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In Support of the National Center on Birth Defects and Developmental Disabilities

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News from Executive Committee

Note from the Chair

Greetings!

Spring is upon us. For many of us, trees and flowers are blooming and the weather is changing (sometimes dramatically in a 24-hour period)! But the weather isn't the only thing changing.

Peggy Honein, Division of Birth Defects and Infant Disorders, has accepted a new position serving as the Senior Scientific Advisor in the Division of Preparedness and Emerging Infections in the Division of Preparedness and Emerging Infections in CDC's National Center for Emerging and Zoonotic Infectious Diseases. Her commitment to partners and excellence are demonstrated in her work, notably her leadership as part of the Zika and COVID-19 Responses. As she takes on this new role within CDC, we know she will always be a part of NCBDDD and will continue as a champion for the populations we serve.

Job postings for the Division of Birth Defects and Infant Disorders Director position are posted. Please share with those who you think would be interested.

- <https://www.usajobs.gov/GetJob/ViewDetails/598030100> (0601)
- <https://www.usajobs.gov/GetJob/ViewDetails/598030800> (0602)

We wish Peggy success in her new endeavor!

If you have any questions, contact me at sstruwe@sbaa.org.

Best,

Sara



New to the Friends?

Have you recently joined the Friends of NCBDDD listserv? If so, please contact [Diana Felner](#) so that you can be added to our Membership Directory. Thank you for supporting the mission of Friends of NCBDDD. Questions can also be directed to [Sara Struwe](#).



Saving Babies

Demonstration on SMA Evaluation via Telehealth Visit

[Cure SMA](#) is pleased to announce the release of "Evaluation of Spinal Muscular Atrophy in the Era of Telehealth," a video series launched in collaboration with *NeurologyLive* and *HCPLive*. The goal of this partnership is to enhance current awareness and understanding of SMA diagnostic requirements, while demonstrating opportunities to screen and evaluate suspected SMA in a remote appointment setting. The telehealth video series features Diana Castro, MD, and Garey H. Noritz, MD, as they discuss:

- The early clinical features of SMA.
- The clinical implications of delayed diagnosis of SMA.
- Diagnosis assessment tools.
- The current state of newborn screening for SMA.
- Resources available for physicians, patients, and caregivers to better manage SMA.
- Resources available for families new to the telehealth system.

The series also includes sample in-person and remote neurological exams to highlight key signals that may be observed in infants with SMA Type 1. The recordings and complementary segments for physical therapists may be accessed on the [NeurologyLive](#) and [HCPLive](#) websites.

Announcing the new **ReproAnswer™ System**

According to the CDC, 9 in 10 women take at least one medication during pregnancy. For most medications, the safety or risk profile is either unknown or difficult to find. RightAnswer's new ReproAnswer™ System is an integrated, multiple data source solution, designed to help healthcare providers and women weigh the risks and benefits of treatment options during pregnancy and lactation.

Developed with CDC sponsored SBIR grants (2015-2019), this web-based and mobile solution enables healthcare providers to more effectively counsel pregnant patients about possible effects of prescription and over-the-counter medications on their developing babies, as well as provide information on substance use, environmental/workplace exposures, infections, vaccines and more.

Healthcare providers have indicated there are four distinct information needs and usages which are addressed by the ReproAnswer™ System:

- Find authoritative information to support medication safety in pregnancy and lactation
- Understand quickly by efficiently searching for topic-specific information
- Decide on the most appropriate medication treatment options
- Explain to patients and family members so they feel more comfortable with decisions

For additional information:

[ReproAnswer System Brochure](#) | [ReproAnswer System Video](#) | www.RightAnswer.com

Webinar: Developmental Neurotoxicity of Methylmercury

Tuesday, May 4, 2021, 12:30 PM - 2:30 PM ET

Mercury is a contaminant of global concern and methylmercury in fish and shellfish is the most important source of exposure for most people. From the identification of methylmercury as the causative agent in the Minamata disease in 1959, through the mass exposure event in Iraq in 1971-72 from grain treated with a methylmercury fungicide, and studies of exposures in high seafood consuming populations, the history of research on the developmental toxicity of methylmercury tracks with the 60-year history of the Society for Birth Defects Research and Prevention. Methylmercury is currently undergoing reassessment under the US EPA IRIS program, highlighting the timeliness of this update on the state of the science on the developmental neurotoxicity of methylmercury. The goal of this webinar is to provide a historical perspective and current understanding of methylmercury exposure and developmental neurotoxicity. Presentations will cover the history of methylmercury research; trends in methylmercury exposure; perspectives on the contribution of animal and in vitro models to the understanding of methylmercury developmental neurotoxicity, an update on current research, and promising lines of future research; the contribution of epidemiological research, particularly large prospective cohort studies of high seafood consuming populations; and how recent epidemiology studies on the neurobehavioral effects of methylmercury will be used to update the EPA IRIS Methylmercury Assessment. This webinar is free and open to anyone. [Register today!](#)

