## **CURRICULUM VITAE**

David Eric Sandberg, Ph.D. Department of Pediatrics

Professor (with tenure), Division of Pediatric Psychology

Faculty Investigator, Susan B Meister Child Health Evaluation and Research (CHEAR) Center University of Michigan Medical School

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# DAVID E. SANDBERG, Ph.D. CURRICULUM VITAE

# **EDUCATION**

1988 - 1990	Hofstra University, Certificate of Respecialization in Clinical
	Psychology (Approved by the American Psychological Association)
1978 - 1982	Concordia University, Montreal Canada, Psychology, Ph.D.
1975 - 1977	Bar-Ilan University, Israel, Experimental Psychology, M.A.
1971 - 1975	Bar-Ilan University, Israel, Psychology, B.A.

# **POST-GRADUATE TRAINING**

09/1985 - 07/1988	Post-Doctoral Research Scientist in Psychiatry, Division of Child &
	Adolescent Psychiatry, College of Physicians & Surgeons of
	Columbia University, New York, NY
09/1983 - 08/1985	Visiting Fellow, Department of Psychiatry, Division of Child &
	Adolescent Psychiatry, College of Physicians & Surgeons of
	Columbia University, New York, NY
08/1982 - 08/1983	Postdoctoral Fellow, Department of Pediatrics, University of Miami
	Medical School, Miami, FL

# **CERTIFICATION AND LICENSURE**

1987, Psychology, New York, #009240-1 (not registered) 2006, Psychology, Michigan, #6301013223 (issued: 04/21/2006)

# **ACADEMIC APPOINTMENTS**

09/2010 - Present	Professor of Pediatrics (tenured), University of Michigan Medical
	School, Ann Arbor, MI
09/2006 - 09/2018	Director, Division of Pediatric Psychology, Department of Pediatrics,
	University of Michigan Medical School, Ann Arbor, MI
09/2006 - 08/2010	Associate Professor of Pediatrics (tenured), University of Michigan
	Medical School, Ann Arbor, MI
07/2000 - 08/2006	Adjunct Associate Professor of Psychology, University at Buffalo,
	The State University of New York, Buffalo, NY
07/1997 - 08/2006	Associate Professor of Psychiatry and Pediatrics, University at
	Buffalo, The State University of New York, Buffalo, NY

06/1995 - 06/2006	Senior Staff Psychologist, Division of Child & Adolescent
	Psychiatry, (Pediatric Psychiatry & Psychology), Women's and
	Children's Hospital of Buffalo, Kaleida Health, Buffalo, NY
07/1993 - 06/1997	Assistant Professor of Psychiatry and Pediatrics, University at
	Buffalo, The State University of New York, Buffalo, NY
07/1990 - 05/1995	Senior Staff Psychologist, Division of Child & Adolescent
	Psychiatry, (Psychoendocrinology Program), Children's Hospital of
	Buffalo, Buffalo, NY
07/1990 - 06/1993	Clinical Assistant Professor of Psychiatry and Pediatrics, State
	University of New York at Buffalo, Buffalo, NY
08/1988 - 07/1990	Assistant Professor of Psychology in Psychiatry and Pediatrics,
	Cornell University Medical College, New York, NY
08/1988 - 07/1990	Staff Psychologist, Department of Pediatrics, Divisions of Pediatric
	Endocrinology, Metabolism and Nutrition and Child & Adolescent
	Psychiatry (Consultation/Liaison), North Shore University Hospital-
	Cornell University Medical College, Manhasset, NY

# **GRANT SUPPORT**

# COMPLETED

National Institute of Child Health and Human Development
1985 - 1987
1F32HD006726-01

Androgen-Related Genital Defects and Male Development

Role: Principal Investigator (individual NRSA)

Human Growth Foundation 1990

Short stature: A survey of psychosocial and academic difficulties

Role: Principal Investigator

\$10,000

Pediatric Endocrine Nursing Society 1990

Influence of growth hormone therapy on patient and family functioning

Role: Co-Principal Investigator (co-PI Barbara Shine, RN and Wanda Grundner, RN)

