Discovery
RESEARCH
at Stanley Manne Children's Research Institute

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IN THIS ISSUE

The Chronic Disease Conundrum: Understanding Low Adherence to Medications

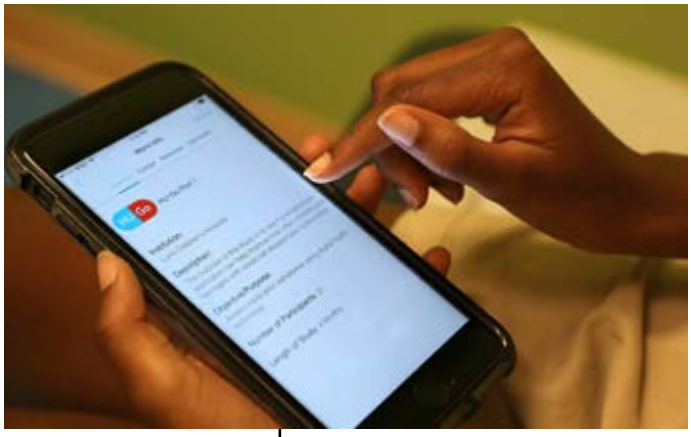
Sherif Badawy, MD, MS, talking to a patient in the clinic. Photo: Jan Terry.

Why do some people with chronic health conditions act in ways that don't seem to make sense? They eat foods that are bad for them, forget to exercise or don't follow a schedule for taking their medications. This is a puzzle that baffles many physicians. They know that their patients are healthier when they take good care of themselves; however telling patients what to do often doesn't seem to work.

Sherif Badawy, MD, MS, has been thinking about this issue and the complicated lives of patients with chronic conditions since he began his pediatric residency in Egypt. He found that the children he saw in the clinic with thalassemia had low adherence levels to the medications that keep them healthy. Thalassemia, an inherited blood disorder in which the body doesn't produce enough red blood cells and hemoglobin, is treated with blood transfusions. One of the effects of transfusion is iron overload, which in turn is treated with iron chelators, medicine that children have to take to remove the excess iron from the body. And yet the children Badawy treated in the clinic didn't always comply. He realized that the reasons for low adherence were not well understood by the medical community, and that more research was needed.

Fast forward to rotations in medical school, that all-important time when opinions are formed and decisions made regarding the choice of a specialty. Badawy was told that the rotation through Hematology-Oncology would be difficult. Instead, he found that he loved it. "More significantly, I enjoyed the science, and it appealed to me as a person to be able to support the whole patient and family, to build a relationship," he explains. This bonding experience had a profound impact on how Badawy chose to practice medicine. "Understanding my patients and families is extremely important to me. I think that it helps me connect with them, and by doing so I help them make the best decisions for their health."

The Chronic Disease Conundrum (continued from page 1)



Sherif Badawy designed the HU-Go app for and with his patients. Photo: Jan Terry.

See our **web extra** about Sherif Badawy, including why he thinks being involved in professional societies is important, and his appreciation for his mentors.

Sickle cell disease – a testing ground

Now focused on sickle cell disease (SCD), Badawy has built a career involving clinical care and research to understand medication adherence and health-related quality of life (HRQOL). "We're finding that these adherence issues are probably common to all chronic conditions. They include everything from costs and access barriers, to forgetfulness, to being depressed, to wanting to fit in with friends. Adherence may not be a top priority among all the things a person needs to do on a day-to-day basis," he says.

SCD is the most common inherited blood disorder in the U.S., with higher prevalence in African Americans. The normally round red blood cells (RBCs) that are supposed to transport oxygen through the body are shaped like bananas, causing them to pile up and create blockages in blood flow. The abnormally shaped RBCs are also destroyed quickly. These systemic problems lead to organ and tissue damage. Currently, the only FDA-approved drug is hydroxyurea. As is true with other chronic conditions, medication adherence is an issue with SCD patients.

In preliminary studies involving adherence levels and HRQOL, Badawy's team found that the most common reasons for non-adherence were forgetfulness and the inability to get prescription refills. "In addition, SCD can affect cognitive abilities and executive functioning, which contribute to forgetfulness," he notes. Negative beliefs and concerns about hydroxyurea were associated with non-adherence as well. "So we see this vicious cycle of patients who are reluctant to take their medication because they are more anxious about its side effects then experiencing poorer outcomes from not taking their medication," he adds.

Badawy proposes to improve adherence among his SCD patients by getting them involved in their own care. "Our job doesn't end with writing the prescription," he explains. "We need to understand the patients and help them understand the disease. My personal philosophy is to start with the why – why they need to take their medications. By getting patients involved, empowering them and giving them feedback, we are more likely to help them overcome their low adherence."

Technology intervention – a mobile app for SCD

Knowing what pre-teens, adolescents and emerging adults prefer, Badawy proposed that he and his colleagues develop a mobile app that could serve as a "one-stop shopping" experience. This app would provide medication reminders, education, clinic and pharmacy locations, social support and community connections. He says, "I have my team's contact information on the platform so that it's easy to find. Our goal is to provide what patients need in order to optimize their medication adherence."

