermann Magnetic Source Imaging; Associate Professor, Department of Pediatrics, Division of Child and Adolescent Neurology McGovern Medical School at UTHealth

Nicaragua, but there are medications that can be delivered at the primary care level, enabling the majority of people to live normal lives without the stigmatization and exclusion that can accompany the disease."

Recent studies in low- and middleincome countries have shown that up to 70 percent of children and adults with epilepsy can be successfully treated with antiepileptic drugs, according to the World Health Organization. Dr. Von Allmen and Dr. Funke, an associate professor of pediatics and director of Magnetic Source Imaging at McGovern Medical School, came to Nicaragua hoping to accomplish what the WHO recommends for developing countries: teach the primary care providers how to diagnose and treat epilepsy.

"A key problem in Nicaragua is the fact that our pediatricians and emergency teams - those who see children first - lack the ability to identify and manage epilepsy cases," says Dr. Gómez, who is now an attending physician in the pediatric service at Managua's Hospital Fernando Vélez Paiz, where she is in charge of the delivery room. In April 2018, Dr. Funke emailed her about the possibility of a twomonth observership at McGovern Medical School, made possible through a stipend from SODI e.V., a German non-governmental organization (NGO) that, together with local partner organizations, realizes

self-help healthcare projects in Latin America and other developing regions of the world. Generous help was provided for other important logistics of her visit by the Houston chapter of The Epilepsy Foundation of Texas, which helped arrange the delivery of funding, and by John Mosher, MD, of McGovern Medical School's department of Neurology, and by Drs. Von Allmen and Funke, who hosted her in their homes during her stay.

The connection with SODI comes through Dr. Funke, who has worked with the German NGO on projects at the Hospital Alemán-Nicaragüense in Managua, where he spent a year as a young resident. For the past 30 years, he has maintained a connection with the hospital and with Nicaraguan friends who finished their residencies and remained in Managua. Dr. Funke is the program director of the MEG Fellowship Program at McGovern Medical School.

"Dr. Gómez was a natural choice to come to Houston for training," he says. "She has a strong interest in pediatric epilepsy, and we maintained contact with her during our visits to Nicaragua, and via email." Dr. Von Allmen and Dr. Funke served as mentors for her thesis, entitled Clinical, epidemiological and therapeutic approach to the febrile convulsive crisis in children treated at the Pediatric Emergency Center of the Hospital Alemán-Nicaragüense.

Dr. Gómez arrived in the U.S. in early November, which allowed her to attend the annual meeting of the American Epilepsy Society in New Orleans. "I was at the conference for five days, two days of which were sessions in Spanish," she says. "The discussions helped me develop ideas about the direction of my future research in pediatric neurology."

During her two-month experience as a visiting scientist at McGovern Medical School, she gained knowledge of epilepsy etiology research, and how to evaluate symptoms to diagnose seizures more accurately. "I learned about new antiepileptic drugs, and developed a clearer idea of how I want to treat kids in my country," she says. "We have only the basic formulary of drugs in Nicaragua, and one of the most important things for me is to be able to control the side effects of these medications, of which there are many."

Dr. Gómez plans to continue her training in pediatric neurology with postgraduate study in Spain, which she will finance herself. The Nicaraguan State My thesis was a first step toward creating those guidelines, and I'm grateful for the help I've gotten from Dr. Von Allmen and Dr. Funke."

Dr. Von Allmen and Dr. Funke have high praise for the Nicaraguans. "Despite their limited resources, families are very knowledgeable about their children, extremely observant of their condition and very involved in their care," she says. "The res-



Pictured left to right: Yurisa Gómez Zelaya, MD; Michael Funke, MD, PhD; Lisa Caballero; Anne Ziems, MD; Karen Heinrich, MD; Nubia Mayorga; Hector Hernandez; Susanne Vogt, MD; and Gretchen Von Allmen, MD.

Department of Health will grant her three years of absence to study abroad.

"When I finish, I will go back," she says.

"Medical school was not easy, but somewhere along the way, you come to love it. Nicaragua paid for my medical training, and I want to pay my country back. What better way to do it than help our two pediatric neurologists who are trying to provide good care for so many kids? Before I leave for Spain, my goal is create an order set for children with epilepsy. As a physician I don't feel secure using antiepileptic drugs without definitive guidelines.

idents we've worked with are passionate about taking care of these kids and learning more about how to treat epilepsy."

