**Presentations, summary, and presenter info**

**Monday June 24:**

**10-10:50 Registration and Poster set up**

**11-11:20 Lunch**

**11:30-11:40 iCAN Summit Welcome & Introduction**

**Charlie Thompson**

**11:40-11:50 Welcome to Kansas City**

**Amanda Woelk**

**Melissa Pulis**

**KIDS KC**

**11:50- 12:20 Reflecting on 5 years of iCAN**

**Amy Ohmer**

**12:20- 12:50 Overview, and Update from executive council**

**Leanne West**

**Christine Woods**

**1-2:20 Poster Sessions and Partner tables:**

**Team updates**

**Partner Tables:**

**iCAN**

**Eli Lilly and Company**

**iact**

**Jumo Health**

**Upopolis**

**PRA Sciences**

**Soatt**

**Boehringer-Ingelheim**

**Pfizer**

**Hope for Henry**

**iQuivia**

**Bionicle**

**Unicef**

**Share4RARE**

**Paradigm**

**What is Spina Bifida and How Does It Affect the Family in the Community?**

Attendees will take away knowledge of the spina bifida diagnosis and strategies for making life easier or even better for the person who has spina bifida and their family if ever they meet. Health care providers will also gain a deeper understanding of the consequences a child and the family face when born with spina bifida and will gain knowledge for identifying opportunities to assist in meeting needs, improving life and reducing suffering for their patients who were born with spina bifida.

Rhonda G. Bolin, BSN, RN, CPN, Spina Bifida Clinic Nurse

**We cannot do research about them, without involving them! Attitudes of researchers and children about the involvement of children as co-researchers in pediatric medical research**

This presentation will be about the importance of the involvement of children in pediatric medical research. During this presentation I will discuss how children are involved in research nowadays and how we can involve them in pediatric medical research.

Laura Postma, BSc, University of Groningen (RUG), University Medical Center Groningen (UMCG)

**2:30- 3:50 The Role of the Institutional Review Board (IRB) and Introduction of IRB project**

Institutional Review Boards (IRBs) are a diverse group of scientists and non-scientists who review research studies to protect the rights and welfare of human subjects. In this presentation we’ll review the (1) purpose and composition of an IRB, (2) the regulations on protecting human subjects and (3) how IRBs conduct their reviews

Ryan McDowell, MS, Director Office of Research Integrity, Children’s Mercy Kansas City

Albert John "A.J." Allen M.D., PhD, Senior Medical Fellow, Pediatric capabilities, Eli Lilly and Company

**4-5:20 Three Different Perspectives of a Case Study: the Patient, the Parent, the Provider**

While experiencing a healthcare experience there are many perspectives to every encounter. This panel discussion between a patient, parent and provider will be moderated by a bioethicist to explore the perspectives of a single case study that was published in a peer-reviewed medical journal.

DeeJo Miller, BA, Patient and Family Engagement Program Manager, Children’s Mercy Kansas City

Hannah Nilsson, BA, Patient Children’s Mercy Kansas City

Karen Lewing, MD, Fellowship Program Director, Division of Hematology/Oncology, Children’s Mercy Kansas City Associate Professor of Pediatrics, UMKC School of Medicine

Gary Douglas (Doug) Myers, M.D. Associate Professor, Pediatric Hematology/ Oncology, Children’s Mercy Kansas City /University of Missouri Kansas City

**5:30-9 Opening Reception**

**Tuesday June 25:**

**9-9:30- Load Busses in POD groups and go to Children’s Mercy**

**9:30-10:20 & 10:30-11:20 Concurrent Rotating Sessions in POD Groups**

**Patient Engagement: The Power of Patients in Healthcare**

As healthcare and research innovation continue to bring new hope for novel treatments and cures, the inclusion of the patient/family voice is paramount to the future of stakeholder collaboration. Learn from the personal journey of a parent whose child was diagnosed with a rare disease and her quest to change the future of rare disease care and research.

Kelly Ranallo

Founder/President: Turner Syndrome Global Alliance (TSGA)

Founder Rare KC

**Implementing Genomic Medicine in Pediatrics**

The rapid development of Next Generation Sequencing (NGS) has transformed genetics; ultimately resulting in a decrease in the time to diagnosis and an increase in novel gene discovery.  However, the expansion of testing requires careful consideration, particularly for consent and the return of results. This lecture will describe NGS technologies, their use in testing, and ethical considerations of consent and return of results.

Emily Farrow, PhD, CGC, Children’s Mercy Kansas City

**Incorporating Diverse Perspectives to Initiate and Sustain Improvements through the Partnership and Collaboration with Patient Family Advisors**

Children’s Mercy has a long history of sustained commitment of partnering with patients and families to improve the quality, safety and experience of care. This presentation will outline the history, growth and examples of programs that foster patient and family engagement and highlight the Family Experience Tracer program.

