
Event Agenda

18th NFXF International Fragile X Conference

Thu, Jul 14, 2022

4:00 PM - 5:00 PM **First-Time Attendee Meet-Up**

Location: Palm 1 & 2

5:30 PM - 7:00 PM **Kickoff Reception**

Location: Flamingo & Lapper Lawns

Fri, Jul 15, 2022

8:00 AM - 9:00 AM **Keynote — Clinical Trials in Fragile X Syndrome**

Location: Town & Country - A

Speakers: Elizabeth Berry-Kravis, MD, PhD, Craig Erickson, MD, Randi J. Hagerman, MD

9:00 AM - 9:30 AM **Break**

9:30 AM - 10:30 AM **Panel Discussion — Clinical Trials in Fragile X Syndrome Questions & Answers**

Location: Town & Country - A

Speakers: Elizabeth Berry-Kravis, MD, PhD, Craig Erickson, MD, Randi J. Hagerman, MD, Hilary Rosselot

9:30 AM - 10:30 AM **Diagnosis and Treatment of Fragile X-Associated Tremor Ataxia Syndrome**

Location: Town & Country - B

Speaker: Deborah Hall

9:30 AM - 10:30 AM **Encouraging Early Communication**

Location: Town & Country - C

Speaker: Anne Hoffmann

9:30 AM - 10:30 AM **Assistive Technology: Tackling the Trends and the Tried & True**

Location: Town & Country - D

Speakers: Laura Greiss Hess, PhD, OTR/L, Kerrie Lemons Chitwood, PhD, CCC-SLP

9:30 AM - 10:30 AM **Research Breakout Session — Fragile X Basic Science**

Location: Palm 1 & 2

Mouse models of fragile x-related disorders: a tale of two species

9:30 AM - 9:45 AM

Location: Palm 1 & 2

Speaker: Frank Kooy

Effects of the Sigma-1 receptor agonist blarcamesine in a murine model of fragile X syndrome: neurobehavioral phenotypes and receptor occupancy