Dr. Funke agrees. "The enthusiasm of the residents is infectious," he says. "They're well educated despite having much less access to educational resources than we have in the United States. Here, we have advanced imaging and other studies to rely on in making diagnoses and treatment decisions. There, they do things more in the traditional way, relying on their experience, observation and intuition. We have much to learn from each other."

# Dr. David Sandberg Receives the American Association of Neurological Surgeons Humanitarian Award

avid I. Sandberg, MD, FAANS, FACS, FAAP, has received the American Association of Neurological Surgeons 2019 Humanitarian Award, one of the highest honors bestowed by the organization. The award recognizes his extraordinary work with children suffering from neurosurgical disorders throughout the world.



DAVID SANDBERG, MD, FAANS, FACS, FAAP Director, Pediatric Neurosurgery; Professor and Chief, Division of Pediatric Neurosurgery; Dr. Marnie Rose Professorship in Pediatric Neurosurgery

McGovern Medical School at UTHealth

Dr. Sandberg is professor at McGovern Medical School at UTHealth and director of pediatric neurosurgery at Children's Memorial Hermann Hospital and Mischer Neuroscience Institute at Memorial Hermann-Texas Medical Center. He also holds the Dr. Marnie Rose Professorship in Pediatric Neurosurgery at UTHealth, and is co-director of the Pediatric Brain Tumor Program at The University of Texas MD Anderson Cancer Center. Fellowship trained in pediatric neurosurgery with a special clinical and research interest in pediatric brain tumors, Dr. Sandberg specializes in minimally invasive endoscopic approaches to brain tumors, hydrocephalus and arachnoid cysts, as well as surgical management of arteriovenous malformations of the brain, congenital spinal anomalies, Chiari malformations and craniofacial anomalies. The recipient of numerous research grants, he is currently principal investigator of two McGovern Medical School at UTHealth single-center trials for patients at Children's Memorial Hermann Hospital investigating direct administration of chemotherapy into the fourth ventricle for treatment of malignant brain tumors that originate from that ventricle.

Dr. Sandberg is a magna cum laude graduate of Harvard University. He received his medical degree at the Johns Hopkins University School of Medicine and completed neurosurgery training at Weill Medical College of Cornell University/New York-Presbyterian Hospital. During his residency, he was awarded the Resident Traveling Fellowship in Pediatric Neurosurgery by the American Association of Neurological Surgeons and the Congress of Neurological Surgeons, which he completed at the Hospital for Sick Children in Toronto, Canada. He completed pediatric neurosurgery fellowship training at the Children's Hospital in Los Angeles. Before joining McGovern Medical School, Dr. Sandberg was an associate professor of clinical neurological surgery and pediatrics at the University of Miami Miller School of Medicine.

He began his medical mission work in high school and college accompanying his father, Miami ophthalmologist Joel Sandberg, MD, on trips to Jamaica, Antigua and the Dominican Republic. His father was his inspiration to practice medicine and also to contribute to the health of the world through international mission work.

As a junior neurosurgery resident, Dr. Sandberg made two trips to Guatemala with Neil Feldstein, MD, director of the division of Pediatric Neurosurgery at Columbia University Medical Center/New York-Presbyterian Hospital, performing surgery on children with spina bifida. As a resident in neurosurgery, he used his vacation time to spend a month in Tegucigalpa, Honduras. There, with the help of Mark Souweidane, MD, director of pediatric neurosurgery at Weill Cornell Brain and

Spine Center, he brought an 8-year-old girl with a brain tumor to the United States for treatment. She was the first of several patients he brought to the U.S.

Dr. Sandberg has been on the Board of Directors of the Foundation for International Education in Neurological Surgery (FIENS) since 2004 and served as secretary of FIENS from 2013 to 2018. Through FIENS, he made multiple neurosurgical humanitarian trips to Honduras, Peru and Guatemala. In 2006, he traveled to Uganda with CURE International.

Since 2007, he has worked with Project Medishare, a Miami-based nonprofit organization with a 20-plus-year history of empowering Haitians to provide quality health care through community-based, Haitian-led programs. Through medical volunteers, the organization treats more than 180,000 people annually. Dr. Sandberg leads a team of pediatric neurosurgeons, pediatric anesthesiologists, nurses and surgical scrub technologists from Children's Memorial Hermann Hospital and McGovern Medical School; they make the trip annually.

