

Pedi Press

A Quarterly Publication of the Department of Pediatrics

Baylor College of Medicine

Volume 8, Issue 3

Summer 2019



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Pedi Press is a quarterly publication of the Department of Pediatrics,
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FEATURE STORIES

Initiative Incorporates Humanities into Medical Practice

"Dan and I had both found the practice of narrative medicine helpful in critical care and palliative care, so when the chance came along to teach residents to apply narrative medicine to challenging primary care situations, we were thrilled."

-- Dr. Gwen Erkonen

"The great thing about narrative medicine practice is how universally applicable it can be. I like to tell trainees that just as they learn a systematic way to read a chest x-ray to not miss the important details, narrative medicine offers a systematic way to read a patient's story to not miss the important details."

-- Dr. Dan Mahoney

In 2017, when the categorical pediatrics residency program started an embedded track called LEAD: Primary Care Leaders Evaluating and Addressing Disparities, Dr. Lanessa Bass and the other LEAD faculty were searching for an opportunity to cultivate the residents' empathy and understanding of the difficult stories and circumstances their patients face daily. They reached out to **Dr. Daniel Mahoney**, a palliative care physician, and **Gwen Erkonen**, a pediatric intensivist, as local content experts in narrative medicine, who jumped at the opportunity to collaborate with trainees.

Narrative medicine, originally described by internist Dr. Rita Charon at Columbia University in 2000, seeks to "fortify clinical practice with the narrative competence to recognize, absorb, metabolize, interpret and be moved by the stories of illness." Evidence from studies of medical students and trainees suggests that regular narrative medicine practice improves empathy while building insight into personal triggers for burnout.



Drs. Mahoney and Erkonen facilitate narrative medicine workshops for LEAD residents and faculty five times each academic year. Workshop themes have included finding one's professional identity, acknowledging the challenges and transformations trainees encounter, and identifying narratives to facilitate advocacy for underserved patient populations.

The LEAD narrative medicine curriculum attracted the attention of other faculty, who

approached Drs. Mahoney and Erkonen with similar requests. Faculty from the Physician Scientist Training and Development Program (PSTDP), the Global Health Resident Elective, and the Hospice and Palliative Medicine Fellowship Program have incorporated narrative medicine into their curricula for trainees. Both the residency program and Fellows' College have requested narrative medicine education as part of their "trainee wellness" endeavors.

Based on these successes, in 2018, Drs. Mahoney and Erkonen took the first steps toward expanding their education and scholarship from exclusively narrative medicine to all medical humanities.



A group from TCH recently attended the first TCH Medical Humanities event of the academic year, a field trip to The Moth at Warehouse Live on Tuesday, August 13. The Moth is an entertaining hour of people telling stories – funny, sad, scary, moving, and everything in between.

Recently featured on the Texas Children’s Hospital Connect, the Medical Humanities Program seeks to enhance the practice of medicine through education of clinical staff, faculty and trainees, as well as through engagement of the entire Texas Children’s community with arts and humanities (including fields such as sociology, anthropology, philosophy, spirituality, and history). The Medical Humanities Program is academically housed within the Section of Palliative Care in the Department of Pediatrics, and the program, the events it hosts and education it provides are open to all faculty and staff. Mahoney and Erkonen hope that by increasing engagement and awareness, they will be able to identify additional collaborators for future medical humanities-related education and scholarship. This goal aligns with that expressed by the Center for Research, Innovation and Scholarship (CRIS), which has included medical humanities as one of the “MURS” (Medical Education Units for Research and Scholarship) it hopes to promote and support.

For now, however, the educational focus remains on narrative medicine. In partnership with individuals at Baylor College of Medicine’s Department of Medicine, the Center for Professionalism and the Center for Medical Ethics and Health Policy, the Medical Humanities Program will be inviting faculty from Columbia University to Houston at the beginning of November, 2019. The visiting faculty will present at Grand Rounds and will lead a facilitator training workshop for those at BCM interested in becoming narrative medicine workshop facilitators. “We are very excited that experts from Columbia will be coming to share their knowledge so that we can expand the pool of faculty able to lead workshops and meet the increasing demand,” Dr. Erkonen says.

For more information on how to collaborate on education or scholarship related to narrative medicine and medical humanities, please reach out to Drs. Mahoney and Erkonen at medicalhumanities@texaschildrens.org.

TEXAS CHILDREN'S HOSPITAL
MEDICAL HUMANITIES PRESENTS
BOOK CLUB

"The Language of Kindness: A Nurse's Story" Written by Christie Watson
Read at your own pace and come for a discussion that best meets your schedule.

Sessions

Thursday, September 19, 2019 ~ 4:00 pm - 5:00 pm
Location: LT 16th Floor - E.1650.10

Friday, September 20, 2019 ~ 8:00 am - 9:00 am
Location: LT 16th Floor - E.1650.10

Friday, September 20, 2019 ~ 12:00 pm - 1:00 pm
Location: LT 16th Floor - E.1650.10

Medicalhumanities@texaschildrens.org
Join the mailing list for updates on Medical Humanities Programs such as this!

@TCHMEDHUM

THE LANGUAGE OF KINDNESS
A NURSE'S STORY
CHRISTIE WATSON

The next event will be the September Book Club discussion, featuring The Language of Kindness: A Nurse's Story by Christie Watson.

Innovative Transition Team Provides Consultative Services



Currently, 90 percent of children and youth with special healthcare needs (CYSHCN) of primarily a physical nature in the United States will enter adulthood. Although CYSHCN are living longer, methods to improve survival

have not been matched by methods to maintain their quality of life and/or medical care as they transition from pediatric to adult-based health care. As a result, increased morbidity and mortality rates have been reported in this post-transition period when the HCT is poorly managed. The need for improved HCT at the local, state and federal levels has been recognized for a generation, and call for action has gained momentum over the past decade.

The Section of **Adolescent Medicine and Sports Medicine Section (AM&SM)**, in conjunction with Texas Children's Hospital (TCH), has taken a leadership role since 2000 in trying to improve HCT. The TCH Health Care Transition (HCT) Planning Team, based in the Section of AM&SM was established as a consultative service for other BCM Pediatric and TCH services wanting to develop and implement a transition planning process for their patients.

Under the direction of **Drs. Albert Hergenroeder**, Professor (above, left), and **Constance Weimann**, Assoc. Professor (above, right), The Transition Planning Team has worked with the Nephrology, Gastroenterology, Rheumatology, Cardiology, Retrovirology, Neurology, Allergy & Immunology, and Physical Medicine & Rehabilitation clinical services directly to begin the development of a structure and process for their HCT programs.

Through various activities, the Transition Planning Team has helped change the culture toward acceptance of successful HCT as an expected outcome of pediatric medicine. They have initiated two major initiatives: 1) establishment of a HCT planning program around an electronic medical record-based transition planning tool and 2) launch of an annual, international HCT conference that brings together a unique collaboration of diverse stakeholders.

The 20th annual conference, sponsored by TCH, will be held October 24 and 25, 2019 in the Texas Medical Conference (see page 7).



To support HCT planning at TCH, the Transition Planning Team developed the TCH Transition Planning Tool (TPT) (See page 7), which has become the prototype in the Epic electronic medical record (EMR) system. Using the TPT as a starting intervention, AM&SM leads the HCT planning efforts at TCH. In 2015, the TPT was selected as a Best Practice by the national Association of Maternal and Child Health Programs (AMCHP). The TPT has been used by 21 TCH clinical services.

With respect to dissemination, the Transition Planning Team has 11 peer-reviewed publications on HCT, and has co-authored the book, *Health Care Transition: Building a Program for Adolescents and Young Adults with Chronic Illness and Disability*. The Team has co-presented 27 abstracts on HCT at national meetings during the past five years and also has provided technical assistance to more than 10 healthcare institutions around the U.S. interested in developing a transition planning program. The Transition Planning Team is currently working to facilitate building transition programs for individual services, such as diabetes, nephrology, and neurology from TCH to BCM.

Since 2009, the Transition Planning Team has received \$3 million in outside funding. Current funded projects include the development and evaluation of a program in which former TCH patients are trained to help current TCH patients develop skills needed to manage their condition in adult-based care. Future projects include the development of an online skills training program for use with hospitalized adolescent patients and a college-prep workshop to prepare TCH adolescent patients and families to manage their health in the college environment.

Tool Developed to Assist with Adolescent Healthcare Transition

The Transition Planning Team at BCM Pediatrics and TCH has developed a Transition Planning Tool (TPT) that provides an infrastructure allowing adolescents and young adults with special healthcare needs (AYASHCN) and their families to plan their healthcare transition (HCT) from pediatric to adult-based care. The TPT was designed as a 'test of mastery' to evaluate and remedy gaps in the patient's condition-specific knowledge and skills needed for successful HCT. TCH integrated the TPT into Epic, its electronic medical record (EMR). The TPT directly or indirectly addresses five of the six core elements suggested for health care transition (see GotTransition.org)

The patient's and/or family's HCT knowledge and skills are assessed through dialogue initiated using 13 core questions, which were based on expert opinion and empirical literature. Content areas include knowing their illness and its manifestations, when an emergency is developing, how to refill prescriptions, and self-administer medications; treatment adherence; issues related to reproductive health, substance use, and insurance; and identifying an adult provider. The first question is "Can you tell me about your disease/disability?"



