

Event Agenda

20th NFXF International Fragile X Conference

Thursday, July 16, 2026

Most sessions will be recorded and available on demand in the app within approximately two weeks and will remain available through October 15, 2026, unless otherwise noted.

- 10:00 AM - 11:00 AM** **Adapting and Building Effective Goals: Creating Success Across the Lifespan**
Location: Marriott Ballroom
- 11:00 AM - 11:15 AM** **Break**
- 11:15 AM - 12:15 PM** **Planning Ahead: Financial, Legal, and Benefits Considerations for Families**
Location: Marriott Ballroom
- 11:15 AM - 12:15 PM** **Self-Advocate: Welcome to the Conference from the NFXF and Board of Directors**
Location: Kentucky Ballroom - First Floor
- 12:15 PM - 1:30 PM** **Lunch Break - On Your Own**
- 1:30 PM - 2:15 PM** **Caregiving Across the Lifespan: Shared Experiences and Support**
Location: Marriott Ballroom
- 1:30 PM - 2:15 PM** **Self-Advocate: Sibling and Self Advocate Network Welcome Session**
Location: Kentucky Ballroom - First Floor
Speakers: Diane Southard, Dillon Kelley, Kelley Dunphy
- 2:15 PM - 2:30 PM** **Break**
- 2:30 PM - 3:15 PM** **Peer Breakout Groups: Connecting Through Shared Experience**
Location: Various
- Peer-to-Peer Breakout Groups (Various Topics)**
2:30 PM - 3:15 PM
- FXTAS Patient and Caregiver Support Group**
2:30 PM - 3:15 PM
Location: Thoroughbred/Filly
Speakers: Deborah Hall, MD, PhD, Michelle Hyczy de Siqueira Tosin, PhD, MSN
- 2:30 PM - 3:15 PM** **Self-Advocate: Q & A with Actor Jack Guzman**
Location: Kentucky Ballroom - First Floor
Speakers: Diane Southard, Jack Guzman
- 3:15 PM - 3:30 PM** **Break**
- 3:15 PM - 4:00 PM** **Self-Advocate: Meet & Greet with Actor Jack Guzman**
Location: Kentucky Ballroom - First Floor
Speaker: Jack Guzman
- 3:30 PM - 4:00 PM** **First Time Attendee**
Location: Rose
- 4:00 PM - 5:00 PM** **Meet the Clinics - Members from the FXCRC Clinics**
Location: Marriott Ballroom Lobby
- 5:00 PM - 6:00 PM** **Welcome Reception**
Location: Marriott Ballroom
Speaker: Hilary Rosselot

5:00 PM - 6:00 PM

Self-Advocate: Meet & Greet with Actor Jack Guzman

Location: Kentucky Ballroom - First Floor
Speaker: Jack Guzman

Friday, July 17, 2026

7:00 AM - 7:00 AM

Most sessions will be recorded and available on demand in the app within approximately two weeks and will remain available through October 15, 2026, unless otherwise noted.

7:00 AM - 7:30 AM

X Strides 2026

Location: Hotel Lobby

8:30 AM - 9:30 AM

Keynote - Embracing the Xtraordinary: Inspiration from the Fragile X Community

Location: Marriott Ballroom
Moderator: Hilary Rosselot

9:30 AM - 9:45 AM

Break

9:45 AM - 10:45 AM

Tentative: Real-World Pathways: Employment, Day Programs, and Life After High School

Location: Marriott Ballroom

9:45 AM - 10:45 AM

FXTAS Overview for Patients and Families

Location: Bluegrass
Speakers: Deborah Hall, MD, PhD, Tentative - Matt Meyers, MD

9:45 AM - 10:45 AM

Symposia: From brains to behavior: clinical translational research to support mental health among FMR1 premutation carriers

Location: Rose

Menopause moderates the relationship between neural sensitivity to rewards and symptoms of depression: Evidence from a cohort of mature adult women with and without the FMR1 premutation

9:45 AM - 10:45 AM

Location: Rose

Speaker: Roslyn Harold, MS

Examining Cerebellar Structure and Function in Female FMR1 Premutation Carriers

9:45 AM - 10:45 AM

Location: Rose

Speaker: Kamryn Witkowiak, BS

Daily experiences of women with the FMR1 premutation in Project WellCAST

9:45 AM - 10:45 AM

Location: Rose

Speaker: Bridgette Kelleher, PhD

9:45 AM - 10:45 AM

ABLE accounts 101: Save, Work, and Protect benefits

Location: Thoroughbred/Filly
Speaker: Jolene Wyler-Brown

9:45 AM - 10:45 AM

Tentative - Partnering with School, a Primer for Families on School Support Negotiations

Location: Salon F - First Floor
Speakers: Tentative - Debra Reisinger, PhD, Michelle Curtin, DO, FAAP