"Education is a major focus for all of our mission trips to Haiti," he says. "We work with a local neurosurgeon, Dr. Yudy Lafortune, to teach him modern neurosurgical care for pediatric patients. This is the 'teach a man to fish' concept. We're training Dr. Lafortune to be the pediatric neurosurgeon for the children of Haiti."

Dr. Sandberg grew up in a family with a strong commitment to public service. "I think how lucky I am to have been born into my family in the United States, and to be able to contribute in a small way to helping children in other countries," he says. "This award is a huge honor for me, and I'm humbled to receive it."

## Helping Hands in Haiti: A Houston Surgical Team Treats Children with Hydrocephalus

n January, 12 medical professionals from McGovern Medical School at The University of Texas Health Science Center at Houston (UTHealth), Children's Memorial Hermann Hospital and Mischer Neuroscience Institute at Memorial Hermann-Texas Medical Center made their annual mission trip to Haiti, where they spent five days providing care for children with hydrocephalus. The team of pediatric neurosurgeons, pediatric anesthesiologists, nurses and surgical scrub technologists travels to Haiti every year in conjunction with Project Medishare, a Miami-based nonprofit organization with a 20-plus-year history of empowering Haitians to provide quality health care through community-based, Haitian-led programs.

The team oriented themselves quickly on the ground by working at Hospital Bernard Mevs in Port-au-Prince. "We hit the ground running," says Katrina Meshell, RN, a pediatric neurosurgery operating room nurse at Children's Memorial Hermann Hospital. "We've made the trip several times, and even though there are always new people with us, we work together well as a team, with a lot of camaraderie. The doctors see patients in clinic while we set up our two ORs with supplies we've collected from our hospital's mission bins."

The Texas team was met by Project Medishare's Margaret "Maguy" Rochelin, RN, who arranged for about 70 children, and their families, to come to the clinic for evaluation on the first day. The team spent long hours in the OR on days two through four, performing seven to 10 surgeries – usually endoscopic third ventriculostomies – on each of the three days. On the final day, physicians saw their patients on the hospital wards, and gave follow-up care plans to Rochelin.

Through medical volunteers, Project Medishare treats more than 180,000 people annually. The contributions of physicians

and staff members affiliated with Memorial Hermann and UTHealth were generously supported by a gift from Houstonian Dick Bassett to the Memorial Hermann Foundation.

Manish N. Shah, MD, has made the trip seven times. "It's a privilege to provide care for the children of Haiti," says Dr. Shah, an assistant professor at McGovern Medical School and pediatric neurosurgeon who directs the Texas Comprehensive Spasticity Center, a collaboration of at Children's Memorial Hermann Hospital, Mischer Neuroscience Institute at Memorial



The Haiti Crew (left to right): Jenny Ermis, RN; Brett Simpson, MD; Samantha Parker, MD; Ana Haley, RN; Angelita Maclao, CST; Maria Matuszczak, MD; Katrina Meshell, RN; Manish N. Shah, MD, Jasmine Strambler, MD; Blake Woods; Dalia Teima, MD; and David Sandberg, MD.

Hermann-Texas Medical Center, UT Physicians and McGovern Medical School at UTHealth. "We've also been helping to train a Haitian fellow, Dr. Yudy Lafortune, to perform hydrocephalus and spina bifida surgeries in Port-au-Prince. He is the future of these treatments for the children of Haiti."

Other team members included David Sandberg, MD, FAANS, FACS, FAAP, professor and chief of pediatric neurosurgery at McGovern Medical School at UTHealth and director of pediatric neurosurgery at Children's Memorial Hermann Hospital and Mischer Neuroscience Institute at Memorial

Hermann-Texas Medical Center; Maria Matuszczak, MD, professor of pediatric anesthesia and director of the Acute Pediatric Pain Service at McGovern Medical School; Dalia Teima, MD, McGovern Medical School assistant professor of anesthesiology; McGovern Medical School neurosurgery residents Samantha Parker, MD, and Brett Simpson, MD; McGovern Medical School anesthesiology resident Jasmine Strambler, MD; and Children's Memorial Hermann Hospital pediatric neurosurgery OR nurses Jenny Ermis, BSN, RN, Katrina Meshell, RN, and Ana Haley, BSN, RN; and Angelita Maclao, CST, surgical scrub technician. Premedical student Blake Woods was also a member.