\$5,000

Pediatric Endocrine Nursing Society 1993

Growth failure: educational functioning and family adjustment

Role: Co-Principal Investigator (Co-PI Barbara Shine, RN and Wanda Grundner, RN)

\$5,000

Human Growth Foundation 1994

School-based survey of the academic achievement and peer relations of children and adolescents with short stature

Role: Principal Investigator

\$7,500

Genentech Foundation for Growth and Development

1994

94-236

Psychological adjustment in children and adolescents with short stature: a school-based study Role: Co-Principal Investigator (Co-PI Susana Campos, MD)

\$35,625

Genentech Foundation for Growth and Development

1995

95-77

Psychosocial and educational aspects of short stature

Role: Co-Principal Investigator (Co-PI Susana Campos, MD)

\$20,000

Genentech Foundation for Growth and Development

1994-1996

Post-treatment outcomes of childhood onset growth hormone deficiency: medical and psychosocial status

Role: Co-Principal Investigator (Co-PI Margaret MacGillivray, MD, Richard Clopper, ScD) \$75,218

Centers for Disease Control and Prevention,

Agency for Toxic Substances and Disease Registry

H75 ATH 29833805

1995-1998

The New York State Angler Cohort Study

Role: Co-Investigator (PI John Vena, PhD)

\$1,236,092 Direct Costs

Genentech Foundation for Growth and Development

1996-1998

96-52

Regimen adherence in growth hormone therapy: an intervention protocol

Role: Principal Investigator

\$93,675

National Institute of Environmental Health Sciences, NIH

1996-1997

1R03ES008500-01

Endocrine disruptors and human gender development

Role: Principal Investigator

\$76,000

Genentech Foundation for Growth and Development

1998-2002

97-110

Effects of growth hormone on psychosocial functioning

Role: Co-Principal Investigator (Co-PI Margaret MacGillivray, MD)

\$300,000

Genentech Center for Clinical Research and Education

2002-2003

900-C07

Accuracy in Parental Reporting of Height: An Endocrine Clinic-based Study

Role: Co-Principal Investigator (Co-PI John Buchlis, MD)

\$24,000

Lawson Wilkins Pediatric Endocrine Society

Intersexuality: A survey of clinical practice

Role: Principal Investigator

\$150,860

National Institute of Child Health and Human Development

2003-2006

2001-2003

R21 HD044398

Psychosexual Differentiation: Biology and Socialization, an Interdisciplinary Research Network

Role: Network Member (PI Sheri Berenbaum, PhD)

\$375,000

National Newborn Screening and Genetics Resource Center (NNSGRC),

Health Resources Service Administration, DHHS

2003-2006

Contract No. 117378/116984

Psychosocial Treatment Manual for Families of Children Born with Congenital Adrenal

Hyperplasia (CAH) Identified Through Newborn Screening

Role: Principal Investigator

\$40,000

Interdisciplinary Research and Creative Activities Funds,

University at Buffalo Office of the Vice President for Research

2004-2005

Psychosocial Treatment for Families of Children Born with Congenital Adrenal Hyperplasia (CAH) Identified Through Newborn Screening

