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## A model for inclusiveness: community-based participatory research

Community-based participatory research (CBPR) is a collaborative approach to research in public health. CBPR equitably engages communities in the design, conduct and use of research to address health disparities and improve health by encouraging community-centered interventions and prevention strategies. This type of research recognizes that health is affected by many complex issues such as social, political and economic factors. Its proponents seek to engage partners, including community organizations, community members and academic researchers in research projects. With historical roots in social science disciplines, CBPR focuses on community priorities, engages community partners and members who are connected to the research issue of focus, and negotiates how resources and responsibilities will be allocated.

CBPR builds on the work that several academic institutions began in the 1990s with communities, including those that are marginalized. At about that time, funders, researchers and communities were coming to recognize that traditional approaches to science weren't usually designed to empower communities to improve health outcomes. Many early adopters of community-engaged research started to discuss ways to move forward that were inclusive and that would facilitate truly meaningful outcomes.

Adam Becker, PhD, MPH worked on a team at the University of Michigan that was one of the early implementers of CBPR. He sees CBPR as a shift in the way researchers think of people in research studies – no longer as subjects but as partners. "Community members have first-hand knowledge of factors that could affect community health. We are more effective when we work together to change environments for healthier living." He stresses that the key to this type of research is relationship building, which takes time and resources.

## About CBPR

— CBPR is a partnership approach to research. All parties are equally involved in the research process.

— CBPR is at one end of the spectrum of community-engaged research with extensive collaboration. However, there are appropriate ways for community involvement in all research.

— CBPR can be thought of as a “bridge” between research and primary care through community engagement, social action and increasing health equity.

— CBPR involves action: research is conducted on a local level, and action is taken.

— Community partners help academic partners recognize issues that are relevant to the community and that affect health.

— Community partners benefit from a deeper understanding of identified health issues, their causes and effects, and develop greater capacity to advocate for change.

— Academic partners look for the impacts of CBPR through positive change in clinical care and public health.

## Cover story: CBPR (continued from page 1)

Maryann Mason, PhD is fairly new to the field but intrigued by its possibilities. “I recently participated in a CBPR academy that trained me, along with the West Humboldt Park Development Council (WHPDC) and 11 other partnerships from around the country, during an intense week at the University of Michigan.” Her partner at the academy was Megan Hinchy, BS, MPH, the WHPDC Healthy Community Initiatives Program Coordinator. Mason and Hinchy are planning a project that focuses on stress and its effect on health. “I attend many community meetings, and the topics that come up over and over are violence and safety, and employment. These are definitely sources of stress in West Humboldt Park, and they could be related to obesity,” says Hinchy.

Hinchy plans to start with information sessions for community members about the project, followed by development of a steering committee that will identify the specifics. The team thinks that beginning the effort with a Photovoice approach, in which adults and youth focus on community stressors and community peace, is a good starting point. Photovoice is a process of taking photographs that highlight research themes, then interpreting them into narratives that are used to plan health or social programs addressing community needs. Mason and Hinchy would like the Photovoice project to build community awareness and involvement in the partnership.

This partnership, still in its early days, expects to inform a community-based approach to stress remediation for interrupting chronic disease processes in Chicago children and families. Mason and Hinchy are encouraged that their group received seed funding from the Alliance for Research in Chicagoland Communities (ARCC), which is based in Northwestern University’s Center for Community Health and serves the Northwestern University Clinical & Translational Sciences Institute (NUCATS) and Northwestern’s Institute for Public Health and Medicine. “It’s important to have institutional support, especially for this type of research that requires long-term projects that build on

strong and lasting relationships,” Mason says.

ARCC Director Jen Brown, MPH says, “ARCC and the Center for Community Health provide infrastructure, resources and services to support academic research teams at Northwestern, Ann & Robert H. Lurie Children’s Hospital of Chicago and community partners that are interested in or conducting community-engaged research.” ARCC is guided by a steering committee consisting of 13 community- and faith-based organizations, the Chicago Department of Public Health, Chicago Public Schools, and 10 Northwestern and Lurie Children’s academic partners.

Becker sees a great deal of progress in the field of CBPR. “Communities are more educated about their rights in terms of research studies. Funding, training and support are increasingly available to researchers, both from their academic institutions and from other funding agencies,” he says. Mason adds, “This research approach is growing and becoming stronger. As the United States becomes more diverse, it is increasingly important to address health disparities.”

For more information about CBPR and community-engaged research, visit the ARCC website and ARCC’s resource directory.

Adam Becker, PhD, MPH is Associate Professor of Pediatrics at Northwestern University Feinberg School of Medicine, and Interim Co-director of the Mary Ann & J. Milburn Smith Child Health Research Program and Executive Director of the Consortium to Lower Obesity in Chicago Children (CLOCC) at Stanley Manne Children’s Research Institute.

Maryann Mason, PhD is Research Assistant Professor of Pediatrics and Preventive Medicine at the Feinberg School, Faculty-Community Research Liaison for ARCC and Director of Evaluation and Community Research at CLOCC.