If the patient does not provide a satisfactory explanation of the disease in the judgment of the clinician asking the question, then one or more of three education options is employed: an explanation of the disease is given by a care provider; a written fact sheet with an explanation of the disease is given; or a printed homework assignment is provided asking the patient to write the name of their disease/disability in the designated space and a short letter to a friend describing their disease/disability. At the next clinic visit, the homework assignment is reviewed. When the patient masters a question a "successfully accomplished" designation appears in the Epic flow-sheet. Ideally, the patient will have successfully accomplished all 13 questions before leaving TCH. The TPT has a prepopulated portable medical summary that can be generated after any clinic visit and can be used in any inpatient or outpatient setting. A subset of questions is available to use with parents/caregivers whose children are developmentally unable to participate. More information on this TPT is available on request and the tool is available for Epic users to incorporate into their hospital/health systems: <https://galaxy.epic.com/?#Browse/page=1!68!600!1733006>.

Providers using the TPT have become more patient-centered, directing their discussions at the patient's actual knowledge and skills, rather than assuming what the patient knows. After using the TPT, one provider realized how little her patients knew about their diseases, despite considerable patient-education efforts. She now starts with the first TPT question in all adolescent patients. Other providers have formalized HCT planning by focusing on the patient, whereas prior to using the TPT they thought they were reinforcing patients' self-management knowledge and skills, when in fact the knowledge and skills were primarily in the hands of the parents.

Providers also have begun to appreciate the complexity of HCT planning and the need to start earlier: documentation of HCT planning is now occurring in 14-year-olds. The TPT has become an intervention that enables AYASHCN and their families to have conversations with their providers about the likelihood that they will survive into the third decade or beyond and the need to plan for independent living. Use of the TPT has expanded since 2014 to 475 individual providers using the TPT with 4,826 individual patients in 34 services across the TCH healthcare system.

Source: Hergenroeder A, Weimann C. Texas Children's Hospital Innovates and Collaborates in Transition. PULSE 2015. Used with permission



DEPARTMENT NEWS

SECTION EVENTS

Department of Pediatrics Annual Education Retreat
Friday, December 6, 2019
Texas Children's Pavilion for Women



October 18, 2019
Deadline for Workshop Abstract Submission
Deadline for Platform Abstract Submission

Friday, November 15, 2019
Deadline for Registration

The retreat is an annual learning and networking event that fosters excellence in teaching and educational scholarship among pediatric faculty. Plenary lectures, workshops for faculty and professional development, and educational scholarship presentations will inspire educators to engage in extant educational activities, advance educational innovations, and collaborate with educators alike to produce scholarship in medical education.

For more information, contact a member of the Planning Committee (Danny Castro, Ankhi Dutta, Julieana Nichols, Rachel Wolfe, Satid Thammasitboon, Remy Elizondo, Karla Gonzales).

BIPAI to Celebrate 20 Years



THROUGH THE LENS

CELEBRATING **20 YEARS** OF THE **BAYLOR COLLEGE OF MEDICINE INTERNATIONAL PEDIATRIC AIDS INITIATIVE (BIPAI)** AT TEXAS CHILDREN'S HOSPITAL

PRESENTED BY **CHEVRON**



The Revaire

7122 Old Katy Road

Houston, Texas 770246

Sponsored by Chevron, a celebration of 20 years since the launch of BIPAI will be held on **September 26, 2019**. Founded by **Dr. Mark Kline**, Chairman, the Baylor College of Medicine International Pediatric AIDS Initiative, has been extended from its first initiative in

The dinner celebration will recognize the accomplishments of BIPAI, and guests will have the opportunity to discuss current global health issues with Global Health Corps physicians. Various sponsorships, including table sponsorships ranging from \$5,000 - \$150,000, to say "thank you" for all BIPAI has done, may be viewed at <http://waystogive.texaschildrens.org/events/through-the-lens/assets/v2-2019-sponsor-benefits.pdf>.

Photographs recording the history of BIPAI, taken by award-winning photographer Smiley N. Pool, will be on display throughout the event.



Second Annual
**Baylor's Avoiding
Lung Injury (BALI)
Conference**



**October 18, 2019
8:00 a.m. to 5:00 p.m.**

Registration fee: **\$100.00**
(Free for Neonatology Fellows)

For registration details, contact:

Dr. Lakshmi Katakam

Katakam@bcm.edu

Ph: 832-826-1306

Online Registration
available at:

<https://www.bcm.edu/bali-conference>

Location:

Texas Children's Hospital

6651 S Main St.

Houston, TX

Activity is approved for 5.25 *AMA PRA
Category1 Credits™*



Gautham K. Suresh, MD, DM, MS
Avoiding Physician-Induced
Lung Injury in the Neonatal
Intensive Care Unit



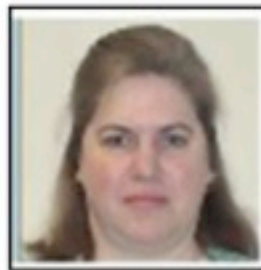
Krithika Lingappan, MD, MS, PhD
What's New on the Neonatal
Respiratory Front?



Nathan C. Sundgren, MD, PhD
Recent Advances in Neonatal
Resuscitation – SAILing
Through the MIST



Binoy Shivanna, MD, DM, PhD
What's HOT about Home
Oxygen Therapy?



**Suzanne Iniguez BS, RN, RRT-
NPS-ACCS, AE-C, C-NPT**
Your RT is Your BFF -
Empowering and Engaging
Respiratory Therapists in the
Neonatal Intensive Care Unit



Annamarie Arias-Shah, MD
Non-invasive Monitoring of
Respiratory Status in the
Neonatal Intensive Care
Unit



Lakshmi Katakam, MD, MPH
Implementing and De-
Implementing Respiratory
Care Practices in the NICU-
Stories from the Trenches

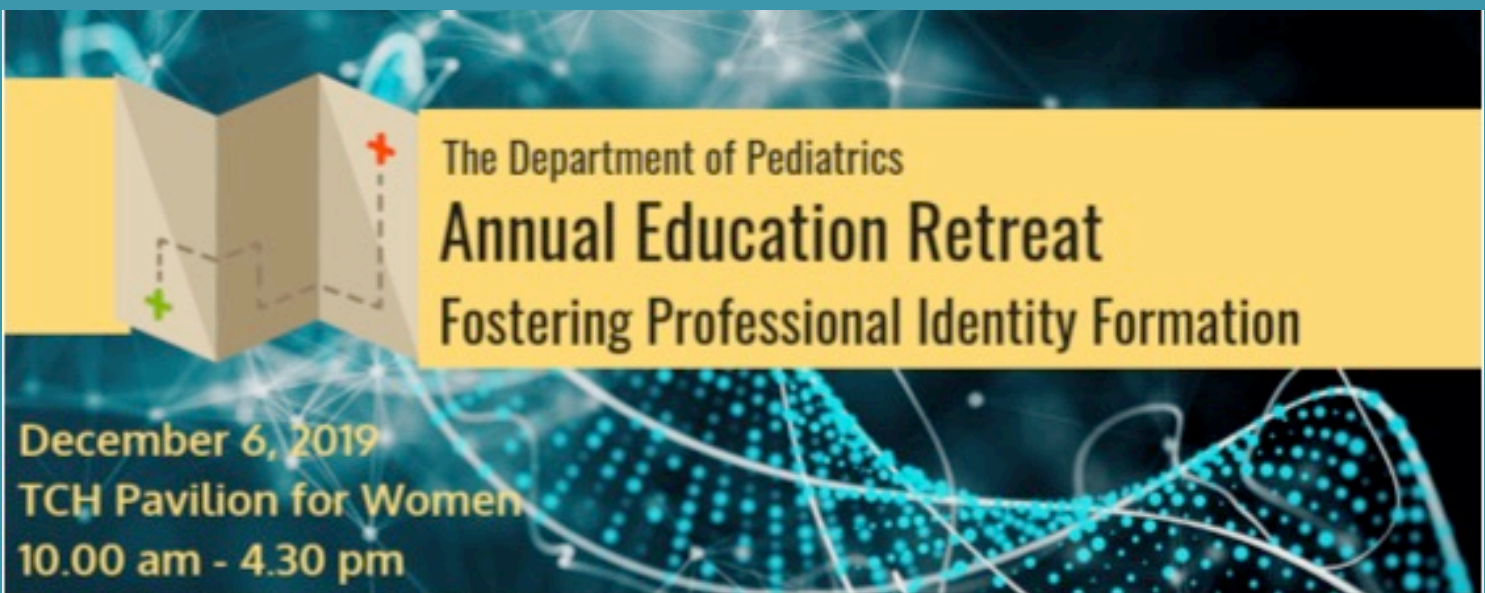
20th Annual
Chronic Illness and Disability Conference:
Transition from Pediatric to Adult-Based Care

October 24-25, 2019



Co-provided by:





The Department of Pediatrics
Annual Education Retreat
Fostering Professional Identity Formation

December 6, 2019
TCH Pavilion for Women
10.00 am - 4.30 pm

To be a physician requires a transformation of the individual—one does not simply learn to be a physician, one becomes a physician. — Abraham Fuks and colleagues

Networking with Educators & Scholars

The education retreat is our largest educational event, a perfect venue for you to network, learn and establish collaboration with others within educational community.

