Epilepsy Genetics Initiative Seeks Enrollees in Database

Three million Americans currently live with epilepsy and 30-40 percent have uncontrollable seizures – of which genetics is proving to be a major cause. Citizens United for Research in Epilepsy (CURE) has partnered with the National Institute of Neurological Disorders and Stroke (NINDS) to create the Epilepsy Genetics Initiative (EGI) – a first-of-its-kind database that aims to unlock the genetic secrets of the disease and drive research into its causes and treatments to ultimately find a cure.

For patients diagnosed with epilepsy, initial DNA analysis may not identify a cause. EGI will permit for reanalysis as breakthrough genetic discoveries are made, linking patients, physicians and scientists together to better customize treatment for different forms of epilepsy.

More than one-third of all those living with epilepsy deal with uncontrolled seizures, living day-to-day at the hand of epilepsy,” explained Dr Tracy Dixon-Salazar, associate research director at CURE and mother of a child with severe epilepsy whose condition has been improved by exome sequencing. “For these one million people, seizures come unannounced and hijack your life – EGI can get us closer to identifying causes and help us find better treatments and cures.”

EGI will allow for the discovery of additional genetic mutations that cause epilepsy, which can lead to better patient care. Knowing a person’s genetic makeup can better inform a physician’s diagnosis and treatment of epilepsy, as well as provide a better understanding of why some patients experience other conditions such as depression, autism or cognitive challenges.

EGI is open to anyone who has epilepsy and has had their exome sequenced. Enrollment is available via one of the eight enrollment sites or remotely by calling 844-EGI-CURE. For more information, visit www.cureepilepsy.org/egi.
**ECHO - CHICAGO**

Dana Sohmer, MA  
Project Coordinator, ECHO - Chicago

ECHO-Chicago is built on the premise that case-based learning is an effective teaching model in clinical education. Following a didactic presentation by a subspecialist, community-based providers present challenging patient cases for a guided in-depth discussion. Through this model, providers increase their knowledge base and capacity to care for patients in the medical home and no longer need to refer those patients to specialty care. Case presentation discussion is integral to the success of the pilot Child & Youth Epilepsy (CYE) telehealth clinic, which wrapped up on August 31st. Ten community-based providers from seven sites and one safety-net hospital in Chicago presented ten patient cases they are managing in the primary care environment.

One such case was a boy who had been experiencing 1-2 seizures/year when he visited his nurse practitioner (NP) at a Federally Qualified Health Center (FQHC) this past winter. The ECHO-Chicago provider was interested in understanding the medical regimen prescribed by the neurologist, the connection between epilepsy and ADHD, and ways to better support the family in disease management and ensuring his safety at school. In a follow-up case discussion six months later, the boy had been seizure free, was tolerating his medications, and with the NP’s support, encouragement, and an action plan set out for his teacher, was able to attend his 8th grade out-of-state field trip. While this boy’s care continues to be co-managed by his neurologist and the ECHO-Chicago trained provider, the NP provides integral care to the family to help him thrive in daily life.

**COLORADO - ECHO**

Carolyn Green, MD  
Pediatric Epileptologist, UC Denver

The Colorado ECHO-CYE team is happy to announce the completion of the first ECHO-CYE series. The last session underscored how the format can promote a community collaborative for process improvement. One of the school nurse participants was excited to learn about the transition to adult care check list. She will carry it to the planning committee for the public school 18 to 21 year old transition program with the recommendation it be used to develop programming to address medical care transitions for their students. In addition, in many of the presentations our epilepsy foundation participants have been able to explain how they can be of help to patients and their families, especially with school planning. Thanks to the AAP and MCHB for their support.
Project staff developed a new conference called “Take the NEXT STEP! Transition Planning For Teens With Epilepsy” which took place from July 31 - August 2, 2015 at Hershey Lodge in Hershey, PA. The program was for youth, ages 14-18, with a diagnosis of epilepsy / seizure disorder and their parent or guardian to navigate the journey of healthcare transition together. More than 60 people participated in large group skill building sessions as well as small group break-out sessions throughout the weekend. The keynote speaker was Patti Hackett-Hunter, MEd, Co-Director at Hackett & Hunter Solutions in Windsor, MA. Other speakers included educational consultant/transition expert, Deborah Evans, Ed.D., Harlem Wizards player/inspirational speaker, Mighty Mike Simmel, and EFWCP volunteers/epilepsy advocates, Heather Green (parent) and Annamarie Green (youth). Participants learned the skills needed to effectively transition to healthcare independence, and provided positive feedback from all who participated in taking the Next Step. The role of the program is to engage these teens to participate in the rebooted Youth Council program, to provide them with an ongoing program to strengthen their abilities and make an impact on others living with epilepsy/seizure disorder.
June 16th - June 18th marked the 2nd annual meetings for the MCHB Project Grantees and Advisory Committee. The two meetings were held in Washington, DC and focused significant objectives such as measuring impact, data collection, educational strategies, rural health/ cultural effectiveness, and quality improvement.

