

Agenda At-A-Glance

WEDNESDAY, JUNE 23, 2004

Session Room Key: RB=Renaissance Ballroom GB=Grand Ballroom AUD=Auditorium
CH=Congressional Hall/Exhibit Hall CH-D=Congressional Hall-Lower

Symbol Key: B=Family-Friendly Session a =Repeat Session

1:00-1:50 p.m.

LOCATION

RB B Welcoming Remarks & Conference Highlights
John Harrigan, President, National Fragile X Foundation
Allan Reiss, M.D., Chair, Scientific & Clinical Advisory Committee
James Hanson, MD, National Institutes of Health

2:00-3:15 p.m.

Sessions A1-A2

RB- West A B Orientation for Newly Diagnosed Families and First-Time Conference Attendees (A1)
John Harrigan, Esq., NFXF Board President, Moderator
Jenny Keenan, M.S., Genetic Counselor
Kristen Head, Parent, President of MD Fragile X Resource Group

RB- East a B Continuum of Educational Placements (A2)
Orah Raia, M.A.T.

2:00-5:00 p.m.

RB- West B B Advocacy Training for Thursday's Advocacy Day on Capitol Hill (B1)

3:30-5:00 p.m.

Sessions C1-C2

RB- West A B Early Intervention (C1)
Steve Warren, Ph.D.

RB- East B Introducción del Síndrome X Frágil (in Spanish) (C2)
Feliciano Ramos, M.D., Ph.D.
Mercè Bellavista

5:00-6:00 p.m.

RB- West B Advocacy Training: Meeting with Congressional Aides

6:00-8:00 p.m. Welcome Reception

Room-3 **B** **The Role of Hyperarousal & Inhibitory Control Deficits in the Speech & Language Difficulties of Individuals with Fragile X (D4)**
Vicki Sudhalter, Ph.D.

Room-4 **Research Abstracts: Behaviors in Fragile X (D5)**
Rebecca Wilson, Ph.D., Chair
John Brown, Ph.D.

Room-5 **Research Abstracts: Mouse and Other Animal Studies in Fragile X (D6)**
Linda Crnic, Ph.D., Chair
Frank Kooy, Ph.D.
Haruhiko Siomi, Ph.D.

Room-16 **Research Abstracts: Attention, Memory and Executive Function in Fragile X (D7)**
Deborah Hatton, Ph.D., Chair

11:00-12:00 p.m.

Sessions E1-E8

Room-2 **B** **Handwriting Issues in Fragile X (E1)**
Jan Olsen, O.T.R.

Room-3 **B** **Assessing your Child's Educational Strengths and Needs (E2)**
Gail Harris-Schmidt, Ph.D.
Gail Spiridigliossi, Ph.D.

GB-South **B** **"Works in Progress: Readings from Fragile X Memoirs" (E3)**
Clare Dunsford (author & parent)
Debra Borchert (author and sibling)

Room-5 **Research Abstracts: Attention and Concentration (E4)**
Kim Cornish, Ph.D., Chair

Room-7 **Research Abstracts: Intermediate Alleles (The Gray Zone) (E5)**
Sarah Nolin, Ph.D., Chair
Stephanie Sherman, Ph.D.

Room-8 **Early Intervention & Behavioral Neurogenetic Research: Is There Any Connection? (E6)**
Heather Erba, Ph.D.
Jennifer Keller, B.A.

Room-16 **Comparing/Contrasting Play-Based Assessments and Standardized Assessments for Children with Fragile X (E8)**
Sarah Scharfenaker, M.A., C.C.C., Chair
Karen Riley, Ph.D.
Tracy Stackhouse, M.A., O.T.R.

12:00-1:30 p.m. Lunch On Your Own

Book Signings

Congressional Hall/Exhibit Hall

“My eXtra Special Brother” by Carly Heyman

“The Source for Fragile X Syndrome” by Gail Harris-Schmidt, Ph.D. & Dale Fast, Ph.D.