9:45 AM - 10:45 AM

Sensory Session for Caregivers - Katie Frank

Location: Salon G - First Floor
Speaker: Katie Frank, PhD, OTR/L

9:45 AM - 10:45 AM

Tentative - Self Advocate: Stay Calm and Regulate: Skills to Manage Emotions

Location: Kentucky Ballroom - First Floor
Speakers: Rebecca Shaffer, PhD, Allison Birnschein, PhD

10:45 AM - 11:00 AM

Break

11:00 AM - 11:45 PM

Building the Future: NFXF Junior Investigators

Location: Marriott Ballroom

Insights into disease pathogenesis from FXTAS Patient iPSC Derived Neurons

11:00 AM - 11:45 AM

Location: Marriott Ballroom

Speaker: Tetsuya Asano, MD, PhD

Mental Health Symptoms, Medication, and Service Use Among Young Women with Fragile X Syndrome

11:00 AM - 11:45 AM

Location: Marriott Ballroom

Speaker: Laura Friedman, PhD, CCC-SLP

Unraveling the Root Cause of Fragile X Syndrome by R-loop Mediated Epigenetic Mechanisms on Repeats

11:00 AM - 11:45 AM

Location: Marriott Ballroom

Speaker: Hungoo Lee

Effects of Kv3 Positive Modulators on EEG Biomarkers in Fmr1 Knockout Mice

11:00 AM - 11:45 AM

Location: Marriott Ballroom

Speaker: Andrew Gaulden, PhD

Diagnosis of the FMR1 premutation in a cohort of children with neurodevelopmental disorders: definition of a pediatric clinical phenotype

11:00 AM - 11:45 AM

Location: Marriott Ballroom

Speaker: Carme Torrents Fenoy

Reduced steady state responses in Fragile X Syndrome highlight difficulties with stimulus representation maintenance that are linked to GABAergic mechanisms

11:00 AM - 11:45 AM

Location: Marriott Ballroom

Speaker: Jordan Norris, PhD

11:00 AM - 11:45 PM

Tentative - Self-Advocate: Improvaneer

Location: Kentucky Ballroom - First Floor

11:45 AM - 1:15 PM

Lunch Break - On Your Own

1:15 PM - 2:15 PM

One Global Fragile X Community: Sharing the Intention and Impact of NFXF, FRAXA, and FraXI

Location: Marriott Ballroom

Speakers: Hilary Rosselot, Anja Schweinberger, Katie Clapp

1:15 PM - 2:15 PM

Medication for Fragile X: Anxiety, Irritable Behaviors, Aggression

Location: Bluegrass

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

1:15 PM - 2:15 PM

Research Clinical/Translational Science - Fragile X

Location: Rose

Subtyping autism spectrum disorder in Fragile X syndrome: analyses of the FORWARD project

1:15 PM - 1:30 PM

Location: Rose

Speaker: Walter Kaufman, MD

Tentative - Comparing Predictors of Future Caregiving Responsibility Among Adult Siblings of Individuals with Fragile X Syndrome and Down Syndrome

1:30 PM - 1:45 PM

Location: Rose

Speaker: Tentative - Carson Cable

Neural Entrainment Reveals Impaired Statistical Learning in Children with Fragile X Syndrome

1:45 PM - 2:00 PM

Location: Rose

Speaker: Jack Liu

Alpha-gamma dysrhythmia in Fragile X syndrome: targets for closed-loop neuromodulation

2:00 PM - 2:15 PM

Location: Rose

Speaker: Peyton Siekierski

1:15 PM - 2:15 PM

Symposia: Neuroimaging correlates underpinning clinical phenotypes in FMR1 premutation carriers with and without FXTAS

Location: Thoroughbred/Filly

Neuroimaging correlates underpinning clinical phenotypes in FMR1 premutation carriers with and without FXTAS

1:15 PM - 2:15 PM

Location: Thoroughbred/Filly

Speaker: Joanne O'Keefe

Investigation of structural brain markers of memory dysfunction in aging female FMR1 premutation carriers

1:15 PM - 2:15 PM

Location: Thoroughbred/Filly

Speaker: Kristen McGatliin

The types of white matter lesion and their association with hypertension, FXTAS severity, CGG repeat length, and APOE genotype in males with fragile X premutation

1:15 PM - 2:15 PM

Location: Thoroughbred/Filly

Speaker: Jun Wang

1:15 PM - 2:15 PM

Tentative - Supporting healthy sexuality, relationships & boundaries for individuals with Fragile X syndrome

Location: Salon F - First Floor

Speakers: Tentative - Vicki Wilkins, MD, Katie Frank, PhD, OTR/L, Tentative - David Tillman, PhD

1:15 PM - 2:15 PM

Tentative - Strategies for Early Literacy Skills

Location: Salon G - First Floor

Speakers: Tentative - Anne Hoffmann, PhD, CCC-SLP, Jessica Klusek, PhD, CCC-SLP, Kristen Vincent, M.A., CCC-SLP

