

Eunice Kennedy Shriver
National Institute of Child Health and Human Development
National Institutes of Health

Trans-NIH Fragile X Research Coordinating Committee
Research Plan for Fragile X and Associated Disorders

May 7–8, 2008
Hyatt Regency Bethesda
One Bethesda Metro Center
Bethesda, MD

WEDNESDAY, MAY 7, 2008

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| 8:00 a.m.–8:30 a.m. | Registration
Continental Breakfast |
| 8:30 a.m.–8:35 a.m. | Welcome
<i>Yvonne Maddox, Deputy Director, Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)</i> |
| 8:35 a.m.–8:50 a.m. | Introductions and Goals for the Meeting
<i>Tiina K. Urv, NICHD</i> |
| 8:50 a.m.–9:10 a.m. | Collaborative Efforts at NIH
<i>Linda Brady, Director, NSC, National Institute of Mental Health (NIMH)</i> |
| 9:10 a.m.–9:15 a.m. | Report to Congress—What Does That Mean?
<i>George Gaines, Chief, Office of Program and Public Liaison, NICHD</i> |
| 9:15 a.m.–9:45 a.m. | Successful Experience—Muscular Dystrophy Report
<i>John Porter, Program Director, National Institute of Neurological Disorders and Stroke (NINDS)</i> |
| 9:45 a.m.–10:15 a.m. | Fragile X Syndrome and Associated Disorders: An Overview of How Far We Have Come...
<i>Randi Hagerman, Professor and Medical Director, University of California, Davis</i> |
| 10:15 a.m.–10:30 a.m. | Break |
| 10:30 a.m.–12:00 p.m. | Working Group Reports

Fragile X Syndrome Working Group
<i>Don Bailey, RTI International</i>

FXTAS Working Group
<i>Paul Hagerman, University of California, Davis</i>

POI Working Group
<i>Stephanie Sherman, Emory University</i> |
| 12:00 p.m.–1:00 p.m. | Working Lunch: Discussion of Working Group Reports
<i>Facilitator: Tiina Urv, NICHD</i> |

1:00 p.m.–2:45 p.m. **Working Group Breakout Work Sessions**

2:45 p.m.–2:55 p.m. **Break**

2:55 p.m.–3:55 p.m. **Working Group Breakout Work Sessions**

4:00 p.m.–4:40 p.m. **Summary of Working Group Progress**
Working Group Chairs

4:40 p.m.–4:50 p.m. **Summation of Day**
Randi Hagerman, University of California, Davis

4:50 p.m.–5:00 p.m. **Overview of Thursday**
Andrea Beckel-Mitchener, NIMH

5:00 p.m. **Adjourn**

THURSDAY, MAY 8, 2008

8:00 a.m.–8:30 a.m. **Continental Breakfast**

8:30 a.m.–8:50 a.m. **FX, FXTAS, POI—Overarching Issues: A Clinical Perspective**
Elizabeth Berry-Kravis, Rush University Medical Center

8:50 a.m.–9:00 a.m. **Explanation of Overarching Goals: FMR1 Sliced Another Way**
Facilitator: Robert Riddle, NINDS

Division of Overarching Breakout Groups (self-select)

9:00 a.m.–10:30 a.m. **Overarching Topic Groups**

Clinical
Facilitator: Andrea Beckel-Mitchener, NIMH

Basic Science
Facilitator: Steve Snyder, National Institute on Aging

Screening and Ethical Issues
Facilitator: Tiina Urv, NICHD

10:30 a.m.–10:45 a.m. **Break**

10:45 a.m.–12:00 p.m. **Breakout Group Presentations: Discussion and Generate Goals**
Facilitator: Karen Usdin, National Institute of Diabetes and Digestive and Kidney Diseases

12:00 p.m.–12:30 p.m. **Working Lunch: FX Research Centers**
David Nelson, Baylor College of Medicine

12:30 p.m.–1:15 p.m. **Final Breakout Working Groups**

1:15 p.m.–1:30 p.m. **Summation of Day**
Randi Hagerman and Tiina Urv

1:30 p.m.–2:00 p.m. **Concluding Comments**
Duane Alexander, Director, NICHD

2:00 p.m. **Adjourn**