Growing up with Disorders of Sex Development (DSD): Critical Developmental Issues for Children and Families Affected by DSD

Natcher Conference Center (building 45), Room D
 NIH main campus, Bethesda, Maryland
 March 26–March 27, 2014

Agenda

March 26, 2014

8:30 a.m. Welcome
Alan Guttmacher
Director, NICHD, NIH, HHS

Workshop overview and goals
Lisa Freund
Chief, Child Development and Behavior Branch (CDBB), NICHD, NIH, HHS

8:45 a.m. Diagnostic factors associated with quality-of-life outcomes at different developmental stages in children and adolescents with DSD
Constantine Stratakis (Moderator), Director, Division of Intramural Research, and Scientific Director, NICHD, NIH, HHS

- Reducing diagnostic uncertainty for disorders of sex development: The promise (and some perils) of novel genomic approaches
  Eric Vilain
  Director, Center for Gender-Based Biology, University of California, Los Angeles

- What’s in a name? Standardizing the anatomic evaluation of DSD
  Margaret Shnorhavorian
  Assistant Professor, Department of Urology, University of Washington

- Optimal management of the XY DSD newborn, child, and adolescent: A complex challenge!
  Charles Sultan
  Professor, Pediatric Endocrine, Gynecological and Molecular Unit, University Hospital, Montpellier, France
• **Transitions in the needs and treatment of adolescents with DSD**  
  *Richard Auchus*  
  Professor, Internal Medicine, Division of Metabolism, Endocrinology, and Diabetes, University of Michigan

10:25 a.m.  **Discussion**

10:45 a.m.  **Break**

11:00 a.m.  **Making decisions**  
  *David Sandberg (Moderator)*, Professor and Director, Division of Child Behavioral Health, Department of Pediatrics, University of Michigan

• **Decision-making in DSD: Ethical considerations**  
  *Alexander A. Kon*  
  Chief, Pediatric Critical Care Medicine, Medical Director, Pediatric Intensive Care Unit, Naval Medical Center San Diego and Clinical Professor, University of California San Diego School of Medicine

• **Decision support tools and potential application to DSD decision-making**  
  *Laura Siminoff*  
  Dean, College of Health Professions and Social Work, Temple University

• **Feminizing genitoplasty in DSD: What’s a surgeon to do?**  
  *Richard C. Rink*  
  Robert A. Garrett Professor, Pediatric Urologic Research, Riley Hospital for Children, Indiana University School of Medicine

• **Making decisions: Patients with congenital concerns of the reproductive tract**  
  *Jennifer Dietrich*  
  Associate Professor, Obstetrics and Gynecology, and Pediatrics, Baylor College of Medicine

12:45 p.m.  **Discussion**

1:00 p.m.  **Lunch**

2:00 p.m.  **Living with DSD**  
  *Lisa Freund (Moderator)*, CDBB, NICHD, HHS

• **Can we all get along? The history and ongoing relations between DSD clinicians, researchers, and patient advocacy organizations**  
  *Janet Green*  
  Interim Executive Director, Accord Alliance

• **Sex hormone contributions to behavior in DSD**  
  *Sheri Berenbaum*  
  Professor, Psychology and Pediatrics, Pennsylvania State University
• Development of gender (and sexuality) in DSD: Spectrum, determinants, brain
  Heino Meyer-Bahlburg
  Director, Program of Developmental Psychoendocrinology, New York State Psychiatric Institute and Department of Psychiatry, Columbia University

• Growing up with a DSD: Implications for emotional, social, and academic development
  Elizabeth McCauley
  Professor, Psychiatry and Behavioral Sciences, University of Washington

3:40 p.m.  Discussion

4:00 p.m.  Break

4:15 p.m.  Living with DSD: What can be learned from other typical and atypical developmental experiences?
  Sheri Berenbaum (Moderator), Pennsylvania State University

• The study of youth with spina bifida: Theoretical and methodological applications to the study of DSD
  Grayson N. Holmbeck
  Professor and Director of Clinical Training, Psychology, Loyola University Chicago

• What we can learn from Lesbian, Gay, Bisexual, and Transgender (LGBT) youth
  Rob Garofalo
  Associate Professor, Pediatrics-Adolescent Medicine and Preventive Medicine, Northwestern University

• Making decisions about surgery to change facial appearance during childhood: Developing a better understanding of the informed consent process to reduce coercion
  Cassandra Aspinall
  Senior Social Worker, Craniofacial Center; and Clinical Assistant Professor, University of Washington

• Causes and consequences of fitting in or being excluded from the peer group
  William Bukowski
  Professor, Department of Psychology, Concordia University, Montréal, Canada

5:55 p.m.  Discussion

6:15 p.m.  DSD-Translational Research Network: A resource for researchers, clinicians and patient stakeholders
  Eric Vilain
  Director, Center for Gender-Based Biology, University of California, Los Angeles
6:30 p.m.  Adjourn for the day

March 27, 2014

8:30 a.m.  Clinical management factors associated with quality-of-life outcomes at different developmental periods in children and adolescents with DSD
Susan Taymans (Moderator), Program Director, Fertility and Infertility Branch, NICHD, NIH, HHS

- A noncategorical approach to the care of persons with DSD and their families
  David Sandberg
  Professor, Pediatric Child Behavioral Health, University of Michigan

- Clinical management of patients with DSD during childhood: An endocrine perspective
  Deborah Merke
  Senior Investigator, Pediatric Services, NIH Clinical Center, NIH, HHS

- Surgical considerations in young children with DSD: Phallic and Müllerian structures, gonads, brain imprinting, and minimizing genital examinations
  Michael DiSandro
  Professor of Urology, University of California, San Francisco

- Adolescents with DSD: Challenging issues for a challenging age
  Elizabeth H. Quint
  Professor, Obstetrics and Gynecology, University of Michigan

10:10 a.m.  Discussion

10:30 a.m.  Break

10:45 a.m.  Social factors associated with quality of life outcomes in children and adolescents with DSD
Susan Newcomer (Moderator), Population Dynamics Branch, NICHD

- Psychosocial factors of DSD in a long-term perspective: What clinical opportunities are there to intervene?
  Anna Nordenström
  Associate Professor, Karolinska Institute, Stockholm, Sweden

- Stigma, isolation, and stress: Education to improve psychosocial outcomes in DSD
Amy Wisniewski
Associate Professor and Director of Clinical Research, Department of Urology,
University of Oklahoma

11:30 a.m.  Discussion

11:50 p.m.  Consequences of the Chicago DSD consensus: A personal perspective
            Ieuan Hughes
            Emeritus Professor of Paediatrics, University of Cambridge, United Kingdom

12:30 p.m.  Lunch discussion
            Lisa Freund (Moderator), Chief, CDBB, NICHD, NIH, HHS

2:30 p.m.   Adjourn