

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)  
National Institutes of Health (NIH)  
*Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)

## **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**

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**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**

*Margarett 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

*David Sandberg*

Professor and Director, Division of Child Behavioral Health, Department of Pediatrics, University of Michigan

**6:30 p.m. Adjourn for the day**

**March 27, 2014**

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**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**