



# **How to Organize an Educational Seminar**

**Tammy and Andy Selinger**

**Fragile X Society of Connecticut**

# Location, Location, Location

- Where:
  - Centrally located
  - Easy to get to
  - Educational facility, hospital, church/synagogue, The ARC, UCEDD (University Center for Excellence in Developmental Disabilities)
- Cost:
  - Free is best and often possible
  - Insurance (if required)
- Keep in mind:
  - Auditorium is better than a flat room
  - A/V needs (ie. laptops, microphones, screens, projector)
  - Seating for lunch
  - Parking
  - Hotel room block (reasonably priced and close to venue)

# Shaping Your Event

- Date
  - Avoid school vacations, holidays and other events
  - Too early in Sept. could be difficult (school budgets and planning)
- Topic
  - If possible, survey members
- Speaker(s)
  - Additional collaborations
    - Colleges
    - Grand Rounds
    - Evaluations
    - LEND (Leadership Education in Neurodevelopmental Disabilities)
  - Great opportunity to collaborate with your partner clinic (if you have one)
  - Awareness opportunities (TV, radio, newspaper)

# No Money? No Resources?

- Action Grant from NFXF (if available)
- Grants (ie. Service Organizations, DDS)
- Registration Fee
  - Affordable
- Fundraisers
  - Gala
  - Bake Sale/Car Wash
- Sponsorships

# Sponsorships

- Potential sponsors
  - Everyone you do business with (ie. accountants, attorneys, doctors, insurance agents, therapists)
  - People you come in contact with (ie. Store owners / managers, restaurant owners / managers)
  - Family and Friends

# Cost Per Person

- Based on:
  - Honorarium(s) – range from \$0 - \$1,500 per speaker
  - Cost of venue
  - Food (breakfast and/or lunch)
  - Materials handed out
  - Transportation, hotel, food for speaker(s)
  - Availability of action grant, grants, sponsorships, sharing expenses (speaker already in the area)
  - No registration fee often means no commitment to attend.

# CEUs – Continuing Education Units

- Offering CEUs can increase the number of professionals that will attend your conference.
- A CEU is a measure used in continuing education programs, particularly those required in a licensed profession in order for the professional to maintain the license.
- Often administered by an educational institution. UCEDDs and Colleges or Universities may be able to administer the CEUs for a FX educational conference.
- Check for a local UCEDD on:  
<http://www.acf.hhs.gov/programs/add/states/ucedds.html>
- Arrange for the CEUs early so that you can include them being offered on the registration form.

# Certificate of Attendance

- If unable to offer CEUs, and even in addition to the CEUs, a certificate of attendance is important to offer.
- When the CEUs offered are “General CEUs”, professionals can often convert the CEUs or the certificate of attendance through their professional organizations to whatever credits they need for their licenses.



# Registration Form

## Registration

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.

Payment: \$50 per attendee

Pay by Check or Credit Card

Check ☐ (Please make Checks payable to: NFXF)

American Exp. ☐ Discover ☐ MasterCard ☐ Visa ☐

Please print clearly:

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

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

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

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

Payment and Registration must be received by  
November 7, 2011.

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 [xfamily@aol.com](mailto:xfamily@aol.com)

[[http://www.fragilex.org/html/ct\\_home.htm](http://www.fragilex.org/html/ct_home.htm)]

National Fragile X Foundation  
1615 Bonanza Street  
Suite 202  
Walnut Creek, CA 94596

## Successful Transitions – Planning for the Education and Employment Years

Featuring Internationally Renowned  
Fragile X Experts

**Vicki Sudhalter, Ph.D.**

New York State Institute for Basic Research  
in Developmental Disabilities

**H. Laurie Yankowitz, Ed.D.**

Heartshare Human Services of New York

**Jane Brown, Ed.D.**

University of Connecticut, School of Law

**Ramzi Nasir, MD, MPH**

Children's Hospital Boston

Saturday, November 19, 2011

7:45 a.m. – 4:30 p.m.

