Registration

Name:

Address:

City/State/Zip:

Email:

Phone: -

Attendee - please check all that apply

Fragile X Family Member	
Physician	
Teacher	
Therapist	
Other	

Payment \$60 per attendee

Online Registration

CLICK HERE - https://give.fragilex.org/CTLearn19

Please Register by October 12, 2019.

CEU credit & Attendance Certificate available on request.

In lieu of Online Registration, pay by **Check**, made payable to: **NFXF**)

Mail to: National Fragile X Foundation Connecticut Chapter Tammy and Andy Selinger 20 Mohegan Drive West Hartford, CT 06117

For additional information call: Tammy and Andy Selinger (860) 233-1904 Or e-mail <u>connecticut@fragilex.org</u> On the web: <u>www.facebook.com/FragileXCT</u> On the National Fragile X Foundation website: https://fragilex.org/connecticut-chapter National Fragile X Foundation Connecticut Chapter Tammy and Andy Selinger 20 Mohegan Drive West Hartford, CT 06117

Changing Behaviors and Optimizing Learning Through Integrated Intervention

Featuring Internationally Renowned Fragile X and Autism Spectrum Disorder Experts

Tracy Murnan Stackhouse,

MA, OTR/L Developmental FX

Ruth Meissner, MA, CCC-SLP Developmental FX

Sharyn Lincoln, MS, CGC Boston Children's Hospital

Jonathan Picker, MBChB, PhD Boston Children's Hospital

Saturday, October 26, 2019 8:00 am - 4:30 pm UCONN Health Center Keller Auditorium 263 Farmington Avenue Farmington, Connecticut 06030

Presented by



What will be presented?

- Fragile X syndrome (FXS): the most common cause of inherited mental impairment.
- Fragile X-associated disorders (FAD), which result from a mutation of a single gene within the X chromosome.
- Recent clinical trial results and upcoming new trials.
- The "biological realities" of FXS, particularly hyperarousal and anxiety, attentional difficulties, atypical language profile, social drive associated with social anxiety, gestalt learning, and sequential processing deficit with motor planning and neuromotor difficulties.
- How to address the response to internal drives that result from the "biological reality" created from FXS.
- When these "biological realities" are understood by an individual's team, the primary constraint can be addressed and will result in fewer and less maladaptive behaviors.

How much does it cost?

\$60 per person, which includes breakfast, lunch, and a conference binder.

Who should attend?

 Families, educators, therapists, and providers who care for children and adults with fragile X-associated disorders and autism spectrum disorders.

Agenda

- 8:00 8:45: Registration & Breakfast
- 8:45 9:00: Welcome
- 9:00 9:20: "FX 101" (S. Lincoln)
- **9:20 10:30:** "Part 1 Changing Behaviors and Optimizing Learning Through Integrated Intervention" (R. Meissner , T. M. Stackhouse)

10:30 - 10:45: Break

- 10:45 12:00: "Part 2 Changing Behaviors and Optimizing Learning Through Integrated Intervention" (R. Meissner, T. M. Stackhouse)
- 12:00 1:15: Lunch and Networking
- 1:15 1:45: "Clinics Update and Current Research" (J. Picker)
- 1:45 2:45: "Part 3 Changing Behaviors and Optimizing Learning Through Integrated Intervention" (R. Meissner, T. M. Stackhouse)

2:45 - 3:00: Break

3:00 – 4:30: "Questions and Answers: Panel Discussion" (S. Lincoln, R. Meissner, J. Picker, T. M. Stackhouse)

Directions from I-84

- Exit 39, right onto Rt. 4 East. Right at the 3rd light into the UConn Health Center.
- Enter the roundabout; take the second right. Bear left at the fork; continue up the hill. Continue past the stop sign. Visitor parking is available in or near Garage 3.
- Enter the Main Building. Go down one floor using escalator to your left or elevator to your right.

