



**Intersex Society  
of North America**



# DSD Symposium

October 13-14 2006

Renaissance Parc 55 Hotel, San Francisco

Presented by [Intersex Society of North America](#) and [Gay and Lesbian Medical Association](#)

## Contents

### **Agenda for Change: Psychology and Clinical Management of Disorders of Sex Development in Adulthood**

Lih-Mei Liao PhD

### **Report on Chicago Consensus Conference**

David Sandberg PhD, Cheryl Chase, and Eric Vilain PhD MD

### **Nomenclature Change: I Am Not a Disorder**

Katie Baratz, Arlene Baratz MD, Eric Vilain PhD MD, and Peter Trinkl

### **Counseling Adults**

William Byne MD and Nina Williams PhD

### **How to Build a Team**

Barbara Neilson PhD and Melissa Parisi PhD

### **Handbook for Parents**

Arlene Baratz MD

### **DSDs and Cancer: Caring for Intersex Patients**

Katie Baratz

### **Counseling Parents**

David Sandberg PhD, Arlene Baratz MD, and Ellen Feder PhD

### **Setting the Research Agenda**

Lih-Mei Liao PhD

## Introduction

The Intersex Society of North America hosted the First DSD Symposium, a gathering of intersex adults, parents, and allied healthcare professionals, October 13-14, 2006, at the Renaissance Parc 55 Hotel in San Francisco. This was a chance to meet and learn from others working to improve the quality of healthcare for families with children born with Disorders of Sex Development, and for adults dealing with the many ongoing healthcare concerns that result from DSDs.

The DSD Symposium was a mini-conference, held within the Gay and Lesbian Medical Association's annual conference. Registrants to the GLMA conference (about 400 people) were welcome to attend all DSD Symposium presentations. There were about 40 people registered for the DSD Symposium alone. Spot counts of the room showed a maximum of 97 people attending at one time.

## Background

A new standard of care has been established for medical management of disorders of sex development ("Consensus Statement on the Management of Intersex Disorders"<sup>1</sup>). While certainly not perfect, the new standard incorporates many of the the practices and ideas that ISNA has been recommending for over a decade.

In addition to many valuable changes in the standard of care, the Intersex Consensus Group agreed to update the medical nomenclature, bringing intersex conditions into line with other genetic and endocrine disorders, and with a hope and expectation that these conditions will be brought into the mainstream of evidence-based medicine.

The National Institutes for Health has published its "Strategic Plan for Urology."<sup>2</sup> The Plan recognizes that clinical management of congenital anomalies of sexual differentiation is "in crisis," and calls for efforts to build the skills of qualified mental health professionals; a patient registry; and a broad range of research covering issues of genital surgery; patient and family adaptation with specialist mental health care; decision-making around sex assignment and genital surgery; relationship of gender identity, sexual and reproductive function, and quality of life to early medical, surgical, and psychosocial factors; and molecular markers for rapid diagnosis.

---

<sup>1</sup> Lee, P. A., C. P. Houk, et al. (2006). "Consensus statement on management of intersex disorders." *Pediatrics* 118(2): e488-500. Available at <http://pediatrics.aappublications.org/cgi/reprint/118/2/e488>.

<sup>2</sup> National Institute of Diabetes & Digestive & Kidney Diseases (2006). NIDDK Research Progress Report and Strategic Plan for Pediatric Urology. Available from <http://www.niddk.nih.gov/federal/planning/Pediatric-Urology/>.

ISNA has recently published a pair of handbooks, one focused on the clinician and the other on parents, which offer detailed directions for providing patient-centered care for disorders of sex development. These handbooks are facilitating new collaborations between support organizations on the one hand, and clinicians and parents on the other.<sup>3</sup>

## Program

The DSD Symposium offered a wealth of educational programming, including the following highlights. Our featured speaker was Lih-Mei Liao. Dr. Liao is the recipient of a Gay and Lesbian Medical Association Achievement Award for 2006.

### **Conversation Rounds**

facilitated by Bec Kageyama and Lindsey Rourk

### **Affinity Groups**

facilitated by multiple volunteers

### **Conceptualizing Competent Care for Intersex Adults**

facilitated by Anne Tamar-Mattis JD

### **Agenda for Change: Psychology and Clinical Management of Disorders of Sex Development in Adulthood**

Lih-Mei Liao PhD

### **Report on Chicago Consensus Conference**

David Sandberg PhD, Cheryl Chase, and Eric Vilain PhD MD

### **Nomenclature Change: I Am Not a Disorder**

Katie Baratz and Arlene Baratz MD, Eric Vilain PhD MD

### **Counseling Adults**

William Byne MD, Nina Williams PhD

### **Clinical Guidelines for the Management of Disorders of Sex Development in Childhood**

Charmian Quigley MD

### **How to Build a Team**

Barbara Neilson PhD, Melissa Parisi PhD

---

<sup>3</sup> Consortium on the Management of Disorders of Sex Differentiation (2006). *Handbook for Parents*. Rohnert Park, Intersex Society of North America. Available from [www.dsdguidelines.org](http://www.dsdguidelines.org).

