Orphan Mechanisms of Primary Ovarian Insufficiency: Passion for Participatory Research
October 2-3, 2008 ● The Bolger Conference Center ● Potomac, MD

Sponsors

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Department of Health and Human Services Office on Women’s Health (DHHS-OWH)
National Human Genome Research Institute (NHGRI)
National Institute of Environmental Health Sciences (NIEHS)

Organizing Committee

Chair: Lawrence M. Nelson, Intramural Research Program (IRP), NICHD, NIH
Co Chair: Karima Hijane, President, Rachel’s Well, Inc.
Co Chair: Joan Bailey-Wilson, Intramural Research Program, NHGRI, NIH
Co Chair: Germaine Buck Louis, Intramural Research Program, NICHD, NIH
Co Chair: Crystal Mackall, Intramural Research Program, Pediatric Oncology Branch, NCI, NIH

Alan DeCherney, Program Director in Reproductive and Adult Endocrinology, IRP, NICHD, NIH
Robert Rebar, Executive Director, American Society for Reproductive Medicine
Barbara B. Mittleman, Director, Public Private Partnership Program, NIH
Charisee Lamar, Director, Interdisciplinary Research in Reproduction Program, NICHD, NIH
Lisa Begg, Director, Research Programs, ORWH, NIH
Colleen Choi, Social Scientist, Office of the Secretary, OWH, DHHS
Steven R. Binder, Director, Technology Development, Clinical Diagnostics Group, Bio-Rad Laboratories

Rappateurs

Teresa Woodruff, Professor and Director, Center for Reproductive Research, Northwestern University
Amber Cooper, Clinical Fellow in Reproductive Endocrinology and Infertility, Washington University
Karima Hijane, Advocate and President, Rachel’s Well, Inc.
AGENDA

Thursday, October 2, 2008

11:00 a.m.  Meeting registration (in front of the “Postal Wagon” facing the rear entrance to the North Building)

11:30 a.m. – 12:30 p.m.  Lunch – Osgood’s Dining Room, Main Building

12:45 p.m. – 1:15 p.m.  Convocation – North Building, Room 17

Welcome: Lawrence M. Nelson, Investigator, Intramural Research Program in Reproductive and Adult Endocrinology, NICHD, NIH

Native American Song of Invocation
Sheila Egan, Oklahoma Cherokee
National Integrative Health Congress

Welcome: Karima Hijane, Advocate and President, Rachel’s Well, Inc.

Welcome: Owen Rennert, Scientific Director, Intramural Research Program, NICHD, NIH

1:15 p.m. – 1:30 p.m.  Panel of Patient Advocates
Gail Heyman, Stacey Cudworth, Maureen Bell, Karima Hijane and Mary Beth Busby

1:30 p.m. – 2:00 p.m.  Team Science: Passion for Participatory Research
Keynote address: Teresa Woodruff

TEAM SCIENCE AND SUCCESSFUL RESEARCH CONSORTIA

Chairs—Teresa Woodruff, PhD, Northwestern University; Charisee Lamar, PhD, MPH, NICHD, NIH

2:00 p.m. – 2:15 p.m.  Team Science: Elements of a Successful Genetic Research Consortium
Joan Bailey-Wilson, IRP, NHGRI, NIH

2:15 p.m. – 2:30 p.m.  Team Science: Elements of a Successful Epidemiologic Research Consortium
Germaine Buck Louis, IRP, NICHD, NIH

2:30 p.m. – 2:45 p.m.  Team Science: Elements of a Successful Autoimmune Research Consortium
John Herr, University of Virginia

3:00 p.m. – 3:15 p.m.  Discussion

3:15 p.m. – 3:30 p.m.  BREAK
AN OVERVIEW: THE BASIC MECHANISMS OF PRIMARY OVARIAN INSUFFICIENCY

Chairs—Corrine Welt, MD, Harvard University and James Segars, MD, NICHD, NIH

3:30 p.m. – 3:45 p.m.  Galactosemia and Primary Ovarian Insufficiency
Louis J. (Skip) Elsas, University of Miami