Possible Accommodations

Farmington Inn, 827 Farmington Avenue, Farmington, CT. Deluxe Room Rate - \$93. Room block available until 09/12, then as available. Call 800-648-9804 or visit www.farmingtoninn.com, select Modify/Cancel Reservation, click Add Code, on the drop-down menu, select Group Attendee and then enter Group# 4535.

Conference Gold X Sponsors



Speakers

Tracy Murnan Stackhouse, MA, OTR/L, co-founder, Executive Director and Director of Programs of Developmental FX in Denver, CO, is a leading pediatric occupational therapist involved in clinical treatment, research, mentoring, and training regarding OT intervention and neurodevelopmental disorders, especially Fragile X Syndrome and autism. Tracy is NDT trained and SIPT Certified with advanced autism training including DIR/Floortime, TEACCH and the Early Start Denver Model. She has training in craniosacral therapy and myofascial release, as well as Therapeutic Listening and Porges' Safe and Sound Protocol (SSP). Most recently she has been focused on incorporating trauma-informed care and selfcompassion into her work. She has written several book chapters on sensory integration and neurodevelopmental disorders, and teaches nationally, internationally, and virtually on sensory integration, fragile X, autism, and related topics. Tracy enjoys mentoring clinicians from around the world to improve their clinical reasoning skills. Tracy is the originator of the SpIRiT Model, an extension of the STEPSI that was the original fidelity model for sensory modulation written with colleagues Julia Wilbarger and Sharen Trunnell at Children's Hospital Colorado.

Ruth Meissner, MA, CCC-SLP, is the Speech Pathology Team Leader, Developmental FX Clinical Coordinator, and Fragile X Program Coordinator at **Developmental FX**. She provides therapy and evaluation services to children with

difficulties communication secondary to neurodevelopmental disorders, including those with Fragile X Syndrome. Additionally, Ruth collaborates with parents and families to improve their understanding of children's communication abilities and to implement home programs. She also collaborates with the community through school consultations and information sessions. She has always been interested in the transdisciplinary understanding of development required to make functional changes in communication ability and overall development. Ruth began her near 20-year career in Chicago, IL providing home-based services to the birth-to-three population, and clinic-based services in a multicultural and multidisciplinary outpatient clinic. Collaboration with multiple therapy and medical professionals providing Medical Diagnostic Evaluations translated to valuable experience and perspective on complicated neurodevelopmental issues. Ruth speaks Spanish and is currently completing training for a Professionals Certificate in the DIR-FCD.

Sharyn Lincoln, MS, CGC, Licensed Genetic Counselor, Clinical Coordinator, Fragile X Program, Boston Children's Hospital (BCH). Sharyn received her MS in Genetic Counseling from Brandeis University. She is the program coordinator and a counselor for the Boston Children's Hospital Fragile X Program. Ms. Lincoln is a member of the Fragile X Clinical and Research Consortium (FXCRC) Clinical Committee and Research Committee. She is in close communication with the New England Fragile X Community Support Network groups and actively participates in local conferences and events. In addition to her clinical responsibilities, Ms. Lincoln is the BCH site coordinator for the Undiagnosed Diseases Network.

Jonathan Picker, MBChB, PhD, Joint Appointment between Clinical Genetics and Child and Adolescent Psychiatry at Boston Children's Hospital (BCH); Asst. Professor, Harvard Medical School. Dr. Picker heads the BCH Fragile X Program, providing individuals and families affected by fragile X with evaluation and care supported by the latest medical, educational, and research knowledge. Dr. Picker was a Founding Member of the International Fragile X Clinical & Research Consortium and the chairman of its clinical committee responsible for the development of most of the consensus documents on clinical practice. He is also the co-founder and co-director of the BCH Pharmacogenomics Clinic, which looks at genes that affect an individual's responses to medications and their likelihood of developing side effects; this is especially important for those who have had poor and unexpected responses from medicines.