



PRADER-WILLI SYNDROME RESEARCH STRATEGY WORKSHOP

SUNDAY, NOVEMBER 15, 2009 – TUESDAY, NOVEMBER 17, 2009

DOUBLETREE HOTEL AND EXECUTIVE MEETING CENTER, BETHESDA, MD

Purpose: The purpose of the PWS Research Strategy Workshop is to develop a comprehensive research strategy to advance the science of PWS. Participants will prioritize research questions and identify opportunities and needs. Recommendations will be made with respect to resource development, collaborative opportunities and training mechanisms to facilitate attainment of research goals.

Sunday, November 15th

1:00 PM - 6:00 PM	Registration:	Prader-Willi Syndrome Research Strategy Workshop Location: EMC Foyer, DoubleTree Hotel
3:00 PM -	Hotel Check-In:	DoubleTree Hotel and Executive Meeting Center 8120 Wisconsin Avenue Bethesda, MD 20814
6:00 PM -8:00 PM	Welcome Reception:	Cocktails and heavy hors d'oeuvres
6:00	Reception Begins	Location: Foyer, Level II, Doubletree Hotel
6:30-6:40	Welcome	Location: Grand Ballroom A
6:40-7:00	PWS: A Parent's Perspective	<i>Keegan Johnson</i> <i>President, Foundation for Prader-Willi Research Canada</i>
7:00-8:00	Keynote Address	<i>Francis Collins, MD, PhD</i> <i>Director, National Institutes of Health</i>
8:00	Welcome Reception Ends	
TBD	Dinner on Own	

Monday, November 16th

7:30 AM	Continental Breakfast	Location: Continuous break area, Level II
8:00AM-12:15 PM	General Session	Location: Grand Ballroom D

Goal: In this session, each moderator will present an overview of their area of expertise, providing a 'state of the field' assessment, with an emphasis on areas of particular opportunity and need with respect to Prader-Willi syndrome. A final presentation will introduce the NIH Chemical Genomics Center and the new Therapeutics for Rare and Neglected Disease program.

8:00 – 8:15	Welcome and Workshop Goals	<i>Theresa Strong, PhD</i>
8:15 – 8:45	Overview: Clinical Issues	<i>Dan Driscoll, MD, PhD</i>
8:15 - 9:15	Overview: Obesity, energy balance and hypothalamic function	

Steve O’Rahilly, MD, FRCP, FRS

9:15 -9:45 Overview: Psychopathology and mental illness
Tony Holland, MRCP, MRCPsych

9:45-10:15 Break

10:15-10:45 Overview: Molecular Genetics of PWS (genotype to phenotype)
Uta Francke, MD

10:45-11:15 Overview: Animal models of PWS and related phenotypes
Rachel Wevrick, PhD

11:15-12:15 The NIH Chemical Genomics Center and the Therapeutics for Rare and Neglected Diseases Program
Chris Austin, MD
Director, NIH Chemical Genomics Center
Senior Advisor for Translational Research, NIH

12:15- 1:30 PM Lunch (on site)

1:30- 5:30 PM Breakout Sessions

Location: Jasmine (Clinical), Juniper (Obesity), Lavender (Animal Models), Lilac (Genetics) and Orchid (Mental Health) Rooms (third level)

Goal: Workshop participants will break out into small groups [Genetics, Animal Models, Obesity, Clinical Issues and Mental Health] to discuss specific questions on how best to move the field forward. Moderators will guide the discussion.

1:30 – 3:30 Break out via five designated themes – Definition of research questions

3:30 – 4:00 Break and re-shuffle

4:00 – 5:30 Small group discussions with intermingling of themes to address specific cross-disciplinary questions

7:00 PM – 9:00 PM Dinner at *Trattoria Sorrento* (0.45 mi from hotel)
4930 Cordell Ave, Bethesda

Tuesday, November 17th

7:30 AM Continental Breakfast
Location: Continuous break area, level II

8:30 – 11:15 AM General Session (all participants)
Location: Grand Ballroom D

Moderators’ reports: Moderators will review the plan developed by their group: 15 min presentation + 15 min discussion for each topic area

Clinical Issues 8:30 - 9:00

Obesity 9:00 – 9:30

Mental Health 9:30 - 10:00

Break 10:00- 10:15

Genetics 10:15 -10:45

Animal Models 10:45 -11:15

The remainder of the meeting will be spent addressing unanswered or incompletely answered questions as identified by participants. Issues of resource development, training, and fostering cross-disciplinary studies will be addressed in the context of research needs and opportunities.

11:30 AM - 12:30 PM Working Lunch
Location: Grand Ballroom D

12:30-2:00 PM Finalize Research Strategy

2:00 PM Prader-Willi Research Strategy Workshop concludes

Goal: At the end of the Workshop, participants will have developed a comprehensive research strategy for PWS that will accelerate efforts to understand the disorder at the molecular, cellular and systems level, and ultimately lead to more effective therapeutic interventions. A draft report will:

- Identify gaps in knowledge
- Prioritize basic and clinical research questions
- Ascertain existing resources and technologies that can be applied to the research questions
- Identify needed resources and technologies
- Develop approaches to foster cross-disciplinary collaborations and training opportunities / initiatives

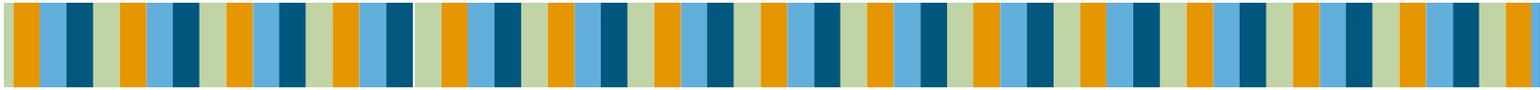
Planning Committee:

Theresa Strong, PhD	University Alabama at Birmingham (Chair)
Dan Driscoll MD, PhD	University of Florida
David Eckstein PhD	Office of Rare Disease Research, NIH
Uta Francke MD	Stanford University
Tony Holland MRCP	University of Cambridge
Stephen O'Rahilly MD	University of Cambridge
Rachel Wevrick PhD	University of Alberta

Sponsors:



Funding for this conference was made possible in part by a grant [1R13DK085332] from the National Institutes of Health. The views expressed in written conference materials or publications and by speakers and moderators do not necessarily reflect the official policies of the Department of Health and Human Services; nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S. Government.



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QUESTIONS TO BE CONSIDERED IN THE MONDAY BREAKOUT SESSION 1:30 – 5:30 PM

For each area [Clinical Issues, Obesity, Mental Health, Genetics, Animal Models]:

What are the current areas of strength?

What are the most pressing research questions that need to be addressed to move the field forward?

What are areas of weakness in addressing those questions?

What resources are currently available that might be applied to these problems? (including infrastructure, IT, financial, and biological)

What resources are currently unavailable, but would significantly impact the field?

What training opportunities exist? Are needed?

What are the opportunities for collaborations/multidisciplinary approaches, what are potential areas of cross-fertilization? What additional areas of expertise are needed to efficiently address research questions?

How can the link between basic and clinical research be strengthened?

What approaches can be taken to foster research in target areas?