1:30-2:45 p.m.

Sessions F1-F8

Room-2 a B Keys to Success Dealing with Health Insurance (F1)
Gail Borgerd

Room-6 a B Hands on Calming Techniques (F2)
Sarah Scharfenaker, M.A., C.C.C.
Tracy Stackhouse, M.A., O.T.R.

Room-3 B Getting Everything You Need From Your Doctor (F3)
Janet Lin, M.D.
Myra Sourkes, M.D.

GB-South B The Legal Basis for Inclusion: What the I.D.E.A. Really Means (F4)
Seline Almazan, Esq.

CH-D a B Toilet Training the Child with Fragile X (F5)
Glen Penkava, M.S.Ed., C.A.S.

Room-5 What about adolescents? Exploring Teens' Perceptions About Genetic Risk (F6)
Allyn McConkie Rosell, Ph.D.
(**B-** See L3 for a family-friendly version of this session)

Room-16 a B Panel: The Early Years: Current & Future Collaborative Research Efforts (F7)
Jane Roberts, Ph.D., Moderator
Deborah Hatton, Ph.D.
Heather Cody, Ph.D.
Heather Erba, Ph.D.

Room-4 Research Abstracts: Speech & Language (F8)
Len Abbeduto, Ph.D., Chair
Joanne Roberts, Ph.D.

2:45-3:00 Break

3:00-4:30 p.m.

Sessions G1-G8

- GB-South** **a B** **The Raging Age: How to Treat Aggressive Behaviors (G1)**
Marcia Braden, Ph.D.
- CH-D** **a B** **Reading, ‘Riting and ‘Rithmetic: Educational Strategies (G2)**
Kelly Geddes, M.A.
Jean Hickey, M.Ed.
- Room-5** **B** **Adult Counseling for Behavior Problems in Fragile X (G3)**
John Brown, Ph.D.
Jennifer H. Epstein, Psy.D.
- Room-4** **a B** **Skills for the Job of Living: Why You Need an OT on Your Team (G4)**
Laura Greiss-Hess, M.S., O.T.R./L
- Room-2** **Panel: Challenges in Genetic Counseling for Fragile X (G5)**
Brenda Finucane, M.S., C.G.C., Moderator
Amanda Bergner, M.S., C.G.C.
Nancy Zellers
- Room-6** **B** **3D Dense Surface Modeling of the Face in Fragile X Syndrome (G6)**
Peter Hammond, Ph.D.
- Room-16** **Panel: From Brain to Behavior (G7)**
Allan Reiss, M.D., Moderator
Heather Cody Hazlett, Ph.D.
Heather Erba, Ph.D.
- Room-3** **Panel: Psychophysiological Processing in Young Children with Fragile X (G8)**
Jane Roberts, Ph.D., Chair
Ric Belser, Ph.D.
Kim Cornish, Ph.D.
David Hessel, Ph.D.
Vicki Sudhalter, Ph.D.

Potomac River Dinner Cruise – *Don't miss this spectacular viewing of the Washington monuments from the air conditioned comfort of the Odyssey!*
(Optional: Please see registration form to sign-up)

- 5:45 p.m.** Buses begin leaving hotel for dock
7:00 - 10:00 Potomac River Dinner Cruise
10:00 Buses return to hotel

Agenda At-A-Glance

FRIDAY, JUNE 25, 2004

Session Room Key: **RB**=Renaissance Ballroom **GB**=Grand Ballroom **AUD**=Auditorium
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Symbol Key: **B**=Family-Friendly Session **a** =Repeat Session

8:00-8:30 a.m. **Morning Food Break in the Congressional Hall/Exhibit Hall**

8:30-9:00 a.m.

LOCATION

GB-North & Central **B** **General Session: Fragile X-Associated Tremor Ataxia Syndrome (FXTAS)**
Paul Hagerman, M.D., Ph.D.

9:00-9:30 a.m.