Kelley Descioli's Memorial Lecture

"Becoming a Member of the Club: Medical Training and the Professionalization of Doctors"
Dr. Hilary Haftel, the Senior Vice President of Education for the American Academy of Pediatrics

Educational Scholarship Showcase & Competition

Submit your abstract to showcase your educational scholarship and win the recognition for your great educational work (link below)



Faculty Development Workshops

Attend a series of great 3-M certified faculty development sessions to learn from your community of educators and scholars on current hot topics in medical education

Keynote Presentation

"Modeling Professional Communication in the Classroom and the Clinic"
Tracy Volz, Professor, Director of the Engineering Communications Program, the George R. Brown School of Engineering, Rice University

Educational Awards Celebration

Join the celebration of the many accomplishments and recognitions of our medical educators in the past year.

<https://orit.research.bcm.edu/R5T80IF3WH2/TCHEducationRetreat/Welcome.aspx>

Group Engages Pediatric Patients in Legos Activities

Everyone loves LEGO® bricks, right? Houston Brick Club uses LEGO(R) bricks and models to provide a little cheer and entertainment to children at Texas Children’s Hospital.

About once a month, members from Houston Brick Club come to the hospital for a play session. The hospital has a collection of LEGO® parts in the Child Life Zone, a room full of games and activities. Club



members build and play with patients and their families; this activity brightens the day of everyone involved.

A couple times a year, several Club members set up a display of built models on the pedestrian bridge in the hospital. Patients, families, and staff take a little time out of their days to slow down and look at all the custom creations built out of LEGO®. They are entertained by spaceships, castles,

trains, city buildings, pop culture scenes, and more. People of all ages are amazed and excited by everything on display.

Houston Brick Club is a group of LEGO® fans that meets monthly and puts on displays around the Houston area.

More information can be found at HoustonBrickClub.com.



One of the exhibitors, Alex (second from right), has trained two pet-therapy dogs owned by Dr. Lee Ligon, Instructor; they do pet therapy at St. Luke’s.



Series Addresses Needs of Busy Faculty Members



The Pediatric Critical Care Medicine Section (PICU and CICU) is staffed by a diverse group of BCM Faculty. In 2010, the Section was composed of 18 Attendings, 16 Advance Practice Providers, and 2 Physician Instructors. Over the years, the Section has steadily grown, and the patient acuity has continued to provide a wonderful training ground for BCM fellows and residents. As of 2019, the Section covers three campuses and has over 80 Attendings, 70 APPs, and 10 Physician Instructors.

Within the Section is also the Texas Children's Kangaroo Crew, a specialized transport service that efficiently and safely brings critically ill babies and children who need specialty pediatric care to Texas Children's Hospital. The specially equipped ground ambulances and customized Cessna airplane transport critically ill newborn babies and children from throughout the United States, Mexico and Central America.

With so many providers caring for critically ill children, the CCM Section noted that individuals were experiencing signs of burnout and the intimacy of the previously small group had been lost. This led to the creation of a committee that brought to life the **Faculty Engagement and Development (FED) Series**.



FED members, spearheaded by **Dr. Lara Shekerdemian**, Chief of CCM, are providing the Faculty with education opportunities that focus on enhancing individuals' personal and professional development. FED is organizing rotating seminars, workshops, invited speakers, happy hours, and family-friendly socials. The activities vary in order to ultimately address the needs of every section member, regardless of what stage in life he or she may be in. Together, the FED series is taking steps to ensure that every Faculty member has the opportunity to combat burnout. The journey to wellness is being faced head-on by this vibrant group of Faculty.

Section Leads in National Spina Bifida Research

The Section and Meyer Center for Developmental Pediatrics, TCH, are the recipients of a CDC grant to continue research on spina bifida. Meaning “split bone,” spina bifida is the most common permanently disabling birth defect in infants in the United States. It occurs when the fetus’ neural tube fails to develop or close properly, and the condition ranges from mild to severe. In the most severe form, myelomeningocele, parts of the spinal cord and nerves extend through the open part of the spine, leading to related problems such as loss of feeling, weakness or paralysis of the feet and/or legs, and problems with bladder and bowel control.

The multidisciplinary Spinal Bifida Program includes experts from neurosurgery, developmental pediatrics, urology, orthopedics, and physical medicine and rehabilitation. They provide prenatal evaluations and follow affected patients from in utero into adulthood.



“Since we are one of the major referral sites for spina bifida in the state of Texas, our team provides the entire spectrum of care to pediatric patients – from prenatal diagnosis, surgical interventions, and postal care until adulthood – for myriad health issues related to spina bifida. This gives our team access to a wide demographic of participants and allows us to conduct unique in-depth studies and comparisons of the outcome measures of current interventions.”

--Dr. Jonathan Castillo, Clinical Director, Spina Bifida Program

In 2011, The Center was among the first to perform open fetal surgery to treat spina bifida, a procedure that involves accessing and repairing the defect in the fetal spine by way of an incision across the mother’s uterus. It is now the standard of care.

In 2014, The Center pioneered a novel, minimally invasive fetoscopic procedure that uses a camera and tiny incisions in the uterus to repair the defect. However, according to Dr. Castillo, “Despite recent advances of in utero repair procedures, surgery is not suitable for all patients and cannot be considered a cure. Additionally, these surgeries may not reverse all the dysfunction or correct all related impairments. Also, these procedures are specific to myelomeningocele and may not help patients with other forms of spina bifida. Therefore, a deeper understanding of the etiology and biology of this condition is crucial to develop better treatment approaches in spina bifida care.”

That same year [2014], a team led by **Drs. Heidi Castillo, Jonathan Castillo, and Duong Tu** received funding from the CDC to develop national standards in healthcare for spina bifida at the population level. BCM and TCH were among the first institutions in the state to participate in the CDC’s Spina Bifida Registry, which collects medical data from this population to improve outcomes. Dr. Jonathan Castillo noted that, “Receiving that grant from the CDC and joining the registry gave us an amazing opportunity to participate in a nation-wide effort to develop better outcomes, interventions, and standards of care for individuals with spina bifida.”

The Center continues to investigate comprehensive, multidisciplinary research initiatives to find safer medical and surgical interventions to improve the quality of life for these patients.

Center Offers Patients in Numerous Activities

The Section held the **2019 Bone Marrow Transplant Long-Term Survivor “Survivor Day” Challenge** in September. Survivors and their siblings participated in activities and games throughout the day. The event was sponsored by His Grace Foundation, Trisha Clark Foundation, and the Texas Children’s Cancer and Hematology Centers.



In celebration of **National Childhood Cancer Awareness Month**, patients, families, and staff at The Center came together in September for the **Going Gold** parade and ribbon-tying ceremony at the Main Campus, sponsored by The Faris Foundation. Participants proceeded through the halls of the hospital and concluded on the Auxiliary Bridge, where gold ribbons were tied in honor of children and families who have been touched by pediatric cancer.

Patients with bone marrow transplants enjoyed the **2019 BMT Unit Summer Camp** in August. It is sponsored by His Grace Foundation and TCH’s Child Life Department. Patients played games, participated in activities, and won prizes.



Dr. Poplack Speaks at Conference Attended by Local Patient



Eden, a 14-year-old Sugar Land native, was diagnosed and treated here for a cancer so rare that she is the only known case. After undergoing 14 surgeries and 23 rounds of chemotherapy, and receiving 30 blood transfusions, she is a survivor sharing her journey with others. She headed with her family and others to Washington, D.C., to raise awareness about the lack of funding for childhood cancer research and treatment. While in D.C., Eden and her family attended the 10th Annual Childhood Cancer Summit, hosted by Representatives Michael McCaul and Jackie Speier and members of the Childhood Cancer Caucus. **Dr. David Poplack** delivered the keynote address.

Section on Hematology & Oncology Announces The 2nd Symposium on Childhood Cancer Health Disparities Disparities and Outcomes in Acute Leukemia November 4, 2019 Houston, Texas

September 23
Deadline for Abstract Submission
October 14, 2019
Deadline for Registration (free)

This conference, which will bring together leaders in the field of acute leukemia research and treatment, will feature moderated research presentations and expert panel discussions. The conference will foster meaningful research collaborations addressing disparities in acute leukemia biology and outcomes, with the ultimate goal of improving the lives of patients affected by this malignancy.

