

## REGISTRATION

Name:

\_\_\_\_\_

Address:

\_\_\_\_\_

City/State/Zip:

\_\_\_\_\_

Email:

\_\_\_\_\_

Phone:

\_\_\_\_\_

*Registrations will only be confirmed by e-mail*

**Attendee(s) - please check all that apply**

- Fragile X Family Member  
 Physician  
 Teacher  
 OT, SLP  
 Other \_\_\_\_\_

**Pre-Registration** (Received By March 31): \$50

**Walk In** (April 14, 2012): \$60

Pay by **Check** or **Credit Card**

**Make Checks payable to: NFXF**

- Check  
 Visa  
 MasterCard

Please print clearly:

Name (*as on card*) \_\_\_\_\_

Card # \_\_\_\_\_

Expiration Date- month/year \_\_\_\_\_

Billing Zip Code \_\_\_\_\_

Total Enclosed: \$ \_\_\_\_\_

**Mail Payment and Registration to:**

Eric Welin  
63 Griswold Street  
Cambridge, MA 02138  
(617) 858-0392  
eric@fragliexma.org

National Fragile X Foundation  
1615 Bonanza St. Suite 202  
Walnut Creek, California 94597

---

# FRAGILE X SYNDROME

## HYPERAROUSAL & SENSORY INTEGRATION

### STRATEGIES FOR HOME AND SCHOOL

---

#### FEATURED SPEAKERS:

Tracy Murnan Stackhouse, MA, OTR  
Developmental FX, Denver, CO

Sarah Sharfenaker, MA CCC-SLP  
Developmental FX, Denver, CO

Sharyn Lincoln, M.S., C.G.C.  
Children's Hospital Boston, Boston, MA

Craig Penz  
Seaside Therapeutics, Cambridge, MA

---

**Saturday, April 14, 2012**

8:00 AM - 4:00 PM

**Arthur and Martha Pappas  
Amphitheatre**

University of Massachusetts Medical  
School

**55 Lake Avenue North  
Worcester, MA 01655**

---

#### HOSTED BY:

**The Fragile X LINKS Group of  
Eastern Massachusetts,**

**The Fragile X Resource Center of  
Western Massachusetts**

**&**

**Fragile X Program,  
Children's Hospital Boston**

---

## Agenda

- 8:00-8:30** Registration and Breakfast
- 8:30-8:55** Welcome and Fragile X 101
- 8:55-9:20** Clinical Trials and Update on STX209
- 9:20-10:30** Hyperarousal Basics
- 10:30-10:50** Break
- 10:50-12:00** Fragile X Learning Style and Hands on Hyperarousal Experience
- 12:00-1:00** Lunch
- 1:00-2:00** Sensory Based Strategies
- 2:00-3:00** Hands-on Workshop
- 3:00-3:15** Break
- 3:15-4:00** Panel Q&A Session

### Who should attend?

Families, educators, OTs, SLPs and other providers who care for and work with children and adults with fragile X syndrome and autism spectrum disorders.

*Pre-registration is encouraged; Fill out the form on back and return with payment to the address listed. Walk In registration may be available.*

### How much does it cost?

\$50 per person (before 3/31).  
Includes breakfast, lunch and materials.

### For More Information:

**Eric Welin** ([eric@fragilexma.org](mailto:eric@fragilexma.org))  
Fragile X LINKS Group of Eastern Massachusetts

**Denise Devine** ([frxrcfwmass@aol.com](mailto:frxrcfwmass@aol.com))  
Fragile X Resource Center of Western Massachusetts

## Getting There:

### From the Mass Pike:

**Eastbound:** At exit 10, take I-290 east to exit 21, turn right at end of ramp and follow Plantation Street south.

**Westbound:** At exit 11, turn left onto Route 122 north for one mile, turn right at third light onto Sunderland road, left at first light onto Lake Avenue for 2.5 miles and cross Route 9. Make U-turn at second break in divider, then turn right into campus.

### From I-495:

**Northbound:** At exit 23, take Route 9 west. Follow Route 9 west for approximately 11 miles. After crossing the Lake Quinsigamond bridge, take first right onto Lake Avenue.

**Southbound:** At exit 25, take I-290 west to exit 22, turn right at end of ramp, at second traffic light turn left at onto Plantation Street and proceed south.

See the conference website at:  
[www.fragilexma.org/conference/y2012](http://www.fragilexma.org/conference/y2012)  
for additional details

### Sponsored By:



NATIONAL FRAGILE X  
FOUNDATION



## Speakers

**Sarah Scharfenaker, MA, CCC-SLP**, fondly known as “Mouse”, is co-founder of Developmental FX. She has worked in the fields of *fragile X syndrome* and *neurodevelopmental disorders* for more than 20 years. She provided speech pathology services to the Denver *Fragile X* Treatment and Research Center at The Children’s Hospital in Denver, Colorado, 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*. She consults and lectures on *Fragile X* treatment both nationally and internationally.

**Tracy Murnan Stackhouse, MA, OTR** is co-founder of the Developmental FX in Denver, Colorado. She 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 has a master’s degree in developmental psychology. She is NDT trained, SIPT Certified. Tracy has written several book chapters on sensory integration and neurodevelopmental disorders, and teaches nationally and internationally on sensory integration, *fragile X* and related topics.

**Sharyn Lincoln, M.S., C.G.C.** is a Licensed Genetic Counselor and the Program Coordinator of the *Fragile X* Program at Children’s Hospital Boston in Boston, Massachusetts. Ms. Lincoln provides genetic counseling to individuals and families with *fragile X* syndrome and *fragile X*-related disorders. As Program Coordinator for the CHB *Fragile X* Program, she coordinates visits to the Program and participates and contributes to diagnostic evaluations within the Program.

**Craig Penz** is a Clinical Program Manager for Seaside Therapeutics. He is currently pursuing a Master’s in Clinical Investigation at Boston University. Has over eight years experience managing clinical trials and has worked on Seaside Therapeutics’ *Fragile X* Syndrome and Autism Spectrum Disorder studies for over three years.