Update

Research Newsletter October 2015

The Power of Knowledge

By Stephen Kanne, Executive Director

Autism research is one of the cornerstones of the mission of the Thompson Center. Better understanding of the genetic and environmental factors in autism lead to better, more effective treatments and supports that improve outcomes for children and adults with autism. Our center has been at the national forefront of autism research since our founding in 2005, having served as a model site in the groundbreaking Simons Simplex Collection genetic research study that collected genetic samples from more than 2,600 families with children with autism. Today, this treasure of genetic information continues to provide the basis of understanding the causes of autism and is helping researchers understand how to treat the many expressions of autism across the spectrum of this complex disorder.

We have continued to partner with the Simons Foundation Autism Research Initiative, participating in the Simons Variations in Individuals Project (VIP) that connects researchers across the country with families who want to contribute their voices about the features of autism and the issues they face. You can read more about VIP on page 2 of this newsletter.

A new landmark study will launch in early 2016: the Simons Foundation's National Autism Cohort project. The Thompson Center has been selected as one of 22 sites across the country to individually recruit 3,000 children and adults with autism spectrum disorder over the next three years – entirely online and from home. The result will be a cohort of 50,000 individuals who contribute medical, behavioral and genetic information to support SFARI's goal to develop better treatments and services to support individuals with autism.

We hope you will consider contributing your family's voice to this incredibly important effort. To express your interest in participating in this project please email our Research Core Administrator Nicole Takahashi at takahashin@missouri.edu.

What's Inside?

Miles publishes review of new uses for existing genetic tests

Thompson Center researcher, geneticist and pediatrician Dr. Judith Miles recently published an invited editorial in the Journal of the American Medical Association reviewing a study of molecular diagnostic tests in children with complex autism.

The techniques used in the study, chromosomal microarray analysis and whole-exome sequencing, allowed researchers at the University of Toronto to attribute complex autism symptoms of participating children with a known genetic mutation in 37.4 percent of cases. Less severe cases of autism, classified as "essential" autism, were only linked to a genetic mutation in 4.2 percent of cases.

Miles said the use of these genetic tests in a new application to autism diagnosis may be as much as seven times more informative than traditional chromosomal testing.

"Foremost, the data indicates that physicians responsible for diagnosing children with autism spectrum disorder should arrange genetic evaluations using techniques that have the best chance of determining a conclusive diagnosis," Miles said in the editorial. "It is undeniable that precise diagnoses pave the way to better medical care, improved surveillance, better functional outcomes and informed genetic counseling, often with the possibility of prenatal or preimplantation diagnosis."

Hear that ECHO?

Telehealth autism clinic receives grant to create 10 new sites

Dr. Kristin Sohl, a developmental-behavioral pediatrician at the University of Missouri Thompson Center for Autism and Neurodevelopmental Disorders, will expand the growing ECHO Autism program to an additional 10 sites aross the country.

Sohl's ECHO Autism project, which launched in March as a pilot program, will be the centerpiece of a recent grant renewal through the federal Health Services Research Administration's Autism Intervention Research Network for Physical Health initiative. The $15 million award is shared among 14 autism centers in North America that are part of the Autism Speaks Autism Treatment Network.

"I am excited to be focusing my efforts on changing the landscape for autism care across North America and working to improve the health system so centers of excellence in autism can improve throughput for more children to enhance quality of life for more families," Sohl said.

ECHO Autism is based on a telehealth specialist network model developed by a hepatologist at the University of New Mexico, Sanjeev Arora, to serve the needs of hepatitis C patients who had no access to treatment where they lived and were dying on the growing waitlist for his clinic.

Extension for Community Healthcare Outcomes (ECHO) pairs specialist centers, such as those at the Thompson Center, with community providers to help them manage cases and empower them with knowledge to help their patients locally.

Sohl's pilot cohort for ECHO Autism, the first ECHO-based project for autism care in the U.S., included 15 providers from all over the country, including rural and underserved areas in Missouri.

With a goal to develop 10 additional centers of excellence in autism care through this program, Sohl's new efforts will bring this specialty knowledge about common medical issues in children with autism and barriers to diagnosis and treatment to an exponentially larger group of physicians.

"Dr. Sohl is a gifted physician who is passionate about caring for children," said Thompson Center Executive Director Dr. Stephen Kanne. "Her efforts to close the gap in access to quality medical care so that children with autism can have the best outcomes possible are vital to extending our center's work to help kids beyond our local and regional communities."

Most importantly, patients served by providers in the ECHO Autism network have the chance to be treated in their own community, without waiting or traveling to see a specialist.

"The ECHO Autism model will improve early identification of autism and increase screening and treatment of common co-occurring conditions in the primary care setting, particularly in underserved communities," Sohl said.