9:45 AM - 10:00 AM

Location: Palm 1 & 2

Speaker: Walter Kaufmann

Astrocyte-mediated mechanism of abnormal inhibition in FXS

10:00 AM - 10:15 AM

Location: Palm 1 & 2

Speaker: Iryna Ethell

9:30 AM - 10:30 AM **Sibling & Self-Advocate Welcome Session**

Location: Palm 8

Speakers: Diane Southard, Dillon Kelley, Kelley Dunphy

10:30 AM - 11:00 AM **Break**

11:00 AM - 12:00 PM **Starting and Monitoring Medications in Fragile X**

Location: Town & Country - B

Speakers: Nicole Tartaglia, Karen Regan

- 11:00 AM - 12:00 PM** **Emotion Dysregulation in Fragile X Syndrome**
 Location: Town & Country - C
 Speaker: Rebecca Shaffer
- 11:00 AM - 12:00 PM** **Interpreting Clinical Trial Headlines and Announcements in Fragile X Syndrome**
 Location: Town & Country - D
 Speakers: Craig Erickson, MD, Elizabeth Berry-Kravis, MD, PhD
- 11:00 AM - 12:00 PM** **Research Breakout Session — Clinical Science and Fragile X Premutation**
 Location: Palm 1 & 2
- Anxiety, but not depression, predicts longitudinal increase in functional tremor symptoms in women with the FMR1 premutation during midlife**
 11:00 AM - 11:15 AM
 Location: Palm 1 & 2
 Speaker: Jessica Klusek, PhD CCC-SLP
- Health concerns for women who carry an FMR1 premutation**
 11:15 AM - 11:30 AM
 Location: Palm 1 & 2
 Speaker: Emily Allen, PhD
- Structural correlates of functional topography in the cerebellum in fragile X-associated tremor/ataxia syndrome**
 11:30 AM - 11:45 AM
 Location: Palm 1 & 2
 Speaker: Karina Mandujano Rojas
- The progression of pathology in longitudinally followed patients with FXTAS (Fragile X-Associated Tremor/Ataxia Syndrome)**
 11:45 AM - 12:00 PM
 Location: Palm 1 & 2
 Speaker: Andrea Schneider, PhD.
- 11:00 AM - 12:00 PM** **VIP Pilates**
 Location: Sunset 1-3
 Speaker: Heather Crosby
- 11:00 AM - 12:00 PM** **Transitioning to Independence in Adulthood: What Helps? What Hurts?**
 Location: Town & Country - A
 Speakers: Leonard Abbeduto, PhD, Jessica Klusek, PhD CCC-SLP, Angie Thurman, Julie Taylor
- 12:00 PM - 12:30 PM** **Break**
- 12:30 PM - 1:45 PM** **Panel Discussion — Research Landscape**
 Location: Town & Country - A
 Speakers: Hilary Rosselot, Missy Zolecki, David Hessel PhD, Angel Wang, Kara Frech, Elizabeth Berry-Kravis, MD, PhD, Amie Milunovich, Laurie Bridges, Tracy King, MD, MPH, Craig Erickson, MD, Randi J. Hagerman, MD, Emily Mack ; Panelist: Jean Luan McColl
- 12:30 PM - 1:30 PM** **Sibling and Self-Advocate Dance Practice**
 Location: Sunset 1-3
 Speakers: Paige Zolecki, Peyton Toman
- 1:45 PM - 2:00 PM** **Break**
- 2:00 PM - 3:00 PM** **Panel Discussion — Fragile X and Associated Tremor/Ataxia Syndrome (FXTAS)**
 Location: Town & Country - A
 Panelist: Randi J. Hagerman, MD, Deborah Hall, Peter Todd, David Hessel PhD
- 2:00 PM - 3:00 PM** **Hands-on Sensory & Body-Based Self-Regulation for Managing Hyperarousal & Anxiety in FXS**
 Location: Town & Country - B
 Speaker: Tracy Murman Stackhouse

2:00 PM - 3:00 PM

Fragile X Protein (FXP) Series

Location: Palm 1 & 2

Reliable Detection of Fragile X Protein Expression in Peripheral Blood

2:00 PM - 3:00 PM

Location: Palm 1 & 2

Speaker: Anna Boggs

The Role of Fragile X Protein in Early Development in Fragile X Syndrome

2:00 PM - 3:00 PM

Location: Palm 1 & 2

Speaker: Kelli Dominick, MD, PhD

Clinical Utility of Optimized Fragile X Protein Assay

2:00 PM - 3:00 PM

Location: Palm 1 & 2

Speaker: Lauren Schmitt, PhD

A sound-driven cortical phase-locking change in the Fmr1 KO mouse requires Fmr1 deletion in a subpopulation of brainstem neurons

2:00 PM - 3:00 PM

Location: Palm 1 & 2

Speaker: Jay Gibson, PhD

Fragile X Protein Level as a Mediator of Treatment Response in Early Phase Target Engagement Drug Studies

2:00 PM - 3:00 PM

Location: Palm 1 & 2

Speaker: Craig Erickson, MD

2:00 PM - 3:00 PM

Stay Calm and Regulate!

Location: Sunset 1-3

Speaker: Rebecca Shaffer

2:00 PM - 3:00 PM

Dads Helping Dads

Location: Town & Country - D

Speaker: Will Bridges

2:00 PM - 3:00 PM

No Tears or Fears in the School Age Years: Make the Most of Your Team's Collaboration

Location: Town & Country - C

Speakers: Kerrie Lemons Chitwood, PhD, CCC-SLP, Anne Hoffmann, Laura Greiss Hess, PhD, OTR/L

3:00 PM - 3:15 PM

Break

3:15 PM - 4:30 PM

Keynote — Industry Updates

Location: Town & Country - A

Speaker: Hilary Rosselot

Asuragen, Inc - Fragile X Testing - Understanding the Whole Puzzle

3:15 PM - 4:30 PM

Location: Town & Country - A

Speaker: Stela Filipovic-Sadic

Zynerba Pharmaceuticals - Development of ZYN002 for the Treatment of Behavioral Symptoms in Fragile X Syndrome: Partnering to advance the care of children and adolescents with Fragile X Syndrome

3:15 PM - 4:30 PM

Location: Town & Country - A

Speaker: Stephen O'Quinn, PharmD

Tetra Therapeutics - Update on the Development of Zatulmilast for Fragile X Syndrome

