

# INTERSEX CONSENSUS MEETING

**Chicago: October 27-31, 2005**

**Organisers: Ieuan Hughes (ESPE)  
Peter Lee (LWPES)**

## FACULTY AND SUMMARY OF QUESTIONS TO BE ADDRESSED

### **GROUP 1    Recent Molecular Genetic Impact of Human Sexual Development**

Co-ordinators:            Olaf Hiort (Germany) and Eric Vilain (USA)

Members:                Jean Wilson (UT Southwest, Dallas, TX)  
                                Vincent Harley (Prince Henry's Institute of Med Research,  
                                Melbourne, Australia)  
                                John Achermann (London)  
                                Erica Eugster (Indiana University)

#### **Questions:**

1.     What is the current state of knowledge of molecular mechanisms of sexual development in humans? Are there "activational" and/or "organisational" effects?
2.     What lessons can be learned from animal models?
3.     Should there be a new nomenclature for the classification of intersexuality based on genetic etiology?
4.     What is the current availability of genetic testing for intersexuality, including prenatal testing. Should there be "Centres of Excellence" for testing?
5.     Is there any genotype/phenotype correlation that would provide clinically useful information?
6.     Are there ethnic or geographic influences on the prevalence of specific intersex conditions? (see also Question 3 in Group 6).

## **GROUP 2 Brain Programming by Genes and Hormones (evidence –based)**

Co-ordinators: Melissa Hines (UK) and Sheri Berenbaum (USA)

Members: Peggy Cohen-Kettenis (Netherlands)  
Jay Giedd (USA)  
Anna Nordenström (Sweden)  
Bill Reiner (USA)  
Emilie Rissman (USA)

### **Questions:**

1. What are the causes of gender identity disorder in individuals without intersex conditions?
2. What are the causes of gender dysphoria and gender change in individuals with intersex conditions?
3. What are the human behavioural effects (excluding gender identity) of prenatal androgens and what characteristics of hormone exposure account for variations across individuals and across behaviours? How are behavioural effects of androgens separable from physical (especially genital) effects?
4. How are neural and behavioural effects of early hormones in rodents and primates dependent on characteristics of hormone exposure and social context? How are behavioural effects of androgens separable from physical (especially genital) effects?
5. What is the role of the sex chromosomes in behavioural masculinisation and feminisation in human and non-human species?
6. How does brain structure differ in human males and females at different stages of development?

**GROUP 3 Investigation and Medical Management of Intersex in the Infant, Child and Adolescent**

Co-ordinators: Pat Donohoue (USA) and Faisal Ahmed (Scotland)

Members: Sylvano Bertelloni (Italy)  
Felix Conte (USA)  
Claude Migeon (USA)  
Chris Driver (Scotland)  
Kenji Fujieda (Japan)  
Cheryl Chase (USA)

**Questions:**

1. What are the definitions of normal and ambiguous genitalia?
2. Description of the evaluation of patients with ambiguous genitalia, including those detected later than the newborn period.
3. What are the factors influencing the choice of sex of rearing?
4. Medical management in cases of gender re-assignment.
5. General description of counselling to be offered to parents of newborns with ambiguous genitalia. (see also Question 1, Group 5).
6. Management of the adolescent with an intersex condition, with attention to fertility concerns.

## **GROUP 4 Surgical Management of Intersex**

Co-ordinators: Laurence Baskin (USA) and Pierre Mouriquand (France)

Members: John Brock (USA)  
Rick Rink (Riley Children's Hospital, USA)  
Mel Grumbach (UCSF Children's Hospital, USA)  
Phillip Ransley (England)

### **Questions:**

1. Clitoris: should surgery be performed on the clitoris?
2. Vagina: surgical management of the common urogenital sinus. Timing and technique.
3. Vagina: vaginal substitution: who, how and when?
4. Penis: reconstruction, durability, hormonal stimulation and tissue engineering.
5. Gonads, Wolffian and Mullerian Structures: cancer risk, removal and timing. (see also Question 4, Group 6).
6. Surgical factors influencing the gender assignment in the "Y deficient" patient.

**GROUP 5    Psychosocial Management of Patients with Intersexuality and Related Conditions**

Co-ordinators:        Heino FL Meyer-Bahlburg (USA) and Polly Carmichael (England)

Members:             David Sandberg (USA)  
                             Froukje Slijper (Netherlands)  
                             Norman Spack  
                             Barbara Thomas (Germany)  
                             Kenneth Zucker (Canada)

**Questions:**

1.     Gender assignment: how should gender assignment be psychosocially managed in newborns?
2.     Gender re-assignment: how should gender re-assignment be psychosocially managed in children, adolescents and adults?
3.     Genital surgery and sex-hormone treatment: how should the psychosocial aspects of genital surgery and sex-hormone treatment be managed?
4.     Information management: how should disclosure of sensitive personal information be handled?
5.     Sexuality: how should intersex-related problems in romantic and sexual functioning and orientation be handled in adolescents and adults?
6.     Structural issues: how can the need for clinical collaboration of multiple disciplines be accommodated?

## **GROUP 6 Outcome Data: Evidence-based**

Co-ordinators: Sten Drop (Netherlands) and Garry Warne (Australia)

Members: B Mendonca (Bra)  
L Looijenga (Netherlands)  
U Thyen (Denmark)  
J Schober (USA)  
A Wisniewski (USA)

### **Questions:**

1. What constitutes “long-term” outcome? Which parameters should we use to measure physical and psychosexual long-term outcome, both subjectively and objectively, for the purposes of this study?
2. What is the long-term outcome per diagnostic category with emphasis on adulthood and type of surgical treatment?
3. What is the role of culture and social circumstances on the long-term outcome?
4. What is the incidence and what are the diagnostic criteria regarding gonadal tumours?
5. What is the impact of repeated medical examination, photography and surgery on the occurrence of the development of the psychological conditions?
6. Are there additional health problems in any of the diagnostic categories of intersex?