
Event Agenda

17th NFXF International Fragile X Conference Virtual Series - Fragile X Research Roundup

Wed, Jul 22, 2020

7:00 AM - 7:00 AM	Pre-Conference Q & A and Whoava How-to
10:00 AM - 10:15 AM	Welcome Speaker: Linda Sorensen
10:15 AM - 11:15 AM	Keynote- Basic Science Research Update: From FMRP biology and FXS disease mechanisms to rationale for therapeutic strategies Speaker: Gary Bassell, PhD
11:15 AM - 11:30 AM	Social
11:30 AM - 12:15 PM	Increasing Access to Services for Families of Infants with Fragile X: Utilizing Telehealth for Genetic Counseling, Assessment, and Intervention Speakers: Anne Wheeler, PhD, Beth Boyea, MA, CGC, Katherine C. Okoniewski, PhD
12:15 PM - 12:25 PM	Social
12:25 PM - 1:20 PM	NFXF Research Facilitation Speakers: Hilary Rosselot, MBA, Craig Erickson, MD
1:20 PM - 1:25 PM	Social

1:25 PM - 3:30 PM

Recent Findings from the FORWARD Project

Introduction to FORWARD

1:25 PM - 1:30 PM
Speaker: Amie Milunovich

Growth Patterns and Obesity in a Fragile X Population

1:30 PM - 1:40 PM
Speaker: Milen Velinov, MD

Medical Problems in Fragile X Syndrome

1:40 PM - 1:50 PM
Speaker: Nicole Tartaglia

Seizures in Fragile X Syndrome

1:50 PM - 2:00 PM
Speaker: Elizabeth Berry-Kravis, MD, PhD

Sleep problems in Fragile X syndrome: Cross-sectional analysis of a large clinic-based cohort

2:00 PM - 2:10 PM
Speaker: Walter Kaufmann

Drug Treatment of Irritability, Aggression, Agitation and Self-Injurious Behavior in Fragile X Syndrome

2:10 PM - 2:20 PM
Speaker: Craig Erickson, MD

Sensory Symptoms and Hyperarousal in Individuals with Fragile X Syndrome: Findings from the FORWARD Registry and Database Multisite Study

2:20 PM - 2:30 PM
Speaker: Walter Kaufmann

The Association between Mosaicism Type and Cognitive and Behavioral Functioning Among Males with Fragile X Syndrome

2:30 PM - 2:40 PM
Speaker: Mary Lu Meng, PhD

Cognitive and Adaptive Behavior Profiles in Fragile X Syndrome: Baseline Cohort in a Multi-site Natural History Study

2:40 PM - 2:50 PM
Speaker: Lisa Cordeiro, MS, CSP

Feasibility and Validity of Standardized Language Assessment in Fragile X Syndrome

2:50 PM - 3:00 PM
Speaker: Anne Hoffmann

Delineating Repetitive Behavior Profiles Across the Lifespan in Fragile X Syndrome: Results from the FORWARD Project

3:00 PM - 3:10 PM
Speaker: Debra Reisinger, PhD

Examination of Correlates to Health-Related Quality of Life in Individuals with Fragile X Syndrome: Results from the FORWARD Project

3:10 PM - 3:20 PM
Speaker: Craig Erickson, MD

Factor Structure of the Aberrant Behavior Checklist in Individuals with FXS: Clarifications and Future Guidance

3:20 PM - 3:30 PM
Speaker: Howard Andrews, PhD, MS

3:30 PM - 3:45 PM

Social

3:45 PM - 4:45 PM

Industry Update: Zynerva

Speakers: Joseph M. Palumbo, MD, FAPA, MAPsych, Wendy Agnese, Pharm.D., Stephen O'Quinn

4:45 PM - 5:00 PM

Social

5:00 PM - 6:00 PM

Industry Update: Tetra/Asuragen/Ovid

Tetra: BPN14770: Phosphodiesterase-4D (PDE4D) Subtype Selective Allosteric Inhibitor for Treatment of Fragile X Syndrome