Registration is required but the symposium is free of charge,
through the generous support of the Northwestern Mutual Foundation

*Registration and submission of abstracts may be done online (Chrome or Firefox recommended) at
<https://orit.research.bcm.edu/R5T80IF3WH2/TXCHDisparitiesAndOutcomes/Welcome.aspx>*

IAR Involved in Community Engagement Activities

On August 10, 2019, the Retrovirology/HIV Research Program held its first annual **Youth Education Workshop** for patients and families. The Norma Cooper Scholarship, named after our former HIV Research Nurse who impacted the lives of many of our youth and families by empowering them to pursue higher education, was introduced to the audience. This scholarship will provide a book stipend and/or tuition assistance to the recipients.



The theme of the workshop was *“Next Steps After High School.”* The morning began with opening remarks by **Dr. Mary Paul**. Guest speakers included high school and career counselors and representatives from community colleges, universities and a technical college. Different speakers gave tips on obtaining financial aid and managing personal finances. In the afternoon there were two separate panel discussions, a Youth Session moderated by Mandi Speer & Dalisa Santiago and a Parent Session moderated by Chivon McMullen-Jackson, with Sara Aguirre as a featured panelist. The youth session included topics on study habits, time management, relationships, and healthy living. Parents discussed striking a balance between support and allowing independence.

Last year, one of our Food Allergy Family Network (FAFN) Leaders, Mr. Sachin Menon, and Theresa Aldape, LMSW (FAFN facilitator), contacted several Major League Baseball Community Event Representatives to learn how various teams started their Peanut Allergy Friendly events. In response, Mr. Van Sickler (Astros-premium sales representative) gave the Food Allergy Team a tour of Minute Maid Park to help us identify an area that would be ideal for our TCH-sponsored **Peanut Allergy Friendly Day**. Thanks to the generosity of the Harris County Houston Sports Authority (HCHSA) and the leadership of **Dr. Carla M. Davis**, the Food Allergy Team held the first **Peanut Allergy Friendly Event** at an Astros game in 2018.



This year, we were once again fortunate enough to have a suite donated by the HCHSA, where we held our 2nd Annual Peanut Allergy Friendly Event on August 24, 2019. The attendant in our suite provided excellent customer service and available to help our team and families with specific questions. Carla M. Davis, MD, Daisy Tran, RN, Lauren Kronisch, RDN, LD and Theresa Aldape, LMSW attended the game to address any concerns from our patients and families. The children also brought posters to support the Astros. The team set up several tables for the children to create art work, get temporary Astros tattoos, and address thank-you cards for our supporters. This year 13 families attended the Peanut Allergy Friendly Event at the Astros game.

Teen Advisory Board on Food Allergies Formed

A **Teen Advisory Board** consisting of 16 teen members was formed in March 2019. It is a leadership program designed to promote awareness of food allergies in the community and to offer mentors to other children with food allergies. The teen leaders participate in the planning of outreach activities, including the Food Allergy Symposium Youth Session, Food Allergy Day at The Health Museum, and community outreach. The teens meet for an official meeting four times a year, and they often convene on other days to prepare for events. The program also has allowed them to form a bond and share personal experiences with each other.



The Food Allergy Program staff and teen members regularly attend community events and school health fairs in the Greater Houston area to provide awareness of food allergies to families and students. The staff also provides a 1-hour in-service on basics of food allergies to school staff, nurses, and students.



Food Allergy Day at The Health Museum took place on August 8, drawing more than 1100 people to the 5-hour time period. The event began with interactive activities for children. **The Teen Advisory Board** developed a passport with learning stations to encourage attendees to visit the stations and learn more about food allergies. The event ended with “Cocktails and Conversations” as an expert panel consisting of physicians with expertise in food allergies, a dietician, and a family spoke about food allergies and answered questions from the audience.

Inaugural Family Conference for EBF3-HADD Syndrome Held



"The conference was the first time most of the patients and their families had met another person with this syndrome. After years of feeling isolated, they were now suddenly in a room with 22 other children with HADD syndrome and their families. It was beautiful to see these children making new friends and parents instantly bonding with one another. This is why we recommend families of other rare disorders to connect with each other and harness the power of social media to form supportive communities. Besides offering crucial social and emotional support, it offers several other practical benefits - having a cohort of patients allows researchers to rapidly catalog the symptoms and their severity, understand the disease trajectory, and quickly identify potential complications. We realized what began as an intellectual curiosity to understand the biology of EBF3 had in such a short time given rise to this wonderful community. It was incredibly heart-warming to witness this growth and transformation. No longer are the families alone in this journey..."

--Dr. Hsiao-Tuan Chao

The inaugural family conference for the EBF3-HADD (Hypotonia Ataxia Developmental Delays Syndrome caused by changes in the EBF3 gene) syndrome was held July 25 – 27, 2019 in Houston, Texas. The conference was organized by the EBF3-HADD Foundation, a new nonprofit organization created in 2018 by families to promote awareness, research, and support for this genetic syndrome.

Currently, 30 EBAF3-HADD syndrome cases have been reported in the literature, and more than 200 patients have been identified worldwide. Most cases seem to result from spontaneous mutations in the gene, with children of both genders being equally vulnerable, and with most appearing to have age-appropriate cognition.

EBF3-related HADD syndrome was co-discovered in 2016 by **Drs. Hsiao-Tuan Chao**, Asst. Professor, Michael Wangler, Hugo Bellen, and their colleagues at the Undiagnosed Diseases Network, Jan and Dan Duncan Neurological Research Institute (NRI) at Texas Children's Hospital, New York University Langone Health, and Baylor College of Medicine. Drs. Chao and Wangler began investigations into the disorder when a child came to them from the NIH's Undiagnosed Diseases Program who had presented with impaired speech and cognition, low muscle tone, balance/gait issues, reduced ability to feel physical pain, and lacked the ability to display strong facial emotional expressions such as a smile, laugh or cry. They selected the most likely candidate gene from a list of potential genes, *EBF3*. Dr. Chao generated fruit fly models that mimicked the patient's mutation to better understand its function. Within a few months, they found three other patients with similar issues and similar alterations in the *EBF3* gene. They reported their findings in 2016; two other multi-national collaborative teams also published their findings concurrently in 2016.

This first conference was attended in person by 22 families, totaling more than 70 people, who came from all over the United States and Canada and via live streaming services by another 13 families from around the world, including Ireland and Australia. In addition to having presentations by physician-scientists and others on a wide variety of topics related to EBF3-HADD syndrome, the conference allowed patients to receive clinical evaluations by Drs. Chao and Wangler, who also have offered monthly clinical evaluations at TCH since 2017.

Together, Drs. Chao and Wangler have now seen the largest number of patients with this condition in a single institution worldwide. They are currently enrolling patients in a natural history study to better understand the condition and to assist in translating research findings into clinical interventions.

Television Interview Addresses Active Shooter Drills



Dr. Laurel Williams, Assoc. Professor and Chief of Psychiatry at TCH was interviewed on video recently concerning the psychological effects of active shooter drills in school. She has recommendations (see side panel) for schools if they determine that these drills are necessary.

The age of children and their developmental stages should be considered when planning these drills, as their emotional and cognitive abilities are vulnerable. She notes that “it is not developmentally normal for young children to not understand time and be able to distinguish between something happening now verses [sic] something possibly happening in the future. From the perspective of a child psychiatrist, I believe that it’s psychologically distressing for young [children] to practice active shooters coming into your area. It’s not clear to them that the drill is not real. The younger the child, the less likely they are to understand that an act of violence is not occurring during a drill.”

One primary concern with implementing these drills is that they (and installation of metal detectors and other protective devices and measures) may reinforce society’s existing struggles with interpersonal connections. The potential for psychological damage should be considered, and the focus should be on teaching children to be more socially interconnected with one another. Otherwise, children may perceive the world as frightening and unpredictable.

Research on the promotion of social connectivity in schools has been shown to decrease the incidence of bullying and the increase children’s academic performance, as well as enhance their mental health.

If schools determine that these drills are necessary, Dr. Williams recommends that schools consider the following key points:

- Provide adequate notice to families and staff regarding the need for the drills and provide an orientation for staff, parents, and students before drills occur
- Provide education to staff and teachers about trauma-informed best practices and seek training for non-mental health professionals on how best to respond in the moment of crisis. Mental Health First Aide is a commonly employed training
- Allow for staff and children who already have experienced trauma to be excused from participating or have very close support before, during and after the drills
- Emphasize during the drills that it is just practice and continuously state the purpose



*Anna Mandalakas, MD, PhD; Janice Endsley, PhD; Stefan Kaufmann, PhD
Maria Elena Bottazzi, PhD; Peter Hotez, MD, PhD; and Larry Schlesinger, MD*

Symposium Addresses TB and Other Neglected Diseases

The Global TB Program at TCH/BCM and the National School of Tropical Medicine at BCM extended gratitude to the Hagler Institute for Advanced Study at Texas A&M University for their gracious support of their recent symposium titled “Tools and Vaccines for the Control of Tuberculosis and other Neglected Tropical Diseases.” The morning session featured a keynote address delivered by Professor Stefan Kaufmann, founding director of the Max Planck Institute for Infection Biology and 2018 Hagler Institute Faculty Fellow. The address was complemented by Texas experts on tuberculosis from partner institutions including BCM, Texas A&M University, Texas Biomedical Research Institute, and The University of Texas Medical Branch. Participants enjoyed a robust discussion regarding recent advances in the fight against TB.