"Because Haiti has no formally trained pediatric neurosurgeons, we help provide pediatric neurosurgical care by rotating with other physician groups who collaborate with Project Medishare so that the hospital has pediatric neurosurgery coverage as often as possible," says Dr. Sandberg, who holds the Dr. Marnie Rose Professorship in Pediatric Surgery at McGovern Medical School at UTHealth. "Our team works very hard for five days. Everyone pitches in and does whatever is needed to help these kids. It's always a very rewarding experience."

Dr. Matuszczak, who has participated in many medical missions and is fluent in French, helped with translation. "We manage difficult cases we normally don't see in the western world, and yet our team works together as if we do this every day. Making all the right decisions for the treatment of these critically ill children takes incredible teamwork from all sides."

Katrina Meshell has been making the Haiti trip since Dr. Sandberg first invited her six years ago. "It's humbling and rewarding, and a real eye-opener that makes me appreciate everything we have here in Houston," she says. "It's so much work, but I haven't been able to walk away. I'll keep going back."

## News of Note

#### Report on the 2019 Run for the Rose

Children's Memorial Hermann Hospital and Mischer Neuroscience Institute at Memorial Hermann-Texas Medical Center, were proud sponsors of the 17th Anniversary Run for the Rose, held Sunday, March 31, at NRG Park in Houston. Participants included patients, family members and supporters who are committed to raising awareness and funds supporting brain cancer research at The University of Texas MD Anderson Cancer Center and McGovern Medical School at UTHealth, as well as neuroscience research and the Pediatric Palliative Care Program at Children's Memorial Hermann Hospital.

The run is sponsored annually by the Dr. Marnie Rose Foundation, which has supported brain cancer research and pediatric health initiatives in Houston since 2003. In 2018, the Foundation made a donation of \$85,000 - funds raised through the Run for the Rose, the Brain Power 5K in Austin and memorials and tributes made throughout the year - to Children's Memorial Hermann Hospital. To date, the Dr. Marnie Rose

Foundation has given more than \$6 million to Children's Memorial Hermann Hospital, MD Anderson Cancer Center and McGovern Medical School. At McGovern Medical School, funds support cutting-edge research and treatment for children with brain tumors, a cause close to Dr. Marnie Rose's heart.

Other race-day activities included a Family 1K and a post-race party at NRG Park for all participants. Awards were given to male and female 5K participants who finished first, as well as the top three male and female finishers in specific-age categories.

## Dr. Manish N. Shah Among Speakers at the 2018 CP Prep for Life Conference

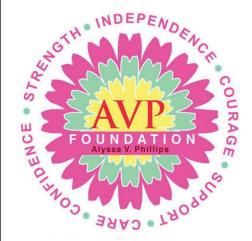
Pediatric neurosurgeon Manish N. Shah, MD, who directs the Texas Comprehensive Spasticity Center, a collaboration of Children's Memorial Hermann Hospital, Mischer Neuroscience Institute at Memorial Hermann-Texas Medical Center, UT Physicians and McGovern Medical School at UTHealth, was an invited speaker at the CP Prep for Life Conference held last August in Dallas. Dr. Shah, assistant professor at McGovern Medical School, is fellowship trained with a special focus on the surgical management

of spasticity and dystonia in children, and is the leading neurosurgeon in the area for selective dorsal rhizotomy.



MANISH N. SHAH, MD
Director, Pediatric Spasticity and
Epilepsy Surgery
Assistant Professor, Division of
Pediatric Neurosurgery
McGovern Medical School at UTHealth

CP Prep for Life is an annual educational conference dedicated to keeping parents, family members, caregivers and others informed about how to help children with



cerebral palsy live their best lives. More than 175 family members attended the conference and heard 22 professionals give talks on specific aspects of cerebral palsy.

A collaboration between the Alyssa V. Phillips Foundation and 1 CP Place PLLC, this one-of-a-kind conference featured top doctors and therapists from across the country, who presented a range of information on the latest treatments, surgical procedures, orthopedic interventions, physical and occupational therapies, assistive technologies and more.

"The conference provides a wonderful opportunity for parents to connect with other parents who are making the cerebral palsy journey with their kids," Dr. Shah says. "For those of us who presented, it was great to be able to talk directly to patients and families about treatment options. Helping children with cerebral palsy achieve a better quality of life in the face of debilitating disease is a privilege and a reward."

The Run for the Rose team from Mischer Neuroscience Institute and Children's Memorial Hermann.



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