When surveyed on what the grantees enjoyed most about the meeting, they replied:

- Liked that the schedule had flexibility and some open space for informal dialogue, which is often the richest!
- Finding out more about their projects was extremely helpful.
- The opportunity to talk with other grantees and learn about their successes and challenges
- The small group work and interactions with fellow grantees.

View the video to learn more about our inspirational grantee meeting
AAP SECTION ON TELEHEALTH CARE UPDATE

The Division of Innovation (DOI), the home of the Coordinating Center on Epilepsy, is an evolving Division that serves as a national program office responsible for managing regional and state grant-funded programs that address access to care through technology and innovation. The DOI also now serves as the home for the Task Force on Pediatric Practice Change and the Section on Telehealth Care (SOTC).

The SOTC is the AAP home for information on the delivery of pediatric care via e-mail, video conferencing, telephone care, telemedicine and other non-face-to-face technologies. As we move forward, we recognize that telehealth care is becoming an increasing component of pediatric practice. Under pressure to limit office and emergency department utilization and with increasing expectations for access by working parents, pediatricians are finding themselves dispensing more and more advice over the telephone, via e-mail visit, both during and after office hours. Practice surveys have reported that non-face-to-face telephone care accounts for at least 20% of all general care in a pediatric practice and as much as 80% of after-hours pediatric care. Faced with the task of meeting the expectations of parents and health plans, pediatricians find themselves compelled to manage complex medical problems over the telephone, dedicate practice resource, and expose themselves to liability risk with little assurances that these efforts will be compensated until now.

Given the multitude of pressures that pediatricians and the health care system at large face, pediatricians are looking for advice on how to provide high quality, safe, and efficient care via the telehealth modalities.

The mission of the SOTC is to improve the provision of in-person and remote care through the use of telehealth technology in a medical home. To accomplish this mission, SOTC will develop guidance and education on telehealth care and advocate for those who receive and provide it.

- Telehealth care is integrated into the menu of services provided through the medical home and is valued by pediatricians, patients and families, and payers and paid at an appropriate rate.

- Pediatricians are compensated appropriately based on the services they provide. These services may be provided in-person or remotely using appropriate telehealth technology, depending on the needs of the patient, without affecting payment.

For more information, please contact the Director, Division of Innovation at tcalabrese@aap.org.
Help us SPREAD THE WORD about the 2015 National Conference in Washington, DC!

Remember, the AAP Conference Planner is a great source to get updated information regarding sessions and events taking place at the 2015 National Conference.

CLICK HERE to learn how to use the AAP Conference Planner.

The Division of Innovation will have an exhibit booth at the NCE this year!

Be sure to stop by for more information about the Division’s activities, most especially, increasing awareness and access to children and youth with epilepsy.

If interested in more information, please contact dsantos@aap.org.

SATURDAY, OCTOBER 24, 2015
Telementoring as a Strategy to Reach Children Globally | 2:00 - 3:30 pm

Faculty: Sanjeev Arora, MD and Sucheta Joshi, MD, MB, MS, FAAP

Children with chronic medical conditions (asthma, diabetes, epilepsy, ADHD, etc.) frequently do not have access to subspecialists and wait times for an appointment can exceed months. This promises to be an inspiring but practically useful interactive group forum as the founder of Project ECHO (Extension for Community Healthcare Outcomes) shares how this model of care has increased access to subspecialty care within the medical home, around the globe for several medical conditions.
One Seizure, Two Seizures: What Do I Do Now? | 7:30 – 8:15 am | Repeats as S2057 on Sunday, October 25, 2015 at 9:30 am

Faculty: Paul Graham Fisher, MD, FAAP

When a child presents with a first or second seizure both temperature and anxiety can be high. Do you know how to evaluate and manage the child with a first or second febrile seizure or seizure without fever? Come review the most current approach for handling a child with new-onset seizures, and review AAP guidelines that address this topic.