## Director's Message



Mary J.C. Hendrix, PhD, Children's Research Fund Professor, William G. Swartchild, Jr. Distinguished Research Professor, President & Scientific Director, Stanley Manne Children's Research Institute

A trajectory of scholarly activity is proudly presented in this issue of InTouch—thanks to hard work of our faculty, staff and trainees dedicated to the mission of advancing scientific breakthroughs to address diseases affecting children and their families. Please enjoy reading about: innovative community-based research activities; our summer research students and their training experiences; faculty in the news; basic, clinical and translational research discoveries; high profile publications, and more. Especially noteworthy is the herculean effort to secure extramural funding for these scholarly activities, and I am delighted to share our progress for the first two months of the fiscal year with you:

September through October FY totals to date	FY15	FY16
<b>Awards:</b>		
Award Count	53	76
Payment Count	75	124
Direct Costs	\$2.7M	\$5.2M
Indirect Costs	\$0.7M	\$1.1M
<b>Total</b>	<b>\$3.4M</b>	<b>\$6.3M</b>
<b>Proposals:</b>		
Count	95	109
Multi-year funding requests	\$27.7M	\$27.0M
<b>IRB Review:</b>		
Full Board Actions	53	38
Expedited Review	433	506
<b>Total</b>	<b>486</b>	<b>544</b>

These data demonstrate an 85% growth in awards derived from new grants, clinical trials, continuations, supplements and amendments. Proposal counts are robust (+15%), and IRB transactions are also strong (+12%).

This is a small snapshot of the extraordinary collective effort of our dedicated investigators and staff of the Stanley Manne Children's Research Institute. Thank you for all your efforts, and keep up the great work!



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Stanley Manne Children's Research Institute is the research arm of Ann & Robert H. Lurie Children's Hospital of Chicago, and 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 200 investigators and over \$30 million in external funding for research, two-thirds from the NIH and other federal agencies.

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# Robert Louis Katz Summer Scholars

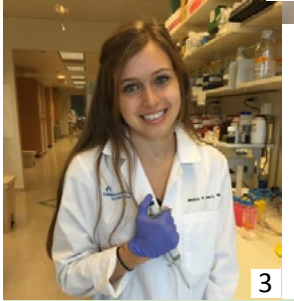
by Francine Blazowski



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The Robert Louis Katz Medical Research Foundation has provided approximately 50 high school, undergraduate and graduate students with scholarship opportunities to nurture their interest in biomedical research since 2000. The Foundation was established through the generosity of James and Ellyn Katz in memory of their son, Robert, to support research for diseases in children. The Robert Louis Katz Summer Scholars are mentored in research laboratories, culminating in presentations to Mr. and Mrs. Katz, mentors and peers. The students, their mentors, and the scientific community of the research institute would like to thank the Katz family for its commitment to research and training.

**1. Jeffrey N. Gross • University of Illinois at Urbana Champaign • Bachelor of Science Molecular & Cellular Biology 2015 • Laboratory of Simone T. Sredni, MD, PhD (mentor) • *Avoiding unnecessary toxicity and improving survival of children with low grade gliomas***  
Pediatric low grade gliomas (LGG), among the most common childhood brain tumors, frequently present in areas that are essential for function, resulting in residual tumor after surgical resection. The tumors may recur or progress, but 30-48% spontaneously involute after subtotal surgical resection. Jeffrey isolated DNA and RNA from samples to evaluate genes involved in spontaneous involution of LGG to understand its biological basis, uncover molecules that can induce involution and be targeted for therapy, and develop a test to identify LGGs that may involute spontaneously or remain stable after incomplete resection.

**2. Nancy Hua Su • Northwestern University undergraduate • Laboratory of Nikia Laurie, PhD (mentor) • *Identification of novel therapeutic targets for retinoblastoma***  
Retinoblastoma is the most common pediatric cancer of the eye. In the United States the majority of retinoblastoma patients are diagnosed before their 2<sup>nd</sup> birthday, and many lose their sight due to this disease. Advanced retinoblastoma is a greater clinical challenge in developing countries, where the mortality rate for advanced metastatic retinoblastoma is as high as 80%. Nancy studied how gene regulators affect the ability of retinoblastoma tumor cells to grow and become aggressive, and how targeting these gene regulators can inhibit or halt retinoblastoma growth.

**3. Tiffany Toni • University of Notre Dame undergraduate • Laboratory of Edward Gong, MD • Mentor: Robert Dettman, PhD • *Examination of sonic hedgehog's role in bladder smooth muscle progenitor stem cell signaling***  
Males born with pediatric urethral valves are at high risk for urological and kidney complications as young adults. This disease causes obstructed urethras that prevent urination. Surgeons ablate the valves or obstructions, but over time the bladder's functionality is compromised. Dettman is investigating whether the molecular pathway identified as sonic hedgehog (Shh) signaling is malfunctioning in the bladders of boys

with the valves. Tiffany conducted experiments using a gene that showed whether Shh signaling is different in mouse bladders that are surgically obstructed. She also conducted experiments to identify which cells use the Shh signaling pathway.



