

Baltimore, Maryland
June 4th and 5th, 2009

**PWSA SCIENTIFIC MEETING
AND INTERNATIONAL
HYPERPHAGIA CONFERENCE**

Caveat

- ◎ These were very scientific meetings aimed at medical professionals
- ◎ These are non-professional interpretations of what was heard and seen



**BAD
SCIENCE**

Two Distinct Conferences

- ◎ 24th Annual PWSA Scientific Meeting
 - Focus on obesity and eating issues
 - Presentation of research from a number of disciplines
- ◎ International Conference On Hyperphagia
 - An effort to bring together the medical community to share understanding of hyperphagic tendencies in a number of syndromes

24th Annual PWSA Scientific Meeting

Personal Overall Takeaways

- ⦿ Much more scientific research occurring than I had previously thought
- ⦿ A general feeling that we were getting close to really understanding the mechanics behind hunger and satiation
- ⦿ A number of different disciplines are intertwined to understand the problem and find a solution
- ⦿ The importance of the data we as parent's provide through surveys and participation

What Was It?

- ◎ Primarily a place for the medical community and behavioral experts to share findings and research directions
- ◎ A contact point between the professional communities and the families and individuals effected by PWS

Who Attended?

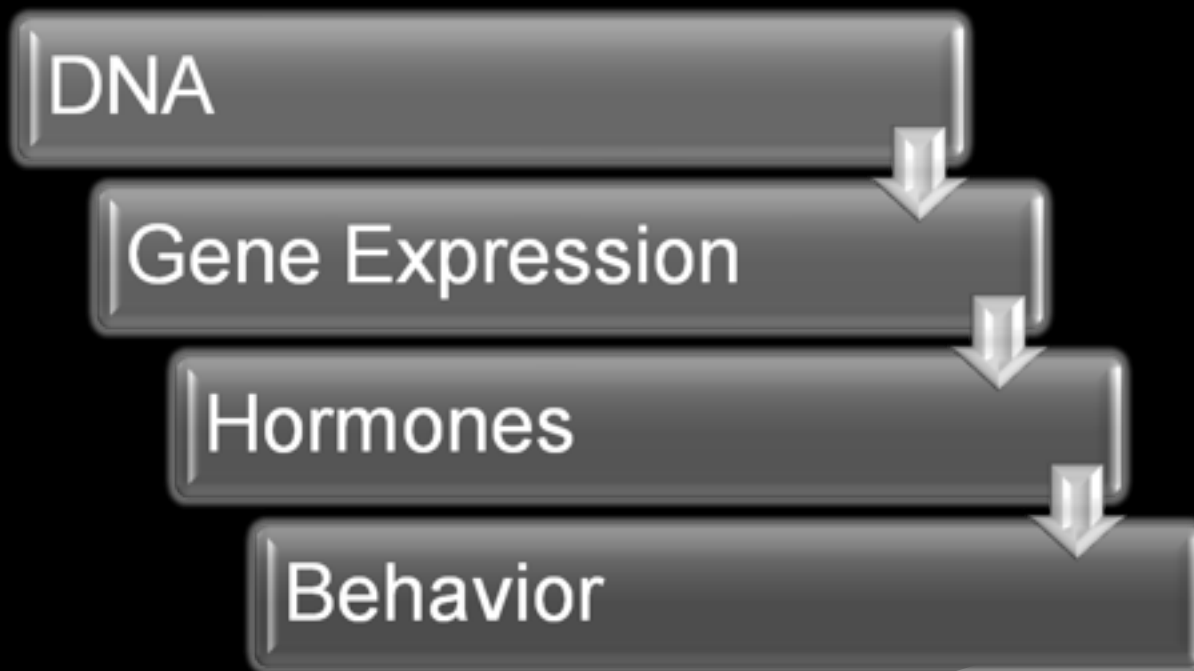
- ⦿ Geneticists
- ⦿ Endocrinologists
- ⦿ Behavioral Scientists
- ⦿ Biologists
- ⦿ Pediatricians
- ⦿ Caregivers
- ⦿ Parents

Why Is It Important To Us?