5:00 PM - 5:20 PM
Speaker: Brian Marron, PhD

Asuragen: Fragile X Molecular Testing: What, When, Why & How

5:20 PM - 5:40 PM
Speaker: Gary Latham, PhD

Ovid: Update on Rocket Results & Ovid Fragile X program

5:40 PM - 6:00 PM
Speaker: Mathews Adera

6:00 PM - 6:05 PM

Final Thoughts/Happy Hour

Speaker: Linda Sorensen

- 6:30 PM - 7:00 PM** **Clinical Trials in Fragile X Syndrome**
Speakers: Elizabeth Berry-Kravis, MD, PhD, Craig Erickson, MD, Randi Hagerman, MD
- 7:00 PM - 8:00 PM** **Cattell-Horn Carroll Theory-based Cognitive Profile of Children with Fragile X Syndrome using the Woodcock Johnson, Fourth Edition**
Speaker: Christina Aguirre-Kolb, MS, LEP
- 7:00 PM - 7:00 PM** **Differences in Temporal Parietal Junction Activation Between fragile X Premutation Carriers Who Do and Do Not Convert to Having fragile x-Associated Tremor Ataxia Syndrome (FXTAS)**
Speaker: Diego Placido
- 7:00 PM - 8:00 PM** **Child Challenging Behavior Influences Maternal Mental Health and Relationship Quality Over Time in Fragile X Syndrome**
Speaker: Heather Fielding-Gebhardt
- 7:00 PM - 8:00 PM** **Age-Related Decline in Cognitive-Linguistic Skills in Carriers of the FMR1 Premutation: Syntactic Complexity Declines across Midlife in Women with Family Histories of FXTAS**
Speaker: Jessica Klusek, PhD CCC-SLP
- 7:00 PM - 8:00 PM** **Auditory Hypersensitivity and Cognitive Performance in fMR1 Premutation Carriers**
Speaker: Jordan Norris
- 7:00 PM - 8:00 PM** **Transient Brain Microstate Activation and Sensory Processing in Fragile X Syndrome**
Speaker: Lauren Ethridge, PhD
- 7:00 PM - 8:00 PM** **Behavioral Rigidity in Fragile X Syndrome: Using EEG to Provide Novel Insights into Its Neural Underpinnings**
Speaker: Lauren Schmitt, PhD
- 7:00 PM - 8:00 PM** **Feasibility of Utilizing Functional Near-Infrared Spectroscopy (fNIRS) as an Imaging Tool in Young Children with Fragile X Syndrome (FXS)**
Speaker: Victoria Rosen, BS, MRes
- 7:00 PM - 8:00 PM** **Cardiovascular problems in the fragile X premutation: case series and review**
Speaker: Nattaporn Tassanakijpanich, MD
- 7:00 PM - 8:00 PM** **The Parent Adjustments and Accommodations Questionnaire in Fragile X Syndrome: A Pilot Study**
Speaker: Ashley Hugh, BS
- 7:00 PM - 8:00 PM** **A comparison of the expressed emotion of parents of children with FXS and parents of children with different causes of intellectual disability**
Speaker: Jeanine Coleman
- 7:00 PM - 8:00 PM** **Cerebellar-Cortical Function and Connectivity during Sensorimotor Behavior in Aging FMR1 Gene Premutation Carriers**
Speaker: Walker McKinney, MA
- 7:00 PM - 8:00 PM** **Interviews with mothers of children with Fragile X Syndrome provide important perspectives on stress and coping**
Speaker: Jessica Hunter, PhD
- 7:00 PM - 8:00 PM** **Complexity and Coherence Across Language Contexts in Females with Fragile X Syndrome**
Speaker: Hannah Barton, B.A.
- 7:00 PM - 8:00 PM** **Patterns of Visual Attention and Narrative in Males and Females with Fragile X Syndrome**
Speaker: Janna Guilfoyle, MA
- 7:00 PM - 8:00 PM** **Social Attention Profiles Reflect Autism Symptoms in Fragile X Syndrome**
Speaker: Molly Winston