Afternoon lectures included founding Dean of the National School of Tropical Medicine Peter Hotez’s plenary lecture “Blue Marble Health and Neglected Tropical Diseases” and lectures on Chagas disease, West Nile Virus, and tick-borne diseases. Dr. Kathryn Jones also spoke regarding Tropical Medicine’s therapeutic Chagas Disease vaccine, which is prepared to enter clinical trials, and Leroy Versteeg spoke on modern technologies for new vaccines.

Dr. Hotez Recognized by Universidad de Monterrey

Dr. Peter Hotez, Professor and Dean of the National School of Tropical Medicine, received the Laboris Chair, granted by the Universidad de Monterrey in July 2019. He is also Professor of Molecular Virology and Microbiology at BCM and Director of the TCH Center for Vaccine Development. The Laboris Chair seeks to recognize experts in different areas of expertise, with a solid and proven career, to share experiences with students. Since 2007, the the University has awarded the “Catedra Laboris” to distinguished physicians with extensive trajectories in the fields of teaching and research. Among the recipients is our own **Dr. Fernando Stein**, Assoc. Professor and former President of the American Academy of Pediatrics.



In his remarks, Dr. Hotez noted that he is a vaccine scientist, pediatrician, and father of a girl on the autism spectrum. In questioning the relationship between vaccines and autism, he said that he has become “the number one enemy of the anti-movement vaxers.” He continued by explaining that, with efforts of scientists and experts, as well as the World Health Organization, an infrastructure and culture could be created in which vaccines would be seen as one of the most important tools to protect and guarantee the health of people. Noting that there “were fewer convalescent people and fewer deaths due to diseases than can prevented with vaccines,” he pointed out that from 1974 to 2000, the number of children dying from measles dropped from 2.5 million to one-half million. This situation was especially pertinent to Dr. Hotez, as he began his work in Pediatrics in 1987, at a time when he was admitting a child every 2 weeks with measles, and the experience was traumatic because there was no effective vaccine and many children did not survive. Today, with the advent of the measles vaccine, that situation is changed.

Dr. Bottazzi Gives Keynote Address at Symposium

On July 20, 2019, Tropical Medicine’s **Dr. Maria Elena Bottazzi** gave the keynote lecture, titled “Leadership: Curiosity, Courage, Commitment and Community” at the Texas Medical Center Academic Research Career (ARC) Symposium. The Symposium, produced jointly by MD Anderson Cancer Center, Baylor College of Medicine, and the University of Texas Health Science Center at Houston, covered important topics including mentoring, funding and grant writing, career transitioning, and academic-industry collaborations. The wide range of speakers included researchers, professors, and industry professionals.



Dr. Bottazzi is a Fellow of the Leshner Leadership Institute for Public Engagement (Infectious Diseases) of the American Association for the Advancement of Science (AAAS) and a Sr. Fellow of the American Leadership Forum (ALF), as well as an Emerging Leader in Health and Medicine Scholar of the National Academies of Medicine. She discussed her professional journey from student/researcher to Associate Dean of the National School of Tropical Medicine, with a focus on what she calls “Transformational Leadership,” and explained some of the challenges and success her teams have faced in vaccine development, while stressing the importance of science advocacy.

Innovation Symposium Draws Enthusiastic Participants

DESIGN THINKING



The 1st **Innovation Symposium** at Texas Children’s took place on August 15, 2019, with a great success. Attendees learned about integrating the knowledge of the natural, social, and humanistic sciences into adequate solutions. Dr. Kirsten Ostherr, Gladys Louise Fox Professor of English and Director of the Medical Futures Lab at Rice University, (pictured top right) presented the plenary overview and engaged participants. Seven teams representing different Sections in the Department participated in the “Design



The Winners for the Design Sprint Challenge

1st Place

*“Defying the Status Quo: Adaptable Quality and Safety Education and the potential to Learn”
(Eric Williams, Joyee Vachani, Cara Doughty, and Jordana Goldman, along with faculty from PEM and PHM)*

Two Runner-up Teams were:

“Fellow College Revitalization”

(Jen Rama, Melissa Carbajal, Austin Stuckert, and Kristen Derey Valencia)

*“A Web-based Educational Tool for Ventricular Assist Devices for Pediatric Patients and Caregivers”
(Lauren Williams, Patricia Bastero, and Corey Chartan)*



ENTREPRENEURSHIP in Medical Education

November 11, 2019, Feigin Center 1A, 9.30 am-2 pm

Join these two special workshops and learn tips and tools to transform creativity to innovation and entrepreneurship in medical education



The Model for Innovation and Entrepreneurship in Medical Education: The Development of OPENPediatrics-a Global Learning Community
Traci Wolbrink, MD, Director of the OPENPediatrics, Boston Children's Hospital

Securing Educational Grants: Money is not the Only Answer But it Makes A Difference!
Ashley Siems, MD, Education Scholar/Researcher, Children's National Medical Center



To Register:
<https://www.eventbrite.com/e/entrepreneurship-in-medical-education-tickets-72089614979>
(\$25 fee, Networking Lunch included)

Contact: CRIS@texaschildrens.org for questions

Center for Research, Innovation and Scholarship in Medical Education



DEPARTMENT NEWS

FACULTY, FELLOWS & STAFF FEATURES

Professor Named Chair of Department at BCM

Dr. Margaret “Peggy” Goodell, Professor (pictured above), was named chair of the Department of Molecular and Cellular Biology at BCM by the College’s Board of Trustees, effective October 1, 2019. She succeeds Dr. Bert O’Malley, who led the department for more than 45 years.

Dr. Goodell is a leader in the field of stem cell research and a Professor in several departments in addition to Pediatrics, and was the founding director of the Stem Cells and Regenerative Medicine Center at BCM. She holds the Vivian L. Smith Chair in Regenerative Medicine and is a co-leader of the Cancer Cell and Gene Therapy Program in the Dan L. Duncan Comprehensive Cancer Center.

She received her bachelor’s degree from Imperial College, London, and her doctorate from the University of Cambridge, United Kingdom. She completed postdoctoral fellowships at Whitehead Institute at MIT and Harvard Medical School. She is known for discovering a novel method to isolate adult stem cells.

New Executive Vice-Chairs Announced



On September 6, Dr. Mark Kline, Chairman, announced the appointment of Drs. Tammy Kang (left) and Joan Shook (right) to Executive Vice-Chair positions, effective October 1. Drs. Kang and Shook will work with the department's third Executive Vice-Chair, Dr. Gordon Schutze, as well as the Sections Heads and Vice-Chairs for Clinical Affairs, Research, Education, Community Health, and Behavioral. Dr. Kline thanked Drs. Susan Blaney and Shelly Kaplan for their service for the past ten years, including in the role of Executive Vice-Chair since the inception of the



title. He noted that, "Both have been and will continue to be trusted friends, colleagues, and advisers." Dr. Blaney will continue as Section Head for Hematology-Oncology, and Dr. Kaplan will continue as Section Head for Infectious Diseases.

Pediatric Residency Associate Program Directors Named



In July, Dr. Elaine Fielder, Asst. Professor and Director of the Pediatric Residency Program, announced that two members of the Department had been named as Pediatric Residency Associate Program Directors. Dr. Lanessa Bass, Assoc. Professor and Co-Director of the Pediatric Primary Care L.E.A.D. Program (left) joined the team, having 8 years of APD experience, as well as a Masters of Education from the University of Cincinnati. Her interests include curriculum development, primary care education, social determinants of health, and health disparities. Dr. Brian



Dr. Brian Rissmiller, Asst. Professor and a former Pediatric Chief Resident at TCH (right) focuses on innovation in medical education, how novices become experts, diagnostic reasoning, and critical thinking. They join other members of the pediatric residency leadership team that includes Drs. Alisa Acosta, Mark Ward, and Teri Turner.

Pediatric Residency Assistant Program Directors Named



Dr. Elaine Fielder, Asst. Professor and Director of the Pediatric Residency program (left), announced on September 9, 2019, that Drs. Andria Tatem (right, top) and Linessa Zuniga (right, bottom), both Fellows in the Section of Academic General Pediatrics, joined the pediatric residency leadership team as Assistant Pediatric Program Directors-in-Training. In their roles, Drs. Tatem and Zuniga will work closely with Dr. Fielder and the Associate Program Directors to guide the educational activities of the residency program and provide coaching and support to the residents. Dr. Fielder noted that both Drs. Tatem and Zuniga "bring their enthusiasm and experiences in graduate medical education, curriculum development, and program administration to their new positions.



IAR Faculty Featured in Different Venues



Faculty members at the Texas Allergy, Asthma and Immunology Society (TAAIS) meeting where five BCM faculty members lectured to residents across the state.

Dr. Aikaterini Anagnostou, Assoc. Professor, was interviewed on Fox 26 News on August 19, 2019, prior to school starting. She represented IAR well and educated the public about food allergies.