Family VIPs

Research Core Administrator Nicole Takahashi recently supported the Simons Variation in Individuals Project (VIP) at its annual Family Meeting in July. The project supports the study of genetic variants linked to developmental delays, and the family meetings allow participants to connect to all of the ongoing studies at once and get updates on newly published research.

Thompson Center Executive Director Dr. Stephen Kanne and Training Core Administrator Anna Laakman were members of the original VIP consortium while at Baylor College of Medicine in 2011. As executive director of the affiliated Texas Children's Hospital Autism Center, Kanne oversaw the launch of the Simons VIP project at the Houston site.

MU's Takahashi provided overall research coordination at this year's meeting, which included 40 families from across the country (plus a few international families from Sweden and Australia) and 40 researchers collecting data for 12 different studies.

For more information, visit www.simonsvip.org

Engineering research links health data with genetics and autism symptoms

Multidisciplinary research collaborations are a hallmark of Thompson Center investigations.

Since the formation of the center in 2005, researchers from genetics, psychology, psychiatry, neuroscience and clinical practice created teams to research the causes of autism and newer, more effective treatments.

Over the last several years, we've expanded collaborations even further into the realms of engineering and computer science. The explosion of health data available combined with the power of innovative technology and analytical approaches to that data promise to propel autism knowledge and care into new frontiers.

In collaboration with Dr. Gang Yao in MU's Department of Electrical Engineering, geneticist Dr. Judith Miles is helping to narrow down the physical biomarkers that indicate predisposition to autism and to apply those noninvasive screening techniques to newborns and infants. Building on their study that discovered a delay in the pupillary light reflex in children with autism, Yao is now working on a device that can be incorporated into a bassinet to record this reflex as a screen for autism in infants. Their goals is to ensure that children who have a delay in this reflex are followed more closely with developmental care to ensure the earliest possible diagnosis and intervention for those who later develop autism.

Dr. Chi-Ren Shyu, director of the MU Informatics Institute and a professor of electrical and computer engineering, is also partnering with the Thompson Center's Executive Director, Dr. Stephen Kanne, and Dr. Miles on a new research venture. Using the data from the Simons Simplex Collection study, for which the Thompson Center was a model site, Shyu will investigate correlations between genetic data and symptom information to uncover how certain genetic mutations and chromosomal variations are linked to the presence and severity of symptoms of autism.

By identifying tentative subtypes of autism based on groups of symptoms linked to genetic variations, the project's findings could lay the foundation for treatments tailored to those subtypes to see a greater improvement in symptoms for those individuals.

Cheak-Zamora honored by public health group

Congratulations to Dr. Nancy Cheak-Zamora for receiving the Young Professional Award from the Maternal & Child Health section of the American Public Health Association (APHA).

The award honors professionals age 40 or younger who have made a significant contribution to the field of maternal and child health. Further, the recipient must show potential for making a sustained and meaningful impact on the field in years to come.

Dr. Cheak-Zamora will receive the award at the APHA annual conference on Nov. 2, and the following day she will present her recent Photovoice research project that she conducted at the Thompson Center. Cheak-Zamora utilized Photovoice methods to engage young adults with autism in documenting and talking about their transition to adulthood.

The project used a series of photographs taken by the young adults, interviews, group activities and a public exhibit of the photographs to provide insight on their perceptions of adulthood, their goals and the services they need to succeed.

WANT TO HELP? JOIN A STUDY!

Autism Impact Measure

The purpose of this study is to test a new tool for assessing improvement in children's autism symptoms. The tool was designed to be easy-to-use and sensitive to short-term treatment effects. This project will examine the tool's ability to track change over the course of two different types of treatment: early intensive behavioral intervention and social competence intervention.

- **Eligibility:** Individuals ages 2-14 with a diagnosis of an autism spectrum disorder, enrolled in EIBI or social competence intervention
- **Time required:** 2 visits, 2.5 hours each/ 3 phone interviews, 30 min each
- **Location:** Thompson Center and various locations statewide
- **Monetary compensation:** Yes
- **Contact:** Thompson Center Research Core, 573-884-6092, tcresearch@missouri.edu

Just Announced: National study

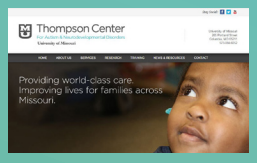
The Simons Foundation Autism Research Initiative has selected the Thompson Center at University of Missouri as one of three pilot sites across the country to open recruitment for its National Autism Cohort project, before the end of 2015.

Want more information? Email takahashin@missouri.edu to receive updates about recruitment for this landmark genetic study.

Interested in being contacted for future studies?
Call 573-884-6092 or email tcresearch@missouri.edu

Stay Connected.

Keep in touch with all that's happening at the Thompson Center. Find us:



thompsoncenter.missouri.edu @mutcautism facebook.com/thethompsoncenter

205 Portland St.
Columbia, MO 65211
573.882.6081
1.888.720.0015

Thompson Center for Autism & Neurodevelopmental Disorders
University of Missouri