GB-North & Central **B** **General Session: The mGluR Theory of Fragile X Mental Retardation**
Mark Bear, Ph.D.

9:30-9:45 a.m. Break

9:45-10:50 a.m.

Sessions H1-H9

Room-2 **B** **IDEA: Present & Future: What Does it Mean to You? (H1)**
Steve McKee
Gail Harris-Schmidt, Ph.D.

GB-South **B** **Sexuality and Fragile X (H2)**
Marcia Braden, Ph.D.
Brenda Finucane, M.S., C.G.C.

Room-3 **B** **Speech, Language, Hearing, and Oral Motor Skills of Preschool and Elementary Age Males with Fragile X Syndrome (H3)**
Joanne Roberts, Ph.D.
Elizabeth Barnes, Ph.D.
Elizabeth Hennon, Ph.D.

- Room-6 a B Hands on Calming Techniques (H4)**
Sarah Scharfenaker, M.A., C.C.C.
Tracy Stackhouse, M.A., O.T.R.
- Room-5 B Females with the Fragile X Premutation- Review of Data and Q&A (H5)**
Allan Reiss, M.D.
Ave Lachiewicz, Ph.D.
- Room-16 B A Review of the Many Reproductive Options (H6)**
Alan Horwitz, M.D.
Debbie Stevenson (parent)
- AUD. B Panel: FXTAS Update for Families: Q&A (H7)**
Elizabeth Berry-Kravis, M.D., Ph.D., Co-Chair
Randi Hagerman, M.D., Co-Chair
Kim Cornish, Ph.D.
Louise Gane, M.S.
Claudia Greco, M.D.
Jim Grigsby, Ph.D.
Sebastien Jacquemont, M.D.
Arie Smits, Ph.D.
- Room-17 Research Abstracts: The Relationship Between Fragile X & Autism (H8)**
Vicki Sudhalter, Ph.D., Chair
Ted Brown, M.D., Ph.D., Chair
- Room-4 Latest Development in the FMR1 Gene (H9)**
Stephen Warren, Ph.D.

11:00-12:00 p.m.

Sessions I1-I9

- Room-2 B Dental Issues in Fragile X and Help for the Caregivers (I1)**
Edward Perlow, D.D.S.
- GB-South B Panel: Aggression and Fragile X (I2)**
Marcia Braden, Ph.D., Moderator
Karen Riley, Ph.D.
Rebecca Wilson, Ph.D.
- CH-D B Combining Occupational Therapy & Speech Therapies (I3)**
Sarah Scharfenaker, M.A., C.C.C.
Tracy Stackhouse, M.A., O.T.R.

Room-3 B Panel: The Federal Government's Response to Fragile X: A Review of Current Federal Activities (I4)

Jeffrey Cohen, Esq., Moderator
Mary Lou Oster-Granite, Ph.D. (NICHD)
Dr. Michelle Lloyd-Puryear, M.D.,Ph.D.,(HRSA)
Coleen Boyle, Ph.D. (CDC/NCBDDD)
Madeleine Will (Invited) - (PCPID)

Room-17 B Panel: Why Test for Fragile X? (I5)

Amanda Bergner, M.S., C.G.C., Moderator
Brenda Finucane, M.S., C.G.C.
Louise Gane, M.S.
Jennifer Keenan, M.S.

Room-5 Longitudinal Studies in School Aged Children & Adolescents (I6)

Allan Reiss, M.D.

Room-4 Newborn Screening for Fragile X (I7)

Don Bailey, Ph.D.
Roger Stevenson, M.D.

Room-6 B Mathematics Learning Disability and its Manifestation in Girls with Fragile X (I8)

Michelle Mazzocco, Ph.D.

Room-16 Panel: Synaptic Structure-Focused on LTP, LTD & Glutamatergic Activity (I9)

Julie Lauterborn, Ph.D., Moderator
Mark Bear, Ph.D.
Peter Carlen, M.D., F.R.C.P.
John Larson, Ph.D.