Role: Principal Investigator

\$27,000

University of Michigan Initiative on Rare Disease Research

2008-2009

Symposium Support Grant

Disorders of Sex Development: Research Framework for the Study and

Enhancement of Health-Related Quality of Life Outcomes

Role: Principal Investigator

\$20,000

University of Michigan Institute for Clinical and Health Research

2008-2009

Parental Decision Making for Children Born with Disorders of Sex Development

Role: Principal Investigator

\$50,000

National Institute of Child Health and Human Development

2009-2010

R41 HD057714

Family Education for Confirmed Newborn Screen

Role: Principal Investigator

\$96,158

National Institute of Child Health and Human Development

2008-2012

R01 HD053637

Quality of Life in Intersexuality: A Pediatric Clinical and

Research Tool

Role: Principal Investigator

\$1,378,553

National Institute of Child Health and Human Development 2009-2011 R01 HD053637-02S1 (Supplement) Quality of Life in Intersexuality: A Pediatric Clinical and Research Tool Role: Principal Investigator \$119,603 Doris Duke Clinical Scientist Award (PI: Eric Vilain; UCLA) 2009-2012 Disorders of Sex Development Role: Consultant/Co-Investigator \$ 156,116 (subcontract) Michigan Department of Community Health 2010-2013 Genetics-Newborn Endocrinology Services – Behavioral Health Demonstration Project Role: Principal Investigator \$163,381 National Institute of Child Health and Human Development 2011-2017 R01 HD068138 Disorders of Sex Development: Platform for Basic and Translational Research Role: Sandberg / Vilain (UCLA) Multiple Principal Investigators (MPI) \$4,100,464 Patient-Centered Outcomes Research Institute (PCORI) 2013-2017 Decision Support for Parents Receiving Genetic Information about Child's Rare Disease Role: Principal Investigator \$1,377,164 University of Michigan, Dept. Pediatrics & Communicable Diseases 2015-2017 Benz Birth Defects Research Award Psychological Support for Patients and Families with Disorders of Sex Development Role: Principal Investigator \$20,000 National Institute of Child Health and Human Development 2020-2021 3 R01 HD086583-04S1 (Supplement) Decision-Making for Patients Born with Differences of Sex Development (DSD) Role: Principal Investigator \$153,654 **CURRENT** National Institute of Child Health and Human Development 2016-2023 R01 HD086583

Role: Principal Investigator

Decision-Making for Patients Born with Differences of Sex Development (DSD)

\$2,598,495

David E. Sandberg, Ph.D. September 6, 2023 6

National Institute of Child Health and Human Development
R01 HD092595
Pathways to Care and Health Outcomes Among DSD Patients
Role: Goodman (Emory) / Sandberg MPI
\$3,116,318

National Institute of Child Health and Human Development R01 HD093450

2018-2024

R01 HD093450

Disorders/Differences of Sex Development (DSD) -Translational Research Network Role: Sandberg / Vilain (Children's National Health System) MPI \$3,740,873

National Institute of Child Health and Human Development

2016-2024

R01 HD093450-05S1 (Supplement)

Disorders/Differences of Sex Development (DSD) - Translational Research Network

Role: Principal Investigator

\$132,600

GME Innovations Grants Program, University of Michigan Medical School
Training Residents in Shared Decision-Making: Proxy Decision-Makers and
Provider-Family Communication
Role: Principal Investigator

\$50,000

# HONORS AND AWARDS

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1978 - 1981	Concordia University Graduate Fellowship (Montreal, Canada)
1978 - 1981	Predoctoral Fellowship from the Ministry of Education, Quebec, Canada
1982 - 1984	Postdoctoral Fellowships from the Quebec Medical Research Council and the
	Natural Sciences and Engineering Research Council (Canada)
2001	Fellow, American Psychological Association
2001	Charter Fellow, Society of Pediatric Psychology
2002	Organizer and participant in NICHD-sponsored interdisciplinary Research
	Planning Workshop on Intersex, May 2002
2005	Invited attendee to NIH/NIDDK Workshop. Research Progress Report and
	Strategic Plan for Pediatric Urology. Adelphi, MD, February 2-4, 2005
2005	Member, Psychosocial and Psychosexual Issues and Management work group,
	Lawson Wilkins Pediatric Endocrine Society/European Society for Pædiatric
	Endocrinology Consensus Meeting on Intersexuality, Chicago, IL, October 27-
	29, 2005
2005	Award for Outstanding Achievements in Research, Department of Psychiatry,
	University at Buffalo, State University of New York
2007	Member, Consensus Guidelines for the Diagnosis and Treatment of Children
	with Idiopathic Short Stature. Lawson Wilkins Pediatric Endocrine Society and
	the European Society for Pediatric Endocrinology, Santa Monica, CA, October
	17-20, 2007