Sheryl Chadwick, BS, Patient and Family Engagement Program Manager Children’s Mercy Kansas City

DeeJo Miller, BA, Patient and Family Engagement Program Manager Children’s Mercy Kansas City

Katie Taff, MBA, MHA, CPXP, Manager, Patient and Family Engagement Children’s Mercy Kansas City

**11:30-12:20 Lunch**

**12:30-1:20 Concurrent Rotating Session Continue**

**1:30-3:45 Tour of Children’s Mercy in POD Groups**

**4-5:50:** **First Lego League (FLL): You’re never too young to innovate!**

FLL offers youth the opportunity to learn and apply the design method, both in developing a robot for a fun competition, and to solve real-world problems. The 2018 theme was “Into Orbit”; youth were invited to solve problems related to keeping humans healthy during long space travel (e.g., to Mars). Dr Clements coaches two FLL robotics teams; he and his assistant coaches will guide two FLL teams as they present on their robot design and on their solution for healthy humans in space!

Mark A Clements, MD PhD CPI FAAP, Children’s Mercy Kansas City

**At Hotel:**

**4-4:50 Directors meeting (by invitation)**

**5-5:50 Committee Chairs and Leader Meeting (by invitation)**

**Wednesday June 26:**

**9-9:50 Upopolis: Connecting Youth Online with Peers, Resources, and Empowerment Opportunities**

Join the Upopolis team for an introduction into Upopolis, a social media platform that addresses the isolation and anxiety that is felt by many youth with long-term medical experience and/ or chronic illness.

Krista L. Naugler, BAA(CYS), CCLS, Upopolis National Program Manager, Kids’ Health Links Foundation  
Jessica Miller-Poesch, MA, CCLS, Upopolis Program Coordinator, Kids’ Health Links Foundation, UPEDIA Program Manager, Kids’ Health Links Foundation

**10-11:20 POD IRB Project (Part 1)**

Groups will be assigned a study protocol and consent form to review. Using IRB review checklists groups will discuss the study protocol and consent form and determine if the materials meet the criteria for IRB approval. Ryan McDowell, MS, Director Office of Research Integrity, Children’s Mercy Kansas City

Albert John "A.J." Allen M.D., PhD, Senior Medical Fellow, Pediatric capabilities, Eli Lilly and Company

**11:30-12:20 Lunch**

**12:30-1:20**: **Innovation in Pediatric Diabetes Care: using the design method and small tests of change to make a big difference!**

In medicine, there are problems that need solving every day. Big problems and little problems. Dr Clements will describe what innovators worldwide are doing to improve the lives of children and adults with diabetes. Some of these solutions are really creative! He will also describe innovations in the Children’s Mercy Diabetes Center that are improving the way we care for children & teens and their families. Some innovations have taken years to develop, but some were developed in as little as 3 days and still had a big impact!

Mark A Clements, MD PhD CPI FAAP

**1:30-2:50 POD IRB Project (Part 2)**

Groups will continue their IRB review of their assigned study protocol and consent forms. Is the study approvable as written? Does your group have any ethical concerns with the study? Are there any changes you’d like to ask the researcher to make?

Ryan McDowell, MS, Director Office of Research Integrity, Children’s Mercy Kansas City

Albert John "A.J." Allen M.D., PhD, Senior Medical Fellow, Pediatric capabilities, Eli Lilly and Company

**3-3:50 Let’s Get REAL: real kids, real families, real stories, real medical journeys!**

Jumo Health develops age­-appropriate, educational resources for patients and caregivers for use throughout their medical journey. With the belief that an informed patient is a capable patient, Jumo Health designs its solutions for outcomes. With experience in more than 60 countries and 50+ languages covering more than 200 topics, our mixed media solutions range from comic books to animated and live action videos, activity and appreciation items, and much more. To learn more about Jumo Health, please visit jumohealth.com.

During this session, Jumo will show how they use real kids, real families and real advocates to lead children, young adults and their care circles through their medical journey. Join this fun and informative session to experience stories about medicine and research like never before!

Kirsten Sherman Cervati, Senior Director, Center for Pediatric Clinical Development, PRA

Nikki Fink, Senior Director, Strategic Solutions with Jumo Health

**4-4:15**

**PARADIGM, a public private partnership to advance patient engagement in medicines R&D with a focus on young persons**

Strong of 34 partners (patient organizations, pharmaceutical / biotech companies, regulators, HTA bodies and academic teams), PARADIGM (for Patients Active in Research and Dialogues for an Improved Generation of Medicines) will strengthen the understanding of stakeholders’ needs, the systems-readiness, ensure maximum synergies with other initiatives and develop an inventive and workable sustainability roadmap. It aims to focus on adult patients, and also young people and older people with dementia.