University of Connecticut

Health Center

263 Farmington Avenue

Farmington, Connecticut 06030



### What will be presented?

- Understand what a Fragile X Clinic can provide for an individual with Fragile X Associated Disorders.
- Transitions through the life span - demonstrating what steps are needed in order to make transitions easier.
- Accommodations for hyperarousal as part of the IEP for any child with FXS.
- Triggers of hyperarousal that commonly affect teens and adults. Strategies that teens and adults themselves can adopt to cope with unavoidable hyperarousal.
- How Fragile X Syndrome (FXS) affects your young adult.
- Information on transitioning to programs after high school.
- Learn the differences between high school and college and how to prepare for those changes.
- Information about college options for students with FXS, where the programs are located, and what supports are provided.
- The importance of accessing services from the state system while the individual is still in school.
- Documentation of eligibility and other state requirements.
- Eligibility for Medicaid for virtually all state funded services for adults. How those with FXS will be eligible.

### Agenda

7:45 - 8:30: Registration & Breakfast.

8:30 - 8:40: Welcome.

8:40 - 9:15: "FX 101: What's Available at Children's Hospital Boston" (Dr. R. Nasir).

9:15 - 10:15: "Hyperarousal and IEPs in Relation to Transitions and Younger Children" (Dr. V. Sudhalter).

10:15 - 10:30: Break.

10:30 - 11:15: "The Teen Years - Beginning the Transition Plans" (Dr. L. Yankowitz).

11:15 - 12:15: "Hyperarousal in Teens and Adults" (Dr. V. Sudhalter).

12:15 - 1:30: Lunch & Networking.

1:30 - 2:30: "College and Post-secondary Programs for Students with Fragile X Syndrome" (Dr. J. Brown).

2:30 - 3:30: "Accessing Adult Services and Employment" (Dr. L. Yankowitz).

3:30 - 3:45: Break.

3:45 - 4:30: "Questions and Answers: Panel Discussion" (Speakers).



Linking Individuals  
Nationally in  
Knowledge  
and Support

### Who should attend?

Families, educators, therapists, and providers who care for children and adults with FXD.

### How much does it cost?

\$50 per person. This includes breakfast, lunch, and a conference binder.

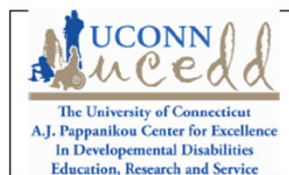
### Does the conference have impact?

"After attending the fall 2010 conference with our 6 1/2 year old son's teacher, we adapted our approach to teaching him sight words to give him the foundation to begin reading. With the new strategies in place, our son learned words ahead of his IEP goals. He continues to be visibly proud of himself for being able to recognize his sight words in books." *Scott Locke, father, New York.*

### Directions From I-84

Exit 39, right onto Rt. 4 East. Right at the 3<sup>rd</sup> light into the UConn Health Center. Follow the signs to the hospital, upper campus/main entrance. Free parking is in the visitor lots beyond the guard shack. Enter through the main entrance. Take escalator on left to lower level.

### Conference Gold X Sponsors



### Speakers

Jane Brown, Ed.D., is the Director of Student Services at UConn's School of Law and is the mother of three children, the youngest being a 19 year old son with Fragile X Syndrome (FXS). Dr. Brown has worked in Disability Services for 30 years. She has served as the Coordinator of Disability Services at the University of Rhode Island, directed a federal grant program on women with disabilities in higher education at Barnard College, serves as one of the principles of collegeautismspectrum.com,

and helps direct a program for college students on the autism spectrum at UConn. Her book, "Students with Asperger's: A Guide for College Professionals," was published in 2009. The partner book, "College Students on the Autism Spectrum: A Guide for Parents, Teachers and Clinicians," will publish in 2011.

Ramzi Nasir, MD, MPH, is an Assistant in Medicine at the Developmental Medicine Center of Children's Hospital Boston. He is an instructor in Pediatrics at Harvard Medical School and is Board Certified in Pediatrics and Developmental Medicine. His specialties include behavioral and developmental disorders in genetic diseases, developmental and behavioral pediatrics, and psychopharmacology.

Vicki Sudhalter, Ph.D., has been working in the field of FXS for 25 years striving to gain a better understanding of the characteristics of individuals with FXS, of how students' individualized education plans (IEPs) are developed and implemented, and of how to help parents advocate for their children's needs in school systems. She has done research into the gaze aversion, hyperarousal, and language problems of males with FXS. She was honored with the 2006 Jarrett Cole Clinician Award for service to families with FXS and is a member of the National Fragile X Advisory Committee. Dr. Sudhalter co-founded the Fragile X Clinic at the New York State Institute for Basic Research in Developmental Disabilities in 2000, where she currently is Head of their Clinical Psycholinguistics Laboratory.