1:15 PM - 2:15 PM

Self- Advocate: Males with FXS

Location: Kentucky Ballroom - First Floor

Speaker: Marcia Braden, PhD

2:15 PM - 2:30 PM

Break

2:30 PM - 3:30 PM

Panel Discussion: Housing Options for Individuals with Fragile X Syndrome

Location: Marriott Ballroom

2:30 PM - 3:30 PM

Treatment of Fragile X-associated Tremor Ataxia Syndrome

Location: Bluegrass

Speakers: Deborah Hall, MD, PhD, Joanne O'Keefe, Tentative - Matt Meyers, MD

2:30 PM - 3:45 PM

Symposia: Children with Premutation Symposium

Location: Rose

Identifying a Clinically Vulnerable Phenotype in Children with an FMR1 Premutation

2:30 PM - 3:45 PM

Location: Rose

Speakers: Nicole Tortora, Tatyana Adayev, PhD

Neurodevelopmental Outcomes in an Unreferred Cohort of Children with a Fragile X Premutation Allele

2:30 PM - 3:45 PM

Location: Rose

Speaker: Jessica Ezzell Hunter, PhD

Association of Prenatally Identified Fragile X Premutation with Behavioral and Cognitive Skills in Children

2:30 PM - 3:45 PM

Location: Rose

Speaker: Emily Allen, PhD

Tentative - Cognitive performance in school age children with a premutation: Strong skills with mild social pragmatic weakness for boys

2:30 PM - 3:45 PM

Location: Rose

Speaker: Tentative - Veronica Hinton, PhD

Parent-Reported Diagnoses and Service Utilization in Children With and Without FMR1 Premutations

2:30 PM - 3:45 PM

Location: Rose

Speaker: Tatyana Adayev, PhD

2:30 PM - 3:30 PM	<p>What Caregivers Should Know About the Sibling Experience: A Conversation for Family Members</p> <p>Location: Salon F - First Floor Speakers: Cora Taylor, PhD, Barbara Haas-Givler, MEd, BCBA, Paige Zolecki, BS</p>
2:30 PM - 3:30 PM	<p>Tentative - Teaching Parents Behavioral Strategies to Address Challenging Behaviors in Their Children with Fragile X Syndrome</p> <p>Location: Salon G - First Floor Speaker: Tentative - Lauren Moskowitz, PhD</p>
2:30 PM - 3:30 PM	<p>Tentative - Self-Advocates: Staying Cool When Things Get Tough: De-Escalation Skills for Self-Advocates with Fragile X</p> <p>Location: Kentucky Ballroom - First Floor Speaker: Tentative - Debra Reisinger, PhD</p>
2:30 PM - 3:00 PM	<p>You DO Know Jack*! How the Ordinary Can Become X-traordinary (*inspired by Jack, our family's FX patriarch)</p> <p>Location: Thoroughbred/Filly Speakers: Ilana Garber, Adam Berkowitz</p>
3:00 PM - 3:30 PM	<p>Our Family Journey Raising Females Living with Fragile X syndrome (age 0 -26)</p> <p>Location: Thoroughbred/Filly Speaker: Roger Kuperman</p>
3:45 PM - 4:45 PM	<p>2026 Industry Updates</p> <p>Location: Marriott Ballroom Lobby</p>
3:45 PM - 4:45 PM	<p>Self-Advocate: Let's Dance Practice Session</p> <p>Location: Kentucky Ballroom - First Floor Speakers: Peyton Toman, Paige Zolecki, BS</p>
4:45 PM - 5:00 PM	<p>Break</p>
5:00 PM - 6:30 PM	<p>Session A - 2026 Junior Investigator Award Poster Presentation</p> <p>Location: Marriott Ballroom Lobby</p> <div style="border-left: 1px solid black; padding-left: 10px;"> <p>Insights into disease pathogenesis from FXTAS Patient iPSC Derived Neurons</p> <p>5:00 PM - 6:30 PM Location: Marriott Ballroom Lobby Speaker: Tetsuya Asano, MD, PhD</p> <p>Mental Health Symptoms, Medication, and Service Use Among Young Women with Fragile X Syndrome</p> <p>5:00 PM - 6:30 PM Location: Marriott Ballroom Lobby Speaker: Laura Friedman, PhD, CCC-SLP</p> <p>Unraveling the Root Cause of Fragile X Syndrome by R-loop Mediated Epigenetic Mechanisms on Repeats</p> <p>5:00 PM - 6:30 PM Location: Marriott Ballroom Lobby Speaker: Hungoo Lee</p> <p>Effects of Kv3 Positive Modulators on EEG Biomarkers in Fmr1 Knockout Mice</p> <p>5:00 PM - 6:30 PM Location: Marriott Ballroom Lobby Speaker: Andrew Gauden, PhD</p> <p>Diagnosis of the FMR1 premutation in a cohort of children with neurodevelopmental disorders: definition of a pediatric clinical phenotype</p> <p>5:00 PM - 6:30 PM Location: Marriott Ballroom Lobby Speaker: Carme Torrents Fenoy</p> <p>Reduced steady state responses in Fragile X Syndrome highlight difficulties with stimulus representation maintenance that are linked to GABAergic mechanisms</p> <p>5:00 PM - 6:30 PM Location: Marriott Ballroom Lobby Speaker: Jordan Norris, PhD</p> </div>