**Victoria Wu • Northwestern University medical student • Laboratory of Sookyong Koh, MD, PhD (mentor) • *Preliminary efficacy study of a mobile cognitive intervention in children with epilepsy***  
Many children with epilepsy, one of the most common childhood neurological disorders, have

cognitive difficulties, which affect school performance and the ability to learn. The Koh lab is exploring whether cognitive training provided on an iPad tablet helps epileptic children overcome these problems. The training program – Constant Therapy – is comprised of a series of video game-like tasks designed to improve attentional abilities. Victoria was responsible for coordinating study appointments, preparing research materials, administering the study, working with patients and their parents, analyzing data and results, and preparing a written cumulative paper.



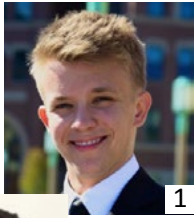
**Joshua Wynne • Northwestern University undergraduate • Laboratory of Mark Wainwright, MD, PhD (mentor) • *Effect of thrombin on astrocyte in vitro: the role of ROCK and MLCK signaling pathways***

The integrity of the blood brain barrier (BBB) is temporarily compromised following brain injuries including traumatic brain injury (TBI), stroke or central nervous system infections. This leaking may be important in processes that lead to long-term neurologic complications including epilepsy. The Wainwright lab has identified a critical role for the protein myosin light chain kinase in the BBB after TBI. Joshua assisted in examining how this protein is regulated, particularly in response to the serum protein, thrombin. The results may shed light on how to protect the BBB after TBI, and help in developing therapies to prevent long-term complications.

## 2015 Summer Students

by Francine Blazowski

The research institute and Lurie Children's hosted 28 summer student laboratory interns from June through August this year. The students were placed in the Cancer Biology & Epigenomics, Clinical & Translational Research, Developmental Biology, Human Molecular Genetics and Neurobiology Programs, and the Center for Autonomic Medicine in Pediatrics (CAMP). A welcome luncheon was held on July 2 at the research institute where the summer students were greeted by Mary J.C. Hendrix, PhD, President & Scientific Director of the research institute, and Philip Iannaccone, MD, PhD, director of the research institute Training Program.



1

**1. Sebastian Agignoe** • Laboratory of Jacek Topczewski, PhD • *On Using Zebrafish to Model Congenital Human Disorders in Sterol Biosynthesis* • Senior, Loyola University Chicago (Biochemistry and Music)



2

**2. Furgan Attar** • Laboratory of Tadanori Tomita, MD • Mentor: C. Shekhar Mayanil, PhD • *Role of Brain Endothelial MicroRNA Let7f in Regulation of Blood Brain Barrier Function During Inflammation* • Sophomore, University of Illinois at Chicago (Neuroscience/Pre-med)



3

**3. Maya Behn and 4. Meredith Hollender** • Laboratory of Simone T. Sredni, MD, PhD • *Making Kinase Library in AT/RT Cell Line Using CRISPR/Cas9 Technology* • **Maya**, Sophomore, Haverford College (Chemistry) • **Meredith**, Sophomore, University of Notre Dame (Neuroscience & Behavior)



4

**5. Benjamin Best** • Laboratory of Tadanori Tomita, MD • Mentor: C. Shekhar Mayanil, PhD • *Molecular Stitching: In Utero Repair of Myelomeningocele* • MS4, Medical College of Wisconsin



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**6. Kevin P. Christensen** • Laboratory of Xiao-Di Tan, MD • Mentor: Suhail Akhtar, PhD • *Applications of PCR on Mouse Tissue* • Senior, University of Illinois at Urbana-Champaign (Biology)



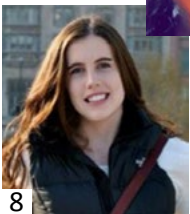
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**7. Mimi Guo** • Laboratory of Edward Gong, MD • Mentor: Robert Dettman, PhD • *Androgen Modulation of Primary Human Bladder Smooth Muscle Cell Proliferation and Gene Expression* • Senior, Miami University (majoring in Zoology, minoring in Chinese)



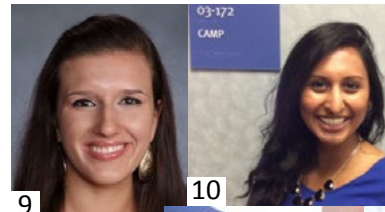
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**8. Katherine Kelly** • Laboratory of Arun Gosain, MD • Mentor: Jolanta Topczewska, PhD • *Testing the Feasibility of Zebrafish Model for Craniosynostosis Research* • Senior, Northwestern University (Cognitive Science with a focus on Neuroscience)



8

**CAMP summer students** • CAMP Director and Mentor, Debra Weese-Mayer, MD: **9. Kristen Kelly**, **10. Cia Mathew**, **11. Grace Niewijk**, **12. Saajidha Rizvydeen** and **13. Molly Winston** • *Control ANS (Collection of Pupillary Response, Peripheral Skin Temperature, Head-Up Tilt Test, Genotype, and Phenotype Information in Controls Matched to Patients with Disorders of Autonomic Nervous System Dysfunction)* • **Kristen**, Junior, University of Wisconsin-Madison (Biology and Psychology) • **Cia**, MS2, Warren Alpert Medical School of Brown University • **Grace**, Sophomore, Yale University • **Saajidha**, M2, Marian University College of Osteopathic Medicine • **Molly**, Senior, Colorado College (Neuroscience)