In developing the app, called HU-Go, Badawy took patient engagement seriously. "We used their input and feedback to customize the technology for our sickle cell patients. These kids are tech savvy, and they will teach you what they want you to know. Our design approach is user-centered and iterative. Patients use HU-Go, and based on their feedback we make changes," he says. "Once patients realize that we are working with them, listening to them and taking their preferences seriously, they want to become more involved," he continues.

One way to test whether HU-Go is working is to conduct a clinical trial and assess the effect of the HU-Go app on hydroxyurea adherence. Badawy says, "If the patient reports fewer pain crises, better physical functioning, more energy, and lower levels of depression and anxiety, we have reason to believe that the app is helping. I want to do everything I can to help improve the adherence of my patients as well as those with chronic health conditions so they can lead the healthiest lives possible," he concludes.

Sherif Badawy, MD, MS, is an attending physician in the **Division of Hematology, Oncology, Neuro-Oncology & Stem Cell Transplantation** at Lurie Children's and Instructor of **Pediatrics** at Northwestern University Feinberg School of Medicine.

Chief Research Officer's Message

Thomas P. Shanley, MD, is Chairman of the Department of Pediatrics
Chief Research Officer, Stanley Manne Children's Research Institute
Founders' Board Centennial Professor in Pediatrics
Ann & Robert H. Lurie Children's Hospital of Chicago
Northwestern University Feinberg School of Medicine

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Research at Ann & Robert H. Lurie Children's Hospital of Chicago is conducted through the Stanley Manne Children's Research Institute. The Manne Research Institute is focused on improving child health, transforming pediatric medicine and ensuring healthier futures through the relentless pursuit of knowledge. The research institute is a virtual center for pediatric research at Northwestern University Feinberg School of Medicine. Founded in 1989, the research enterprise has grown to include more than 500 investigators and over $30 million in external funding for research, two-thirds from the NIH and other federal agencies.

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Summer in Chicago is upon us and while the city hosts tourists from around the world with a myriad of events, the Stanley Manne Children's Research Institute continues to bustle with its own energy and activities. We will be presenting our Board with our proposed FY'18 budget for approval. This year we are supporting ongoing growth in our infrastructure capacity designed to enable greater efficiency in our operations and research business management. I am confident these investments will enable us to achieve our annual goal of establishing a Clinical Trials Office that will build upon our existing strength in this area.

We aim to build on the success of this past year's investments that allowed us to hire three excellent research business managers who have not only succeeded in closing a number of inactive accounts, but also captured over $400,000 in research reimbursement providing a terrific return on our investment in this great team. I am looking forward to other operational changes they will implement to further ease our research teams' jobs. In addition, I want to thank those who were engaged in our search for a new Chief Operating Officer at the research institute.

The search was successful in recruiting **Cassandra Lucas, PhD**, currently Vice President for Research Administration and Operations Management at TGen in Phoenix. Cassandra has had a distinguished research operations career, serving at the University of Minnesota as administrative coordinator and the University of Chicago as executive administrator before moving to TGen in her current role in 2008. We are very excited that Cassandra will be starting at the research institute in August.

Of course, this was an incredibly important, yet difficult task to identify someone with the skills to fill this role and succeed our irreplaceable COO who has steered the research institute ship for the past 22 years. As many know, **Phil Spina** will be stepping down from his role as Vice President for Research and Chief Operating Officer this year. Phil has been instrumental to the operations and success of the research institute and truly been the face of the institute for so many years. He has overseen substantial growth in the number of grant submissions and investigators within the research institute and set the institute on a solid foundation and provided the vision to create an excellent trajectory for our ongoing growth and success. I'll look forward to celebrating Phil's retirement and acknowledging his amazing service to Lurie Children's and the Stanley Manne Children's Research Institute in the coming months.

I hope you all have a wonderfully productive summer.

Tom

Appointments

Aimen Shaaban, MD

Aimen Shaaban, MD, a pediatric surgeon and leading expert in fetal surgery, has joined Lurie Children's as Director of The Chicago Institute for Fetal Health and Professor of Surgery at the Feinberg School. The Chicago Institute has a multidisciplinary, multi-institutional mandate to provide a complete spectrum of care for the fetus and mother. This addition helps support Lurie Children's mission to provide the best possible care for our patients and their families.

Since 2012 Shaaban has been a fetal surgeon and Director of the Center for Fetal Cellular and Molecular Therapy at Cincinnati Children's Hospital Medical Center, and Professor of Surgery at the University of Cincinnati College of Medicine.

"Dr. Shaaban's unique skills are shared by only a handful of pediatric surgeons in the world," said **Marleta Reynolds, MD**, surgeon-in-chief at Lurie Children's, the Lydia J. Fredrickson Professor of Pediatric Surgery and Professor of Surgery at the Feinberg School. "We are very pleased to have him join the Division of Pediatric Surgery at Lurie Children's."

Shaaban is among the most well-respected fetal intervention surgeons in the world. His clinical research contributions surround the diagnosis and treatment of congenital diseases such as spina bifida, congenital diaphragmatic hernia, sacrococcygeal teratoma, congenital pulmonary airway malformation, gastroschisis, omphalocele, twin-twin transfusion syndrome, and fetal bladder outlet obstruction. He has published extensively in these areas and receives support for his basic science research from the NIH.