Consortium on the Management of Disorders of Sex Differentiation (2006). *Clinical Guidelines for the Management of Disorders of Sex Development in Childhood*. Rohnert Park, Intersex Society of North America. Available from [www.dsdguidelines.org](http://www.dsdguidelines.org).

## Handbook for Parents

Arlene Baratz MD

## Counseling Parents

David Sandberg PhD, Arlene Baratz MD, Ellen Feder PhD

## Setting the Research Agenda

Lih-Mei Liao PhD

## Speakers

We are thrilled to introduce you to our featured speaker, **Lih-Mei Liao, BSc Hons, MSc, PhD**. Dr. Liao's research has repeatedly broken new ground in posing nuanced questions about the effects of DSDs and medical interventions on psychosocial functioning and adaptation.

As a Consultant Clinical Psychologist, Dr. Liao has played a part in shaping the development of the Middlesex Centre in the UK. The Centre provides clinical services and also carries out research to contribute to the evidence base in DSDs. She is interested in models of sexuality in DSD management and has a broader interest in social constructions in medical procedures for asymptomatic patients in general.

**Arlene Baratz MD** is a physician and mother. Arlene works with a support group of adults with AIS and parents with AIS children. She participated in creating the *Clinical Guidelines for the Management of Disorders of Sex Development in Childhood* and companion *Parent Handbook* as models of patient-centered care for DSDs. Arlene has long experience in the comprehensive care model through her career in the specialty of Mammography and Breast Imaging Radiology.

**Katharine Baratz** is a senior at Haverford College in Philadelphia. She is currently studying Classical Culture and Society, with an emphasis on gender dynamics in ancient literature. Katharine plans to enroll in medical school in the Fall of 2007 and hopes to practice Pediatric Endocrinology. Through her mother, Arlene Baratz, MD, Katharine has become involved with the Androgen Insensitivity Support Group and looks to continue to advocate for this and other DSD support groups.

**William Byne MD** is a board certified psychiatrist whose clinical practice has included adults with disorders of sex development. He is currently an associate professor of psychiatry at the Mount Sinai School of Medicine in New York where, in addition to directing a brain research laboratory, he teaches medical students and residents about sexual minority issues. His research has included investigations of sexual differentiation of the brain in both animals and humans. He has published several critiques and scholarly reviews of data pertaining to biological contributions to sexual orientation and gender identity. He has been active with ISNA since 1995 and is currently a member of ISNA's medical advisory board.

**Cheryl Chase** is the founder and executive director of Intersex Society of North America. Her work has been recognized in diverse publications and broadcasts, including including *Newsweek*, the *New York Times*, NPR's *Fresh Air*, and *NBC Dateline*. Her presentation "Sexual Ambiguity: The Patient-Centered Approach" at the 2000 meeting of the Lawson

Wilkins Pediatric Endocrine Society is considered an unprecedented patient-led breakthrough in medical reform. She produced the videos "Hermaphrodites Speak!" (1997) and "The Child with an Intersex Condition: Total Patient Care" (2003). Chase was one of two intersexed adults (with Barbara Thomas, from Germany) who participated with fifty healthcare professionals in creating the 2006 "Consensus Statement on Intersex Disorders."

**Ellen Feder PhD** teaches philosophy at American University. She contributed to the Hastings Center project, "Surgically Shaping Children," and is a member of ISNA's Medical Advisory Board and Speakers' Bureau. Her book, *Family Bonds: Genealogies of Race and Gender*, is forthcoming from Oxford University Press, and she is currently working on a new project in ethics and the management of DSDs, *Fixing Sex*.

**Lih-Mei Liao, BSc Hons, MSc, PhD** has worked as a consultant clinical psychologist in the National Health Service in the UK for 20 years. For the past 8 years or so, she has played a key role in developing the Middlesex Centre in London UK, a main research and treatment centre for DSDs. She works with newly diagnosed women as well as those transferred from pediatric services. DSD management is political and dialogue is crucial for progress. She liaises with peer support groups in the UK and also co-founded Critical Sexology Seminar to facilitate inter-disciplinary debate. An important aspect of my work is to contribute to the evidence base in DSD management. In collaboration with like-minded colleagues and students, she has supervised psychological and multi-disciplinary clinical research. Two key themes that capture her interests in research and practice are: 1) Social constructions in medical complaints and decisions to undergo complex treatments; 2) Models of sexuality in clinical/social practices.

**Barbara Neilson MSW, Res Dip SW, RSW** has been a social worker with Toronto's Hospital for Sick Children for 16 years. Her clinical work has been with the pediatric urology population, and includes patients with rare congenital conditions as well as patients with ambiguous genitalia and gender re-assignment.

**Melissa Parisi PhD** received her PhD degree in Developmental Biology and MD degree from Stanford University. She is a pediatric geneticist at the University of Washington and has been a member of the multidisciplinary Gender Assessment Team at Children's Hospital in Seattle since 1997, serving as lead physician for the team for the past 2 years. The team provides evaluation, management, and counseling for families, infants, children, and adolescents with Disorders of Sex Development.