Mathieu Boudes, PhD

**4:15-5:20** **What difference does patient engagement make for young people and medicines development?**

How does your voice make a difference in medicines development? What does it bring to you, your friends and your family? In this session, we will have an interactive exercise to discuss what change patient engagement makes. We hope to learn from you what outcomes really matter to you.

Mathieu Boudes, PhD

Begonya Nafria, Patient Advocacy Manager

Nicole Goedhart, MSc

**5:30-7:30 PODS \_\_\_ on BBQ Tour**

**6:00-8:00 PODS \_\_\_ on BBQ Tour**

**Thursday June 27:**

**9-9:50 Optimizing the Health and Development of Children and Adults with, or at Risk for Disabilities**This presentation will provide an overview of the programmatic work being done in the Division of Human Development and Disability (DHDD) within the Center for Disease Control and Prevention’s (CDC) National Center on Birth Defects and Developmental Disabilities. DHDD focuses on better health and brighter futures for children and adults with or at risk for disability, by leading inclusive programs to optimize the health and development of those groups.

Valerie Godoshian, MPH, CHES

**10-11:20 POD IRB Project (Part 3)**

Groups will start compiling their review and composing their final IRB Review Presentation. Also, groups will discuss a take-home project that you can share with your local chapter in order to teach them about the role of the IRB and human subject’s protections.

Ryan McDowell, MS, Director Office of Research Integrity, Children’s Mercy Kansas City

Albert John "A.J." Allen M.D., PhD, Senior Medical Fellow, Pediatric capabilities, Eli Lilly and Company

**11:30-12:20 Lunch**

**12:30-1:20 Concurrent Sessions**

**Let’s Talk About Antibiotics: Engaging English and Spanish speaking parents to develop an  
intervention to increase appropriate antibiotic use.**

Antibiotic overprescribing is a significant public health issue contributing to adverse side effects and antibiotic resistant infections. Parents’ direct or perceived expectations for antibiotics are associated with increase rates of over prescribing in pediatric settings. We will explore the process, impact, and lessons learned from engaging English and Spanish speaking parents in the development of an intervention to increase appropriate antibiotic prescribing in pediatric outpatient settings.

Panel- Andrea Bradley‐Ewing, MPA, MA, Director of Community Engaged Research Health Services and Outcomes Research Children’s Mercy Hospital

Carey Bickford, BA, Parent Advisory Board Children’s Mercy Kansas City  
Terrence Gallagher, MA, Parent Advisory Board Children’s Mercy Kansas City

Monica Mendez, BA, Parent Advisory Board Children’s Mercy Kansas City

**“It actually felt like I was a researcher myself”  
Involving children in medical research: a VIP (very interactive presentation)!**

In this project, children were involved as co-researchers in the analysis of findings from a qualitative interview study about young people’s experiences of participation in medical research, using video analysis. During the iCAN Advocacy Research Summit we will discuss successes and pitfalls in the process, and reflect on participants’ involvement and engagement. The presentation will be interactive, and the presenter welcomes input from the audience.

Malou Luchtenberg, MD/PhD student Department of Pediatrics & Ethics Department, University of Groningen, University Medical Center Groningen

**1:30-2:20 Concurrent Sessions**

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**Developing a patient perspective on use of Continuomics**

The workshop presents the concepts relevant to “Continuomics” (continuous clinical data collection), the promise of technologies, concerns and privacy, focusing on pediatric trials. Can we take the technology that monitors the performance of our cars to improve how we monitor our health? Attendees will discuss different uses of “Continuomics” (general health, chronic disease, life-threatening disease) and various sensors or devices used for continuous data collection.

Tony Fantana, PhD, Advisor-GPS Analytics Epidemiology-GPS,, Eli Lilly and Company   
Mary A Short RN, MSN, Sr. Clinical Research Advisor, Pediatric Capabilities Function, Eli Lilly and Company

Albert John "A.J." Allen M.D., PhD, Senior Medical Fellow, Pediatric capabilities, Eli Lilly and Company

**The Cool Stuff Being Done at Stowers Institute**

R. Scott Hawley Ph.D., American Cancer Society Research Professor, Investigator, Stowers Institute for Medical Research, Founding Dean, Graduate School at Stowers Institute

Recently, my lab has been developing new techniques to gain a deeper mechanistic understanding of the synaptonemal complex, a larger protein structure that assembles between the chromosomes during meiosis. This proposal will take advantage of recent microscopy and CRISPR advances to examine the regulation and assembly of the synaptonemal complex during meiosis. Our lab is uniquely suited to complete this work because we have the tools and expertise already in-house. This study will help us identify key regulatory mechanisms that will potentially be applicable both in the treatment of cancer and in preventing birth defects and infertility.