5:00 PM - 6:30 PM

Session A: Poster Session - Basic/Translational Science (Fragile X)

Location: Marriott Ballroom Lobby

Resting-State EEG Alpha Dynamics Highlight Differences Across Brain Systems in Fragile X Syndrome

5:00 PM - 6:30 PM

Location: Marriott Ballroom Lobby

Speaker: Shelby Dauterman, BS

Analyzing FMR1 Sequence-Specific Factors affecting FMRP expression for optimized gene therapy

5:00 PM - 6:30 PM

Location: Marriott Ballroom Lobby

Speaker: Christina Gross

Exploring the Relationship Between Fragile X Syndrome and Autism: A Bibliometric Analysis of Global Research Trends

5:00 PM - 6:30 PM

Location: Marriott Ballroom Lobby

Speaker: Alyson Kaplan

5:00 PM - 6:30 PM

Session A: Poster Session - Basic/Translational Science (Fragile X Premutation)

Location: Marriott Ballroom Lobby

Long-read sequencing reveals extensive FMR1 somatic mosaicism in human brain from individuals with FXTAS

5:00 PM - 6:30 PM

Location: Marriott Ballroom Lobby

Speaker: Anna Dischler

Impact of Adverse Childhood Experiences on Language in Adulthood Among Male and Female FMR1 Premutation Carriers

5:00 PM - 6:30 PM

Location: Marriott Ballroom Lobby

Speaker: Davina Hammann

5:00 PM - 6:30 PM

Session A: Poster Session - Clinical Science (Fragile X)

Location: Marriott Ballroom Lobby

Executive Function and Language in Females with Fragile X Syndrome

5:00 PM - 6:30 PM

Location: Marriott Ballroom Lobby

Speaker: Amy Banasik, M.S., CCC-SLP

Adapting a Behavioral Intervention for Parents of Children with Fragile X Syndrome and Down Syndrome: A Pilot Study of RUBI-DD

5:00 PM - 6:30 PM

Location: Marriott Ballroom Lobby

Speaker: Allison Birnschein, PhD

Single-dose SPG601 rescues aberrant resting EEG power and improves executive function in men with fragile X syndrome

5:00 PM - 6:30 PM

Location: Marriott Ballroom Lobby

Speaker: Craig Erickson, MD

Engineering FMRP as a Protein Replacement Therapy for Fragile X Syndrome

5:00 PM - 6:30 PM

Speaker: Eric Escobar, PhD

Fragile X Syndrome in Adult Women: Neurodevelopmental Trajectories and Psychiatric Misinterpretation

5:00 PM - 6:30 PM

Location: Marriott Ballroom Lobby

Speaker: Priya Khalsa, MD, JD, MSW

FX Roots Aim 3: Single-Dose Clinical Trial of Memantine, Ethosuximide, and Placebo in Adolescents with Fragile X Syndrome

5:00 PM - 6:30 PM

Location: Marriott Ballroom Lobby

Speaker: Sarah Richter

Single-Dose Study of Baclofen, Roflumilast, Memantine, and Placebo in Adults with Fragile X Syndrome

5:00 PM - 6:30 PM

Location: Marriott Ballroom Lobby

Speaker: Sarah Richter

From Clinic to Couch: Improving Access and Expanding Fragile X Research Into the Home

5:00 PM - 6:30 PM

Speaker: Hannah Sachs

Bringing EEG Home: Studying Fragile X Syndrome Through Brain Activity

5:00 PM - 6:30 PM

Speaker: Lisa De Stefano, PhD

5:00 PM - 6:30 PM

Session A: Poster Session - Clinical Science (Fragile X Premutation)

Location: Marriott Ballroom Lobby

Tentative - Word Finding in Women with the FMR1 Premutation and Its Association with FXTAS-Related Motor Symptoms and FMR1 Premutation Allele Expression

5:00 PM - 6:30 PM

Location: Marriott Ballroom Lobby

Speaker: Tentative - Thomas Christensen, MS, CCC-SLP

Educational Attainment May Be Associated with Delayed Onset of FXTAS Phenocconversion

5:00 PM - 6:30 PM

Location: Marriott Ballroom Lobby

Speaker: Pari Mungalpara, BS

Tentative - Markers of Gait Deficiencies in Fragile X-Associated Tremor/Ataxia Syndrome (FXTAS) Across Disease Stages