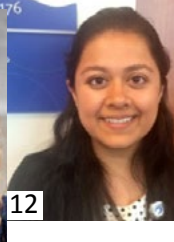


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**14. Rebecca Lewis** • Laboratory of Tadanori Tomita, MD • Mentor: Guifa Xi, MD, PhD • *Histone Modification as a Mechanism Driving Chemo- and Radio-Resistance in Pediatric Glial Derived Tumors* • Junior, University of Rochester (Biomedical Engineering)



15

**15. Meredith Lilly** • Laboratory of Edward Gong, MD • Mentor: Robert Dettman, PhD • *Resident Smooth Muscle Progenitor Cells in the Murine Bladder* • MS2, Georgetown University School of Medicine



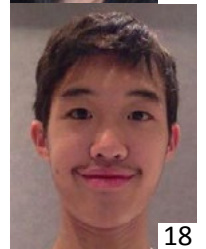
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**16. Devin Midura** • Laboratory of Arun Gosain, MD • Mentor: Jolanta Topczewska, PhD • *Analysis of Candidate Genes in Patients with Nonsyndromic Craniosynostosis* • MS2, Albany Medical College



17

**17. Grace Ng** • Laboratory of Mark Wainwright, MD, PhD • *Effect of Thrombin on Astrocytes In Vitro: The Role of ROCK and MLCK Signaling Pathways* • Sophomore, Stanford University (Symbolic Systems/Pre-med)



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**18. Hayden Ngan** • Laboratory of Tadanori Tomita, MD • Mentor: C. Shekhar Mayanil, PhD • *New Insights into Folate Receptor  $\alpha$  (FR $\alpha$ ) Signaling in Neural Crest Stem Cells* • Senior, King George V High School, Hong Kong



Lindsay Stolzenburg, a graduate student in the laboratory of Ann Harris, PhD, has received a National Research Service Award (NRSA) F31 Fellowship from the National Heart, Lung, and Blood Institute for a project entitled "A novel microRNA in pulmonary fibrosis". Lindsay studies fibrotic diseases of the lung including chronic obstructive pulmonary disease (COPD), idiopathic pulmonary fibrosis (IPF), and cystic fibrosis (CF). Together, these conditions are a major health burden, almost always resulting in respiratory failure. In all cases, disease progression involves repeated cycles of inflammation, followed by injury and repair. The net result is scarring and fibrosis of lung tissue.

The cystic fibrosis transmembrane conductance regulator (CFTR) gene, which when mutated causes cystic fibrosis in humans, is a focus of the Harris laboratory. It is not known why patients with the same mutation within CFTR can show significant differences in their lung disease severity. Similarly, environmental factors are known to influence development of COPD and IPF, but lung disease progression is not well correlated with exposure to the insults. These observations suggest that many factors converge to impact the process of pulmonary fibrosis.

Lindsay says, "We don't know what specific genes and pathways govern these processes. MicroRNAs, small RNAs that are responsible for repressive gene regulation, are compelling candidates for modulating lung epithelial repair in disease." Of particular interest is miR-1343, which is located in a genomic region associated with CF lung disease severity. Additionally, there is evidence to suggest that miR-1343 actively represses transforming growth factor beta (TGF- $\beta$ ) signaling, which plays a critical role in cell proliferation and differentiation to control lung health. TGF- $\beta$  signaling is intimately involved in regulating fibrotic responses to lung injury, and polymorphic variants in TGF- $\beta$ 1 are known to modify CF lung disease severity. "This research will be of fundamental importance to identify novel biomarkers and therapeutic strategies for the treatment of multiple chronic lung diseases," Lindsay concludes.

2015 Summer Students (continued from page 5)



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**19. Kiana Ongbueco** • Laboratory of Xiao-Di Tan, MD • Mentor: Hua Geng, PhD • *Long non-coding RNA H19 in Gut Inflammation* • Sophomore, Marquette University (Biological Sciences)



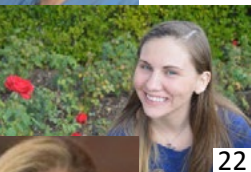
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**20. Max Passo** • Laboratory of David Walterhouse, MD • Mentor: Joon Won Yoon, PhD • *RH30V Genomic DNA Sequencing* • Senior, Purdue University (Biology)



21

**21. David Reed** • Laboratory of Mary J.C. Hendrix, PhD • Mentor: Thomas M. Bodenstine, PhD • *Evaluating the Effect of Nodal inhibition on Chemotherapy Sensitivity in Breast Cancer Cells* • Senior, University of Notre Dame Science Pre-Professional program



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**22. Elina Sagaydak** • Laboratory of David Walterhouse, MD • Mentor: Joon Won Yoon, PhD • 4<sup>th</sup> year, combined BA/MD 6-year program, University of Missouri Kansas City



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**23. Katherine Shanahan** • Laboratory of Mary Beth Madonna, MD • Mentor: Fei Chu, MD, PhD • *Synergistic Cytotoxicity of Digoxin and 5-Flourouracil in Doxorubicin-Resistant Breast Cancer Cell Line* • Sophomore, Marquette University (Biology)