**2:30-3:20**

**How does a CRO support development of medicines for children?**

Dr Martine Dehlinger-Kremer, Vice President, Pediatric Development | synteract®

Children have the same right as adults to appropriate and safe treatment with medicinal products. However, today over 50% of medicines administered to children have never been tested in this population, and it increases to 90% in neonates. In the last decades, pediatric regulations have been implemented in the US, EU, and recently in Switzerland requiring the conduct of more pediatric clinical trials. As a result, drug developers have gained pediatric drug development experience. Some of them have established a Pediatric Development Center (PDC) to develop medicines where appropriate for pediatric patients to fulfill unmet medical needs and limit off-label use and also to fulfill regulatory requirements. A PDC enhances how a company organizes itself internally for pediatric trials, as well as facilitating critical external relationships and collaboration with research networks, academic institutions, and patient’s organizations. However, not all companies have the infrastructure and resources to establish a PDC, e.g, smaller biotechs. These companies typically collaborate with CROs that have a cross-functional PDC in place that can include support from pediatricians, regulatory experts, PK/PD, modeling & simulation, formulation development, pre-clinical, patient safety, and clinical operations. The PDC is in place to optimize and better address the development of pediatric medicines in the rapidly evolving regulatory and scientific framework. This session will describe ways in which the CRO with a PDC can support the development of new medicines for children.

**3:30-4:20**

**iCAN Committee Fair**

**Youth council, parents council, technology committee, education committee, and events planning committee**

Coordinated by Amy Ohmer

**Team Facilitators meetings**

Lead by Amanda Woelk

**Friday June 28:  
9-9:50 Panel Presentation on partnership with iCAN and ISPI**

**10-11:20**

**Words Matter: Decoding Effective Communication Techniques with the Adolescent Patient**

This session will focus on the importance of provider to patient communication, and just as important, how the teen and adolescent patient communicates to their hospital providers. A patient panel from KIDS-KC will lead the conversation and facilitate small-group discussions during the session.

Laura Miller, Patient Experience Consultant

KIDS KC Panel

Sophia Klaudt

Lauren Spector

Audrey Beebe

Lauryn Birmingham

Caleb Wolf

**11:30-12:20**

**E-Cigarettes, JUUL and Vaping: What you Need to Know (Youth only)**

E-cigarette use, sometimes called “vaping,” is growing rapidly in popularity among adolescents and young adults. Adolescents are uniquely vulnerable to nicotine addiction, and those who use e-cigarettes are more likely to progress to using other tobacco products. In this session, Dr. Susan Walley, Chair of the AAP Section on Tobacco Control, will present the current evidence around vaping, describe health effects, and discuss effective strategies for protecting adolescents and young adults from nicotine addiction. The presentation will include an interactive dialogue where attendees can ask questions and share their experiences with vaping and e-cigarettes.

Susan Walley, MD, FAAP

**12:30-12:50 Pick up Lunch and take to next session**

**1-1:50 Concurrent Sessions**

**Caregiver and Youth Perspectives on Barriers to Academic Success While Living with Medical Challenges**

A comparative study involving educators, healthy students, caregivers, and students who have experienced or are living with an injury, medical challenge, or illness. Methodology used will be a survey-response format, distributed digitally and collected anonymously. Both quantitative and qualitative analysis will be performed and data driven actionable measures will be presented to engage and advocate for students living with medical challenges

Stephanie Meisner, RN, BSN, CCRP Director-Clinical Research, Children’s Healthcare of Atlanta  
Jake Haygood Student   
Ananya Ganesh Student

Hampton Woods Student   
Paige Meisner Student

Kalee Polk Student

**It’s no choke! (Pill swallowing without tears)**

Swallowing medicine in pill form will benefit a person throughout their lifetime. Teaching this life skill to young children can enable accurate dosing of important medicines to the child. We have gathered 4 methods of pill swallowing techniques into one toolbox. We hope that this session will give us feedback on the materials and obtain suggestions of tools to add to the box.  
Melissa Keeney, Consultant, Drug Product Design and Development, Eli Lilly and Company

Mary A Short RN, MSN, Sr. Clinical Research Advisor, Pediatric Capabilities Function, Eli Lilly and Company

Courtney Tate, PhD

**2-2:50**

**More Than Medicine: Reimagining How Hospitals Care for Seriously Ill Children and Their Families**

This presentation will open participant’s eyes to the availability of a state-of-the-art pediatric patient incentive program that engages patients positively in their own recovery while increasing adherence to difficult, painful, and lengthy medical plans. Currently being piloted at nine hospitals throughout the US, this program will be available to hospitals nationwide in the coming year.  
Carolyn Schneiders Fung, CCLS, Director of National Programs at Hope for Henry Foundation

**3-4:50 POD IRB Presentations**

Each group will present the study that they’re group reviewed and whether they approved the study. Presentations should include what issues the group discussed, any questions/changes they may have for the research team and their rationale for their determination.

**5-9 Closing Ceremony**