3:45 p.m. – 4:00 p.m.  The FMR1 Premutation and Primary Ovarian Insufficiency
Stephanie Sherman, Emory

4:00 p.m. – 4:15 p.m.  Autoimmunity and Primary Ovarian Insufficiency
Corrine Welt, Harvard

4:15 p.m. – 4:30 p.m.  Iatrogenic Primary Ovarian Insufficiency
Teresa Woodruff, Northwestern

4:30 p.m. – 4:45 p.m.  Estrogen Receptors and their Role in Ovarian Function
Karina Rodriquez, NIEHS

4:45 p.m. – 5:00 p.m.  Discussion

BASIC MECHANISMS OF AUTOIMMUNE PRIMARY OVARIAN INSUFFICIENCY

Chairs—Vincent Tuohy, PhD, Cleveland Clinic and Susan Taymans, PhD, NICHD, NIH

5:00 p.m. – 5:15 p.m.  The AIRE Gene and Primary Ovarian Insufficiency
Mark Anderson, U.C. San Francisco

5:15 p.m. – 5:30 p.m.  Inhibin and Autoimmune Primary Ovarian Insufficiency
Vincent Tuohy, Cleveland Clinic Foundation

5:30 p.m. – 5:45 p.m.  Oocyte Autoimmunity and Primary Ovarian Insufficiency
John Herr, University of Virginia

5:45 p.m. – 6:00 p.m.  Discussion

6:00 p.m. – 8:00 p.m.  MIXER / RECEPTION
Cash Bar, Raku-fired Pottery Display
Sponsored by the American Society for Reproductive Medicine and Rachel’s Well, Inc.
Friday, October 3, 2008

07:00 a.m.
Continental breakfast in Osgood’s dining room for overnight guests
Light breakfast near meeting room for day guests

07:45 a.m.
Opening

Native American Song of Invocation
Sheila Egan, Oklahoma Cherokee
National Integrative Health Congress

PUBLIC PRIVATE PARTNERSHIPS
Chairs—John Herr, PhD, University of Virginia and Teresa Woodruff, PhD, Northwestern

8:00 a.m. – 8:15 a.m. The Nonprofit Perspective of Public Private Partnerships
Andrea Baruchin, Foundation for NIH

8:15 a.m. – 8:30 a.m. Working with an Industrial Partner to Develop New Diagnostic Tests
Steven R. Binder, BioRad

8:30 a.m. – 8:45 a.m. The NIH Perspective of Public Private Partnerships
Barbara Mittleman, OD, NIH

8:45 a.m. – 9:00 a.m. Discussion

TRANSLATIONAL RESEARCH: GALACTOSEMIA AS A MODEL FOR GENETIC MECHANISMS OF PRIMARY OVARIAN INSUFFICIENCY
Chairs—Louis J. (Skip) Elsas, MD, University of Miami and Joan Bailey-Wilson, PhD, NIH

9:00 a.m. – 9:15 a.m. Biomarkers of Ovarian Function in Classic Galactosemia
Judith Fridovich-Keil, Emory

9:15 a.m. – 9:30 a.m. Galactosemia: A Translational Approach
Catherine Gordon and Gerard Berry
Children’s Hospital, Boston

9:30 a.m. – 9:45 a.m. Discussion

9:45 a.m. – 10:00 a.m. BREAK

ENVIRONMENTAL AND IATROGENIC PRIMARY OVARIAN INSUFFICIENCY
Chairs—Teresa Woodruff, PhD, Northwestern University; Alicia Armstrong, MD, MHSCR, NICHD, NIH

10:00 a.m. – 10:15 a.m. Environmental and Occupational Exposure and Primary Ovarian Insufficiency
Glinda Cooper, EPA

10:15 a.m. – 10:30 a.m. Translational Models for Studying Iatrogenic Primary Ovarian Insufficiency
Kutluk Oktay, New York Medical College

10:30 – 10:45 a.m. Psychosocial Aspects of Iatrogenic Primary Ovarian Insufficiency,
Leslie Schover, U of Texas, M. D. Anderson Cancer Center