Award Received for ART Early Treatment

On behalf of Baylor College of Medicine and Texas Children's Hospital's Global TB Program, **Dr. Anna Mandalakas** (Professor and Program Director, Global TB Program) attended the 10th International AIDS Society Conference of HIV Science in Mexico City, Mexico, on July 19 - 25. At the conference, Dr. Mandalakas accepted the "IAS TB/HIV Research Award" for the team's exceptional research demonstrating that ART initiation within 8 weeks of TB treatment leads to superior TB outcomes in ART-naïve children and adolescents living with HIV.



faculty highlights...

Dr. Carl Allen, Asst. Professor, received a \$150,000 Innovation Award from St. Baldrick's Foundation, to investigate the role of inherited genes, acquired gene mutations, and the origin of tumor cells to define the causes of Langerhans Cell Histiocytosis.

Dr. Alison Bertuch, Assoc. Professor, recently was named chair of the Molecular Genetics B / (MGB) Study Section of the National Institutes of Health Center for Scientific Review, for a two-year term. Applications reviewed by the MGB study section involve molecular mechanisms of genome replication, maintenance and gene expression.

Dr. Susan Blaney, Professor, was honored with the Elise C. Young Chair in Pediatric Oncology in recognition of her service as chief of pediatric hematology/oncology and director of the Texas Children's Cancer Center. She joined the faculty in 1995.

Tasha Bryant, Nurse Practitioner, was appointed Adjunct Faculty at Texas Tech University Health Sciences Center School of Nursing through 8/31/2023.

Dr. Benjamin Choi, Asst. Professor, along with VITLS, has devised a flexible, waterproof, unobtrusive and noninvasive wearable device that monitors body temperature, heart rate, respiration rate, blood oxygen levels, sleep and movement (including fall detection). This allows for continuous and remote monitoring of patient's vital signs reliably and undisturbed. A pilot clinical trial is planned in pediatric emergency room patients. The work was funded with seed grants for novel pediatric medical device development, by the Southwest National Pediatric Device Consortium.

Dr. Shailendra Das, Asst. Professor, along with Dr. David Spielberg and Strados Labs, has developed a small wearable device and connected platform that tracks respiratory rate and detects and records abnormal breath sounds such as wheezing. A pilot clinical trial in inpatient pediatric asthma patients is planned to validate the device's sound algorithms in the pediatric population. It has the potential to be used for real-time monitoring of asthma patients, as well as to help children identify unrecognized symptoms of poor asthma control. The work was funded with seed grants for novel pediatric medical device development, by the Southwest National Pediatric Device Consortium.

Dr. Heather Haq, Asst. Professor

-- was selected to participate in the American Academy of Pediatrics Young Physicians Leadership Alliance, a 3-year longitudinal training program designed to develop leaders and build a leadership community amongst early career pediatricians and pediatric subspecialists.

-- was recently elected to serve in the Executive Committee of the Section of International Child Health of the American Academy of Pediatrics.

Dr. Peter Hotez, Professor and Dean of the National School of Tropical Medicine, explains how vaccines work and why nearly eradicated diseases are re-emerging in "Outbreak," the latest episode of Body of Work, the podcast in which BCM scientists and physicians explore the impact of "hot button issues" on healthcare, research, community and education.

Dr. Katherine King, Assoc. Professor, received the Presidential Early Career Award for Scientists and Engineers. The Department of Health and Human Services nominated her for this high honor bestowed by the federal government to outstanding scientists and engineers who are beginning their independent research careers and who show exceptional promise for leadership in science and technology.

Dr. Joseph Knadler, clinical fellow, was one of 9 winners to receive the 2019 CVRI Symposium Best Abstract and Best Poster from the BCM Cardiovascular Research Institute. Each winner got an engraved plaque and a \$150 cash award (supplemental pay for BCM affiliates).

Dr. M. Regina L. Lantin-Hermoso, Assoc. Professor

-- received her 2nd Norton Rose Fulbright Educational Award in Enduring Materials .

-- was invited by the editors of *Pediatrics* to write an editorial /commentary on a multi-center study looking at the neurodevelopmental abilities of 6-year-old children who had undergone palliation for hypoplastic left heart syndrome.

Dr. Holly Lindsay, Asst. Professor, recently was appointed to serve as the American Academy of Pediatrics representative to the Institute for Advanced Clinical Trials for Children Steering Committee. In this role, she will advocate for the inclusion of pediatric and adolescent patients in adult clinical trials to increase the therapies available for these patients. Lindsay is part of the Texas Children's Cancer Center and Baylor College of Medicine's Adolescent and Young Adult Oncology Program.

Dr. Joseph Lubega, Asst. Professor, recently was appointed vice chair of the Global Special Interest Group of the American Society of Pediatric Hematology/Oncology (ASPHO). His responsibilities will include organizing the annual special interest group meeting, engaging members who have an interest in global care, and working to extend the reach of ASPHO beyond the U.S. Lubega previously served as medical director of the Texas Children's Cancer Center's Global Hematology Oncology Pediatric Excellence (HOPE) Program in Uganda.

Dr. Philip Lupo, Assoc. Professor

-- received a \$400,000 Consortium Research grant from St. Baldricks' Foundation to better characterize ethnic disparities in those diagnosed with acute leukemia and develop novel risk prediction models for treatment-related toxicities and relapse.

-- along with Drs. Sharon Plon, Will Parsons, and Michael Scheurer, was invited to participate in the Childhood Cancer Data Initiative symposium at the National Cancer Institute July 29-31, along with other scientific stakeholders and leaders. This symposium was the scientific planning session for the proposed initiative, announced during the State of the Union address in February, to spend \$500 million on childhood cancer research over the next 10 years, including efforts to collect, analyze and share data to make it easier for researchers and oncology care teams to learn from every child, adolescent and young adult with cancer.

Dr. Shaine Morris, Asst. Professor, received a distinction award from The Marfan Foundation during the 35th Marfan Foundation Conference.

Dr. Antonio Mott, Assoc. Professor, received the BCM Pediatric House Staff Award in recognition as the Outstanding Teaching Attending in the department

Dr. Will Parsons, Assoc. Professor and Deputy Director of Texas Children's Cancer and Hematology Centers

-- received a \$150,000 Innovation Award from the St. Baldricks' Foundation to use a team science approach in studying the biologically and clinically-relevant genomic alterations in high-risk and rare pediatric cancers and how precision oncology can help treat childhood cancer patients.

-- along with Drs. Sharon Plon, Michael Scheurer, and Philip Lupo, was invited to participate in the Childhood Cancer Data Initiative symposium at the National Cancer Institute July 29-31, along with other scientific stakeholders and leaders. This symposium was the scientific planning session for the proposed initiative, announced during the State of the Union address in February, to spend \$500 million on childhood cancer research over the next 10 years, including efforts to collect, analyze and share data to make it easier for researchers and oncology care teams to learn from every child, adolescent and young adult with cancer.

Dr. Sharon Plon, Professor, along with Drs. Will Parsons, Michael Scheurer, and Philip Lupo, was invited to participate in the Childhood Cancer Data Initiative symposium at the National Cancer Institute July 29-31, along with other scientific stakeholders and leaders. This symposium was the scientific planning session for the proposed initiative, announced during the State of the Union address in February, to spend \$500 million on childhood cancer research over the next 10 years, including efforts to collect, analyze and share data to make it easier for researchers and oncology care teams to learn from every child, adolescent and young adult with cancer.

Priscilla Reid, cardiology nurse practitioner, was selected as one of the *Houston Chronicle's* 2019 Salute to Nurses Top 15 Nurses.