Changing the World of Pediatrics: How Telementoring Can Aid in Reaching Children Globally | 10:00 am – 10:40 am

Faculty: Sanjeev Arora, MD

Children in the United States and across the globe with chronic medical conditions (asthma, diabetes, epilepsy, ADHD, etc) often lack access to subspecialists, as wait times for an appointment can exceed months. In rural areas, it is not uncommon for families to drive nearly 200 miles to see a subspecialist, resulting in costly travel, time away from work/school, and parents feeling intimidated by "big city" navigation. This plenary session promises to be inspiring and thought provoking, as the founder of Project ECHO (extension for community healthcare outcomes) shares how this model of care has increased access to subspecialty care within the medical home and around the globe for several medical conditions.

What Happens Next: Update on Epilepsy Treatment | 4:00 - 5:30 pm | Repeats as S4106 on Tuesday, October 27 at 4:00 to 5:30 pm

Faculty: Dewi Frances T. Depositario-Cabacar, MD and Ajay Gupta, MD, FAAP

Nearly 30% of patients with epilepsy have seizures that are not controlled by medication. There are many options for this population, including newer medications, epilepsy surgery, dietary therapy, and nerve stimulation. Recent media reports have highlighted supplements and plant-based therapies as well. Come listen to our experts discuss what to do when the older medications are not working.

Shake, Rattle, and Roll: Was That a Seizure? | 4:00 - 4:45 pm

Faculty: Sarah Nicole Kelley, MD and Eric Heath Kossoff, MD

Did you see that? Was that a seizure? Something else? A breath holding spell, myoclonus, shuddering attack, migraine, tic, faint, or something else? Come learn how to sort out and identify the spells that will present in your practice, and lean what is neurological, cardiac, or even benign.
WEBINAR - EPILEPSY & SEIZURES IN SCHOOLS

The Epilepsy Foundation is sponsoring a FREE live webinar titled “Supporting Students with Epilepsy & Seizures in Schools: What You Need to Know School” on Tuesday, September 15 at 8:00 p.m. EDT. Join nurses Donna McKenny and Rebecca J. Schultz as they discuss the challenges both parents and school personnel face when a student with epilepsy goes to school, and provide practical guidance on how to create a safe and supportive learning environment. Learn More and Register Now

AAP COUNCIL ON CHILDREN WITH DISABILITIES (COCWD)

The COCWD is dedicated to providing its nearly 500 members with a forum for education, communication, networking and advocacy. Current COCWD policies, publications, educational offerings, and initiatives focus on: Autism; Care Coordination; Cerebral Palsy; Chronic Health Conditions; Developmental Screening; Early Intervention Services; Education Services; Home Care; Learning Disabilities; Medical Complexity; Motor Disabilities; Neurodevelopmental Disabilities; Parent, Provider, & Community Partnerships; Sexuality; Spina Bifida; Transitioning to Adult Care; and more.

Opportunities available to COCWD members include:

- providing expert review and feedback on publications, policies, state and national topics affecting the disabilities population and their families
- submitting ideas for educational topics
- serving as faculty at national conferences

The COCWD is also the home of all autism activities at the Academy. Membership in the COCWD is available to pediatricians, residents, nurse practitioners, physician assistants, and more.

Click here to join the COCWD.

Did you know that AAP has a new Twitter handle dedicated to highlighting global child health news and activities? The handle shares original content about the Academy’s work, news from partners and campaigns, and messages spotlighting our members’ international efforts.

We encourage you to join the conversation by following @AAPGlobalHealth.

We’ve had a great 3.5 months with 600+ followers!

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Call for Applications: Innovative and Promising Practices in Pediatric Medical Home Implementation

Are you working with practices, families, states, and/or other organizations to implement pediatric medical home? Showcase your work through the National Center for Medical Home Implementation (NCMHI) by completing an application for innovative and promising practices in pediatric medical home implementation. All pediatric medical home stakeholders are eligible to apply. This includes, but is not limited to, clinicians, practices, family organizations, community-based organizations, and state agencies. Applications will be reviewed by an expert panel and selected innovative and promising practices will be published on the NCMHI Web site. Complete an electronic submission or email medical_home@aap.org to receive a Microsoft Word® Document application.
As we embark upon the fall season in the Midwest, it reminds us of the magnificence of change. We foresee a vibrant future ahead that will help transform and enrich the world of pediatrics.

Achieving quality care for all children along the way.

Children are the Priority.
Change is the Reality.
Collaboration is the Strategy.

—Judith Billings—