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**24. Elaine Sobel** • Laboratory of Simone T. Sredni MD, PhD • *Hailey Fish: A Zebrafish Model of Malignant Rhabdoid Tumor* • Senior, Walter Payton College Prep



25

**25. Tommi Tsao** • Laboratory of Philip Iannaccone, MD, PhD • *Into the Hive: A Closer Look at Cornea* • Sophomore, Boston University (Biomedical Engineering)



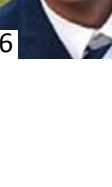
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**26. Akshay Verma** • Laboratory of Xiao-Di Tan, MD • Mentor: Xiao Wang, MD, PhD • *Investigating the Role of Protein Receptor TIM4 in the Regulation of Phagocytosis by Hepatic Stellate Cells* • Senior, Illinois Mathematics and Science Academy



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**27. Victoria Wang** • Laboratory of Lauren M. Pachman, MD • *The Role of miR-10a in Human Endothelial Cell Function* • Senior, Wellesley College (Biological Sciences/Psychology)



28

**28. Veronica Williams** • Laboratory of Philip Iannaccone, MD, PhD • Mentor: Ronnie Childs, PhD • *Determining the Proteins Involved with the Gli1 Complex* • Junior, Creighton University (Biology and Spanish)



## Awards & Honors



Mina Dulcan, MD

Mina Dulcan, MD, Chair of the Department of Child and Adolescent Psychiatry at Lurie Children's, received the 2015 Virginia Q. Anthony Outstanding Woman Leader Award from the American Academy of Child and Adolescent Psychiatry in honor of her exemplary career as a leader in the field. Dulcan is Professor of Psychiatry and Behavioral Sciences and Pediatrics at the Feinberg School and holds the Margaret C. Osterman Professorship in Child & Adolescent Psychiatry.

Joel Frader, MD, head of the Division of Academic General Pediatrics and Primary Care at Lurie Children's, received the 2015 Excellence in Pediatric Palliative Care Award from the Greater Illinois Pediatric Palliative Care Coalition. Frader is Professor of Pediatrics and Education in Medical Humanities and Bioethics at the Feinberg School and holds the A Todd Davis, MD Professorship in General Academic Pediatrics.

Ann Harris, PhD, director of the Human Molecular Genetics Program at the research institute, received the Faculty Service Award at the Fourth Annual Driskill Day, an event to celebrate the Walter S. and Lucienne Driskill Graduate Program in Life Sciences at Northwestern University. Harris is Professor of Pediatrics at the Feinberg School and holds the Valerie and George D. Kennedy Research Professorship in Human Molecular Genetics.

Stephen Hoff, MD, Assistant Professor of Otolaryngology - Head and Neck Surgery at the Feinberg School and a pediatric otolaryngologist at Lurie Children's, received the Feinberg Academy of Medical Educators (FAME) Outstanding Teacher Award in August. The FAME award promotes and recognizes teaching excellence across the entire Feinberg School.

John Sarwark, MD, division head of Orthopaedic Surgery at Lurie Children's, received the American Academy of Pediatrics (AAP) Section on Orthopaedics 2015 Distinguished Service Award. Sarwark is Professor of Orthopaedic Surgery at the Feinberg School and holds the Martha Washington Foundation for Handicapped Children Professorship in Pediatric Orthopedics.

### NUCATS welcomes new KL2 scholars

NUCATS (Northwestern University Clinical and Translational Sciences Institute) is welcoming three new scholars who are participating in the Multidisciplinary Mentored Career Development Program (KL2). The awardees and their projects are:

- Amanda Saratsis, MD, Assistant Professor of Neurological Surgery at the Feinberg School; her project is focused on investigation of histone modifications in pediatric brainstem glioma.
- Lisa VanWagner, MD/MSc, Assistant Professor of Medicine-Gastroenterology and Hepatology and Preventive Medicine.
- R. Gregory Webster, MD, MPH, Assistant Professor of Pediatrics-Cardiology; his project is focused on evaluation of first-degree relatives after sudden cardiac death.

Saratsis and Webster are Lurie Children's clinicians and researchers. Says Saratsis, "Diffuse intrinsic pontine glioma is the most morbid pediatric solid cancer, and we don't have a treatment for it despite 40 years of clinical trials. One of the reasons it's so difficult to study and treat is because it lives in the brainstem and can't be surgically removed. We've found a clever way of looking at the biology of the tumor using human tumor cells and we're just now scratching the surface of this discovery. I think our analysis will apply to other pediatric tumors too. This support from NUCATS is going to have a much wider impact."

Webster is investigating first-degree relatives who have had a sudden, unexplained death in the family. He says, "Studies suggest that 30 to 50 percent of the victims suffered from a cardiac disorder. We're trying to determine how genetic testing can help us identify relatives who need to be protected from a second death in the family." He will utilize KL2 funds for a team of researchers and a genetic counselor to complete interviews and exams. "The award will enable me to build the skills necessary to grow and contribute to the cardiology mission of Northwestern."