2012 - 2015	Member, Steering Committee, International - Disorders of Sex Development
	Registry (I-DSD)
2012 - 2019	World Professional Association for Transgender Health (WPATH): Chair,
	Disorders of Sex Development Committee
2014	Planning group and invited attendee to NIH (NICHD and ORD) Growing up
	with DSD: Critical Developmental Issues for Children and Families Affected by
	Disorders of Sex Development, Bethesda, MD, March 26-27, 2014
2015	Association of American Medical Colleges (AAMC) Advisory Committee on
	Sexual Orientation, Gender Identity, and Sex Development (Axis); Chair,
	Differences of Sex Development Ad Hoc Committee
2016	Co-Lead, Neurocognition & Behavior Committee, International Turner
	Syndrome Clinical Care Guidelines Consensus Meeting. Cincinnati, OH, July
	24-26, 2016
2016 - 2019	Member, National Institutes of Health (NIH) Sexual and Gender Minority
	Research Working Group (SGMRWG)
2018 - 2021	Chair, Independent Advisory Board, European Registries for Rare Endocrine
	Conditions (EuRRECa)
2019	American Psychological Association, Division 54 – Society of Pediatric
	Psychology, Dennis Drotar Distinguished Research Award in Pediatric
	Psychology
2019 - 2022	Member, Task Force on Differences of Sex Development, American
	Psychological Association
2022 - 2024	Member, I-DSD / I-CAH / I-TS patient registries Quality Improvement
	Committee <a href="https://home.i-dsd.org/qi-committee-members/">https://home.i-dsd.org/qi-committee-members/</a>

# **MEMBERSHIPS IN PROFESSIONAL SOCIETIES**

MEMBERS	HIPS IN PROFESSIONAL SOCIETIES
1984 –	American Psychological Association
1988 –	Member, Pediatric Endocrine Society (formerly Lawson Wilkins Pediatric
	Endocrine Society)
1998 - 2013	Member, Society for Developmental and Behavioral Pediatrics
2002 –	Charter Fellow, Society of Pediatric Psychology – Division 54
2002 –	Fellow, American Psychological Association
2003 –	Member, International Academy of Sex Research
2009	Executive Member, International Society of Hypospadias and Disorders of Sex
	Development (ISHID)
2009 –	Member, Society of Clinical Child and Adolescent Psychology – Division 53
2010 - 2020	Member, World Professional Association for Transgender Health (WPATH)
2010 –	Member, Organization for the Study of Sex Differences (2010-2013, Program
	Planning Committee)
2012 - 2015	Member, Association for Psychological Science
2012 –	Member, European Society for Paediatric Endocrinology
2014 –	Member, American Pediatric Society (APS)
2017 –	Co-Chair (since 2019), Society of Pediatric Psychology, Differences of Sex
	Development, Special Interest Group
2018 –	Member, Pediatric Endocrine Society, Disorders of Sex Development, Special
	Interest Group

2018 – 2022 Member, Task Force on Differences of Sex Development, American

Psychological Association

2020 – Member, Societies for Pediatric Urology

# EDITORIAL POSITIONS, BOARDS, AND PEER REVIEW SERVICE

#### **Editorial Board**

2003 - 2017	Journal of Pediatric Psychology, Editorial Board
2004 - 2010	Growth, Genetics & Hormones, Associate Editor
2008 - 2014	International Journal of Pediatric Endocrinology, Associate Editor
2009 – Present	Faculty of 1000, Medicine ( <a href="http://f1000medicine.com/home">http://f1000medicine.com/home</a> ), Faculty Member
2012 – Present	Hormone Research in Paediatrics, Editorial Board
2013 – Present	LGBT Health, Editorial Board
2015 – Present	Archives of Sexual Behavior, Editorial Board
2016 - 2017	Guest Editor, Journal of Pediatric Psychology Special Section on Disorders of
	Sex Development
2018 2022	Padiatric Endocrinology Paviews, Editorial Roard