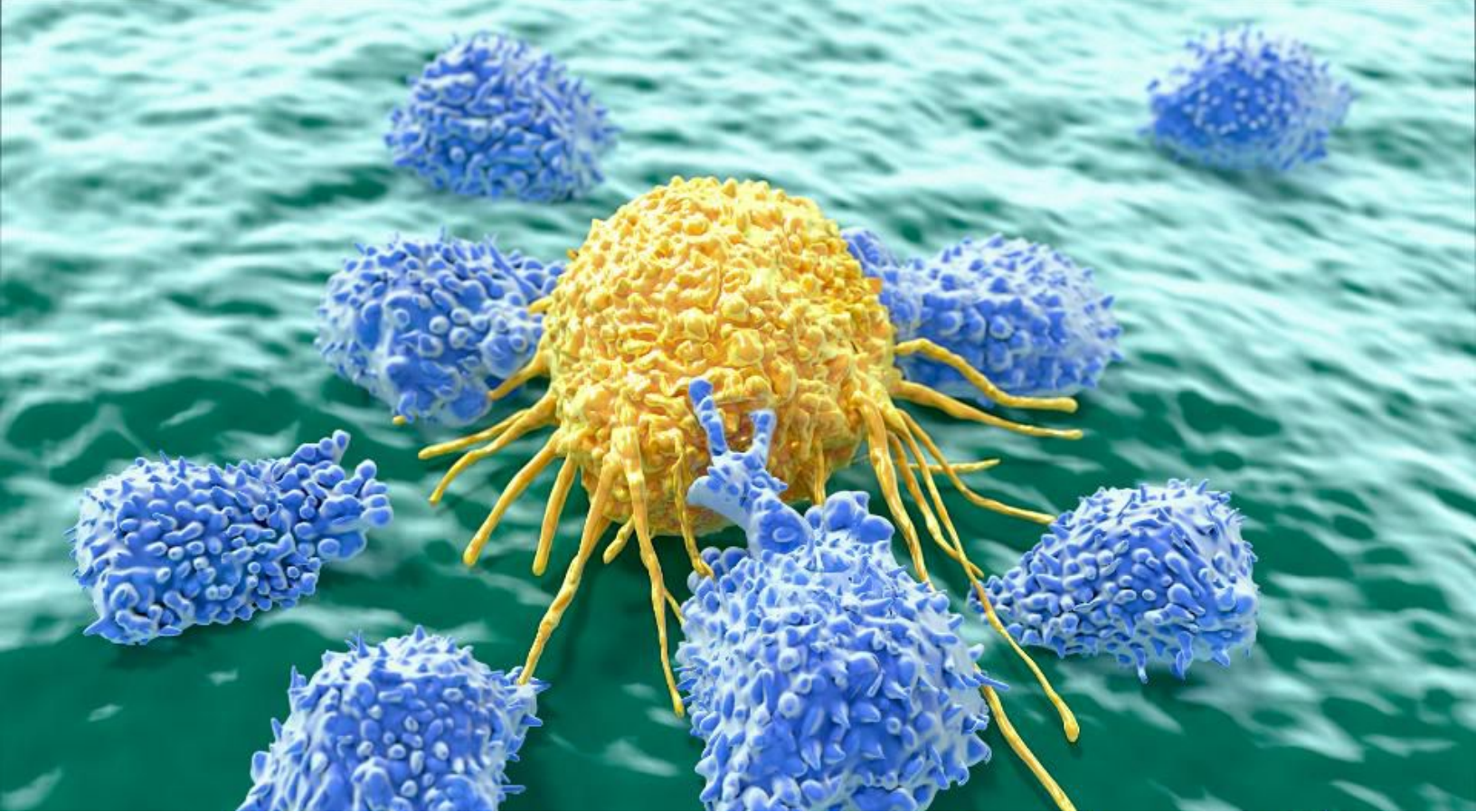
Dr. Michael Scheurer, MD, along with Drs. Sharon Plon, Will Parsons, and Philip Lupo, was invited to participate in the Childhood Cancer Data Initiative symposium at the National Cancer Institute July 29-31, along with other scientific stakeholders and leaders. This symposium was the scientific planning session for the proposed initiative, announced during the State of the Union address in February, to spend \$500 million on childhood cancer research over the next 10 years, including efforts to collect, analyze and share data to make it easier for researchers and oncology care teams to learn from every child, adolescent and young adult with cancer.

Dr. Sarah Scollon, Asst. Professor, received the Diane Baker Alumni from the University of Michigan Genetic Counseling Program, where she earned a master's degree in genetic counseling. The award honors genetic counselors who display the same vision and commitment to the field as its namesake. Dr. Scollon will deliver the annual Diane Baker Alumni Lecture in September.

Dr. David Spielberg, Asst. Professor, along with Dr. Shailendra Das and Strados Labs, has developed a small wearable device and connected platform that tracks respiratory rate and detects and records abnormal breath sounds such as wheezing. A pilot clinical trial in inpatient pediatric asthma patients is planned to validate the device's sound algorithms in the pediatric population. It has the potential to be used for real-time monitoring of asthma patients, as well as to help children identify unrecognized symptoms of poor asthma control. The work was funded with seed grants for novel pediatric medical device development, by the Southwest National Pediatric Device Consortium.

Dr. Peter Wasswa, Asst. Professor, was selected by St. Baldrick's to received \$115,000 International Scholar grant to support his study of prevalent types of leukemia and lymphoma in children in Malawi and how their genetic code may affect response to chemotherapy.

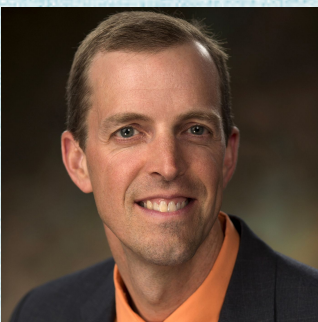
Dr. Huda Zoghbi, Professor, will be honored with the 2019 Victor A. McKusick Leadership Award from the American Society of Human at its annual meeting in Houston in October. The award recognizes her work demonstrating the value of genetics and genomics research across the spectrum.



DEPARTMENT NEWS

RESEARCH

Analyzer Provides Risk Scores for Susceptibility to Infection



Through a collaboration with the Jeffrey Modell Foundation and TCH, Dr. Nicholas Rider’s team used an algorithm called the SPIRIT Analyzer to screen more than 185,000 TCH Health Plan members for risk of primary immunodeficiency. SPIRIT stands for Software for Primary Immunodeficiency Recognition, Intervention, and Tracking.

The SPIRIT Analyzer rapidly provides an individual’s risk score for having an underlying susceptibility to infection. This important pilot study suggested that approximately 5% of a high-risk cohort could have underlying immune disease, and the algorithm can detect them before ongoing illness occurs.

Initial results were published in March *Frontiers of Pediatrics* (“Calculation of a Primary Immunodeficiency ‘Risk Vital Sign’ via Population-Wide Analysis of Claims Data to Aid in Clinical Decision Support”) (<https://www.frontiersin.org/articles/10.3389/fped.2019.00070/full>)

The team has now begun to implement a machine learning component to the SPIRIT Analyzer and will be validating the tool longitudinally, supported by a \$250,000 grant from the Jeffrey Modell Foundation. Dr. Rider is an Associate Professor in the Section of Allergy, Immunology and Retrovirology.

Study Finds Connection Between Ataxin-1 Gene and Alzheimer's

Dr. Huda Zoghbi, Professor and Director of the Jan and Dan Duncan Neurological Research Institute at TCH, was part of a collaborative study including researchers at Baylor College of Medicine and Massachusetts General Hospital at Harvard Medical that revealed in an article published in the journal *Cell* that the ataxin-1 gene, which is known to cause the rare neurodegenerative disease called *spino-cerebellar ataxia type 1* (SCA1), also can increase the risk of developing Alzheimer's disease in a mouse model of the condition.

Drs. Rudolph E. Tanzi and Jaehong Suh and their colleagues had examined the effect of knocking out the ataxin-1 gene in mice and found that the animals had learning deficits, suggesting a potential role of ataxin-1 in learning and memory. They approached the Zoghbi

Results from the current study revealed that knocking out the ataxin-1 gene had different consequences, namely that the effects were focused on the hippocampal region of the cerebrum, rather than the cerebellum. They found evidence of increased generation of amyloid beta peptides and disruption of both neuronal connectivity and neurogenesis, which may help explain early observations of patients having difficulty with learning and memory.

Dr. Suh also noted that investigation of the molecular mechanism involved resulted in the identification of alterations in a molecular cascade, including an increase in the BACE1 enzyme, which plays a key role in the formation of amyloid beta peptide, the primary constituent of amyloid beta plaques that accumulate in the brains of patients with Alzheimer's disease.

"In this study we collaborated with the laboratory of Dr. Rudolph E. Tanzi, professor and director of the Genetics and Aging Research Unit at Massachusetts General Hospital (MGH), and the laboratory of Dr. Jaehong Suh, assistant professor of neurology at Harvard Medical School and assistant neuroscientist at MGH, whose previous family-based genome-wide association study (GWAS) had shown that variants of the ataxin-1 gene might be risk factors for Alzheimer's disease."

---Dr. Huda Zoghbi
Co-corresponding Author



laboratory for further research because that lab is where the ataxin-1 gene was discovered and where it has been extensively studied for more than 20 years in the context of SCA1, according to Dr. Suh.

Previous studies in the Zoghbi lab in collaboration with Dr. Harry Orr at the University of Minnesota had revealed that the repetition of certain regions of the ataxin-1 gene causes SCA1, a condition that is the result of the cerebellum wasting away. The consequences typically are a progressive deterioration of motor coordination and balance and difficulties with swallowing and breathing.

Dr. Tanzi, also noted that their discovery that ataxin-1 is genetically and functionally associated with the risk for developing formation of amyloid plaque, opens an entirely new therapeutic avenue for preventing Alzheimer's disease.

Dr. Zoghbi added that the findings were possible due to the generous support of funding institutions and foundations, such as the Jeffry and Barbara Picower Foundation, that provide opportunities for nurturing collaborations such as this study.

Researchers Identify Increased Risk Factors for Cancer



Dr. Philip Lupo, Assoc. Professor and Co-Director of the Childhood Cancer Epidemiology and Prevention Program at TCH (left), led a multi-institutional study that found that children and adolescents with specific birth defects are at increased risk of developing certain cancers. Also involved in the study were **Dr. Sharon Plon**,

Professor and Co-Director of the Cancer Genetics and Genomics Program at TCH (right), and Dr. Jeremy Schraw, a post-doctoral fellow.