Joel Frader, MD



Stephen Hoff, MD

## Appointments & Promotions



James W. Schroeder, Jr., MD, Associate Professor of Otolaryngology - Head and Neck Surgery and Medical Education at the Feinberg School, has been appointed the McGaw Medical Center of Northwestern University Director of Fellowship Accreditation and Review. In this role Schroeder will conduct internal reviews for all Accreditation Council for Graduate Medical Education (ACGME) accredited fellowships campus wide. Schroeder's appointment will dramatically improve McGaw's ability to provide direct oversight for the medical center's ACGME-accredited fellowship programs. Schroeder has an extensive history of excellence in medical education including serving as program director of the Pediatric Otolaryngology fellowship, active membership on the Graduate Medical Education Committee, graduate of the Searle Fellows Program, Feinberg Academy of Medical Educators (FAME) member and co-directing the Problem-Based Learning course for medical students.



Narasimhan Jagannathan, MD, Associate Professor of Anesthesiology at the Feinberg School, has been promoted to Associate Chair for Academic Affairs for the Department of Anesthesiology at Lurie Children's.

Janice Lasky Zeid, MD and Bahram Rahmani, MD, MPH of the Division of Ophthalmology at Lurie Children's have been promoted to Associate Professor in the Department of Ophthalmology at the Feinberg School. Hawke Yoon, MD has been promoted to Assistant Professor.



### Lurie Children's Gives KIDS a Voice in Pediatric Clinical Research

Adapted from NUCATS News

by Amanda Mozer, October 7, 2015

Lurie Children's has formed a Kids and Families Impacting Disease Through Science (KIDS) advisory group with patients of their Kids Advisory Board and teenagers from Walter Payton College Preparatory High School in Chicago. KIDS is focused on understanding, communicating and improving health, medicine, research and innovation for children.

"Lurie Children's has an extensive history of engaging patients in our efforts. In fact, the patient advisors on our Kids Advisory Board had an active voice in the design of the hospital's new building and provided architectural feedback on how patient rooms and other areas should be constructed," said Susanna McColley, MD, Professor of Pediatrics, Associate Director of NUCATS for Child Health at the Feinberg School, director of the Clinical and Translational Research Program and Deputy Director for Clinical Research at the research institute. "When I told them about the opportunity to create a KIDS advisory group here, they jumped at the chance!"

McColley is a member of the AAP Section on Advances in Therapeutics and Technology (SOATT) and collaborated with Charles Thompson, MD, FAPP, chair of SOATT and director of the Pediatric Center of Excellence at Pfizer, to bring the KIDS advisory group to Chicago. "Our goal is to involve these kids in helping researchers plan and perform studies to make better treatments for childhood diseases," said McColley.

She has worked with science teachers from Walter Payton College Prep to create a Kids Advisory Board seminar emphasizing clinical and translational (C&T) research, which kicked off this September. Students learn about the C&T research process while engaging in discussions on research conducted by Lurie Children's scientists and a local pharmaceutical company specializing in rare pediatric diseases. Students will provide input on study design, emphasizing how researchers can make trial design more "kid friendly".



From top: James Schroeder, Jr., MD; Narasimhan Jagannathan, MD; Janice Lasky Zeid, MD; Bahram Rahmani, MD





### Sickle cell patients: time to get moving

Patients with sickle cell disease have red blood cells (RBC) that are sickle shaped. These cells live on average for 15 to 20 days, much less than the 120 day lifespan for normal RBCs. As a result, sickle cell patients are anemic, causing them to feel tired, cold, dizzy and irritable, experience shortness of breath or headaches. In addition, the sickle RBCs pile up in blood vessels and cause acute pain episodes, the most common reason for hospitalization in sickle cell patients. Blockage of blood vessels by sickle RBCs can also damage organs over time – particularly the heart and lungs – because blood isn't getting to them properly. All of these factors make it difficult for children with sickle cell to exercise. In fact, doctors and parents may discourage them from exercising out of fear that the physical symptoms could worsen.

Robert Liem, MD and a team of hematologists, pulmonologists and exercise physiologists designed a research study using bicycle exercise stress tests to see how sickle cell patients and normal volunteers differ in the way their bodies respond to exercise challenge. The study, published in *Physiological Reports*, found that while sickle cell patients do have limitations in how their cardiovascular system and lungs handle exercise, the exercise they performed – even at high levels during testing – was not harmful to them. Other studies by Liem and his team have determined that inflammation, normally increased during exercise, is no greater in sickle cell patients than in normal children. The bottom line is that it is safe for these patients to exercise.

These findings have significant implications for the quality of life that sickle cell patients experience. Knowing that exercise is good for the body and for our frame of mind, Liem is encouraging his patients and families to be physically active. "Many of these kids want to join organized sports. Their quality of life definitely improves when they exercise. It improves the way they feel about themselves, and it could improve their physical functioning," says Liem.