Society for Birth Defects Research and Prevention Virtual Annual Meeting

June 24 - July 1, 2021

[The 61st Annual Meeting of the Society for Birth Defects Research and Prevention](#) will be a fully online, virtual experience that will take place weekdays from June 24 to July 1, 2021. The Keynote Lecture will be given by Dr. Carleigh Krubiner, Johns Hopkins Berman Institute of Bioethics. Dr. Krubiner's research focuses on ethical issues surrounding the equitable development and delivery of health interventions in low and middle-income settings. For the past several years, Dr. Krubiner has co-lead work focusing on how epidemic vaccine development and deployment can be more responsive to the health interests of pregnant women, with more recent work focusing on COVID-19 vaccine R&D and distribution. The meeting program includes the following sessions:

- Approaches for Mechanistic Evidence Analysis in Hazard Evaluation of Reproductive Toxicology Data
- The Effects of Water Fluoridation on Neurodevelopment and Other Health Outcomes

- Neglected Diseases/Neglected Patients
- Cannabis in Pregnancy and Through Generations
- Nonclinical Considerations for Inclusion of Pregnant and Lactating Women in Clinical Trials
- Current Topics and Updates for Pregnancy Registries
- Can Experimental Animal Studies Be Used in Counseling
- Molecular Mechanisms of Fetal Alcohol Spectrum Disorders in Humans and Animal Models

Additionally, education courses throughout the month of July will focus on Craniofacial Morphogenesis and Teratogenesis, Development and Disorders of the Gastrointestinal Tract, and Single-Cell RNA Sequencing in Understanding Normal and Abnormal Development.



Helping Children

Autism Acceptance Month with AMCHP's State Public Health Autism Resource Center (SPHARC)

The Association of Maternal & Child Health Programs' (AMCHP) [State Public Health Autism Resource Center \(SPHARC\)](#) is excited to announce their Autism Acceptance Month 2021 activities!

On Thursday, April 1, SPHARC hosted a Twitter chat to kick off Autism Acceptance Month. SPHARC will also host a series of four coffee talks every Wednesday in April from 2:00-2:45pm EST that cover a variety of topics across the lifespan. Each coffee talk will feature brief presentations followed by a question-and-answer session with participants. [Register to attend](#). Topics are in the process of being finalized and are subject to change. Information for joining the coffee talks will be sent upon registration.

Title V MCH & CYSHCN leaders, autistic individuals and their families, students and peer mentors, public health professionals, and others wanting to learn more about supporting and accepting autistic individuals are encouraged to participate.

For the most up-to-date information on SPHARC Autism Acceptance Month activities, please visit <http://bit.ly/AMCHPacceptance> or contact [Paige Bussanich](#) with any questions.

Virtual Tourette Association of America Conference: Working Together, Living Better

May 14 - May 16, 2021

The [Tourette Association of America](#) is hosting the [2021 Virtual Conference for the Tourette Syndrome and Tic Disorder community](#) on May 14 – 16, 2021. Focusing on Working Together and Living Better, the three-day event will offer a comprehensive Research Symposium, a Newly Diagnosed Seminar and over 20 highly engaging educational programs for our community to learn, engage, and connect with each other. In addition, there will be [accredited programming](#) offered for education and health professionals to expand knowledge of the disorder to improve treatment and care.

Provider Education Webinar Series: Advances in the Treatment of Tics

Thursday, June 10, 2021, 3:00 - 4:00 PM ET

This series of webinars is geared towards medical providers who are interested in learning more about Tourette Syndrome (TS) treatment and management strategies. We invite physicians, nurses, nurse practitioners, and psychologists, regardless of Tourette Syndrome experience, to attend these webinars. All webinars will be accredited for CMEs; more information will be provided soon.

Motor and phonic tics associated with Tourette syndrome (TS) can range in severity from barely perceptible to disabling and most patients have a variety of behavioral co-morbidities, particularly, attention deficit disorder and obsessive-compulsive disorder. Therefore, therapy must be tailored to the individual needs of the patients. In addition to behavioral therapy, oral medications such as alpha agonists, dopamine depletors, anti-psychotics, and topiramate are used to control the involuntary movements and noises. Botulinum toxin injections are particularly effective in patients with troublesome focal motor and phonic tics, including coprolalia. Deep brain stimulation may be considered for patients with "malignant" TS, that is, refractory to medical therapy. When appropriate therapy is selected and implemented, most patients with TS can achieve their full potential and lead essentially normal life.