More than 250,000 children globally are diagnosed with cancer annually; in the United States, cancer remains the leading cause of death by disease among children and adolescents. One of the key objectives of the study was to identify children who are at increased risk of developing cancer, as recognizing subsets of children has the potential to benefit future generations by screening and better clinical management.

The study, which was published in *JAMA Oncology*, is the largest population-based assessment to date of cancer risk among children with birth defects and childhood cancers. It revealed that children with multiple major non-chromosomal birth defects have an increased risk for developing cancers.

Being born with a chromosomal birth defect has been recognized as a one of the strongest known risk factors for developing childhood cancer. An example is children with trisomy 21, who have a 20-fold increased risk of developing acute lymphoblastic leukemia. However, prior to this study, conclusively establishing a link between certain rare and/or non-chromosomal birth defects such as craniosynostosis has been difficult because of the lack of a sufficient population to assess. Although a growing number of studies had suggested a link between the number of birth defects and an increased risk for developing cancer, the insufficient numbers of patients to study precluded establishing clear associations.

The researchers addressed the problem of the paucity of patients by pooling statewide registry data on births, birth defects, and cancer from Texas, Arkansas, Michigan, and North Carolina, which yielded a diverse and large population-based cohort that included more than 10 million children born between 1992 and 2013. The children were monitored up to 18 years of age for a diagnosis of cancer, and the researchers performed rigorous statistical analyses to explore trends and potential novel associations.



Their results showed that children with chromosomal anomalies were approximately 11 times more likely to develop cancer and those with non-chromosomal defects were twice as likely, compared with children with no birth defects. Children with two or more major birth defects had markedly greater risks compared with children with fewer or no birth defects. Hepatoblastoma and neuroblastoma were found to be the most frequently occurring cancer types in children with non-chromosomal defects.

The researchers also found novel associations between specific non-chromosomal birth defects and childhood cancers, such as craniosynostosis and hepatoblastoma, pyloric stenosis, and medulloblastoma, as well as the presence of several congenital cardiac defects and neuroblastoma. Some tumors, including germ cell tumors, were strongly associated with defects in several different organ systems, whereas some cancers (e.g., ALL) were associated with only a few types of birth defects and others (e.g., bone tumors) were not strongly associated with birth defects.

The researchers hope these findings will help establish new guidelines for regular surveillance and screening for particular types of cancers in children with specific defects. Early detection of cancer can lead to better outcomes in these patients, who already may be dealing with several severe health issues and disabilities.

Study Reveals Need for Autism Screening Follow-up



A study published recently in *Pediatrics* (lead author, **Dr. Sonia Montiero**, Asst. Professor)* explored providers' diagnostic and referral practices for children who failed the Modified Checklist for Autism in Toddlers (M-CHAT) at the 18-month and/or 24-month visits. The M-CHAT is a popular screening tool for autism-spectrum disorder (ASD), for which the American Academy of Pediatrics recommends screening at the 18- and 24-month well-child visits. The standardized questionnaire, which screens for behaviors related to toddlers who may have ASD, can be administered in a pediatrician's office or accessed free online.

A follow-up interview helps clarify the behaviors endorsed on failed exams, which may include the child failing to respond to his/her name or preferring to play alone. However, the interview is not used routinely in clinical practice. The researchers found that, despite high rates of screening with the M-Chat at both suggested clinic visits, only 31 percent of providers placed autism-specialist referrals after failed screens. Further, only about half of the families that received referrals completed them.

The findings reveal that ASD screening alone does not translate into earlier diagnoses for autism. In order for children to be diagnosed earlier, providers must act on failed screens and parents must follow through on referrals, if appropriate interventions, such as applied behavior analysis (ABA), are to be initiated at an optimal time. The authors noted that educational tools and support should be placed in clinics to empower providers to make diagnoses of ASD when the symptoms are clear and to be better informed about making referrals.

**Sonia A. Monteiro, Jack Dempsey, Leandra N. Berry, Robert G. Voigt, and Robin P. Goin-Kochel. "Screening and referral practices for autism spectrum disorder in primary pediatric care. Pediatrics 2019*

Trauma Center Receives Funding for Mental Health Needs



The Trauma and Grief (TAG) Center received funding from the Robert Wood Johnson Foundation to partner with the Boys and Girls Club of Puerto Rico in an effort to assist children and families impacted by Hurricane Maria. The grant (PI: **Dr. Julie Kaplow**, Assoc. Professor) will support a large-scale mental health needs assessment and training of community-based clinicians in evidence-based, culturally-informed treatments for childhood trauma and grief. When the hurricane made landfall in Puerto Rico, initial recovery was slow and uneven; the official death toll was 3,000. Thousands more still struggle to regain a quality of life after being without electricity, working water systems, or ready access to health care. Low-income families in communities that had limited access to basic needs even before the storm were disproportionately affected. In Phase I, a team led by Dr. Kaplow travelled to Puerto Rico to meet the leadership and community stakeholders to gain a better understanding of the prevailing needs. Phase Two (July-November 2019) will include a full-scale needs-assessment, creation of a roadmap for collaboration in Puerto Rico, training of local clinicians in a modified version of Heart (Hurricane

NIH Funding will Help Global Health with TB Research

BCM Pediatrics and TCH's Global TB Program announced that it is the recipient of two National Institutes of Health (NIH) awards.

In April 2019, **Dr. Andrew DiNardo**, Asst. Professor – Global TB Program, received an NIH K23 Career Development Funding Award for his project titled “Persistent DNA Hyper-Methylation of the INF Signaling Pathway During Tuberculosis.” The bulk of his work will occur in the Kingdom of Eswatini (formerly known as the Kingdom of Swaziland). The total award amount is \$879,120 USD, and the funding will last over the course of five years – ending in 2024.

Also, the Global TB Program was awarded NIH R01 funding for a project titled “Quantifiable Stool-based TB PCR to Improve Diagnostics and Treatment Monitoring.” This prospective study compares the yield of novel TB diagnostic methods employing respiratory and non-respiratory specimens in children with and without HIV-infection. This study will enhance the team's ability to accurately diagnose TB in key populations while improving the capacity to effectively monitor TB treatment and detect drug resistant TB. The project will be implemented in Manhica (Mozambique), Mbeya (Tanzania), and Mbabane (Eswatini) through the duration of activities. The total award amount is \$2,475,880 USD, with funding lasting over the course of four years.



Dr. Andrew DiNardo in Eswatini at the Baylor-Swaziland Center of Excellence, using lab local equipment

Funding To Be Used to Develop App for Chronic Pain



Dr. John Hollier, Asst. Professor, has received a Mentored Patient-Oriented Research Career Development Award from the National Institutes of Health to support development of an app to deliver health care for patients with functional abdominal pain disorders (FAPDS). These disorders, of which irritable bowel syndrome is one, affect approximately 15% of school-aged children and adolescents worldwide. Some children with FAPDs have impaired suppression of pain sensations from the gut. Although psychological therapies have been used to help “retrain” the brain to better suppress these sensations, few children are referred to psychologists for effective psychological therapies such as guided imagery therapy (GIT). Further, the number of qualified therapists to deal with the issue is inadequate, and patients and their families often hesitate to consult a mental health professional because of insufficient insurance coverage.

Recognizing the need for providing optimal care for patients with FAPDs, Dr. Hollier proposes turning smartphones into therapeutic devices that will deliver on-demand GIT to these patients. He noted that, “Given how ubiquitous cell phones are and how popular they are among kids, we think this approach would be the ideal way to deliver effective ‘brain-gut training’ to patients. We developed a mobile smartphone application (app) prototype, which provides GIT to children with FAPDs anywhere, any time they live. We believe this approach will dramatically improve access to optimal care for many children with FAPDs and improve their quality of life.” Although the mobile app has the potential to help numerous children with FAPDs, more development is needed before it will be ready for debut. The NIH grant support has provided the opportunity for Dr. Hollier and his multidisciplinary team to take the next step in a rigorous pre-development stage, engaging various stakeholders in conversations and receiving their feedback.

Upcoming Events . . .



Disparities and Outcomes in Acute Leukemia
The 2nd Symposium on Childhood Cancer Health Disparities
November 4, 2019
Deadline for Abstract Submission
September 23, 2019

Education Grand Rounds
“Big Ideas in Health Professions Assessment – An Overview”
October 3, 2019
12:00 – 1:00

Abstract Book Cover Art Contest
2020 Pediatric Research Symposium
Deadline for Submission of Artwork & Brief Description
October 11, 2019

2020 Pediatric Research Symposium
Tuesday, March 24, 2020
Abstract Submission BEGINS November 4, 2019

Faculty Development Workshops
**“The Model for Innovation and Entrepreneurship in Medical Education:
The Development of OPENPediatrics—a Global Online Learning Community”**
“Securing Educational Grants
November 11, 2019
9:00 am – 2:00 pm

Department of Pediatrics Annual Education Retreat
“Fostering Professional Identity Formation”
December 6, 2019
10:00 am – 4:30 pm

Soft Tissue Sarcoma Conference
February 6 – 7, 2020
txchconference@texaschildrens.org