2018 – 2022 Pediatric Endocrinology Reviews, Editorial Board 2021 – Present Biology of Sex Differences, Editorial Board

2022 – Present Clinical Practice in Pediatric Psychology (CPPP), Editorial Board

## **Ad Hoc Reviewer of Manuscripts**

AACE Journals International Journal of Pediatric Endocrinology

Acta Pædiatrica Journal of Affective Disorders
Archives of Disease in Childhood J Child Psychol Psychiatry

Archives of Pediatrics & Adolescent Medicine
Biology of Sex Differences

Journal of Clinical Endocrinology & Metabolism

Journal of Developmental and Behavioral Pediatrics

BioMed Central Pediatrics Journal of Family Psychology

BMJ Paediatrics Open Journal of Pediatrics

Clinical Endocrinology
Developmental Psychology
Developmental Psychology
Developmental Of Sex & Marital Therapy
Journal of Sex & Marital Therapy

European Journal of Endocrinology Pediatrics Frontiers in Behavioral Neuroscience PLoS One

Health Psychology Psychology and Sexuality Hormones and Behavior Quality of Life Research

Hormone and Metabolic Research Sex Roles

Hormone Research in Pædiatrics The Lancet Diabetes & Endocrinology International Journal of Behavioral Development The New England Journal of Medicine

## **Ad Hoc Grant Reviewer**

National Institutes of Health (1996; 2002; 2016)

Pediatric Endocrine Nursing Society

**Human Growth Foundation** 

Marsden Fund Council of the Royal Society of New Zealand (2016)

ZonMw - The Netherlands Organisation for Health Research and Development (2020)

# **TEACHING ACTIVITIES**

# College of Physicians & Surgeons of Columbia University

- 1987 Continuing Medical Education Lectures, Rockland Children's Psychiatric Center, Orangeburg, New York. Structured and semi-structured child and adolescent psychiatric interviews. June 2, 9, 1987
- 1987 Co-taught sections of Child Development course to child & adolescent psychiatry fellows

## **Cornell University Medical College:**

1988 - 1990 Lectures directed toward psychology externs and interns, pediatric residents, and child and adolescent psychiatry fellows, Departments of Psychiatry and Pediatrics, North Shore University Hospital, in areas of clinical research methodology and psychoendocrinology

#### University at Buffalo, School of Medicine & Biomedical Sciences

- 1990 2006 Lectures within field of psychoendocrinology to medical students and pediatric residents; monthly lectures
- 1991 2006 Behavior Therapy module of Seminar in Therapies for Children and Adolescents, Child Psychiatry Residency Program; 5 one-hour lectures
- 1999 2006 Moderator of Journal Club, Child & Adolescent Psychiatry Residency Program; monthly
- 1995 2006 Short Stature, Precocious Puberty, and Gender Identity Disorders: Seminar in Child Psychopathology and Neuropsychiatric Disorders, Child Psychiatry Residency Program; 3 one-hour lectures
- 1995 2006 Research Seminar, Child & Adolescent Psychiatry Residency Program; 12, 1.5-hour lectures
- 1997 2001 Human Behavior I: Human Psychosexual Differentiation. Lecture to all M2 students; 1, 2-hour lecture
- 2002 2006 Endocrine/Reproductive Biology/Life Cycle Module, Lecture to all M2 students; 4, 1-hour lectures