### Autonomic (dys)regulation tool

The PhenX Toolkit, a project funded by the National Human Genome Research Institute, has selected an autonomic (dys)regulation questionnaire tool developed by Debra Weese-Mayer, MD and colleagues in the Center for Autonomic Medicine in Pediatrics (CAMP) at Lurie Children's to be part of its collection. The Toolkit provides standard measures related to complex diseases, phenotypic traits and environmental exposures. Use of PhenX measures facilitates combining data from a variety of studies, and makes it easy for investigators to expand a study design beyond the primary research focus. Weese-Mayer is Professor of Pediatrics at the Feinberg School and Beatrice Cummings Mayer Chair in Pediatric Autonomic Medicine.

### Scientists speak up

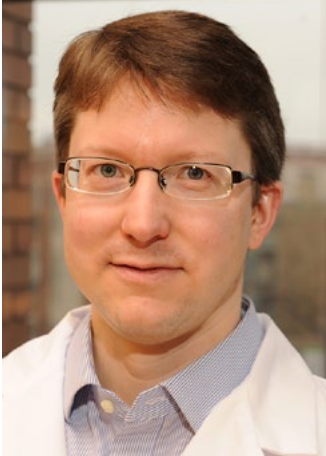
As part of Research!America's Campaign for Cures, several scientists at Manne Research Institute discussed why research funding is critical to the continuing success of biomedical research in finding therapies and cures for pediatric diseases. This YouTube video features Mary J.C. Hendrix, PhD, president and scientific director of the research institute, a PhD candidate, a postdoctoral fellow and a clinical fellow. Hendrix is on the Board of Directors of Research!America.

### New book releases

Santhanam Suresh, MD, FAAP and Ban C.H. Tsui are editors of the first edition of *Pediatric Atlas of Ultrasound- and Nerve Stimulation-Guided Regional Anesthesia*. This is the first comprehensive text-atlas that shows how to use ultrasound technology and nerve stimulation techniques to guide regional blockade in children. Suresh is Chair of the Department of Anesthesiology and director of the Pain Management Team at Lurie Children's and holds the and Arthur C. King Professorship in Anesthesiology. He is Professor of Anesthesiology and Pediatrics at the Feinberg School. Mina Dulcan, MD, Chair of the Department of Child & Adolescent Psychiatry at Lurie Children's has published

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the second edition of *Dulcan's Textbook of Child and Adolescent Psychiatry*. Many faculty members in the department contributed chapters to the book.



Christopher Payne, PhD

### Grant to study targets for male contraception

Adapted from NUCATS News  
by Amanda Mozer, August 5, 2015

Christopher Payne, PhD, Assistant Professor of Pediatrics and Obstetrics and Gynecology at the Feinberg School, has received a grant from The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). The project aims to identify and characterize small molecule inhibitors of an enzyme exclusive to sperm as a means to develop a reversible, non-hormonal male contraceptive. Payne utilized funding from the NUCATS Voucher Program to collect the preliminary data needed to apply for this grant. His research team screened 36 molecules, analyzed their inhibitory effects of the enzyme and included the results in the grant application. This next phase of research will consist of large-scale screening to look for more effective inhibitors to block the enzyme. Payne is a member of the Human Molecular Genetics Program of the research institute. [Read more.](#)

### Identifying pediatric heart transplant recipients at high risk of graft loss

Elfriede Pahl, MD is senior author on a multicenter analysis that reviewed Pediatric Heart Transplant Study data from 1993 to 2009. The researchers sought to evaluate whether assessment of systolic and diastolic graft function, in addition to angiography, improves the recognition of patients at high risk of graft loss. Their analyses indicate that graft dysfunction identified children at greater risk for graft loss even in patients with mild angiographic vasculopathy. It is hoped that these findings will help pediatricians determine which patients should receive more frequent follow-up and potentially changes in therapy to extend graft survival. The study is published in the August 2015 issue of the *Journal of the American College of Cardiology*.



Elfriede Pahl, MD

### Partnership unites all fields of HIV research

Adapted from Feinberg School News Center  
by Nora Dunne, August 31, 2015

A new five-year, \$6.25 million grant from the National Institutes of Health (NIH) will help experts in a wide range of medical and academic fields at Northwestern University, and others across the city of Chicago, work together to slow and stop HIV. The funding, from the National Institute of Allergy and Infectious Diseases (NIAID), supports the creation of the Third Coast Center for AIDS Research (CFAR), a partnership between Northwestern University, the University of Chicago, the Chicago Department of Public Health, the AIDS Foundation of Chicago, the Alliance of Chicago Community Health Services and the Center on Halsted.

CFAR will provide services through five cores. The Clinical Sciences Core will include a data and specimen repository of newly diagnosed subjects collected in collaboration with the Center on Halsted and a registry of patients with HIV from the partnered university clinics and local federally qualified health centers through the Alliance of Chicago. It will be led by Babafemi Taiwo, MBBS, Associate Professor of Infectious Diseases, Ellen Chadwick, MD, Professor of Pediatrics, and David Pitrak, MD, University of Chicago. Chadwick is Co-Medical Director of Pediatric and Maternal HIV Infection and Interim Division Head of Infectious Diseases at Lurie Children's, and Irene Heinz Given and John LaPorte Given Chair in Pediatrics.