12:30-2:00 p.m.

Luncheon – Grand Ballroom

Special Guest: Mitchell Beck

2:15-3:30 p.m.

Sessions J1-J9

Room-2 a B Keys to Success for Dealing with Health Insurance (J1)

Gail Borgerd

AUD. B Panel: Parents' Success Stories (J3)

Arlene Cohen, Moderator
Fran Davidson
Gail Heyman
Ollie Moochler
Liz Porter

Room-5 **B** **Panel: Fair Hearing/Due Process** (J4)
John Harrigan, Esq., Moderator
Judge Mary Margaret Anderson
Phil Porterfield

Room-3 **a B** **Reading, ‘Riting and ‘Rithmetic: Educational Strategies** (J5)
Kelly Geddes, M.A.
Jean Hickey, M.Ed.

CH-D **B** **Making It Happen:**
Accommodations and Adaptations from Kindergarten Through High School (J6)
Marcia Braden, Ph.D.
Colleen Bovi, M.Ed.

Room-6 **B** **Travel Instruction: Moving Towards Independence** (J7)
Michelle Holsopple
Patti Voorhees

Room-17 **Research Abstracts: Medication & Fragile X** (J8)
Elizabeth Berry-Kravis, M.D., Ph.D., Chair

Room-4 **Research Abstracts: Molecular Models** (J9)
Stephen Warren, Ph.D., Chair
Michael Fry, M.D.

3:30–3:45 p.m. Break

Sessions K1-K10

3:45-5:00 p.m.

AUD. **a B** **The Raging Age: How to Treat Aggression** (K1)
Marcia Braden, Ph.D.

GB-South **B** **New Students, New Questions** (K2)
Norman Kunc
Emma Van der Klift

CH-D **B** **Panel: Adult Aging Issues in FX: Questions & Answers** (K3)
Randi Hagerman, M.D., Moderator
John Brown, Ph.D.
Ed Goldson, M.D.
Andrew Levitas, M.D.
Arie Smits, Ph.D.

- TBA** **B Panel: International Parent Support – Reports from Around the World (K4)**
Robert Miller, USA, Moderator
Lynne Zwink, United Kingdom, Co-Moderator
Gabriella Goldzen, Argentina
Rashelle Cohen, Australia
Martine Borghgraef, M.D., Ph.D, Belgium
Martha Carvalho, Brazil
Carlo Paribello, Canada
Ofer & Rachel David, Israel
TBA- Mexico
Ragnar Toennesen, Norway
Mercè Bellavista, Spain
Li-Ping Tsai, Taiwan
Khaled Amiri, Ph.D., U.A.E.
Kristen Head, U.S.A.
Daniela Sniadower, Uruguay
- Room-2** **Neurobiological Studies in Mouse Models (K5)**
Ted Brown, M.D., Ph.D.
Peter Carlen, M.D., F.R.C.P.(C)
- Room-6** **Research Abstracts: Neurofunctional Measures of Fragile X (K6)**
Jennifer Hill Karrer, Ph.D., Co-chair
Susan Rivera, Ph.D., Co-chair
- Room-3** **Panel: New Treatments: MPEP & Beyond (K7)**
David Nelson, Ph.D., Moderator
Mark Bear, Ph.D.
Robert Bauchwitz, M.D. Ph.D.
Stephen Warren, Ph.D.
- Room-4** **Panel: Relationship Between Fragile X & Autism (K8)**
Beth Goodlin-Jones, Ph.D., Moderator
Leonard Abbeduto, Ph.D.
Don Bailey, Ph.D.
Jennifer H. Epstein, Ph.D
David Hessel, Ph.D.
Vicki Sudhalter, Ph.D.
- Room-5** **B Panel: Finding Common Ground: Various Perspectives on Building a Unified National Disability Policy Agenda (K9)**
Steve McKee, NFXF, Moderator
Steve Eidelman, Ph.D., The ARC
George Jesion, Ph.D., AUCD
Rob Beck, Ph.D., (Invited) ASA

**Room-
16**

Research Abstracts: Psychological Implications of the Female Carrier (K10)

Kim Cornish, Ph.D., Chair

Stephanie Sherman, Ph.D.