3:15 PM - 4:30 PM

Location: Town & Country - A

Speaker: Chad Coberly

Healx Ltd.- Discovery of multiple clinical candidates for treatment of Fragile X Syndrome using AI-Enabled drug discovery

3:15 PM - 4:30 PM

Location: Town & Country - A

Speaker: Wayne Chadwick

(1) Of Mice and Humans: Hypersensitivity to Distractors in Fragile X syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Anu Goel

(2) Evaluation of a CRISPR gene editing strategy in CGG knock-in mice

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Carolyn Yrigollen

(3) Human Stem Cell Models for Investigating Disease Mechanisms of Fragile X-Associated Tremor/Ataxia Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Connor Maltby, PhD

(4) Gait impairments distinguish Fragile X-associated Tremor/Ataxia Syndrome from Parkinson disease and essential tremor

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Erin Robertson

(5) FXPOI alters omega-6 fatty acid metabolism and formation of pro-inflammatory metabolites compared to FMR1 PM carriers without FXPOI

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Katharine Shelly

(6) Metabolic profile in the brain with Fragile X-associated Tremor/Ataxia Syndrome (FXTAS)

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Maria Jimena Salcedo-Arellano, MD

(7) Development of Fragile X-Associated Tremor Ataxia Syndrome Rating Scale (FXTAS-RS)

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Michelle Tosin

(8) Developing Improved Outcome Measures in FXS: Key Stakeholder Feedback

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Sungeun Kang, PhD

(9) Using Qualitative Methods to Enhance our Understanding of Anxiety in Individuals with Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Talia Thompson, PhD

(10) Brain anatomy in child and adolescent girls with and without fragile X syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Tracy Jordan

4:30 PM - 7:00 PM

Poster Presentations — Family Friendly Topics

Location: Town and Country Foyer

(11) The Value of Martial Arts Training for Individuals with Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Amy DeBernardis

(12) The progression of pathology in longitudinally followed patients with FXTAS (Fragile X-Associated Tremor/Ataxia Syndrome)

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Andrea Schneider, PhD.

(13) The Diagnostic Experience of Women with Fragile X-Associated Primary Ovarian Insufficiency (FXPOI)

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speakers: Bonnie McKinnon, MMSc, Emily Allen, PhD

(14) Managing Powerful Emotions for Young Children with FXS: Integrated Preschool Social & Emotional Skills Groups

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Jeanine Coleman

(15) Creating Inclusive Camp/Recreation Programs For All

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Jennifer Phillips

(16) Uncapping the Possibilities for EEG Success in FXS

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Lisa De Stefano, PhD

(17) The bidirectional relationship between individuals with FXS and their ecological systems

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Morgan McNeill

(18) Moms with a Full Mutation

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Nicole Tartaglia

(19) Learn to Ski, the Fragile X Way

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Stephen Weiss

(20) Achieving a Transdisciplinary Strengths Based Approach to Learning and Living

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Tracy Murnan Stackhouse

(21) Momentary Snapshots of Caregiver Life During COVID-19: Health Behaviors, Caregiving, and Mental Well-Being

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Bridgette Kelleher

(22.5) Primary Care in the World of Fragile X

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Susan Howell, MS, CGC, MBA

4:30 PM - 7:00 PM

Poster Presentation — Basic Science - Fragile X

Location: Town and Country Foyer

(22) Parvalbumin+ GABAergic Interneurons are reduced in number in the human Fragile X amygdala and hippocampus

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Brett Dufour

(24) Lateralization of Alpha Oscillatory Dynamics in Fragile X Syndrome Linked to Characteristics of Autism Spectrum Disorder

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Jordan Norris

(25) Characterization of Antisense FMR1 (ASFMR1) Gene and Identification of Novel Splice Variants with Long-Read Sequencing

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Marwa Zafarullah, PhD

(26) Impaired temporal interval learning in Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Shazia Ali

(27) FMRP quantification in newborn dried blood spots: considerations for newborn screening

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Tatyana Adayev

(28) Progress Towards an Ovine Model of Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Victoria Hawkins

4:30 PM - 7:00 PM

Poster Presentation — Clinical Science - Fragile X

Location: Town and Country Foyer

(29) Long-term Safety and Sustained Efficacy of ZYN002 Cannabidiol Transdermal Gel in Children and Adolescents with Fragile X Syndrome (ZYN2-CL-017)