- ◎ Still hungry for a cure
- ◎ “Cure”
 - Symptomatic approach
 - Root cause approach
 - Can help us to remove or alleviate symptoms or understand why our therapies might work

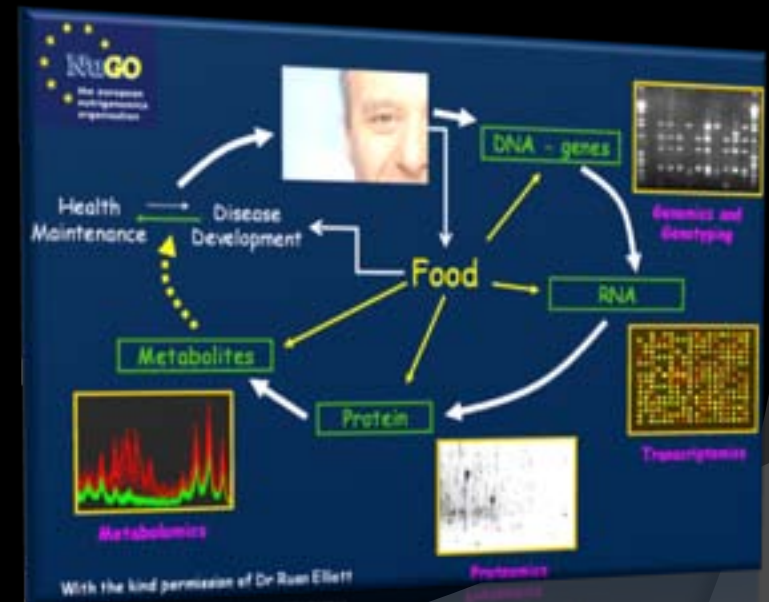
What Was Discussed?

- ◎ Primary focus on obesity and the hunger cycle



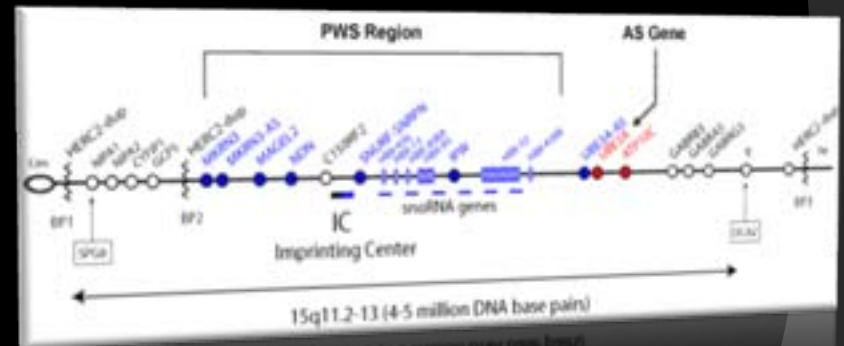
Keynote

- ◎ Dr. Ruth DeBusk, PhD, RD
 - Nutritional Genomics and its Role in Diets and Nutrition