Laurel Beckett, Ph.D.

5:00-7:00 Poster Reception in the Congressional/Exhibit Hall

Dinner On Your Own

- continued on next page -

Room-5 **Research Abstracts: X-Linked Mental Retardation (L5)**

Giovanni Neri, M.D., Chair
Vincent Des Portes, M.D., Ph.D.

Room-16 **Research Abstracts: Neurobiology of the Synapse (L6)**

Gary Bassell, Ph.D., Chair
Robert Bauchwitz, M.D., Ph.D.
William Greenough, Ph.D.

AUD. **Stem Cell Research and Fragile X (L7)**

Phil Schwartz, Ph.D.
Flora Tassone, Ph.D.

GB-South **B Medical Issues with the Full Mutation (L8)**

Jonathan Cohen, M.D., Moderator
Ann Reynolds, M.D.

11:00-12:00 p.m.

Sessions M1-M8

Room-2 **a B Skills for the Job of Living: Why You Need an OT on Your Team (M1)**

Laura Greiss-Hess, M.S., O.T.R./L

GB-South **B It's Not Easy Being Green-Building Social Skills (M2)**

Marcia Braden, Ph.D.
Aaron Sanger

GB-North **B Planning Your Future: Conservatorships, Trusts, & Wills (M3)**

William Parker, C.S.A., C.E.P.

Room-3 **B Panel: Effective Advocacy: Working Together to Build a Strong National Response to Fragile X (M4)**

John Harrigan, Esq., Moderator, NFXF
David Busby, Esq., Fraxa
Jeffrey Cohen, Esq. NFXF
Diane Dorman, NORD

Room-4 **B Wearing 2 hats – A Mother and Geneticist Works to Help Her Family with Fragile X Syndrome and Reproduction (M5)**

Cynthia Roberts, Ph.D., FHGSA

Room-5 **Research Abstracts: Molecular & Biological Studies: FMRP and FMR1 (M6)**

Flora Tassone, Ph.D., Chair
Stephanie Ceman, Ph.D.
Edward Khandjian, D.Sc.
Karen Usdin, Ph.D.

AUD. **Updates on Ampakine Research (M7)**
Elizabeth Berry-Kravis, M.D., Ph.D.
Julie Lauterborn, Ph.D.

Room-16 **a B Panel: The Early Years: Current & Future Collaborative Research Efforts (M8)**
Jane Roberts, Ph.D., Moderator
Heather Cody, Ph.D.
Heather Erba, Ph.D.
Deborah Hatton, Ph.D.

12:00-1:30 p.m.

Lunch On Your Own, or participate in one of the five workshops noted below.

NOTE: To participate in the following sessions, you must sign up on site and prior to the session. Box lunches are available but must be reserved in advance by Thursday, 12:00 p.m., June 24th.

12:15-1:30 p.m.

Mothers' Workshop(s):
Father's Workshop(s):
Sibling Workshop(s):
Grandparents' Workshop(s):

Room-16 **Panel: Update on National Fragile X Research Centers of Excellence**
Randi Hagerman, M.D., Moderator
Don Bailey, Ph.D.
Linda Crnic, Ph.D.
Charles Laird, Ph.D.

1:45-3:00 p.m.

Sessions N1-N9

Room-2 **B Panel: Sibling Issues (N1)**
Deborah Kwan, Moderator
Debra Borchert
Carly Heyman
T.J. Nestheide, M.A.
Amy Porterfield

GB-Central **B Psychopharmacology for Parents (N2)**
Elizabeth Berry-Kravis, Ph.D.
Andrew Levitas, M.D.