"Fetal surgery is a highly complex symphony of multidisciplinary expertise that comes together to achieve the daunting mission of correcting congenital defects of the fetus," said **Fizan Abdullah, MD, PhD**, Vice-Chair of the Department of Surgery and head of the Division of Pediatric Surgery at Lurie Children's; Orvar Swenson Founders' Board Chair in Pediatric Surgery and Professor of Surgery at the Feinberg School. "Dr. Shaaban has made exceptional contributions to the clinical and research arenas. I am thrilled to welcome such a surgeon of national and international renown to Lurie Children's."

Joseph Forbess, MD

Internationally renowned neonatal heart surgeon, **Joseph Forbess, MD**, joined Lurie Children's in July as the Associate Division Head of Pediatric Cardiovascular-Thoracic Surgery and Surgical Director of the Single Ventricle Reconstruction Program.

Forbess comes from the University of Texas Southwestern Medical Center, where he was Professor of Surgery and Director of Cardiothoracic Surgery at Children's Medical Center Dallas from 2004 to 2016. Forbess has published over 100 peer-reviewed articles and book chapters.

In addition to his surgical expertise in complex single and biventricular reconstruction in neonates, Forbess is a well-established scientist. His research interests include the development of bioresorbable (or naturally dissolving) stents, coatings and nanoparticles for use in pediatric vascular and airway applications. He will continue this innovative work at the Manne Research Institute. Forbess' contributions also will allow for important growth and development of the Heart Center at Lurie Children's.

John Walkup, MD, will join Lurie Children's in October as Chair of the Department of Child and Adolescent Psychiatry. Walkup is a recognized authority on the Tourette syndrome. He also has been involved in developing and evaluating interventions to reduce the large mental health disparities facing Native American youth, focusing on drug use and suicide prevention.

Most recently Walkup was Director of the Division of Child and Adolescent Psychiatry at NewYork-Presbyterian Hospital and Vice-Chair of Child and Adolescent Psychiatry in the Department of Psychiatry at Weill Cornell Medical College. He has published over 150 peer reviewed articles and book chapters.

The prototype for a device that detects button batteries (top) has been developed by Jonathan Ida (left) and Bharat Bhushan (right). They are members of the Division of Otorhinolaryngology - Head and Neck Surgery at Lurie Children's. Ida is Assistant Professor and Bhushan is Research Assistant Professor of Otolaryngology - Head and Neck Surgery at the Feinberg School.

Amanda Saratsis, MD

Button battery ingestions or aspirations are among the most challenging clinical scenarios for pediatric emergency services due to their life threatening consequences. The difficulty is in making an early validation that an ingested foreign body is a battery. In children, button batteries 20 mm and larger can easily lodge in the esophagus and cause significant damage. Current clinical guidelines for foreign body ingestion call for x-ray imaging to make the diagnosis and to confirm the object's exact location. However, being able to differentiate between a battery and a coin is sometimes difficult or impossible using x-ray, because an obvious notch, or step off – characteristic of button batteries – cannot always be seen.

To address this unmet need, **Bharat Bhushan, PhD**, and **Jonathan Ida, MD, FACS**, have developed a novel device that measures the magnetic field of the ingested material and is able to identify a functional battery. In addition, the ability to detect small magnetic fields allows for the identification of ingested magnets, which also constitute an emergency. Magnets, in pairs or together with some metal objects can "pinch", damage and penetrate the digestive tract.

Before adjusting clinical practice to handle small children after foreign body ingestion and moving a product to the market several questions must be addressed. Bhushan and Ida seek to determine the sensitivity and specificity of the device prototype, validate the results and submit an Investigational Device Exemption (IDE) to the Food and Drug Administration (FDA).

Bhushan and Ida have submitted a provisional patent in conjunction with Lurie Children's and Northwestern University to protect this work. Bhushan recently submitted an NIH grant to support this work.

An accelerator group from Northwestern University has accepted this device as their final project and has presented it to investors, who were receptive to the proposal.

Diffuse midline gliomas are aggressive and treatment resistant tumors that typically occur in young children. They are characterized by a high rate of histone H3 mutation, which enables easy categorization. However, these gliomas are located in the brainstem or thalamus, making the process of obtaining tissue extremely risky.

Now, scientists at Lurie Children's and Northwestern University have identified a reliable, and safer, way to detect mutations in the tumors. The research group led by **Amanda Saratsis, MD**, sought to discover whether collecting cerebrospinal fluid (CSF) would allow for the detection of histone H3 mutations. If successful, this method of "liquid biopsy," which is less invasive and far less risky than obtaining tumor tissue, could be implemented, thus facilitating targeted therapies. The group evaluated two strategies to reliably analyze the DNA, and validated test sensitivity and specificity. The results, published in *Acta Neuropathologica Communications*, indicate that histone H3 mutation is detectable in CSF-derived tumor DNA from children with brain tumors, suggesting that this method can be employed reliably for stratification to targeted therapies and monitoring treatment response. The publication was featured in a BioMed Central research blog posting.