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Stephen O'Quinn, PharmD

(30) RECONNECT (ZYN2-CL-033): Design of a Phase 3 Trial of ZYN002 Cannabidiol Transdermal Gel in Children and Adolescents with Fragile X Syndrome Based Upon Learnings from CONNECT-FX (ZYN2-CL-016)

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Stephen O'Quinn, PharmD

(31) FXS Community Insights and AI Methods Drive Compounds to the Clinic

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Bruce Bloom

(32) Effects of Social Pressure on Language in Girls with Fragile X

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Aaron Piccirilli

(33) Associations in developmental change between cognitive skills and adaptive functioning in fragile X syndrome, Down syndrome and idiopathic intellectual disability

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Andrew Dakopoulos

(34) Behavioral Inflexibility in FXS: Accounts from Parents and Self-Advocates

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Angelina Jones

(35) Cognitive Features Related to Fragile X Protein Levels and Peak Alpha Frequency Differentially in Males and Females with Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Angelina Jones

(36) Neural response to speech in children with Fragile X Syndrome and Autism Spectrum Disorder

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Anna Benedict

(37) Analysis of a Repetitive Language Coding System: Comparisons between Fragile X Syndrome, Down Syndrome, and Autism

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Anne Hoffmann

(38) Parents and Infants with fragile X syndrome Intervention (PIXI)

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Anne Wheeler, PhD

(39) Application of the Child Sociability Rating Scale to assess social-emotional functioning in adolescent females with FXS

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Audrey Gorman

(40) Pragmatic Language is Associated with Daily Living Skills in Adolescents and Adults with Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Carly Moser

(41) Pilot Study of BAER-101, a selective GABA A alpha 2,3 agonist in adults with fragile X syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Craig Erickson, MD

(42) Single Dose Racemic Baclofen EEG-Focused Target Engagement Across Species in Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Craig Erickson, MD

(43) Pharmacological and non-pharmacological treatments of individuals with fragile X syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Dejan Budimirovic, MD

(44) Benefit of BPN14770 for Cognition, Language and Daily Function in Adults with Fragile X Syndrome: A Randomized, Placebo-Controlled, Phase 2 Clinical Trial

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Elizabeth Berry-Kravis, MD, PhD

(45) FXLEARN Trial: Effects of AFQ056 on Language Learning in Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Elizabeth Berry-Kravis, MD, PhD

(46) Individual Peak Alpha Frequency and language and communication abilities in Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Elizabeth Smith

(47) Neural discrimination of speech sounds and noise in Fragile X Syndrome using functional Near Infrared Spectroscopy

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Elizabeth Smith

(48) Electroencephalography use in FXS Research

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Emma Auger

(49) Neocortical Localization and Thalamocortical Modulation of Neuronal Hyperexcitability in Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Ernest Pedapati, MD

(50) Conservation of Fmr1^{-/-} Knockout Neurodynamic Gamma Spectral Events within Human Fragile X Syndrome, Autism Spectrum Disorder, and Control Subgroups

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Grace Westerkamp

(51) The Impact of the COVID-19 Pandemic on School-Aged Children with Fragile X

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Hailey Silver, MA

(52) Executive Dysfunction and Frontal Hyper-Connectivity in Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Joy Li

(53) Early Communication Development in Infants and Toddlers with Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Laura Mattie

(54) Lessons from Taking a Second Look: Clinical Trial of Acamprosate in FXS

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Lauren Schmitt, PhD

(55) Bully Victimization in Young Females with Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Lorena Joga

(56) A Novel Psilocybin Microdose Treatment of Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Marvin Hausman

(57) Profiles of Speech Prosody in School-Age Children with Fragile X Syndrome and Autism

4:30 PM - 7:00 PM

Location: Town and Country Foyer

(58) Child Language and Autism Symptoms Influence Maternal Expectations and Transition Planning in Adolescents with Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speakers: Nancy Brady, PhD, Olivia Boorum, MS, CCC-SLP

(59) Intra and Inter-tissue mosaicism and FMR1 allelic instability

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Poonnada Jiraanont

(60) Arbaclofen produces clinically meaningful improvements in individuals with Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Randall Carpenter