5:00 PM - 6:30 PM

Location: Marriott Ballroom Lobby

Speaker: Tentative - Ellery Santos

Assessing Fragile X-Associated Neuropsychiatric Disorders (FXAND) and the Mental Health Landscape of Women with the FMR1 Premutation

5:00 PM - 6:30 PM

Location: Marriott Ballroom Lobby

Speaker: Julie Schrey

6:30 PM - 8:00 PM

Session B: Poster Session - Basic/Translational Science (Fragile X)

Location: Marriott Ballroom Lobby

Caregiver Perceptions About CRISPR and Other Biological Treatments for Fragile X Syndrome Compared With Sickle Cell Disease (2000-2025)

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Ethan Hunter, BS

Linking RNA- and Protein-Based Molecular Markers to Behavioral & Clinical Metrics in Fragile X Syndrome: Methodology, Early Results, & Future Implications

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Eva McCord

Gallic Acid Partially Restores Circadian and Sleep Phenotypes in a Fragile X Fly Model: A Dose-Response Study

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Dragana Protic, MD, PhD

Optimizing prime editing of an FMR1 Iso304Asp mutation to evaluate FXS gene editing in vivo

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Carolyn Yrigollen, PhD

6:30 PM - 8:00 PM

Session B: Poster Session - Basic/Translational Science (Fragile X Premutation)

Location: Marriott Ballroom Lobby

Uncovering Cell-Type Specific Alterations in Female FMR1 Premutation Brain

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Susana Lopez-Ignacio

6:30 PM - 8:00 PM

Session B: Poster Session - Clinical Science (Fragile X)

Location: Marriott Ballroom Lobby

Home Literacy Environment and Vocabulary Development in Young Children with Fragile X Syndrome

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Laura Mattie, PhD

Sensory Profiles in Young Children with Fragile X Syndrome

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Lindsey Mountcastle, MA

Autism Assessment in Fragile X: An Item-Level Comparison of ADOS-2 Profiles in FXS and ASD

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Meredith Nelson, PhD

Infant Temperament in Fragile X Syndrome

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Allison Tay

Evaluation of the Safety and Tolerability of MRM-3379, a Selective PDE4D Inhibitor

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Lawrence P. Carter, PhD

Design of the Phase 2 BLOOM Study Evaluating the Safety and Tolerability of MRM-3379, a Highly Brain-Penetrant PDE4D Inhibitor, in Fragile X Syndrome

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Lawrence P. Carter, PhD

Evaluation of MRM-3379, a PDE4D inhibitor, in a mouse model of Fragile X Syndrome

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Sravan Jaggamantri

Intentional Communication with Caregivers vs Clinicians in Fragile X Syndrome

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speakers: Brooke Mathews, Danny Variano

Using the NIH Toolbox V3.0 Speeded Matching Task as a Potential Marker of Attention and Processing Speed in Youth with IDD

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Numfon Vilay

Communication Milestones in Fragile X Syndrome

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speakers: Tentative - Anne Hoffmann, PhD, CCC-SLP, Annie Kaplan, Sandra Sobus

Tentative - Development of a positive modulator of BK channels for the treatment of Fragile X Syndrome (FXS)

6:30 PM - 8:00 PM

Speaker: Tentative - Valerie Olivier

Tentative - The Fragile X Friendly Research Visit: Strategies to Support Participants and Families

6:30 PM - 8:00 PM

Speaker: Tentative - Nicole Tartaglia

Translating "translational": what does translational science mean and why is it important for clinical trials in FXS?

6:30 PM - 8:00 PM

Speakers: Lauren Ethridge, PhD, Tentative - Ernest Pedapati

Tentative - Mini Mice, Big Breakthroughs: How Mouse EEGs Are Powering Fragile X Progress

6:30 PM - 8:00 PM

Speaker: Tentative - Richard Lacher, BS

The Power to Try: The Benefits of Sibling Co-Enrollment in Research

6:30 PM - 8:00 PM

Speaker: Allison Lacroix

FX ENTRAIN

6:30 PM - 8:00 PM

Speaker: Lynxie Voorhees

The Benefits and Drawbacks of Conducting In-Clinic, At-Home, and Virtual FORWARD-MARCH Research Visits

6:30 PM - 8:00 PM

Speaker: Ryan Zix

6:30 PM - 8:00 PM

Session B: Poster Session - Clinical Science (Fragile X Premutation)

Location: Marriott Ballroom Lobby

Prevalence and perceptions of GLP-1 use among Fragile X premutation carriers

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Katharine Shelly, PhD

Hearing Loss in Adult Women with the FMR1 Premutation

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Jessica Klusek, PhD, CCC-SLP

Tentative - CGG Repeat Length and AGG Interruptions in FMR1: Association with Expansion Risk in a Reproductive Carrier Screening Population

6:30 PM - 8:00 PM

Location: Marriott Ballroom Lobby

Speaker: Tentative - Deepa Eveleigh, MS, MB(ASCP)CM

Saturday, July 18, 2026

8:00 AM - 8:00 AM

Most sessions will be recorded and available on demand in the app within approximately two weeks and will remain available through October 15, 2026, unless otherwise noted.

