

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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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 *FMRI* 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
Colleen Choi, Social Scientist, Office of the Secretary, OWH, DHHS
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Linda Mehta, ANYAS
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Barbara B. Mittleman, Director, Public Private Partnership Program, NIH
Robert Rebar, Executive Director, American Society for Reproductive Medicine
Janine Smith, ORWH, NIH
Adrienne Smith, DHHS, OWH
Wendy Smith, Public Private Partnership Program, NIH
Natalie Street, CDC
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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
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