[Register today!](#)

Education Professional Webinar Series: Handwriting and TS: Common Issues that Impact Learning

Wednesday, June 16, 2021, 7:00 - 8:00 PM ET

This webinar series has been created to provide educators working in the classroom and school setting with further information on Tourette Syndrome (TS), its co-occurring conditions and management strategies.

Students with TS present with multiple underlying issues that interfere with their ability to produce legible, written material that accurately reflects their knowledge and subject mastery. Participants will learn how the complexity of each of these individual issues can combine to create a barrier to written work production. In addition to outlining the steps needed to accurately assess the student's difficulties, appropriate, individualized accommodations and interventions will be discussed. Case vignettes and work samples will be shared. [Register today!](#)

Provider Education Webinar Series: Transitioning to Adult Care: Time is Ticking Away

Tuesday, July 13, 2021, 3:00 - 4:00 PM ET

This series of webinars is geared towards medical providers who are interested in learning more about Tourette Syndrome treatment and management strategies. We invite physicians, nurses, nurse practitioners, and psychologists, regardless of Tourette Syndrome experience, to attend these webinars. All webinars will be accredited for CMEs; more information will be provided soon.

In this webinar, we will discuss the process of transitioning from Pediatric to Adult care for patients with Tourette Syndrome, Chronic Tic Disorders, and co-occurring conditions. There are a number of dramatic contrasts between Pediatric and Adult medicine that often complicate transition process. For example, the dynamics of an adult medical visit are completely different than in a Pediatric medical visit. Also, coordination of care between medical providers is often more complicated and is more patient driven. Participants of this webinar will be presented with strategies to manage these and other challenges inherent to the transition process. [Register today!](#)

Education Professional Webinar Series: Positive and Proactive Supports for Challenging Behaviors Associated with Tourette Syndrome and Co-Occurring Conditions

Wednesday, July 21, 2021, 7:00 - 8:00 PM ET

This webinar series has been created to provide educators working in the classroom and school setting with further information on Tourette Syndrome (TS), its co-occurring conditions and management strategies.

Tourette syndrome and the common co-occurring disorders can be challenging for students, their family and the education team. This webinar will provide successful philosophies and strategies that focus on positive and proactive supports for students with TS. [Register today!](#)

Maternal-Infant Health Interview Opportunity

The American Academy of Pediatrics (AAP) is recruiting pediatric primary care practices to participate in informative interviews to discuss models of care that embrace the core tenants of the pediatric medical home. This project aims to augment the current digital library of practice models that foster supportive environments for the families affected by parental opioid use. Interviewees will be asked to reflect on how they reinforce families' strengths and support parents in recovery. Promising Practices are an approach to encourage pediatric practices to consider recovery friendly approaches within the pediatric medical home framework. A Maternal-Infant Health Excellence Award and a letter of recognition are offered to the participating practices as a means for facilitating internal and external communication with their local, state or regional stakeholders. Interested practices are invited to [submit their application](#).

Training and Continuing Education on ADHD

CHADD's National Resource Center on ADHD in collaboration with the US Centers for Disease Control and Prevention is now providing training and continuing education on ADHD through it's Pocket MD podcast learning platform. The podcast-based courses will help healthcare providers to effectively diagnose, treat, and manage ADHD in children and adults. Continuing education credits available include CME, CNE, CEU, and CECH. Access the learning platform at [Training and Continuing Education on ADHD](#).



Protecting People

Roland B. Scott Memorial Symposium on Sickle Cell Disease

May 19, 2021, 10:00 AM- 4:00 PM ET

Join Howard University for research, advocacy and community building for all ages focusing on sickle cell disease, "Glimmers of Hope for Sickle Cell Disease: 2021." Join the conversation about new treatments for sickle cell disease and panel discussions on stigma, sexuality, aging, and insurance. Join through the web and the Whova app that can be downloaded after registration for a real interactive experience.

Speakers include Greg Kato, MD; Shawn Bediako, PhD; Lakshmanan Krishnamurti, MD; and Ahmar U. Zaidi, MD. [Register today for free!](#) This will be a virtual event. All are welcome! Questions, contact hupeds@howard.edu



Improving Health

Participants Needed: 2021 National Survey on Health and Disability

Survey closes April 30th, 2021

Share how access to health care, insurance and the COVID-19 pandemic affects your life. The NIDILRR-funded Collaborative on Health Reform and Independent Living (CHRIL) at the University of Kansas is looking for adults with disabilities to complete an online survey about health insurance, health care access and the current pandemic.