8:30 AM - 9:30 AM

Keynote - NFXF Clinical Trials Committee: Shaping the Future of Fragile X Clinical Trials

Location: Marriott Ballroom

Speakers: Hilary Rosselot, Anna DeSonia, Elizabeth Berry-Kravis, MD, PhD, Randi Hagerman, MD, Craig Erickson, MD

9:30 AM - 9:45 AM

Break

9:45 AM - 10:30 AM

Q & A with the NFXF Clinical Trials Committee: Shaping the Future of Fragile X Clinical Trials

Location: Marriott Ballroom

Moderator: Hilary Rosselot ; Panelist: Anna DeSonia, Elizabeth Berry-Kravis, MD, PhD, Craig Erickson, MD, Randi Hagerman, MD

9:45 AM - 10:30 AM

Research Basic/Translational Science - Fragile X Premutation

Location: Bluegrass

Mechanistic synergy drives neuroinflammation and neurodegeneration in FXTAS model systems.

9:45 AM - 10:30 AM

Location: Bluegrass

Speaker: Peter Todd, MD, PhD

Language use and links with age and executive functioning among male and female PM carriers

9:45 AM - 10:30 AM

Location: Bluegrass

Speaker: Nell Maltman, PhD

Improving Women's Healthcare Providers' Knowledge about Fragile X-Associated Primary Ovarian Insufficiency Through a Novel Educational Tool

9:45 AM - 10:30 AM

Location: Bluegrass

Speaker: Emily Allen, PhD

9:45 AM - 10:30 AM

Tentative - Supporting Individuals with Higher Support Needs

Location: Rose

9:45 AM - 10:30 AM

Whats my status? Exploring considerations for Fragile X testing of family members and its impact on future care

Location: Thoroughbred/Filly

Speaker: Makenzie Woltz, MS, CGC

9:45 AM - 10:30 AM

Transition from Pediatric to Adult Care in Fragile X

Location: Salon F - First Floor

Speakers: Ronda Franke, CPNP, Tentative - Nicole Tartaglia, MD

9:45 AM - 10:30 AM

Take a Deep Breath: Teaching Coping Strategies for Your Child with Fragile X

Location: Salon G - First Floor

Speakers: Dinah Godwin, LCSW, Jennifer Cervantes, LCSW-S

9:45 AM - 10:30 AM

Tentative - FXTAS Caregiver Support Group - Deb Hall

Location: Show - First Floor

Speakers: Deborah Hall, MD, PhD, Michelle Hyczy de Siqueira Tosin, PhD, MSN

9:45 AM - 10:30 AM

Self-Advocate: Panel

Location: Kentucky Ballroom - First Floor

Moderator: Robby Miller ; Panelist: Carly Dolan, Elizabeth Hosley, Sean Sawicki

10:30 AM - 10:45 AM

Break

10:45 AM - 11:45 AM

Panel Discussion: Education

Location: Marriott Ballroom

10:45 AM - 11:45 AM

FORWARD Publications Update: Advancing Knowledge in FXS

Location: Bluegrass

CDC Fragile X Syndrome Studies

10:45 AM - 11:45 AM

Location: Bluegrass

Speaker: Angela Thompson-Paul

Factors associated with social participation among children with fragile X syndrome

10:45 AM - 11:45 AM

Location: Bluegrass

Speaker: Maria Gonzalez, MPH

Characterizing Populations Based on Proximity to a Fragile X Syndrome Specialty Clinic

10:45 AM - 11:45 AM

Location: Bluegrass

Speaker: Sarah Tinker, MPH, PhD

Early Intervention in Children with Fragile X Syndrome: Prevalence, Timing, and Family Perception

10:45 AM - 11:45 AM

Location: Bluegrass

Speaker: Alicia Dunajcik, MPH

Medical and behavioral comorbidities in adults with Fragile X syndrome

10:45 AM - 11:45 AM

Location: Bluegrass

Speaker: Marc Schweizer, MBChB

Nonpharmacological Therapies in Children and Adolescents with Fragile X Syndrome and Autism Spectrum Disorder Diagnosis

10:45 AM - 11:45 AM

Location: Bluegrass

Speakers: Walter Kaufman, MD, Craig Erickson, MD

Experiences of Adults with Fragile X Syndrome: Transition Services, Employment and Social Participation

10:45 AM - 11:45 AM

Location: Bluegrass

Speaker: Elizabeth Berry-Kravis, MD, PhD

10:45 AM - 11:45 AM

Research Clinical Science - Fragile X Premutation

Location: Rose

Advancing Clinical Trials (ACT) for FXTAS

10:45 AM - 11:45 AM

Location: Rose

Speaker: David Hessler, PhD

Defining What Matters in FXTAS: Patient, Care-Partner, and Expert Priorities to Guide Clinical Outcome Assessments Selection

