

## Registration

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Name: \_\_\_\_\_

Address: \_\_\_\_\_

City/State/Zip: \_\_\_\_\_

Email: \_\_\_\_\_

Phone:           -           - \_\_\_\_\_

**Attendee** - please check all that apply

Fragile X Family Member

Physician

Teacher

Therapist

Other

**CEU credit & Attendance Certificate available on request.**

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**Payment** \$60 per attendee

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**\*\* NEW! Online Registration - [CLICK HERE!](#)**

(or [www.eventbrite.com](http://www.eventbrite.com), search "Fragile X" if link is bad.)

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

**Please Register by October 24, 2015.**

Mail to:  
Fragile X Society of Connecticut  
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 [CentralCT@fragilex.org](mailto:CentralCT@fragilex.org) or [xfamily@aol.com](mailto:xfamily@aol.com)  
On the web: [www.facebook.com/FragileXSocietyofCT](http://www.facebook.com/FragileXSocietyofCT)

Fragile X Society of Connecticut  
Tammy and Andy Selinger  
20 Mohegan Drive  
West Hartford, CT 06117

# Creating Successful IFSPs, IEPs and Adult Programs

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**Featuring Internationally Renowned  
Fragile X and Autism Spectrum  
Disorder Experts**

**Vicki Sudhalter, Ph.D.**

New York State Institute for Basic Research  
in Developmental Disabilities

**Sharyn Lincoln, MS, CGC**

Boston Children's Hospital

**Jonathan Picker, MBChB, PhD**

Boston Children's Hospital

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**Saturday, November 7, 2015**

**8:00 am - 4:30 pm**

**University of Connecticut**

**Health Center**

**Keller Auditorium**

**263 Farmington Avenue**

**Farmington, Connecticut 06030**

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**Presented by**



**FRAGILE X SOCIETY  
OF CONNECTICUT**

## 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.
- Introduction to the relationship between the medicines being studied and the genetics.
- Recent clinical trial results and upcoming new trials.
- The FXS phenotype - behavioral, psychological, physical - and knowing why the phenotype is so crucial to understanding how to create a good IFSP/IEP/IP\*.
- Therapies, curriculums, and programs finding success in individuals with FXS.
- How to write attainable measurable goals in IFSP/IEP/IP using proven specific programs and therapies, with suggested ways of measuring progress.
- The various components of an effective IFSP/IEP/IP.
- The audience will understand how to evaluate if the IFSP/IEP/IP is working and what to look for in a school or adult program.

\* IFSP - Individual Family Service Plan - is a plan for special services for children from birth to three years old with developmental delays.

\* IEP - Individualized Education Program - is a written statement of the educational program designed to meet a child's individual needs.

\* IP - Individual Plan - is for all individuals who receive ongoing DDS (Department of Developmental Services) supports and services and guides all supports and services provided to the individual/adult.

## Agenda

**8:00 - 8:45:** Registration & Breakfast

**8:45 - 9:00:** Welcome

**9:00 - 9:30:** "FX 101 and Drug Trials" (S.L. and Dr. J.P.)

**9:30 - 10:30:** "The Fragile X Phenotype and the IFSP/IEP/IP" (Dr. V.S.)

**10:30 - 10:45:** Break

**10:45 - 12:15:** "Therapies, curriculums, and programs for the individual with FXS including case studies" (Dr. V.S.)

**12:15 - 1:30:** Lunch and Networking

**1:30 - 3:30:** "The IFSP/IEP/IP - Pulling it all together for successful outcomes" (Dr. V.S.)

**3:30 - 3:45:** Break (collect questions for Panel Discussion)

**3:45 - 4:30:** "Questions and Answers: Panel Discussion" (S.L., Dr. J.P., Dr. V.S.)

## Who should attend?

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

## How much does it cost?

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

## Directions From I-84

- Exit 39, right onto Rt. 4 East. Right at the 3<sup>rd</sup> 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 past the gate.
- Enter thru main entrance. Take escalator down on left.

## Possible Accommodations

Farmington Inn, 827 Farmington Avenue, Farmington, CT. Deluxe Room Rate - \$82.  
Reservations: 800-648-9804; www.farmingtoninn.com  
Ask for the "Fragile X Conference Block" when reserving.

## Conference Gold X Sponsors



## Fragile X Society of Connecticut

Special thanks to our medical advisor, **Dr. Mark A. Greenstein**, Professor of Pediatrics, Divisions of Genetics and Child Development, **UConn School of Medicine** and our Fragile X Clinical & Research Consortium member, **Boston Children's Hospital**.

## Speakers

**Vicki Sudhalter, Ph.D.**, has been working in the field of Fragile X Syndrome for over twenty-five years, during which she has strived to gain a better understanding of the characteristics of individuals with this disorder. In addition to conducting research into the language, gaze aversion and hyperarousal problems of males with Fragile X Syndrome, she has done extensive outreach to educators throughout the Northeast to help them adapt their programs to the special needs of these children. She frequently acts as a parent advocate, helping to develop Individualized Educational Programs (IEPs) that provide appropriate services for children with Fragile X Syndrome, and representing their interests to teachers and school administrators. In conjunction with Dr. Ted Brown and Nancy Zellers, Dr. Sudhalter established the **Fragile X Clinic at the New York State Institute for Basic Research in Developmental Disabilities**, where she currently is Head of their Clinical Psycholinguistics Laboratory. She is a member of the National Fragile X Advisory Committee, and she was the 2006 recipient of the "Jarrett Cole Clinician Award" for service to families with Fragile X Syndrome. In 2014, the National Fragile X Foundation recognized Dr. Sudhalter with their "Al and Melissa Blount Lifetime Achievement Award" for sustained and generous support of the NFXF and the Fragile X community.

**Sharyn Lincoln, MS, CGC**, Licensed Genetic Counselor, Clinical Coordinator, **Fragile X Program, Boston Children's Hospital (BCH)**. Sharyn provides genetic counseling to individuals and families with fragile X syndrome. She coordinates medical evaluations and contributes to diagnostic evaluations within BCH's Fragile X Program. Additionally, Sharyn co-chairs the International Fragile X Clinic & Research Consortium (FXCRC) executive council, responsible for overseeing the organization and its future development.

**Jonathan Picker, MBChB, PhD**, Joint Appointment between Clinical Genetics and Child and Adolescent Psychiatry at BCH; Asst. Professor, Harvard Medical School; Founding Member of the FXCRC. 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 the chairman of the clinical committee responsible for the development of most of the consensus documents on clinical practice provided by the FXCRC.