This work was supported by grants from the National Center for Advancing Translational Sciences (NCATS) of the NIH, a grant from Northwestern University Clinical and Translational Sciences Institute (NUCATS), and a donation from the John McNicholas Pediatric Brain Tumor Foundation. Saratsis is an attending physician in the Division of Neurosurgery at Lurie Children's and Assistant Professor of Neurological Surgery at the Feinberg School.

Heart health in children will be the focus of three closely synergistic research projects and an integrated multidisciplinary training program that are newly funded by a $3.7 million four-year grant led by **Bradley Marino, MD, MPP, MSCE**, attending physician in the Division of Cardiology at Lurie Children's and Professor

Research News (continued from page 5)

Bradley Marino, MD, MPP, MSCE

Amir Kagalwalla, MBBS

Sigita Plioplys, MD

of Pediatrics and Medical Social Sciences at the Feinberg School. As one of only four centers selected to participate in the American Heart Association's Strategically Focused Children's Research Network, research by Marino and colleagues will provide evidence for innovative policies, programs and practices to preserve cardiovascular health in childhood and beyond. The grant will fund population, clinical and epigenetic studies on cardiovascular health in children. Read more.

Children with eosinophilic esophagitis (EoE) – a chronic inflammatory disease that injures the esophagus – who temporarily eliminated cow's milk, wheat, egg and soy from their diet for eight weeks had their symptoms and esophageal swelling resolve, according to a study published in *Clinical Gastroenterology and Hepatology*. This elimination diet is less restrictive than the standard of care six-food elimination diet that is approved to treat EoE, a condition in which an abnormal immune response is triggered by certain foods, causing symptoms that range from difficulty swallowing to abdominal pain and vomiting. After remission, foods are reintroduced one by one until the food that triggers esophageal swelling and symptoms is identified and eliminated from the child's diet. This is a lengthy process that involves multiple endoscopies to monitor the effect of reintroduced foods on the esophagus.

"Excluding many foods from a child's diet is a major challenge for families. Our study shows that we can achieve nearly the same results with four instead of six foods that children with EoE need to avoid initially," says lead author **Amir Kagalwalla, MBBS**. "Also it takes much less time to reintroduce the foods and fewer endoscopies to determine which foods truly need to be avoided to maintain remission. These are huge benefits." Kagalwalla is an attending physician in the Division of Gastroenterology, Hepatology and Nutrition at Lurie Children's and Associate Professor of Pediatrics at the Feinberg School. Read more.

Sigita Plioplys, MD, is a co-author of a chapter in Psychogenic Nonepileptic Seizures: Toward the Integration of Care, edited by Barbara A. Dworetzky and Gaston Baslet, published in 2017 by Oxford University Press. The chapter is entitled: "Clinicians' Response to the Diagnosis." Plioplys is head of the Pediatric Neuropsychiatry Program in the Department of Child and Adolescent Psychiatry at Lurie Children's and Associate Professor of Psychiatry and Behavioral Sciences at the Feinberg School.

Lurie Children's Surgery Center verification as Level I

For the second year, Lurie Children's has been named a Level I pediatric surgery center by the American College of Surgeons (ACS). In 2016 Lurie Children's became the first children's hospital in Illinois to earn this status and is currently one of only five in the country.

The Level I verification is awarded by a multi-organizational taskforce led by the ACS, the body responsible for setting the nation's standards for quality of surgical care, practice and training.

To be verified as a Level I surgery center, a children's hospital must demonstrate it has the expertise, resources and capacity to deliver timely, safe, appropriate and multidisciplinary surgical care for even the most complex and rarest of cases and do so around the clock. In addition to children's surgeons, Level I centers must have 24/7 availability of specialists in children's anesthesiology, radiology and emergency medicine, and must provide round-the-clock critical and intensive care for children and infants of all ages, including severely premature newborns. A Level I center must also provide education, training, leadership and research in the field of children's surgery and may offer residency and fellowship training for the next generation of children's surgeons and surgical subspecialists.

"We are very proud and honored to earn this recognition for the second year in a row," said **Marleta Reynolds, MD**. "Quality and safety remain at the core of everything we do, which ultimately benefits our patients."

Alexis Thompson, MD, MPH

Alexis Thompson, MD, MPH, has been awarded the Frank A. Oski Memorial Lectureship from the American Society of Pediatric Hematology/Oncology (ASPHO). Thompson was selected based on her significant achievements as a clinical researcher, physician scientist, teacher and mentor to improving outcomes for patients with nonmalignant hematological disorders, including sickle cell disease and thalassemia. She is an attending physician in the Division of Hematology, Oncology, Neuro-Oncology & Stem Cell Transplantation and section head of Hematology at Lurie Children's, the A. Watson and Sarah Armour Chair of Childhood Cancer and Blood Diseases, and Professor of Pediatrics at the Feinberg School.