**Charmian Quigley MBBS** is a Senior Clinical Research Physician in pediatric endocrinology at Lilly Research Laboratories in Indianapolis, Indiana, and also holds a teaching position in pediatric endocrinology at Indiana University. She is a graduate of the University of New South Wales in Sydney, Australia. After completing her pediatric residency and pediatric endocrinology clinical fellowship in Sydney, she moved to the US and undertook a fellowship in molecular endocrinology at the Laboratories for Reproductive Biology at the University of North Carolina at Chapel Hill, North Carolina, where she focused on the molecular biology of the androgen receptor. It was this work that stimulated Dr. Quigley's interest in the area of sex differentiation and development. Following 3 years as a full-time member of the clinical faculty at Indiana University, she moved to her current position at Eli Lilly and Company in 1997, where she directs Lilly's research studies in pediatric patients in the United States.

**David Sandberg PhD** is Associate Professor and Director of the Division of Child Behavioral Health in the Department of Pediatrics at the University of Michigan in Ann Arbor. He obtained his doctorate from Concordia University in Montreal, Canada and completed postdoctoral fellowships at the University of Miami and at the College of Physicians & Surgeons of Columbia University. His research activities include the study of psychosocial aspects of short stature and the psychosocial management of individuals born with disorders of sex development (DSD). He recently served as co-investigator of an (NICHD-sponsored) interdisciplinary research network concerned with biological and socialization factors in sexual differentiation, is developing a psychoeducational treatment manual for clinicians caring for newborns with congenital adrenal hyperplasia identified by newborn screen, and is designing health-related quality of life measures for individuals with DSD and their families.

**Anne Tamar-Mattis J.D** is a recent graduate of Boalt Hall School of Law, is the founder and Executive Director of the Institute for Intersex Children and the Law. Before attending law school, Ms. Tamar-Mattis served for many years as an organizer in the LGBTQI communities. She is the former Director of the LYRIC Youth Talkline, and former Program Director of the San Francisco LGBT Community Center. She and her partner, Suegee Tamar-Mattis MD, are the parents of two children.

**Eric Vilain MD PhD** was born in Paris, France and is currently an Associate Professor of Human Genetics, Pediatrics and Urology at UCLA. Dr. Vilain received his Ph.D. at the Pasteur Institute in 1994. In 1995, Dr. Vilain received his M.D. at the Faculte de Medecine Necker Enfants Malades. He is currently achieved the Chief of Medical Genetics at UCLA, the Director of Research on Sexual Medicine in the Department of Urology, the Graduate Advisor in the Department of Human Genetics and an attending physician in the Department of Pediatrics at UCLA.

In addition to his clinical responsibilities, Dr. Vilain is the Principal Investigator of a laboratory working at discovering the genetic bases of sex determination and sexual orientation. He has received numerous awards, notably from the NIH and the March of Dimes. Dr. Vilain is an expert in the field of the genetics of sexual development. He has deciphered a large number of molecular mechanisms responsible for intersexuality in humans, such as mutations in the sex-determining genes SRY and SOX9. His laboratory continues to work on the mechanisms of early gonadal development and brain sexual differentiation.

**Nina Williams PhD** is a clinical psychologist in private practice in Somerset, NJ. She specializes in the psychodynamic treatment of sexual disorders and trauma. She is a member of the Medical Advisory Board of the Intersex Society of North America, and has written and presented many workshops on the treatment of individuals with disorders of sexual development. Dr. Williams is an adjunct associate professor in the Department of Psychiatry at Robert Wood Johnson Medical School, a supervisor and lecturer at the Graduate School of Applied and Professional Psychology, Rutgers University, and on the faculty of the Institute of Psychoanalysis and Psychotherapy of New Jersey.

## Sponsors

We are grateful to all of ISNA's individual donors for helping to make the DSD Symposium possible. Would you like to become a donor? Please visit <http://www.isna.org>.

We are particularly grateful to Arcus Foundation, for a \$150,000 grant for general operating expenses in the years 2006-2009.

## **Schedule**

### **Friday October 13, 2006**

Friday 10-12—Conversation Rounds and Affinity Groups

Friday 1:30—Conceptualizing Competent Care for Intersex Adults

Friday 3:00—Agenda for Change: Psychology and Clinical Management of Disorders of Sex Development in Adulthood

### **Saturday October 14, 2006**

Saturday 8:45—Welcome to the DSD Symposium

Saturday 9:00—Report on Chicago Consensus Conference

Saturday 9:45—Nomenclature change

Saturday 10:30—Adult Counseling

Saturday 11:30—Lunch

Saturday 1:15—Clinical Handbook

Saturday 2:00—How to Make a Team

Saturday 3:00—Parents Handbook

Saturday 3:45—Counseling Parents

Saturday 5:00—Setting the Research Agenda

Saturday 5:45—Closing