(61) Parent and Caregiver Perspectives Towards Cannabidiol as a Treatment for Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Reymundo Lozano, MD, MS

(62) Exploring parents' concerns regarding long-term supports/living arrangements for their children with FXS

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Reymundo Lozano, MD, MS

(63) Social Gaze Behavior and Hyperarousal in Young Females with Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Roxanna Sharifi

(64) Relationships Among Parental Responsivity, Child Language, and Child Characteristics in Families of Children with Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Sarah Nelson Potter, PhD, CCC-SLP

(65) Healthcare Utilization Among Youth With Fragile X Syndrome: A PEDSNET STUDY

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Shanlee Davis

(66) System-Based Diagnoses In Youth With Fragile X Syndrome: A PEDSNET STUDY

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Shanlee Davis

(67) Associating FMRP levels with IQ and Adaptive Behavior in Male Individuals with Fragile X Syndrome

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Jessica Tang

4:30 PM - 7:00 PM

Poster Presentation — Basic Science and Fragile X Premutation

Location: Town and Country Foyer

(23) FXTAS presents with widespread reactive gliosis and white-matter specific astrocyte degeneration

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Brett Dufour

(68) Oculomotor Response Inhibition and Accuracy Associated with Symptoms of FXTAS in Female FMR1 Premutation Carriers

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Heather Fielding-Gebhardt

(69) Genetic Factors which correlate with Somatic Instability in FMR1 Premutation Carriers

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Ye Hyun Hwang, BS

4:30 PM - 7:00 PM

Poster Presentation — Clinical Science and Fragile X Premutation

Location: Town and Country Foyer

(70) When Ataxia, etiology unspecified, is FXTAS

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Cornelia Lieb-Lundell, PT, MA, DPT

(71) Quality of Life in Fragile X-Associated Tremor/Ataxia Syndrome (FXTAS)

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Danielle Thordarson

(72) The International Fragile X Premutation Registry: Building a Resource For Research and Clinical Trial Readiness

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: David Hessler PhD

(73) Distinct subgroups of the broad autism phenotype in premutation carriers and parents of individuals with autism

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Janna Guilfoyle

(74) Vocal Quality in Women with the FMR1 Premutation

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Laura Friedman

(75) Identification of Metabolomic Biomarkers and their Association with Area of the Pons in Fragile X Premutation Carriers at Risk for Developing FXTAS

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Marwa Zafarullah, PhD

(76) Increased executive and social problem behaviors in boys in an un-referred sample of school age children with a fragile X premutation allele

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Nicole Tortora

(77) Fragile X-Associated Neuropsychiatric Disorders (FXAND) in young fragile X premutation carriers

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Aishworiya Ramkumar

(78) Overlapping Characteristics of Speech Prosody Reflect a Component Feature of Pragmatic Language in Women with the FMR1 premutation and Mothers of Autistic Individuals

4:30 PM - 7:00 PM

Location: Town and Country Foyer

Speaker: Stephanie Crawford

Sat, Jul 16, 2022

8:00 AM - 9:00 AM

Keynote — A Day in the Life of a Fragile X Doctor

Location: Town & Country - A

Speaker: Nicole Tartaglia

9:00 AM - 9:30 AM

Break

9:30 AM - 10:30 AM

Medication for Fragile X: Anxiety, Irritable Behaviors, Aggression

Location: Town & Country - A

Speakers: Elizabeth Berry-Kravis, MD, PhD, Missy Zolecki, Craig Erickson, MD

9:30 AM - 10:30 AM

Strategies to Improve Executive Functioning Skills for School-Aged Females with Fragile X

Location: Town & Country - B

Speaker: Barbara Haas-Givler, MEd, BCBA

9:30 AM - 10:30 AM

Promoting Inclusive Early Childhood Environments for Young Children with Fragile X Syndrome

Location: Town & Country - C

Speaker: Jeanine Coleman

9:30 AM - 10:30 AM

Common Behaviors and Available Treatments Across the Lifespan

Location: Town & Country - D

Speaker: Debra Reisinger, PhD

9:30 AM - 10:30 AM

Research Basic Science - Fragile X Premutation

Location: Palm 1 & 2

The effect of hypertension, diabetes, and ventricle enlargement on white matter hyperintensities and FXTAS progression in males with fragile X premutation

9:30 AM - 9:45 AM

Location: Palm 1 & 2

Speaker: Jun Yi Wang, PhD

Start with the end in mind: Translational frameshifting and ribosomal quality control in CGG repeat associated neurotoxicity.