Mary Clyde Pierce, MD

Mary Clyde Pierce, MD, attending physician in the Division of Emergency Medicine at Lurie Children's, has received awards for best abstracts from two major organizations – the American Academy of Pediatrics (AAP) Section on Emergency Medicine and the Ray E. Helfer Society, a professional society for child abuse pediatricians. These abstracts stem from Pierce's research to determine clinical decision rules to discriminate bruising caused by physical child abuse. This research is funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). Pierce is Professor of Pediatrics at the Feinberg School.

The Manne Research Institute Internal Grant Awards (IGA) program provides resources to researchers in order to develop projects that will lead to highly competitive extramural applications for sustained research support. Five types of awards were granted this spring:

Proposal Revision Award to support the preparation of a revision and re-submission of a federal grant:

- **Isabelle De Plaen, MD**, Neonatology, and Associate Professor of Pediatrics at the Feinberg School, for "The role of the intestinal microvasculature in necrotizing enterocolitis"
- **Xiao-Di Tan, MD**, Director of the Center for Intestinal and Liver Inflammation Research (CILIR), Dorothy M. and Edward E. Burwell Professor in Immunobiology, and Research Professor of Pediatrics and Pathology at the Feinberg School, for "The role of PMP22 in preservation of intestinal barrier function"
- **Jacek Topczewski, PhD**, Crown Family Research Scholar in Developmental Systems Biology at the Manne Research Institute, and Associate Professor of Pediatrics at the Feinberg School, for "The role of cholesterol biosynthesis in skeletogenesis"

Visionary Award to support potentially paradigm-shifting research:

- **Jennifer Schneiderman, MD, MS**, Hematology, Oncology, Neuro-Oncology & Stem Cell Transplantation, and Assistant Professor of Pediatrics at the Feinberg School, for "Safety and efficacy of ECP treated donor cells in prevention of allograft rejection and xenogenic GVHD"
- Mary Clyde Pierce, MD, for "Epigenetics and child abuse: a pilot study"
- **William Tse, MD, PhD**, Hematology, Oncology, Neuro-Oncology & Stem Cell Transplantation, and Assistant Professor of Pediatrics at the Feinberg School, for "Immune checkpoint-expressing T cells as a biomarker for AML diagnosis and therapy"

Program Accelerator Award to support planning and development of program project-related applications:

- **Hara Levy, MD, MMSc**, Pulmonary Medicine, and Associate Professor of **Pediatrics** at the Feinberg School, for "Molecular dissection of clinical phenotypes within and across boundaries in cystic fibrosis and chronic obstructive pulmonary disease"

Interdisciplinary Colloquia Award to promote the development of working groups around novel multidisciplinary areas of research relevant to children's health:

- **Anna Fishbein, MD**, Allergy & Immunology, and Assistant Professor of Pediatrics at the Feinberg School, and **Amy Paller, MD**, Dermatology, and Walter J. Hamlin Professor and Chair of the Department of Dermatology at the Feinberg School, for "CREATE (Consortium for Research and Education on ATopic Eczema)"
- **Naomi Fogel, MD**, Endocrinology, and Assistant


Jacqueline Pongracic, MD


Ruchi Gupta, MD, MPH


Robert Garofalo, MD, MPH

Professor of Pediatrics at the Feinberg School, for a "Diabetes Center of Excellence Workshop"

Scientific Advocacy Award to support society fees and travel to meetings where the awardee will be engaging in advocacy on behalf of children's health research:

- **Jami Josefson, MD**, Endocrinology, and Assistant Professor of Pediatrics, and **Wendy Brickman, MD**, Endocrinology, and Associate Professor of Pediatrics at the Feinberg School, for "Childhood obesity prevention"

Jacqueline Pongracic, MD, is the inaugural recipient of the Işil Berat Barlan Memorial Lectureship, which she presented at the annual meeting of the American Academy of Allergy, Asthma and Immunology in March. The title of her presentation was "What are the environmental determinants and causative pathways that lead to asthma severity?" Dr. Barlan was a visionary physician-scientist who made a profound impact on science and health care delivery in Allergy and Immunology. She had a particular interest in women's advancement in science, an issue that she strongly advocated for in both national and international forums. Pongracic is honored to be the first recipient of this lectureship named in honor of Dr. Barlan. She is the head of the Division of Allergy and Immunology at Lurie Children's and Professor of Pediatrics at the Feinberg School.

Ruchi Gupta, MD, MPH, has been awarded a RO1 grant by the National Institute of Allergy and Infectious Diseases (NIAID) to lead the multi-site project, Food Allergy Outcomes Related to White and African American Racial Differences (FORWARD). The project will develop a prospective longitudinal cohort to systematically investigate disparities between African American and White children in food allergy clinical and psychosocial outcomes, phenotypes and endotypes, and management practices. Gupta is an attending physician in the Division of Academic General Pediatrics and Primary Care at Lurie Children's, Director of Science and Outcomes of Allergy and Asthma Research (SOAAR) at the Mary Ann & J. Milburn Smith Child Health Research Program, Associate Professor of Pediatrics and Medicine, and a member of the Center for Community Health at the Feinberg School.