H. Laurie Yankowitz, Ed.D., has more than 25 years experience working with families of individuals with developmental disabilities and has expertise in the learning and behavioral profile of FXS. She consults with families, schools, and other organizations to develop curriculum and in-service staff to promote skill development for people with intellectual disabilities that promote self-reliance, a sense of well-being, and a sense of belonging. She collaborates with others on efficient and effective ways to measure effectiveness of skill development programs for individuals and/or groups of people. Dr. Yankowitz is currently the Senior Director of Family Support Services at Heartshare Human Services of New York.

### 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, Children's Hospital Boston.

# Spreadsheets

- Very important to keep up with recording everything
- Excel spreadsheets are great to use since you have the ability to sort the same information in many ways for different uses.
- Use the spreadsheet to keep track of:
  - Sponsors solicited, replies and benefits at their sponsorship level
  - Attendees, payment information, name for nametag

# Marketing

- NFXF
  - Decide on groupings based on expense, distance and NFXF resources available
    - “Snail Mail” to an area based on a mile radius
    - Email blast to a larger group
- Save the date should go out early
- Social media (ie. Facebook)
- Poster containing basic information for publicizing the conference and to email along with the registration form for others to post or display.

- Email everyone that you can think of!
  - School districts based on a mile radius of the conference location
    - Superintendents, Pupil Services Directors, Teachers, Therapists
  - Private schools
  - Organizations (ie. OT/PT/SLP organizations, Autism organizations, Special Education PTAs)
  - Birth – 3 Providers
  - Adult Services Providers
  - DDS Employees
  - DDS Approved Providers
  - Wrightslaw Yellow Pages for Kids with Disabilities resources in your region ([www.yellowpagesforkids.com](http://www.yellowpagesforkids.com))



# Binders, Handouts, Materials

- Include in the materials:
  - Speaker powerpoints (if possible)
  - Sponsor information
  - Index cards for Q & A
  - Facility map
  - Questionnaire/Survey
  - Additional information and resources


# Working with speakers


- Set date and topic
- Discuss timeline
- Discuss needs
  - Biography (for registration form)
  - Information for CEU requirements
  - Powerpoint (if possible)
  - Proof registration form before distribution
  - Honorarium
  - Travel arrangements


# Other Details

- Media –
  - Opportunity for awareness
  - Might interest the media by honoring a person or legislator
- Volunteers needed for the registration table (name tags, material handout, conference day registrations and payments)
- For LINKS groups only – Contact NFXF for their tax exempt number



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- Signage – Should be as specific and large as possible
  - Raffles, vendor sales – Need to consider the rules of the facility first
  - If there are other LINKS group representatives attending, you can offer them a table in the sponsor area to give attendees from their groups a chance to find and meet them.
  - Announce at the beginning of the conference if any of the powerpoint presentations are not included in the materials.
  - **Keep to the agenda and time.** Discuss with the speakers the method of letting them know when they are close to the ending time of that part of the agenda.

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- Have a plan for technical difficulties and hope not to need it.
    - Designate a person who is familiar with computers, powerpoints, etc. to be available to help
    - Depending on how long it will take to resolve, think about adding some additional Q & A time, rather than having everyone just wait. If it is close to lunch and it is available, break for lunch a few minutes early.
  - A pre- or post-conference dinner for the speakers and those involved in putting together the conference is a nice way to thank everyone and a special opportunity for those who worked hard to have some time to socialize with the speakers. An added bonus if it is a pre-conference dinner is that you are assured that the speakers are in town!

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- Good opportunity:
    - To tell attendees of upcoming FX events
    - To briefly make attendees aware of FX Advocacy efforts and what they can do to get involved. This can be anything from sending an email to writing a letter to visiting in-state representatives as well as attending the annual NFXF Advocacy Day in Washington DC.
  - Extra benefit- AWARENESS:
    - Every email and “snail mail” registration form has the potential of reaching a person who hadn’t heard of FX until *you* contacted them!



# DON'T LET TIME GET AWAY FROM YOU!

It has been done successfully in  
2-3 months, but give yourself at  
least 4-8 months.