10:45 a.m. – 11:00 a.m. Discussion
FORUM: INTERNATIONAL COLLABORATION ON PRIMARY OVARIAN INSUFFICIENCY

11:00 a.m. – 11:30 a.m.   Moderators: John Herr, PhD, University of Virginia and Vaishali Popat, MD, MPH, FDA
Participants: Luca Persani, Vrinda Khole, and Wendy Wolfman

EXPERT PANELS: A RESEARCH AGENDA FOR THE 21ST CENTURY—PRIMARY OVARIAN INSUFFICIENCY

11:30 a.m. – 12:30 p.m.   Working Lunch - Three breakout teams to develop recommendations
12:30 a.m. – 1:30 p.m.   Plenary meeting for each team to present recommendations for discussion
1:30 p.m. – 2:30 p.m.   Develop a draft report:
“A Manifesto for the Primary Ovarian Insufficiency Community”
What are your motives?
What are your views?
What are your intentions?
2:30 p.m. – 3:30 p.m.   Further Synthesis and Closing Remarks
*Teresa Woodruff and Barbara Mittleman*
3:30 p.m.   Native American Song of Power and Hope
Sheila Egan, Oklahoma Cherokee
National Integrative Health Congress

ADJOURNMENT

Breakout Teams

**Baseball Commissioner - Teresa Woodruff**

**The Florida Marlins - Defining the Molecular Mechanisms of POI**
Head coach – Louis J. (Skip) Elsas, Pediatrics and Biochemistry, University of Miami
First base coach - Germaine Buck Louis, Intramural Research Program, DESPR, NIH
Third base coach - Cristina Justice, Intramural Research Program, NHGRI, NIH

**The Boston Red Sox - Resources for the Clinical Investigation of POI**
Head coach – Corrine Welt, Medical Endocrinology, Harvard Medical School
First base coach - Joe Leigh Simpson, Reproductive Genetics, Florida International University
Third base coach - Crystal Mackall, Pediatric Oncology, NCI, NIH

**The San Francisco Giants - Structural Issues in Building the POI Community and Consortium**
Head coach – Valarie Baker, Reproductive Endocrinology, Stanford
First base coach - Diane F. Merritt, Adolescent Gynecology, Washington University, St. Louis
Third base coach - Colleen Choi, Social Scientist, Office of the Secretary, OWH, DHHS
TEAM ROSTERS

The Florida Marlins - Defining the Molecular Mechanisms of POI
Head coach – Louis J. (Skip) Elsas, Pediatrics and Biochemistry, University of Miami
First base coach - Germaine Buck Louis, IRP, DESPR, NIH
Third base coach - Cristina Justice, IRP, NHGRI, NIH

Mark Anderson, Genetics of Autoimmune Disorders, UCSF
Joan Bailey-Wilson, IRP, NHGRI, NIH
Lisa Begg, Director, Research Programs, ORWH, NIH
Maureen Bell, Parents of Galactosemic Children
Mickie Cheng, UCSF
Lou De Paolo, NICHD, NIH
Linda Mehta, ANYAS
Kutluk Oktay, Reproductive Endocrinology/Fertility Preservation, New York Medical College
Luca Persani, Italy
Karina Rodriguez, Reproductive Toxicology, NIEHS/NIH
Mary Ryan, Informationalist, NIH
James Segars, NICHD/NIH
Stephanie Sherman, Human Genetics, Emory
Susan Taymans, NICHD
Vincent Tuohy, Basic Immunology, Cleveland Clinic Foundation