Matt Davis, MD, MAPP, A Todd Davis, MD Professor of General Academic Pediatrics and Mary Ann & J. Milburn Smith Research Professor for the Director of Child Health, and **Kelly Michelson, MD, MPH**, Julia and David Uihlein Professor of Bioethics and Medical Humanities, are recipients of seed grants from the Alliance for Research in Chicagoland Communities (ARCC). Each grant goes to a partnership that includes a member of a local community-based organization and a scientist from Northwestern University. The grants support the development and growth of community-engaged research partnerships. Davis is head of the Division of Academic General Pediatrics and Primary Care at Lurie Children's, Director of the Smith Child Heath Research Program and Associate Chief Research Officer for Health Services and Policy Research at the Manne Research Institute, and Professor of Pediatrics at the Feinberg School. Michelson is an attending physician in the Division of Critical Care at Lurie Children's, Associate Professor of Pediatrics and Director of the Center for Bioethics and Medical Humanities at the Feinberg School. Read more.

The Chicago-based Jordan Michael Filler Foundation has made a $1 million commitment to establish a substance abuse and prevention program for teens and youth at Lurie Children's. The groundbreaking program will be the region's first substance abuse program to be imbedded in a medical setting. Based within Lurie Children's Division of Adolescent Medicine, led by **Robert Garofalo, MD, MPH**, it will fill Chicago's growing need for a primary care-based program offering comprehensive care – from prevention to early intervention and treatment – for adolescents and young adults struggling with substance use. The Jordan Michael Filler Foundation was founded by Julie and Mark Filler of Highland Park, whose son Jordan died in 2014 at age 23, of a heroin overdose. Garofalo is head of Adolescent Medicine at Lurie Children's and Professor of Pediatrics at the Feinberg School.

Colleen Cicchetti, PhD

With the support and clinical guidance of **Colleen Cicchetti, PhD**, and the Center for Childhood Resilience (CCR) team, U.S. Senator Dick Durbin and U.S. Representative Danny Davis unveiled the Trauma-Informed Care for Children and Families Act, which is designed to address the toxic stress and trauma that impacts many children from Chicago's most violent neighborhoods. This Act seeks to reach kids where they are – schools, at home, health and social service providers, and after-school programs, among other locations. The bill would equip teachers, doctors and other adults serving children to recognize the signs of trauma, weave this knowledge into their practice, and make the policy changes and workforce investments needed to provide support to those who need it. To achieve this, Durbin and Davis' legislation would:

- Provide more teachers, doctors, social service providers and first responders with the resources necessary to help children who have experienced trauma by allowing funding for more than two dozen federal grant programs to be used for this training. Funding streams include Head Start, formula funding for public schools, social services, health care, child welfare, home visiting for parents with at-risk children, among others;
- Expand Medicaid coverage for child trauma services, increase mental health care in schools, and enlist trained mentors and community leaders to help;
- Expand loan repayment and graduate school behavioral health training programs to increase the number of clinicians in our communities, and enhance teacher-training programs;
- Create a large grant program to bring together stakeholders to identify needs, collect data, and target efforts. It also allows communities to pool federal grants from multiple agencies and focus the funding on increasing trauma services for children;
- Create a federal task force to recommend improvements for identifying, referring and supporting children and families that have experienced trauma.

Helping to stop the cycle of violence can start with helping kids overcome anger

WGN News June 29, 2017

by Katharin Czink and Dina Bair

In a recent three-part series on WGN News, Cicchetti was featured as part of a group of people and programs providing resources and support to Chicago communities most impacted by violence and trauma. Cicchetti's first-person account demonstrates how being trauma-informed can make a real difference in the lives of children and families affected by violence.

Cicchetti is a psychologist in the Department of Child and Adolescent Psychiatry at Lurie Children's and Assistant Professor of Psychiatry and Behavioral Sciences at the Feinberg School. Watch here.

Here's why your mouth might get itchy or tingly when you eat fresh fruits and veggies

Business Insider, May 26, 2017

by Lydia Ramsey and Mike Nudelman

It started after a bite of a peach one summer. I was in high school, and I'd never had an allergic reaction. But here I was, just trying to enjoy some late-summer fruit – instead, the back of my throat felt itchy and my lips were swollen.

Soon I realized I had the same experience with carrots, apples, pears, cherries and on occasion, almonds. The surprising culprit: a seasonal allergy to pollen that manifests itself in some of the raw foods I ate. It's called oral allergy syndrome.

The most common symptoms of oral allergy syndrome, according to the American Academy of Allergy Asthma and Immunology, are an itchy mouth along with swelling of the lips, mouth, throat, face, and tongue. **Jacqueline Pongracic, MD**, told Business Insider that she sees cases of oral allergy syndrome (also called pollen allergy syndrome) regularly, though there aren't really any good numbers on how many people nationally have it. Read more.