9:45 AM - 10:00 AM

Location: Palm 1 & 2

Speaker: Peter Todd

Differences in regional grey matter volume in fragile-X premutation carriers who convert to FXTAS: A longitudinal voxel-based morphometry study

10:00 AM - 10:15 AM

Location: Palm 1 & 2

Speakers: Varun Arunachalam, PhD, Susan Rivera

Neurodegenerative synergy between RAN translation and CGG repeat RNA toxicity in rodent models of FXTAS

10:15 AM - 10:30 AM

Location: Palm 1 & 2

Speaker: Samantha Grudzien

9:30 AM - 10:30 AM

Panel Discussion - Self Advocate

Location: Sunset 1-3

Panelist: Tess Swayne, April Forehand, Luke Alan Forehand, Matthew Fasciano, Jason Fishman ; Moderator: Robert Miller

10:30 AM - 11:00 AM

Break

11:00 AM - 12:00 PM

Panel Discussion — Females with Fragile X Syndrome

Location: Town & Country - A

Panelist: Rebecca Shaffer, Nicole Tartaglia, Barbara Haas-Givler, MEd, BCBA, Jennifer Barber, Susan Howell, MS, CGC, MBA ; Moderator: Laurie Bridges

11:00 AM - 12:00 PM

Premutation Concerns

Location: Town & Country - B

Speaker: Randi J. Hagerman, MD

11:00 AM - 12:00 PM

Using Visuals to Support Daily Function

Location: Town & Country - C

Speaker: Tracy Murnan Stackhouse

11:00 AM - 12:00 PM

Research Clinical Science — Fragile X

Brain activity measures as reliable indicators of genetically mediated subgroups in Fragile X Syndrome: Relevance to Clinical Trials

11:00 AM - 11:15 AM

Location: Palm 1 & 2

Speaker: Lauren Ethridge, PhD

Developmental trajectory of anxiety, depression, and social skills in young females with fragile X syndrome

11:15 AM - 11:30 AM

Location: Palm 1 & 2

Speaker: Amy Lightbody

Observable Signs of Anxiety in Individuals with Fragile X Syndrome: Caregiver and Self-Advocate Perspectives

11:30 AM - 11:45 AM

Location: Palm 1 & 2

Speaker: David Hessl PhD

Fragile X Gray Zone Alleles Are Associated With Signs of Parkinsonism and Earlier Death

11:45 AM - 12:00 PM

Location: Palm 1 & 2

Speaker: Deborah Hall

11:00 AM - 12:00 PM

Navigating the Challenges of Puberty and Adolescence for Youth with Fragile X Syndrome

Location: Town & Country - D

Speakers: Holly Harris, Dinah Godwin

11:00 AM - 12:00 PM

Self-Advocate Session: Transitioning to Independence in Adulthood: What helps? What Hurts?

Location: Sunset 1-3

Speakers: Leonard Abbeduto, PhD, Jessica Klusek, PhD CCC-SLP, Angie Thurman

12:30 PM - 1:45 PM

Panel Discussion — Fragile X Premutation

Location: Town & Country - A

Moderator: Hilary Rosselot ; Panelist: Randi J. Hagerman, MD, Deborah Hall, David Hessler PhD, Emily Allen, PhD

1:45 PM - 2:00 PM

Break

2:00 PM - 3:00 PM

Panel Discussion — Education Question & Answers

Location: Town & Country - A

Moderator: Linda Sorensen ; Panelist: Jeanine Coleman, Tracy Murnan Stackhouse, Anne Hoffmann

2:00 PM - 3:00 PM

How Many Times Is He Going to Ask That? Perseverative Questioning and Other Behavioral Inflexibility in Fragile X Syndrome — What It Looks Like and How to Deal with It

