

X-pert Advice: Living the Fragile X Way for Home, School, Work and Play

Featuring Renowned
Fragile X Experts

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Friday, June 12, 2015
8:00 am - 5:00 pm
Tulane University School of Law
6329 Freret Street
New Orleans, Louisiana 70115



Conference Agenda:

8:30 - 8:45: Welcome and Introductions
8:45 - 9:30: What is Fragile X?
9:30 - 10:45: Setting the groundwork: Understanding the Fragile X Learning Style; Motor planning and imitation in Fragile X.
10:45 - 11:00: BREAK
11:00 - 12:00: Hands-On hyperarousal experience; What is hyperarousal?
12:00 - 1:15: LUNCH
1:15 - 3:15: Sensory, Routines and Language based strategies for home, school and beyond.
3:15 - 3:30: Break
3:30 - 4:30: Sensory, Routines and Language based strategies continued
4:30 - 5:00: PANEL: Questions and Answers

Registration Information and FAQ

- Event Cost \$45, including breakfast, lunch, and materials
- Register at [Louisiana Fragile X Conference Homepage](#) (or www.eventbrite.com, search "Fragile X" if the hyperlink does not work).
- Applications for 6.5 hours ST and OT CEUs pending.
- **Who should attend?** Anyone who lives or works with individuals with Fragile X, including families; physical, occupational, and speech therapists; occupational therapists; special needs instructors; teachers; physicians; and Early Steps providers.
- For information regarding hotels, parking, directions, and more, visit [Louisiana Fragile X Conference Homepage](#)
- For more information, contact Abigail Gaunt at 917-836-7993 or CentrallA@fragilex.org



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Learning Objectives

- Participants will gain an understanding of Fragile X syndrome (FXS), the most common cause of *inherited* mental impairment and the leading single gene cause of Autism.
- Participants will learn about how FXS relates to Autism.
- Participants will learn how to identify who should be tested for Fragile X.
- Participants will learn about new clinical treatments for individuals with FXS
- Participants will be able to define the primary learning style of individuals with FXS.
- Participants will be able to identify hyperarousal in individuals with FXS and will understand the impact of hyperarousal on language, learning and daily living skills.
- Participants will understand the importance of using pro-active strategies in managing hyperarousal on a day-to-day basis and be able to identify at least three specific methods for calming, coping and comfort as they apply to the common anxiety, hyperarousal and behavioral issues in FXS.
- Participants will understand the components of managing hyperarousal across daily environments using evidence based strategies from the disciplines of Occupational Therapy, Speech/Language Therapy and general development.
- Participants will learn about the components of managing motor planning across daily environments with strategies pulled from best practice in Occupational Therapy, Speech/Language Therapy and general development.
- Participants will learn specific means for promoting play skills therapeutically as well as in daily family life.
- Participants will identify motor planning and imitation strengths and weaknesses in FXS.

Speakers

- **Sarah Scharfenaker, MA, CCC-SLP**, Sarah, fondly known as “Mouse”, is vice-president, CFO and co-founder of **Developmental FX** (a non-profit organization dedicated to assessment, research, resource development, and treatment in the Fragile X and neurodevelopmental areas). She has worked in the fields of Fragile X Syndrome and neurodevelopmental disorders for more than 25 years. She received both her undergraduate and graduate degrees from the University of Montana, Missoula. She provided speech pathology services to the Denver Fragile X Treatment and Research Center at The Children’s Hospital and accompanied Dr. Randi Hagerman to the UC Davis M.I.N.D. Institute to initiate its program. Mouse has published many chapters and articles on intervention for Fragile X, and consults and teaches nationally and internationally. Her special connection with children and adults as well as her extensive expertise allow her to bring a depth to her work that is unmatched and well-remembered by those who have seen her.
- **Tracy Murnan Stackhouse, MA, OTR**, Tracy is president and co-founder of **Developmental FX**. She is a leading pediatric occupational therapist (OT) involved in clinical treatment, research, mentoring, and training regarding OT intervention for persons with neurodevelopmental disorders, especially Fragile X Syndrome and autism. She received her undergraduate degree in occupational therapy from Colorado State University and a master’s degree in developmental psychology from the University of Denver. She received her NDT training with Lois Bly. She is SIPT Certified (Sensory Integration and Praxis Test) and was the clinical specialist in sensory integration at The Children’s Hospital in Denver as well as the OT for the Fragile X Research and Treatment Center. Tracy continued her clinical and research work with Dr. Randi Hagerman at the UC Davis M.I.N.D. Institute during its start-up year. Tracy has written several book chapters on sensory integration and neurodevelopmental disorders, and teaches and consults nationally and internationally on sensory integration, Fragile X and related topics.
- **Louise Gane, MS**, Louise W. Gane, M.S. is a Genetic Associate. She was previously associated with the University of California Davis MIND Institute Fragile X Research and Treatment Center under the Directorship of Randi J. Hagerman, M.D. She participated in research projects sponsored by the National Institutes of Health (NIH), clinical trials as well as patient clinical care. Louise is nationally and internationally recognized for her work in the field of fragile X-associated disorders (FXD). She began working with patients who have Fragile X syndrome (FXS) and their family members in 1984. Currently, Louise is working with the National Fragile X Foundation (NFXF) as a member of Fragile X Clinical and Research Consortium Membership and Infrastructure Committee and the Scientific Advisory Board. She lectures nationally and internationally, presents at scientific conferences and family-friendly forums as well as having authored and being included on many scientific publications. She is a past member of the NFXF Board and in 2004 received the NFXF Jarret Cole Clinical Services Award.