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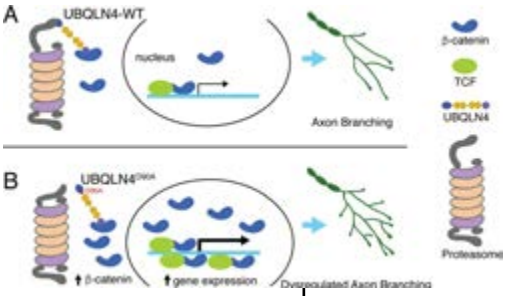

Figure 5.Schematic model illustrating proposed roles for wild-type (A) and ALS-associated UBQLN4D90A (B) in motor axon morphogenesis. From: A novel ALS-associated variant in UBQLN4 regulates motor axon morphogenesis. eLife 2017;6:e25453 doi: 10.7554/eLife.25453

ALS/FTD genes reveal pathways to pathology

Alzforum June 24, 2017

Research by the lab of **Yongchao C. Ma, PhD**, was featured on Alzforum. Conducted with colleagues at Northwestern University, the study debuts a new amyotrophic lateral sclerosis (ALS) gene, UBQLN4, identifying a rare genetic mutation found in a woman with familial ALS. When expressed in a model system, the variant impairs function and causes abnormal sprouting and branching of motor axons. The results, published in *eLIFE*, highlight the role of protein homeostasis in neuronal health and disease.

Ma told Alzforum the group is now working on additional models that will enable a more thorough examination of the mutant's impact across the lifespan. He hopes that β-catenin, an important regulator of neuronal development, or other substrates of UBQLN4, could become useful therapeutic targets in ALS. First author Brittany Edens is a graduate student in the Ma lab. Read the full Lurie Children's press release.

Ma is Ann Marie and Francis Klocke, MD Research Scholar and Assistant Professor of Pediatrics, Neurology and Physiology at the Feinberg School.

Mitochondria are tiny, free-floating organelles inside cells. New research has discovered that they play an important role in hematopoiesis, the body's process for creating new blood cells.

Mitochondria behind blood cell formation

Feinberg School News Center, June 12, 2017

by Nora Dunne

Research published in *Nature Cell Biology* has shown that mitochondria, traditionally known for their role creating energy in cells, also play an important role in hematopoiesis, the body's process for creating new blood cells. "Historically, mitochondria are viewed as ATP – energy – producing organelles," explained principal investigator Navdeep Chandel, PhD, the David W. Cugell Professor of Medicine in the Division of Pulmonary and Critical Care Medicine at the Feinberg School. "Previously, my laboratory provided evidence that mitochondria can dictate cell function or fate independent of ATP production. We established the idea that mitochondria are signaling organelles."

Paul Schumacker, PhD, is a co-author. He is the Patrick M. Magoon Distinguished Professor of Neonatal Research and Professor of Pediatrics, Cell and Molecular Biology and Medicine at the Feinberg School. Schumacker and Chandel are both members of the Robert H. Lurie Comprehensive Cancer Center of Northwestern University. Read more.

Milestone for Simpson Querrey Biomedical Research Center

Feinberg School News Center, June 27, 2017

by Anna Williams

A ceremonial steel support beam was set in place atop the Louis A. Simpson and Kimberly K. Querrey Biomedical Research Center. The "topping-off" ceremony marked a major milestone in the construction of the 14-story, 600,000-square-foot building, which will significantly expand the Feinberg School's research enterprise, and will include four floors occupied by Manne Research Institute scientists.

The first phase of the Simpson Querrey Biomedical Research Center is scheduled to be completed in late 2018 with 14 stories, including nine laboratory floors dedicated to biomedical research. The building, designed to support collaboration among scientists throughout Northwestern University and the Manne Research Institute, will be connected floor-by-floor to the Robert H. Lurie Medical Research Center. Read more.

Children's Research Fund Chair Donna Drescher with Patrick Seed, MD, PhD (center) and Thomas Shanley, MD.

Letter from the Children's Research Fund Chair

At the June board meeting, the Children's Research Fund board voted to approve a **new $10 million, five year commitment** to support the full spectrum of research activity through the Manne Research Institute. The new commitment addresses what Dr. Shanley, Chief Research Officer, calls the **five pillars of exploration**: basic research, translational research, clinical research, health effectiveness research and community health services and policy research.

I am excited by this commitment because it allows us to help fund many leading edge research projects, impacting so many children with various conditions and diseases. It reflects the Children's Research Fund's mission to fund and advance a diverse spectrum of pediatric medical research to improve outcomes for all children. As the hospital draws near to launching a new research-focused campaign, we are proud to be Lurie Children's longest-standing partner for innovative research and to reaffirm our commitment to a broad range of transformative pediatric medical research.

We were also proud to see **Patrick Seed, MD, PhD, invested as the Children's Research Fund Chair in Basic Science** in July**.** Dr. Seed is Associate Chief Research Officer for Basic Sciences at the Manne Research Institute and Professor of Pediatrics – Infectious Diseases at Northwestern University Feinberg School of Medicine, as well as an attending physician in Lurie Children's Division of Infectious Diseases. He is leading groundbreaking pediatric studies to pinpoint how microbes assemble in our bodies even before we are born, and make children healthy or cause diseases. Dr. Seed spoke to our board this spring, and our members were inspired and energized by the possibilities for finding new treatments for debilitating disease and birth defects – the very core of the Children's Research Fund's mission.

It is so gratifying to know that our endowed chair will not only support Dr. Seed's basic research at the research institute today but also provide resources for those who will occupy this chair in the future. What better way to improve the lives of future generations of children?