Location: Town & Country - B

Speaker: Lauren Schmitt, PhD

2:00 PM - 3:00 PM

Improving Sleep in Children and Youth with Fragile X Syndrome

Location: Town & Country - D

Speaker: Carol Delahunty, MD

2:00 PM - 3:00 PM

Sibling & Self Advocate Dance Session — Part 2

Location: Sunset 1-3

Speakers: Paige Zolecki, Peyton Toman

2:00 PM - 3:00 PM

Recent Findings from the FORWARD Project — Part 1

Location: Palm 1 & 2

Introduction to FORWARD

2:00 PM - 3:00 PM

Location: Palm 1 & 2

Speaker: Amie Milunovich

Seizures in Fragile X Syndrome: Associations and Longitudinal Analysis of a Large Clinic-Based Cohort

2:00 PM - 3:00 PM

Location: Palm 1 & 2

Speaker: Elizabeth Berry-Kravis, MD, PhD

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

2:00 PM - 3:00 PM

Location: Palm 1 & 2

Speaker: Elizabeth Berry-Kravis, MD, PhD

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

2:00 PM - 3:00 PM

Location: Palm 1 & 2

Speaker: Dejan Budimirovic, MD

Height and Body Mass Index in Fragile X Syndrome: A Longitudinal Assessment

2:00 PM - 3:00 PM

Location: Palm 1 & 2

Speaker: Milen Velinov, MD

Medical Problems in Fragile X Syndrome: FORWARD Results from over 1400 participants Age 0-21 with the Fragile X Full Mutation

2:00 PM - 3:00 PM

Location: Palm 1 & 2

Speaker: Nicole Tartaglia

3:00 PM - 4:15 PM

Recent Findings from the FORWARD Project — Part 2

Location: Palm 1 & 2

Speaker: Amie Milunovich

Experiences of Adults with Fragile X Syndrome

3:00 PM - 4:15 PM

Location: Palm 1 & 2

Speaker: Melissa Raspa, PhD

Impact of Age of Access and Early Intervention Services on Long Term Outcomes in FXS

3:00 PM - 4:15 PM

Location: Palm 1 & 2

Speaker: Melissa Raspa, PhD

Age of Developmental Milestones for Boys and Girls with FXS

3:00 PM - 4:15 PM

Location: Palm 1 & 2

Speaker: Anne Wheeler, PhD

Latent profile analysis identifies distinctive cognitive and behavioral subphenotypes in fragile X syndrome

3:00 PM - 4:15 PM

Location: Palm 1 & 2

Speaker: Walter Kaufmann

The effect of medications on longitudinal behavior and symptoms in Fragile X Syndrome

3:00 PM - 4:15 PM

Location: Palm 1 & 2

Speaker: Craig Erickson, MD

Cognitive and Adaptive Functioning Profiles of Individuals with FXS Across the Lifespan

3:00 PM - 4:15 PM

Location: Palm 1 & 2

Speaker: Nicole Tartaglia

3:00 PM - 3:15 PM

Break

3:15 PM - 4:15 PM

Panel Discussion — Sibling Perspective

Location: Town & Country - A

Panelist: Paige Zolecki, Kelley Dunphy, Hailey Silver, MA, Josee Slama ; Moderator: Abigail Gaunt

3:15 PM - 4:15 PM

Setting the Stage for Success: Effective Strategies to Promote and Support Social Skills

Location: Town & Country - B

Speaker: Barbara Haas-Givler, MEd, BCBA

3:15 PM - 4:15 PM

Movement & Relaxation

Location: Sunset 1-3

Speaker: Tracy Murnan Stackhouse

4:15 PM - 6:00 PM

Break

6:00 PM - 8:00 PM

Farewell Party

Location: Flamingo & Lapper Lawns

Sun, Jul 17, 2022

9:00 AM - 10:15 AM

Panel Discussion — Behavior

Location: Town & Country - A

Moderator: Linda Sorensen ; Panelist: Tracy Murnan Stackhouse, Elizabeth Berry-Kravis, MD, PhD, Craig Erickson, MD, Randi J. Hagerman, MD, Lauren Schmitt, PhD

10:30 AM - 11:45 AM

Panel Discussion — Medications

Location: Town & Country - A

Moderator: Hilary Rosselot ; Panelist: Randi J. Hagerman, MD, Elizabeth Berry-Kravis, MD, PhD, Craig Erickson, MD, Reymundo Lozano, MD, MS ; Speaker: Nicole Tartaglia