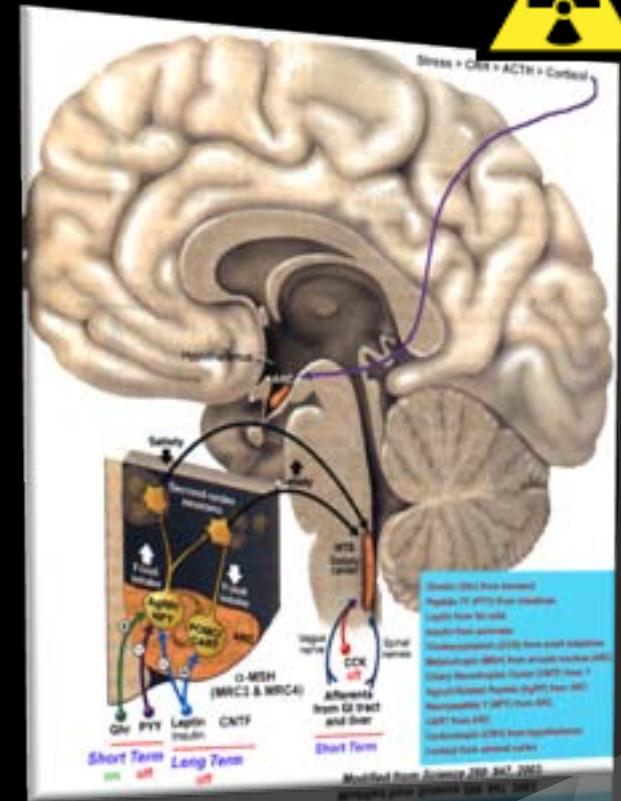
Genetics

☉ Mouse models



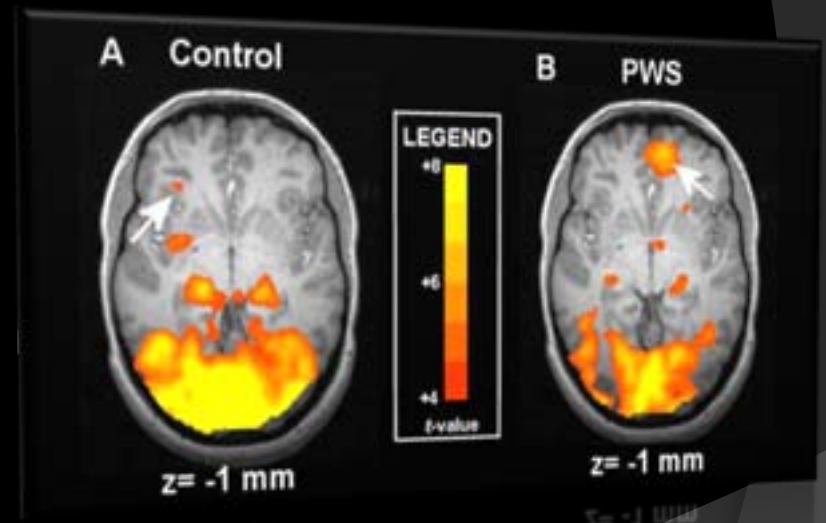
Hormones

- ◎ Corto-Limbic system
- ◎ Ghrelin, Leptin, Cortisol



Behavior

- ⦿ Neural responses to food stimuli
- ⦿ Central Adrenal insufficiency



Others

- ◎ Perinatal Complications
- ◎ Assisted Reproductive Technology and Twinning
- ◎ Nicotine Dependence
- ◎ Parental Stress



More Information

- ◎ Conclusions are available in the July-August 2009 edition of the Gathered View
- ◎ Abstracts should be available online at the member section of the PWSA USA site
- ◎ Weight Regulation in PWS: Theoretical and Practical Considerations document

HYPERPHAGIA CONFERENCE

What Was It?

- ◎ The first ever conference to bring together researchers involved with uncommon disorders with hyperphagic-like symptoms or phases
- ◎ Creating a forum and platform for obesity research using PWS and other diseases as a critical link

Who Attended?

- ◎ Specialists in each of the uncommon disorders
- ◎ Attendees of the Scientific meeting

Why Is It Important To Us?

- ◎ PWS is the most common disorder which has a direct link with obesity
- ◎ Obesity is one of the greatest health concerns currently facing the North American population
- ◎ Creates an opportunity for research and funding into some of the facets of PWS

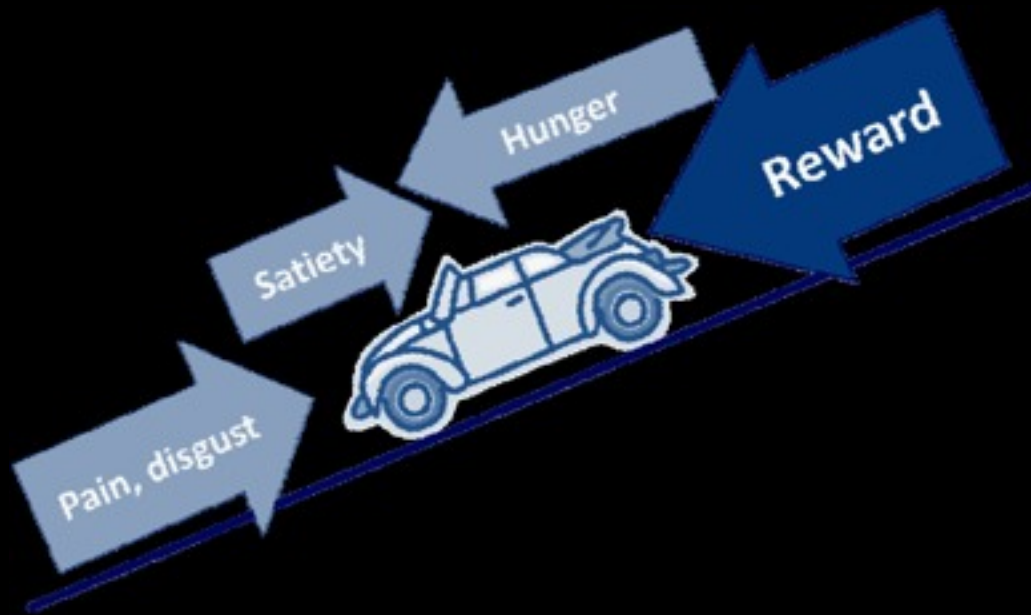
What Was Discussed?



- ◎ Prader-Willi syndrome
 - ◎ Alström syndrome
 - ◎ WAGR syndrome
 - ◎ Fragile X syndrome
 - ◎ Bardet-Biedl syndrome
-
- ◎ Roundtable discussions on information that could be shared

Keynote

- © Dr. George A. Bray, MD
 - Metabolic and Hedonic aspects of food intake regulation



Conclusions

- ⦿ Compare taste, smell, reward systems for different disorders
- ⦿ Look at genes involved in addiction
- ⦿ Study the BDNF phenotype
- ⦿ Identify critical periods of development
- ⦿ Compare gut hormone levels in different disorders
- ⦿ Common questionnaires for all disorders

Other thoughts

- ◎ Some effective therapies to look at
 - Vagus stimulation
 - Mediform – drug
 - Gastric bypass surgery



Thank You