Donna Drescher
Chair, Children's Research Fund

About the Children's Research Fund

The Children's Research Fund has firmly established itself as one of Chicago's leading philanthropic organizations dedicated to funding basic and clinical medical research. Over the years, Children's Research Fund support has led to advanced investigation in cancer, heart disease, genetics, microbiology and neonatology. Since its affiliation with Ann & Robert H. Lurie Children's Hospital of Chicago in 1991, the Children's Research Fund has contributed more than $70 million in support of research conducted at the Manne Research Institute. To get the latest information on Children's Research Fund events and fundraising campaigns, please visit **www.childrensresearchfund.org**.

Save the date for Barney's: October 19

Karina and Jason Heinrich, Nancy and Phillip Resnick, and Amy and Jason Williams are the co-chairs for an evening of celebration and shopping in support of the Children's Research Fund at Barneys New York, 15 East Oak Street on Thursday, October 19 at 6:00 p.m. Barneys will donate a percentage of shopping proceeds toward the Children's Research Fund's current commitment. For more information, call Katie Cerone at 312.227.7299.

Lindsay Stolzenburg, second from right, with her parents and brother at her thesis defense.

Lindsay Stolzenburg, a graduate student in the Ann Harris lab, was awarded a PhD from the Driskill Graduate Program in the Life Sciences at Northwestern University on June 30. In addition to receiving numerous awards, Lindsay was also featured in an article on the Northwestern Medicine website.

Lindsay presented on her graduate thesis topic, "Mechanisms of gene regulation at the chr:11p13 cystic fibrosis modifier locus". Harris, who is now a faculty member at Case Western Reserve University, praised Lindsay for her persistence on a project that presented many challenges.

She is the winner of several prestigious awards, including Outstanding Graduate Student at the Manne Research Institute in 2016; Graduate Student Research award at the 2016 Research Scholar Day at Lurie Children's; and a grant from the National Heart, Lung, and Blood Institute (NHLBI) of the NIH.

Lindsay will start a postdoctoral fellowship at the University of Chicago in the lab of Alex Ruthenburg, PhD, Department of Molecular Genetics and Cell Biology. Her research will focus on long non-coding RNAs and chromatin biology.

Sophia Bidny presents her research project to peers at a training session.

The Manne Research Institute and Lurie Children's are pleased to announce the four recipients of the 2017 Robert Louis Katz Summer Scholars Program and the five recipients of the research institute Summer Scholarship Award. The students, and their faculty mentors, are participating in an 8 week program to provide students with summer experience in research related to childhood health and disease.

2017 Robert Louis Katz Summer Scholars

Alex Boos (mentor: **Jhumku Kohtz, PhD**, Associate Professor of Pediatrics at the Feinberg School) Topic: "Defining novel regulatory enhancers in GABAergic interneuron progenitors"

Dina O'Connell (mentor: **Fei Chu, MD, PhD**, Research Assistant Professor of Surgery at the Feinberg School) Topic: "Relationship between drug resistance and cancer invasion/metastasis in the development of drug-resistant neuroblastoma tumor cells"

David Reed (mentor: **Debra Weese-Mayer, MD**, Chief of the Center for Autonomic Medicine in Pediatrics at Lurie Children's, Beatrice Cummings Mayer Professor in Pediatric Autonomic Medicine and Professor of Pediatrics at the Feinberg School) Topic: "Does the infrared (IR) imaging measurement of a patient's skin temperature after cooling with a fan have the same precision and accuracy as with the color change powder used in the Thermoregulatory Sweat Test (TST)?"

Jacob Vilker (mentors: **H. William Schnaper, MD**, Kidney Diseases, Vice Chairman of the Department of Pediatrics, Irene Heinz Given and John LaPorte Given Research Professor in Pediatrics and Professor of Pediatrics at the Feinberg School, and **Tomoko Hayashida, MD, PhD**, Research Associate Professor of Pediatrics at the Feinberg School) Topic: "Role of PI3Kgamma in podocyte injury"

2017 Stanley Manne Children's Research Institute Summer Scholarship Awardees

Mudasar Basam (mentor: **Maria Dizon, MD, MSCI**, Assistant Professor of Pediatrics at the Feinberg School) Topic: "Regulation of microRNA-21 by hypoxia inducible factor 1 alpha"

Sophia Bidny (mentor: **Jolanta Topczewska, PhD**, Research Associate Professor of Surgery at the Feinberg School) Topic: "Analysis of a novel zebrafish mutant which displays microcephaly and bone"

Elizabeth Chang (mentor: **Mark Wainwright, MD, PhD**, Founders' Board Professor of Neurocritical Care) Topic: "Astrocyte glutamate transporter function and depression following traumatic brain injury"

Mia DiCara (mentor: **Isabelle De Plaen, MD**) Topic: "Explore mechanism by which inflammatory signals affect VEGFR2 signaling thus contributing to necrotizing eterocolitis"

Gabriel Sagewalker (mentor: **Jacek Topczewski, PhD**) Topic: "Analysis of serpinf1 reporter, first GFP reporter in zebrafish"