10:45 AM - 11:45 AM

Location: Rose

Speaker: Michelle Hyczy de Siqueira Tosin, PhD, MSN

Women with the FMR1 Premutation: A Within Family Sibling Study

10:45 AM - 11:45 AM

Location: Rose

Speaker: Leann DaWalt

Revising the Diagnostic Criteria for FXTAS: Proposal and Call to Action

10:45 AM - 11:45 AM

Location: Rose

Speaker: Deborah Hall, MD, PhD

10:45 AM - 11:45 AM

Understanding & Treating Behavioral Issues

Location: Thoroughbred/Filly

Speakers: Marcia Braden, PhD, Jennifer Epstein, PhD

- 10:45 AM - 11:45 AM** **Tentative - When Emotions Run High: Practical De-Escalation Strategies for Caregivers of Individuals with Fragile X Syndrome**
 Location: Salon F - First Floor
 Speaker: Tentative - Debra Reisinger, PhD
- 10:45 AM - 11:45 AM** **Tentative - Tips and Tricks for Early Communication Development**
 Location: Salon G - First Floor
 Speakers: Tentative - Anne Hoffmann, PhD, CCC-SLP, Kristen Vincent, M.A., CCC-SLP, Laura Mattie, PhD
- 10:45 AM - 11:45 AM** **Self Advocate: Be Flexible! Learning to Go with the Flow**
 Location: Kentucky Ballroom - First Floor
 Speakers: Allison Birnschein, PhD, Rebecca Shaffer, PhD
- 11:45 AM - 1:15 PM** **Lunch Break - On Your Own**
- 1:15 PM - 2:15 PM** **Panel Discussion - Fragile X Premutation**
 Location: Marriott Ballroom
- 1:15 PM - 2:15 PM** **Helping to Secure the Financial Future of Individuals (of all ages) with Disabilities**
 Location: Bluegrass
 Speakers: Kelly Piacenti, ChSNC, Tentative - Jerry Hulick, CLU, ChFC, ChSNC, CLTC
- 1:15 PM - 2:15 PM** **Symposia: Females with FXS and examines neurodevelopmental and mental health outcomes across the lifespan**
 Location: Rose
 Speaker: Audra Sterling
- From Preschool to Motherhood: Neurodevelopmental and Mental Health Outcomes in Females with Fragile X Syndrome**
 1:15 PM - 2:15 PM
 Location: Rose
 Speaker: Lauren Jenner, PhD

Autism, Anxiety, and ADHD in Young Girls with Fragile X Syndrome
 1:15 PM - 2:15 PM
 Location: Rose
 Speaker: Holley Arnold, PhD

Behavioral and Adaptive Profiles of School-Aged Females with Fragile X Syndrome
 1:15 PM - 2:15 PM
 Location: Rose
 Speaker: Mojtaba Norozi, MSc, SLP

Mental Health Symptoms, Medication, and Service Use Among Young Women with Fragile X Syndrome
 1:15 PM - 2:15 PM
 Location: Rose
 Speaker: Laura Friedman, PhD, CCC-SLP
- 1:15 PM - 2:15 PM** **What's it like to have a brother or sister with FXS? What can siblings learn from each other?**
 Location: Thoroughbred/Filly
 Speakers: Barbara Haas-Givler, MEd, BCBA, Cora Taylor, PhD, Paige Zolecki, BS
- 1:15 PM - 2:15 PM** **Emotion Regulation: How Caregivers Can Support Development**
 Location: Salon F - First Floor
 Speaker: Rebecca Shaffer, PhD
- 1:15 PM - 2:15 PM** **Tentative - Attention Deficits, Hyperactivity, and Impulsivity in Fragile X Syndrome – Behavioral and Medication Treatments**
 Location: Salon G - First Floor
 Speakers: Tentative - Nicole Tartaglia, MD, Caroline Dias, MD, PhD
- 1:15 PM - 2:15 PM** **Self-Advocate: Puberty, sexuality, relationships & boundaries**
 Location: Kentucky Ballroom - First Floor
 Speakers: Tentative - Vicki Wilkins, MD, Katie Frank, PhD, OTR/L, Tentative - David Tillman, PhD
- 2:15 PM - 2:30 PM** **Break**
- 2:30 PM - 3:30 PM** **Panel Discussion - Fragile X Syndrome General Treatment and Interventions**
 Location: Marriott Ballroom

2:30 PM - 4:00 PM

Symposia: FXTAS in FMR1 Premutation Carriers: Updates from Ongoing Research FXTAS

Location: Bluegrass

Discussant: Deborah Hall, MD, PhD ; Chair & Presenter: Jessica Klusek, PhD, CCC-SLP ; Presenter: David Hessler, PhD, Matt Mosconi, PhD, Tentative - Yash Kommula