- 7:00 PM - 8:00 PM **Thinking about participating in research? The nuts and bolts of a research visit and strategies for success.**
Speaker: Nanastasia Welnick, BS, CCRC
- 7:00 PM - 8:00 PM **A Qualitative Analysis of Parent Reported Behavior Problems for Children with Intellectual and Developmental Disabilities: A Comparison of Fragile X Syndrome, Down Syndrome, and Autism Spectrum Disorder**
Speaker: Talia Thompson, PhD, NCSP
- 7:00 PM - 8:00 PM **Baseline Toolbox Data from a Multicenter Double-Blind, Placebo-Controlled Trial of Metformin in Individuals with Fragile X Syndrome**
Speaker: Hazel Maridith B. Biag, MD
- 7:00 PM - 8:00 PM **Narrative Ability in FMR1 Premutation Carriers**
Speaker: Emily Landau, BA
- 7:00 PM - 8:00 PM **Parental Well-Being and Family Relationships in Families Affected by Fragile X Syndrome**
Speaker: Sarah Nelson Potter, MS, CCC-SLP
- 7:00 PM - 8:00 PM **Examining Maintenance of Skills Gained in a Parent-Implemented Spoken Language Intervention for Fragile X Syndrome**
Speaker: Amy Banasik
- 7:00 PM - 8:00 PM **Exploring anxiety in girls with fragile X syndrome**
Speaker: Amy Lightbody, PhD
- 7:00 PM - 8:00 PM **Empathy and Anxiety in Young Girls with Fragile X Syndrome**
Speaker: Jonas Miller, PhD
- 7:00 PM - 8:00 PM **Brain Activation During a Social Interaction Task in Girls with Fragile X Syndrome**
Speaker: Matthew Marzelli, MS
- 7:00 PM - 8:00 PM **Here's to the Girls: Preliminary Findings from a Longitudinal Study of Young Females with Fragile X Syndrome**
Speakers: Tracy Jordan, PhD, Cindy Lee, MA
- 7:00 PM - 8:00 PM **Biomarkers predictive of metformin treatment in Fragile X syndrome**
Speaker: Flora Tassone, PhD
- 7:00 PM - 8:00 PM **Telepractice Distance Collaboration: A Qualitative Analysis of Facilitators and Barriers for FXS Families**
Speakers: Kerrie Lemons Chitwood, PhD, CCC-SLP, Laura Greiss Hess, PhD, OTR/L
- 7:00 PM - 8:00 PM **Feasibility of Dual-Task Treadmill Training to Improve Gait and Balance in Patients with FXTAS: A Pilot Trial**
Speaker: Deborah Bang
- 7:00 PM - 8:00 PM **Prodromal Markers of Upper Limb Deficits in FXTAS and Quantitative Measures for Use in Future Clinical Trials in FXTAS**
Speaker: Joan OKeefe
- 7:00 PM - 8:00 PM **The Effects of Dual Task Cognitive Interference and Fast Paced Walking On Gait and Turns in FXTAS**
Speaker: Joan OKeefe
- 7:00 PM - 8:00 PM **Development of Neural Response to Novel Sounds in Fragile X Syndrome: Potential Biomarkers**
Speaker: Elizabeth Berry-Kravis, MD, PhD
- 7:00 PM - 8:00 PM **Initial Double Blind Placebo-Controlled Study of Acamprosate in Fragile X Syndrome**
Speaker: Craig Erickson, MD

- 7:00 PM - 8:00 PM **Double-Blind, Placebo-Controlled, Single-Dose Study of Minocycline and Lovastatin in Adults with Fragile X Syndrome**
Speaker: Craig Erickson, MD
- 8:00 PM - 9:00 PM **Screening Dietary Interventions in Fragile X Models**
Speaker: Cara Westmark, PhD
- 8:00 PM - 9:00 PM **Adeno-Associated Virus (AAV) Mediated Approach to Durably Restore FMRP in Mouse Brain**
Speaker: Lindsay Beasley, BA
- 8:00 PM - 9:00 PM **Validating Gamma Power and Coherence Phenotypes in Fragile X Syndrome: Identifying Unique Sources of High Frequency Activity in EEG**
Speaker: Lisa De Sefano, MS
- 8:00 PM - 9:00 PM **Development of a large mammalian model of Fragile X Syndrome.**
Speaker: Victoria Hawkins
- 8:00 PM - 9:00 PM **Factors Associated with CGG Repeat Instability and mosaicism in Female FMR1 Premutation Carriers**
Speaker: Yehyun Hwang, BS
- 8:00 PM - 9:00 PM **Exploring 5-HT₂ Receptors as Targets for Treating Epilepsy in Fragile X Syndrome: A Preclinical Study of Fmr1 Knock-out Mice**
Speaker: Tanishka Saraf
- 8:00 PM - 9:00 PM **Coupled transcriptional and translational re-activation of the Fragile X locus**
Speaker: Bryana Bayly
- 8:00 PM - 9:00 PM **The eye of tiger sign in males carrying the normal and premutation alleles of the FMR1 gene**
Speaker: Jun Wang, PhD
- 8:00 PM - 9:00 PM **All Three Mammalian MutL Complexes Are Required for Repeat Expansion in a Cell Model of the Fragile X-Related Disorders**
Speaker: Carson Miller, PhD
- 8:00 PM - 9:00 PM **Longitudinal Metabolic Profiling Reveals Potential Biomarkers and Dysregulated Lipid Metabolism Associated with the Development and Progression of Fragile X-Associated Tremor/Ataxia Syndrome (FXTAS)**
Speaker: Marwa Zafarullah