- AUD. B Beyond the IDEA: The Adolescents and Adults Project (N3)**
Robert Miller, Moderator
John Harrigan, Esq.
Barbara Porterfield
Phil Porterfield
- GB-South B Panel: How to Educate Your Schools About Fragile X (N4)**
Stephanie Jacob, Moderator
Arlene Cohen
Carmen Gendel, L.C.S.W.
- GB-North B No Session Scheduled**
- Room-3 Panel: Functional Neuroanatomy (including treatment trials) (N6)**
Allan Reiss, M.D.
- Room-4 Research Abstracts: FXTAS (N7)**
Paul Hagerman, M.D., Ph.D., Chair
Jim Grigsby, Ph.D.
- Room-5 Panel: International Fragile X Research –Summaries from Around the World (N8)**
Moderator: Randi Hagerman, M.D., U.S.A.
Jonathan Cohen, M.D., Australia
Frank Kooy, Ph.D., Belgium
Peter Carlen, M.D., F.R.C.P., Canada
Giovanni Neri, M.D., Italy
Feliciano Ramos, M.D., Ph.D., Spain
Li-Ping Tsai, M.D., Taiwan
Andre Hoogeveen, Ph.D., The Netherlands
Khaled Amiri, Ph.D., U.A.E.
- Room-16 Stress Reactivity in Fragile X: Molecular to Behavioral (N9)**
David Hessel, Ph.D., Moderator
Andrea Bechel-Mitchener, Ph.D.
Ave Lachiewicz, Ph.D.

3:00-3:15 p.m. Break

3:15-4:30 p.m.

Sessions O1-O9

GB-South

B Panel: Females with a Full Mutation (O1)

Marcia Braden, Ph.D., Moderator
Katie Adams
Alli Cohen
Anna Cohen
Amy deBernardis
Caryn Lang
Kristin Lang
Katherine Zwink

Room-2 a B Relationship Development Intervention (O2)

Carmen Gendel, L.C.S.W.

AUD.

B Panel: 50 Ideas in 50 Minutes (O3)

Steve McKee, Moderator
Debra Borchert
Colleen Bovi, M.A.
Kelly Geddes, M.A.
Gail Heyman
Karen Riley, Ph.D.

CH-D a B Toilet Training the Child with Fragile X (O4)

Glenn Penkava, M.S.Ed., C.A.S.

Room-3

Fragile X Screening (O5)

Roger Stevenson, M.D., Chair

Room-4

Fragile X: Epigenetics (O6)

Andre Hooegeven, Ph.D.

Room-5

Premature Ovarian Failure (O7)

Stephanie Sherman, Ph.D.

Room-6

Research Abstracts: Molecular Intervention (O8)

Giovanni Neri, M.D., Chair

Room-16

Communication Studies on Children with Fragile X (O9)

Len Abbeduto, Ph.D.

6:00 pm. – **Banquet, Auction and Dancing in the Grand Ballroom**

Agenda At-A-Glance

SUNDAY, JUNE 27, 2004

Session Room Key: **RB**=Renaissance Ballroom **GB**=Grand Ballroom **AUD**=Auditorium
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Symbol Key: **B**=Family-Friendly Session **a** =Repeat Session

9:00-10:15 a.m.

AUD. **B** **Panel: Psychopharmacology (Medication) and Fragile X**
 Andrew Levitas, M.D.
 Elizabeth Berry-Kravis, M.D., Ph.D.
 Randi J. Hagerman, M.D.

10:30-12:00 p.m.

AUD. **B** **Panel: Questions, Answers, and Difficult Cases: Treatment Issues**
 Randi Hagerman, M.D., Moderator
 Josep Artigas, M.D.
 Elizabeth Berry-Kravis, M.D., Ph.D.
 Marcia Braden, Ph.D.
 Scott Hall, Ph.D., BCBA
 Ann Reynolds, M.D.
 Sarah Scharfenaker, M.A., CCC
 Tracy Stackhouse, M.A., O.T.R.