FXTAS Neuromotor Signs in Women with the FMR1 Premutation: Elevated Risk at Mid-Range CGGs and Attenuation by College Degree Attainment

2:30 PM - 4:00 PM

Location: Bluegrass

Speaker: Jessica Klusek, PhD, CCC-SLP

Scalable solutions for quantifying and tracking FXTAS symptoms

2:30 PM - 4:00 PM

Location: Bluegrass

Speaker: Matt Mosconi, PhD

FXTAS Neurological Quality of Life: Patient Reported Outcomes

2:30 PM - 4:00 PM

Location: Bluegrass

Speaker: David Hessler, PhD

Tentative - Association between FXTAS Status and BMI in Premutation Carriers

2:30 PM - 4:00 PM

Location: Bluegrass

Speaker: Tentative - Yash Kommula

2:30 PM - 3:30 PM

Symposia: Prenatal and Newborn Screening in Fragile X Syndrome (Smith, Wheeler, Adayev)

Location: Rose

Speakers: Elizabeth Smith, PhD, Tentative - Anne Wheeler, PhD

Bridging Prenatal and Newborn Screening in Fragile X: Lessons from Feasibility Studies

2:30 PM - 3:30 PM

Location: Rose

Speaker: Tatyana Adayev, PhD

Tentative - Access to Early Intervention Services for newborns with FXS

2:30 PM - 3:30 PM

Speaker: Tentative - Anne Wheeler, PhD

2:30 PM - 3:30 PM

Tentative - Legal Considerations

Location: Thoroughbred/Filly

2:30 PM - 3:30 PM

Conversations That Matter: Understanding Reproductive Options While Honoring Family Values

Location: Salon F - First Floor

Speaker: Susan Howell

2:30 PM - 3:00 PM

Maximizing Academic Success with "The Fragile X Way"

Location: Salon G - First Floor

Speakers: Julie Thomas, Amy Cornett

2:30 PM - 3:30 PM

Self-Advocate: Hygiene

Location: Kentucky Ballroom - First Floor

Speaker: Katie Frank, PhD, OTR/L

3:00 PM - 3:30 PM

Connecting the Dots: A Fragile X Carrier and all it "carries" with it

Location: Salon G - First Floor

Speaker: Keiko Mathewson

3:30 PM - 3:45 PM

Break

3:45 PM - 4:30 PM

The Belonging Project Updates

Location: Rose

Speakers: Anna DeSonia, Tentative - Debra Reisinger, PhD, Tentative - Vicki Wilkins, MD

3:45 PM - 4:30 PM

Tentative - Women, FXTAS, and FXAND: Supporting Mental Health in the Context of Caregiving

Location: Thoroughbred/Filly

Speakers: Tentative - Andrea Schneider, PhD, Randi Hagerman, MD

3:45 PM - 4:30 PM

When Women with Fragile X Need Mental Health Care: A Self-Advocate Toolkit for Families

Location: Salon F - First Floor

Speaker: Priya Khalsa, MD, JD, MSW

3:45 PM - 4:30 PM

Planning for Transition - Steps to Help Parents

Location: Salon G - First Floor
Speaker: Kara Frech, MBA

3:45 PM - 4:30 PM

Self-Advocate: Let's Dance Practice Session 2

Location: Kentucky Ballroom - First Floor
Speakers: Peyton Toman, Paige Zolecki, BS

4:00 PM - 4:30 PM

Self- Recorded Presentations

Supporting Communication Efficiency in Fragile X Syndrome (FXS): AAC, Gestalt Language Style, Fluency Challenges, and Regulation. Speech presence does not equal speech efficiency.

4:00 PM - 4:30 PM
Speaker: Sara Velenich

Transition to adulthood

4:00 PM - 4:30 PM
Speaker: Nicole Morris, MS

4:15 PM - 5:00 PM

Research Basic Science - Fragile X

Location: Bluegrass

Tentative - Integrated Transcriptomic and Proteomic Profiling of the human FXS brain

4:15 PM - 5:00 PM
Location: Bluegrass
Speaker: Tentative - Nisha Raj, MD

Tentative - Developmental Trajectories of Neural Oscillatory Activity in Young Children with Fragile X Syndrome: Relation to language outcomes in the FXLEARN trial

4:15 PM - 5:00 PM
Location: Bluegrass
Speaker: Tentative - Eunsung Lee

FMR1 expression and mosaicism in the human brain in fragile X syndrome

4:15 PM - 5:00 PM
Location: Bluegrass
Speaker: Caroline Dias, MD, PhD

4:30 PM - 6:00 PM

Break

6:00 PM - 10:00 PM

Saturday Celebration

Location: Marriott Ballroom

Sunday, July 19, 2026

8:00 AM - 1:00 PM

Professional to Professional: From Mechanism to Meaning: Advancing Fragile X Syndrome & Premutation Research Toward Meaningful Clinical Impact

Location: Marriott Ballroom