#### Medical Student Mentoring (NHLBI, NIH, Summer Research Program)

- 2002 2003 Orlando Encarnación, Intersexuality: A survey of clinical practice (Phase I: Survey development)
- 2003 2004 Darrel Manney, University of Pittsburgh. Intersexuality: A survey of clinical practice (Phase II: Survey administration)
- 2004 2005 Latonya Hendricks, Southern Illinois University at Carbondale. Psychosocial treatment for families of children born with congenital adrenal hyperplasia (CAH) identified through newborn screening
- 2005 2006 Lolita Ontiveros, University of Wisconsin-Milwaukee. Psychosocial adaptation to short stature: family contextual variables

# University of Michigan

## College of Literature, Science, and the Arts

2014 Guest lecturer: PSYCH 438 - Hormones and Behavior (Jill Becker, PhD)
Disorders (Differences) of Sex Development: Medical Condition or Identity?
Model for Psychoendocrine Research or Challenge for Health Care Delivery?

2015	Guest lecturer: PSYCH 438 - Hormones and Behavior (Jill Becker, PhD) Disorders (Differences) of Sex Development
2016	Guest lecturer: PSYCH 438 - Hormones and Behavior (Jill Becker, PhD) Factors
2018	that Shape Gender Development Guest lecturer: PSYCH430: Sex Differences in Brain, Behavior, and Disease
2010	(Jennifer Cummings, PhD) Psychosocial Aspects of DSD: Strengths and
	Weaknesses of Current Research and Future Directions
2019	Guest lecturer: PSYCH 337: Hormones and Behavior (Jill Becker, PhD)
	Disorders (Differences) of Sex Development
Research Supe	
_	e Research Opportunity Program (UROP)
2007 - 2008	Luke Carron
2008 - 2009	Nicole Ramanathan, Marissa Flores, Sharan Mullen
2009 - 2010	Ross Goldberg, Lauren Warner
2011 - 2012	Megan Masten, Avery Gleason
2012 - 2013	Megan Masten, Morgan Hawver
2013 - 2014	Morgan Hawrer, Karen Johnson, Gabriel Kirsch
2014 - 2015	Rachel Woods, Nicole Evans
2016 - 2017	Youna Lee, Samantha Bailey, Zachery Hampel
2017 - 2018	Adriene Melong, Summer Eubank
2017 - 2019	Darius Moore
2021 - 2022	Myung Jae Ko, Lauren Penrose, Noelia Dulo
Undergraduate	e Volunteer Research Assistants
2008 - 2009	Sasha Zarins
2009 - 2010	Elissa Sarno, Stephanie Stout, Meagan Carr, Claire Varga
2012 - 2013	Victoria Marchenko, Talia Ribnikleena
2013 - 2014	Carlos Yeguez, Kathleen Martin
2014 - 2015	Eliana Rosen, Arhum Shahab, Victoria Strohm, Aaron, Triweiler
2015 - 2016	Taylor Bringard, Peyton Skupin
2020 - 2021	Madison Helsel, Samantha Philipp, Emma Kaplan
2022 - 2023	Lauren Penrose, Noelia Dulo
Undergraduate	e Independent Study
2010 - 2011	Daniel Anderson
2017 – 2019	Samantha Bailey, Rachel Tanenbaum
University of	Michigan Medical School
2006 - 2014	Developmental-Behavioral Pediatrics resident rotation: Topics in
	Psychoendocrinology (monthly lecture)
2010 - 2016	M2 Elective: Gender & Orientation Issues in Healthcare. Disorders of Sex
	Development (annual)
2014	Genetic Counseling Program, Human Genetics, Psychosexual Differentiation, Psychosocial Aspects of DSD, and Clinical Management (biennial)

2016 – 2018 Guest lecturer: Anatomy/Physiology 541 - Mammalian Reproductive Physiology Carol Elias, PhD) Sex, Gender and More in Disorders/Differences of Sex Development (DSD)

# Michigan Health Sciences Undergraduate Research Academy (Office for Health Equity and

Inclusion; mentored 10-week research training experience)