### Training on depressed Latino adolescents

Alliance for Research in Chicagoland Communities (ARCC) Seed Grant partners, Rebecca Ford-Paz, PhD and Healthcare Alternative Systems, Inc. have published an article, "Training community opinion leaders to raise awareness and promote early intervention for depressed Latino adolescents" in the Summer 2015 issue of *Progress in Community Health Partnerships*. Ford-Paz is Assistant Professor of Psychiatry and Behavioral Sciences at the Feinberg School and a clinical psychologist at Lurie Children's.

## Research News (continued from page 10)



Bradley Marino, MD, MPP, MSCE

### First National Conference on Cardiac Outcomes Transparency

The country's leading experts in pediatric cardiovascular care gathered at Lurie Children's recently to create policy that will support hospitals and providers to be transparent in reporting cardiac outcomes.

The Summit on Transparency and Public Reporting of Pediatric and Congenital Heart Disease Outcomes was in reaction to a yearlong CNN investigation that found a hospital in West Palm Beach, Florida with high mortality rates. The hospital has since closed its pediatric cardiothoracic surgery program and its CEO has resigned.

The pediatric heart surgery program at Lurie Children's is one of three in the U.S. to publicly report quality and outcomes data — in every category as tracked in a CNN transparency report card. "We know from the unfortunate situation in Florida that it is critical for parents to have data they can trust so they can make an informed decision about their child's care," said Bradley Marino, MD, MPP, MSCE, Professor of Pediatrics and Medical Social Sciences at the Feinberg School, and Heart Center co-director, Research and Academic Affairs, Divisions of Cardiology and Critical Care at Lurie Children's. "A number of other hospitals report some data on their websites, but it's typically incomplete. We need to standardize this information and make reporting mandatory."

The event was sponsored by the Pediatric Congenital Heart Association (PCHA) and hosted by Lurie Children's. Marino, who is the national chair of the PCHA medical advisory board, is working with other PCHA leaders to disseminate a national white paper on the results of the two-day summit. "We know that parents of children with congenital heart disease want this information but it is not always readily accessible or easy to understand," said Marino. "It is the right of our patients to have this information."



From left: Amanda Saratsis, MD and Rishi Lulla, MD with a patient

### Modifying the Future for Children with Brain Tumors

by Vita Lerman

How does a gene "decide" to set off a chain reaction that leads to cancer? Scientists at Lurie Children's and Northwestern Medicine are now looking for answers deep within the cell to a tiny structure called chromatin. They hope to reverse the cancer-causing message to the gene long before it starts on a path to cancer.

"Chromatin consists of DNA condensed with certain proteins inside the cell nucleus. It determines whether the gene turns on or off," explains Rishi Lulla, MD, MS, Hematology, Oncology, Neuro-Oncology & Stem Cell Transplantation at Lurie Children's, who is co-principal investigator on this project. "We have increasing evidence that altered chromatin biology is a central feature of cancer development and progression. Our aim is to learn how chromatin can be modified in order to treat the most challenging brain tumors in children. Targeting this mechanism is a relatively new strategy that has been gaining interest in pediatric neuro-oncology."

The multidisciplinary team is using a bedside-to-bench-to-bedside approach. "We are using clinical observation and patient samples to drive basic science investigation, which will then inform the development of novel clinical trials," says co-principal investigator Amanda Saratsis, MD, Neurosurgery, Lurie Children's. "Our initial research focuses on pediatric high grade glioma and diffuse intrinsic pontine glioma because children affected by these brain tumors are in dire need of improved treatment options and outcomes."

Lulla and Saratsis are collaborating on this project with scientists from Northwestern Medicine, including experts in neurology, neurosurgery, biochemistry and molecular genetics. Their work will be accelerated through generous philanthropic support from the John McNicholas Pediatric Brain Tumor Foundation.

## "Science fair for grown-ups" returns by popular demand!

by Maureen King



From left: Rishi Lulla, MD; Erin Rowell, MD; Karna Murthy, MD; Amanda Saratsis, MD; Bradley Marino, MD; Laurence Ducharme-Crevier, MD; and Conrad Epting, MD

The Children's Research Fund has been hard at work on plans for the December 5 Children's Ball at the Hilton Chicago. Returning this year after its launch in 2013 is an exciting cocktail-hour "science fair for grown-ups" that will highlight some of the most innovative projects being done under the auspices of the Stanley Manne Children's Research Institute, giving Ball-goers the opportunity to chat with researchers and ask questions. The featured presentations and the physician-scientists presenting are:

- **Modifying the Future for Children with Brain Tumors**  
by Rishi Lulla, MD, MS and Amanda Saratsis, MD
- **Can we mend a broken heart?**  
by Conrad Epting, MD
- **Prenatal Health and Clinical Research: Bridging the Possibilities**  
by Erin Rowell, MD and Karna Murthy, MD, MSc
- **Big Data, Big Possibilities**  
by Mark Wainwright, MD, PhD and Laurence Ducharme-Crevier, MD
- **Saving Lifetimes—New Possibilities for Heart Patients**  
by Bradley Marino, MD, MPP, MSCE

### 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 \$65 million. To get the latest information on Children's Research Fund events and fundraising campaigns, please visit [www.childrensresearchfund.org](http://www.childrensresearchfund.org).