- Adults, 18 and over, with any type of disability, chronic illness/disease, mental or physical health condition are encouraged to participate
- The survey should take about 20 minutes to complete
- Responses are anonymous
- The survey may look familiar to you. It was posted in 2018 and 2020, and is being posted for a third time now. We welcome participation from those who completed it before and those who have never done it before.

To complete the survey, go to: <http://tinyurl.com/NSHD2021> If you prefer to take the survey over the phone or have any questions about participating, please call toll-free 1-855-556-6328 (Voice/TTY) or email healthsurvey@ku.edu.

ACHA Webinar: Living Life Fully with Pulmonary Arterial Hypertension

Wednesday, May 5, 2021, 7:00 PM - 8:00 PM ET

Did you know that pulmonary arterial hypertension (PAH), which affects up to 10% of adults with congenital heart disease, is a condition where the blood vessels passing to the lungs become unhealthy? This causes the right side of the heart to work harder. PAH limits the ability to exercise, and it also increases the risk for hospitalization and death. Do you want to know more? If so, register today. You will learn more about newest treatment therapies and how to live your life to the fullest with PAH. You don't want to miss this webinar. [Register today!](#)

ACHA Webinar: Lub Dub: What You Need to Know About Heart Rhythms

Wednesday, May 19, 2021, 7:00 PM - 8:00 PM ET

Do you know that rhythm problems or arrhythmias are one of the most common problems faced by adult congenital heart disease (ACHD) patients? Do you have a history of palpitations, or a fast or slow heart rate? Do you wonder if you are at risk of developing rhythm issues as you age? If so, mark your calendars to attend this webinar. Dr. Scott Cohen, ACHD cardiologist, will discuss risk factors and treatment options for arrhythmias in the ACHD population. [Register today!](#)

FREE Webinar on Healthcare Transition

Thursday, May 20, 2021, 7:00 PM ET

Turning 18 is when a teen becomes a legal adult and in charge of many parts of their life, including their medical care. But life out in the adult healthcare world is really different than in the pediatric world. Join Dr. Brandon Rocque and the Hydrocephalus Association's Amanda Garzon for a FREE webinar on May 20th at 7 pm ET entitled **Moving from Pediatric to Adult Care: Are You Ready?** During the webinar, you'll find out where your family stands on the checklist to your teen taking over their medical care so teens can move on and out (of the house) with confidence. Teens, bring your parent(s) and vice versa! This is meant to be an interactive discussion. [Register today!](#)

AUCD's Prepared4ALL Initiative Launches Online Training

The Prepared4ALL initiative, offered by AUCD's new Technical Assistance and Training Center, is excited to announce the launch of their online training, "**Prepared4ALL: Whole Community Inclusive Emergency Planning**". This free self-paced online training aims to help disability organizations increase their knowledge about emergency planning so they can begin or continue to get involved in these efforts in their local community while also building sustainable partnerships with their local emergency and public health professionals. This training is centered around the Prepared4ALL process, a strength-based model which helps organizations creatively and flexibly navigate inclusion and accessibility issues. Visit <http://bit.ly/Prepared4AllOnline> to learn more and enroll today!

Mental Health Support Needed for Transgender Adults with Disabilities

The March 2021 issue of [Disability in Focus](#) from the New Hampshire Disability & Public Health Project shows that in New Hampshire, 2 in 5 adults who are transgender have a disability. When asked about stress, depression, and problems with emotions in the last 30 days, people with disabilities who were also transgender had the most mentally unhealthy days. Review the data and learn strategies to support the mental health of people with disabilities who are transgender.

Disability-Competence Training for Health Care Providers

The *Responsive Practice: Providing Health Care & Screenings to Individuals with Disabilities* training from the New Hampshire Disability & Public Health Project enhances health care providers' ability to deliver disability-competent care that is accessible to people with intellectual, mobility, and other disabilities. Learn strategies to identify, address, and help remove barriers to care. [Responsive Practice](#) trainings are online, on-demand, and free for a limited time.

News from NCBDDD



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NCBDDD Partner Alerts have transitioned to GovDelivery. Haven't subscribed yet? [Register today](#). When the new window opens, enter your email address, and click "submit". When the above process is complete, you are subscribed for future NCBDDD Partner Alerts delivered via GovDelivery!

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Showcase an update or event with the Friends of NCBDDD!

Via the Monthly E-Digest:

Send updates on conferences, meetings, special awards and journal or research announcements for the next edition of the Friends of NCBDDD E-Digest!

Please submit the following information:

1. Title for news item
2. A short summary of 150-200 words
3. Web links or attachment for reference

Submit news items for consideration and questions to friendsofncbddd@gmail.com.

Submit

Via the Listserv:

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