

# CREATING CONNECTIONS COMMUNITY CONFERENCE

## DRAFT AGENDA 2024



A GLOBAL HYBRID GATHERING FOR  
FAMILIES, CLINICIANS &  
SCIENTISTS

JULY 19-20, BETHESDA, MD



July 19, 2024

Time	Description	Presenter
8:00 am - 8:15 am	<b>Welcome</b>	Lisa Manaster, President, CACNA1A Foundation
8:15 am - 9:15 am	<b>CACNA1A 101:</b> The Genetics of CACNA1A; Understanding how the Cav2.1 channel works and what that means for your CACNA1A variant	<ul style="list-style-type: none"> <li>Laina Lusk, MMSc, CGC, Children's Hospital of Philadelphia</li> <li>Jen Pan, PhD, Broad Institute</li> </ul>
9:15 am - 10:15 am	<b>Clinical Trial Readiness Initiatives:</b> Natural History Studies, Biomarker Project, CACNA1A Rare-X Data	<ul style="list-style-type: none"> <li>Terry Jo Bichell, PhD, COMBINEDBrain</li> <li>Wendy Chung, MD, PhD, Boston Children's Hospital</li> <li>Pangkong Fox, PhD, CACNA1A Foundation</li> </ul>
10:30 am - 11:00 am	<b>Science is Better Together: Insights from the Research Roundtable</b>	<ul style="list-style-type: none"> <li>Pangkong Fox, PhD, CACNA1A Foundation</li> <li>Marina Hommersom, PhD, Radboud University</li> <li>Dennis Lal, PhD, UTHealth Houston</li> </ul>
11:00 am - 12:15 pm	<b>Ask Me Anything Panel with Clinicians</b> <ul style="list-style-type: none"> <li>Hemiplegic Migraine</li> <li>Epilepsy</li> </ul> Moderator: Sooky Koh, MD, PhD	<ul style="list-style-type: none"> <li>Danielle Andrade, MD, MSc., FRCPC, CSCN, University of Toronto</li> <li>Alexis Karlin, MD, CHOP</li> <li>Daniel Licht, MD, Children's National</li> <li>Elsa Rossignol, MD, MSc., FRCP, CHU St. Justine, University of Montreal</li> </ul>
1:30 pm - 2:45 pm	<b>Ask Me Anything Panel with Clinicians</b> <ul style="list-style-type: none"> <li>Movement Disorders (Ataxia/Dystonia/Eye Movements)</li> </ul> Moderator: Aasef Shaikh, MD, PhD	<ul style="list-style-type: none"> <li>Kristin Baranano, MD, PhD, Johns Hopkins</li> <li>Chung Lab Team</li> <li>Scott Grossman, MD, NYU</li> <li>Laina Lusk, MMSc, CGC, Children's Hospital of Philadelphia</li> <li>Joanna Jen, MD, PhD, Mt. Sinai</li> <li>Aasef Shaikh, MD, PhD, Case Western Reserve University</li> </ul>
2:45 pm - 3:00 pm	<b>Update on Treatment Guidelines and Overview of Clinical Assessments</b>	Kristin Baranano, MD, PhD, Johns Hopkins
3:15 pm - 5:45 pm	<b>Clinical Assessments, Natural History Studies Enrollment, Genetic Counseling Consults &amp; Poster Session</b>	<ul style="list-style-type: none"> <li>Kristin Baranano, MD, PhD, Johns Hopkins</li> <li>Chung Lab Team</li> <li>Scott Grossman, MD, NYU</li> <li>Laina Lusk, MMSc, CGC, Children's Hospital of Philadelphia</li> <li>Joanna Jen, MD, PhD, Mt. Sinai</li> <li>Aasef Shaikh, MD, PhD, Case Western Reserve University</li> </ul>
6:00 pm - 8:00 pm	<b>Welcome Reception</b> with Clinicians, Researchers and Adult Attendees (Pizza and movie night for children)	

# CREATING CONNECTIONS COMMUNITY CONFERENCE



A GLOBAL HYBRID GATHERING FOR  
FAMILIES, CLINICIANS &  
SCIENTISTS

JULY 19-20, BETHESDA, MD



July 20, 2024

Time	Description	Presenter
8:15 am - 8:30 am	<b>Welcome to Day 2</b>	Sunitha Malepati, Vice President, CACNA1A Foundation
8:30 am - 9:15 am	<b>Empowering Change: The Impact of Community Engagement</b>	<ul style="list-style-type: none"> <li>• Sarah Greathouse - parent/board member/Newly Diagnosed Virtual Group Facilitator</li> <li>• Dr. Deborah Ondrasik - pediatrician/parent/board member</li> <li>• Chris Senaratne - parent/Australian Global Ambassador</li> <li>• Casey Dawley - parent, 5K Committee</li> </ul>
9:15 am - 10:00 am	<b>Mastering the Art of Advocacy in a Healthcare Setting</b>	<ul style="list-style-type: none"> <li>• Amy Junge, parent/board member</li> <li>• Linda Russo, University of Alabama, Center for Excellence in Developmental Disabilities</li> </ul>
10:15 am - 11:15 am	<b>Effective Speech and Language Therapy Strategies for Children with CACNA1A</b>	Fairmount Rehabilitation Programs, Kennedy Krieger Institute: <ul style="list-style-type: none"> <li>• Lynnley Moore, MA, CCC-SLP, CBIS</li> <li>• Rachel Anderson, MS, CCC-SLP</li> <li>• Hayeon Kang, MS, CCC-SLP</li> </ul>
11:15 am - 12:15 pm	<b>Let's talk about Cerebral/Cortical Visual Impairment (CVI)</b>	Rachel Bennett, Director of CVI Now, Parent Advocacy and Support, The CVI Center at Perkins School for the Blind, Watertown, MA
1:30 pm - 2:30 pm	<b>Understanding your Child's Neurodevelopmental or Neuro-Psychological Evaluation</b>	Mary Wojnaroksi, PhD, Nationwide Children's
2:40 pm - 3:25 pm	<b>Breakout Session Discussion Groups I</b> <ul style="list-style-type: none"> <li>• Vocational Rehabilitation - Assisting people with disabilities toward gainful employment</li> <li>• Special Education Survival Guide</li> </ul>	<ul style="list-style-type: none"> <li>• Tim Spong, VR Program Specialist and CACNA1A grandparent</li> <li>• Mary Wojnaroksi, PhD, Nationwide Children's</li> <li>• TBD</li> </ul>
3:30 pm - 4:15 pm	<b>Breakout Session Discussion Groups II</b> <ul style="list-style-type: none"> <li>• Adults with CACNA1A/ Parent/Caregiver Group</li> <li>• Youth Support Group (14-20 years)</li> <li>• Grandparents/Extended Relatives Group</li> <li>• Hemiplegic Migraine/Developmental &amp; Epileptic Encephalopathy Group</li> </ul>	Each group will have a moderator
4:20 pm - 4:30 pm	<b>Closing</b>	Amy Junge, Board Member, CACNA1A Foundation
6:00 pm - 9:00 pm	<b>Dinner &amp; Dance Party (all attendees)</b>	