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Alicia Armstrong, Reproductive Endocrinology, NICHD/NIH
Gerard Berry, Clinical Biochemical Genetics, Children’s Hospital Boston
Steven R. Binder, Director, Technology Development, Clinical Diagnostics Group, Bio-Rad Laboratories
Amber Cooper, Reproductive Endocrinology, Washington University
Alan DeCherney, IRP, NICHD, NIH
Judith Fridovich-Keil, Human Genetics, Emory
John Herr, Cell Biology, University of Virginia
Catherine Kelly, Toronto, Canada
Vrinda Khole, India
Vijay Kumar, Immco Diagnostics
Charisee Lamar, Director, Interdisciplinary Research in Reproduction Program, NIH
Jennifer Levine, Pediatric Oncology, Columbia University
Lubna Pal, Yale
Terry Phillips, Nanoscale Immunodiagnostics, NIBIB, NIH
Vaishali Popat, FDA
Jessica Spencer, Reproductive Endocrinology, Emory
Pamela Stratton, NICHD
Kim Thornton, Reproductive Endocrinology, Harvard Medical School
Kathleen Uhl, MD
Karen Winer, NICHD
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Michael Bailey, FDA
Andrea Baruchin, NIH Foundation
Taryn Becker, Toronto, Canada
Mary Beth Busby, FRAXA
Colleen Choi, Social Scientist, Office of the Secretary, OWH, DHHS
Sharon Covington, Psychosocial, NICHD/NIH
Caroline Dilworth, Epidemiology, CDC
Sheila Egan, Music Therapy, NIH
Diana Gomez De Molina, DSM, CC NIH
Veronica Gomez-Lobo, Adolescent Gynecology, Washington Hospital Center
Catherine Gordon, Pediatric Endocrinology, Harvard Medical School
Gail Heyman, Fragile X Association of Georgia
Karima Hijane, Rachel’s Well, Inc.
Virginia Ladd, American Autoimmune Related Diseases Association, Inc.
Melissa Merideth, MD, MPH, ORD, NIH
John Pollack, DSM, CC, NIH
Nannette Santoro, Reproductive Endocrinology, Einstein
Leslie Schover, Behavioral Science, U.T. MD Anderson Cancer Center
Adrienne Smith, DHHS, OWH
Janine Smith, ORWH, NIH
Wendy Smith, Public Private Partnership Program, NIH
Natalie Street, CDC
Tiina Urv, NICHD
Jackie Wootton, President, Alternative Medicine Foundation
Wendy Wolfman, Toronto, Canada
AREAS OF EXPERTISE

Consortia

Joan Bailey-Wilson, IRP, NHGRI, NIH
Michael Bailey, FDA
Andrea Baruchin, NIH Foundation
Lisa Begg, Director, Research Programs, ORWH, NIH
Germaine Buck Louis, IRP, DESPR, NIH
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Charissee Lamar, Director, Interdisciplinary Research in Reproduction Program, NIH
Linda Mehta, ANYAS
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Barbara B. Mittleman, Director, Public Private Partnership Program, NIH
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Wendy Smith, Public Private Partnership Program, NIH
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Primary Ovarian Insufficiency

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James Segars, NICHD/NIH
Kim Thornton, Reproductive Endocrinology, Harvard Medical School
Corrine Welt, Medical Endocrinology, Harvard Medical School

Galactosemia

Gerard Berry, Clinical Biochemical Genetics, Children’s Hospital Boston
Maureen Bell, Parents of Galactosemic Children
Louis J. (Skip) Elsas, Pediatrics and Biochemistry, University of Miami
Judith Fridovich-Keil, Human Genetics, Emory
Jessica Spencer, Reproductive Endocrinology, Emory
Karen Winer, NICHD
**FMR1, X chromosome, Fanconi’s Anemia**

Mary Beth Busby, FRAXA  
Gail Heyman, Fragile X Association of Georgia  
Cristina Justice, IRP, NHGRI, NIH  
Luca Persani, Italy  
Stephanie Sherman, Human Genetics, Emory  
Joe Leigh Simpson, Reproductive Genetics, Florida International University  
Pamela Stratton, NICHD  
Susan Taymans, NICHD  
Tiina Urv, NICHD

**Autoimmunity**

Mark Anderson, Genetics of Autoimmune Disorders, UCSF  
Steven R. Binder, Director, Technology Development, Clinical Diagnostics Group, Bio-Rad Laboratories  
Mickie Cheng, UCSF  
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