

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

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Time	Description	Presenter
8:15 am - 8:30 am	Welcome to Day 2	Sunitha Malepati, Vice President, CACNA1A Foundation
8:30 am - 9:15 am	Empowering Change: The Impact of Community Engagement	<ul style="list-style-type: none"> • Sarah Greathouse - parent/board member/Newly Diagnosed Virtual Group Facilitator • Dr. Deborah Ondrasik - pediatrician/parent/board member • Chris Senaratne - parent/Australian Global Ambassador • Casey Dawley - parent, 5K Committee
9:15 am - 10:00 am	Mastering the Art of Advocacy in a Healthcare Setting	<ul style="list-style-type: none"> • Amy Junge, parent/board member • Linda Russo, University of Alabama, Center for Excellence in Developmental Disabilities
10:15 am - 11:15 am	Effective Speech and Language Therapy Strategies for Children with CACNA1A	Fairmount Rehabilitation Programs, Kennedy Krieger Institute: <ul style="list-style-type: none"> • Lynnley Moore, MA, CCC-SLP, CBIS • Rachel Anderson, MS, CCC-SLP • Hayeon Kang, MS, CCC-SLP
11:15 am - 12:15 pm	Let's talk about Cerebral/Cortical Visual Impairment (CVI)	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	Understanding your Child's Neurodevelopmental or Neuro-Psychological Evaluation	Mary Wojnaroksi, PhD, Nationwide Children's
2:40 pm - 3:25 pm	Breakout Session Discussion Groups I <ul style="list-style-type: none"> • Vocational Rehabilitation - Assisting people with disabilities toward gainful employment • Special Education Survival Guide 	<ul style="list-style-type: none"> • Tim Spong, VR Program Specialist and CACNA1A grandparent • Mary Wojnaroksi, PhD, Nationwide Children's • TBD
3:30 pm - 4:15 pm	Breakout Session Discussion Groups II <ul style="list-style-type: none"> • Adults with CACNA1A/ Parent/Caregiver Group • Youth Support Group (14-18 years) • Grandparents/Extended Relatives Group • Hemiplegic Migraine/Developmental & Epileptic Encephalopathy Group 	Each group will have a moderator
4:20 pm - 4:30 pm	Closing	Amy Junge, Board Member, CACNA1A Foundation
6:00 pm - 9:00 pm	Dinner & Dance Party (all attendees)	