2019 Joslyn S Smith, Spelman College, Atlanta, GA

#### Medical Student Research Mentoring

2009 - 2010	Halley	Crissman.	<b>MPH</b>	candidate
2007 2010				

- 2010 2011 Student Biomedical Research Program (SBRP): Tola Oyesanya, Aimee Rolston
- 2010 2011 SBRP: Emily Torell, Patricia Szmal
- SBRP: Rachel Hatcliffe
- 2013 2014 Aimee Rolston, Master of Science in Clinical Research, Department of Epidemiology in the U-M School of Public Health
- 2014 2016 SBRP: Megan Lane
- 2018 2022 SBRP: Alison Baskin
- 2022 2023 Nora McVinnie, 2nd-year medical student, University College Dublin, School of Medicine

#### Research Mentoring, Other

2008 – 2010 Emily Haddad, MSW candidate, School of Social Work

#### **Faculty Mentoring**

- 2007 2012 Jennifer Butcher, PhD, Child Behavioral Health, Pediatrics
- 2007 2010 Catherine Peterson, PhD, Child Behavioral Health, Pediatrics
- 2007 2012 Bethany Sallinen, PhD, Child Behavioral Health, Pediatrics
- 2007 2015 Beth Tarini, MD, General Pediatrics (Child Health Evaluation and Research Unit)
- 2012 2020 Blake Lancaster, PhD, Pediatric Psychology, Pediatrics
- 2012 2020 Amy Drayton, PhD, Pediatric Psychology, Pediatrics
- 2014 2020 Rachel Knight, PhD, Pediatric Psychology, Pediatrics
- 2016 2018 Melissa Andersen, PhD, Pediatric Psychology, Pediatrics
- 2016 2018 Eric Scott, PhD, Pediatric Psychology, Pediatrics
- 2016 2018 Melissa Cousino, Pediatric Psychology, Pediatrics
- 2018 2020 Andrew Cook, PhD, Pediatric Psychology, Pediatrics
- 2018 2020 Hannah Ham, PhD, Pediatric Psychology, Pediatrics
- 2018 Courtney Streur, Pediatric Urology, Urology (K23 Mentor)
- 2018 2022 Teryn Bruni, Pediatric Psychology, Pediatrics

# Clinical Supervision (Department of Pediatrics)

# Pediatric Psychology Practicum

- 2016 2017 Alejandra Arango, MA (University of Michigan)
- 2020 2021 Lilianne Gloe, MA (Michigan State University)
- 2021 2022 Mackenzie Norman, MA (Michigan State University)
- 2022 2023 Lindsay Poole, EdS (Michigan State University)

## Pediatric Psychology Intern

2022 - 2023	Emily Mace, EdS (University of Kansas)
2023 –	Ashley Hudson, MA (University of Denver)

Melissa Andersen, PhD

#### Pediatric Psychology Post-Doctoral Fellows

2006 - 2007	Jennifer Butcher, PhD
2007 - 2008	My Lien, PhD
2007 - 2009	Dawn Dore-Stites, PhD
2008 - 2009	Matthew Myrvik, PhD
2010 - 2011	Kavita Desai, PhD

#### Master's Thesis Committees

2012 - 2013

2012 - 2014	Michelle E. Ernst, MS candidate, Genetic Counseling, University of Michigan,
	Genetic Counseling Program

- 2014 2016 Linford Williams, MS candidate, Genetic Counseling, University of Michigan, Genetic Counseling Program
- 2016 2018 Stephanie Wiryaman, MS candidate, Genetic Counseling, University of Michigan, Genetic Counseling Program
- 2019 2020 Grace Kavanaugh, MS candidate, Genetic Counseling, California State University, Stanislaus

# <u>Post-Doctoral Research Fellows</u> S.B. Meister Child Health Evaluation and Research Center

- 2008 2009 Natashia Robbins, PhD, Postdoctoral Translational Scholars Program (PTSP), Michigan Institute for Clinical and Health Research
- 2014 2016 Nina Callens, PhD, Visiting Scholar, Belgian-American Educational Foundation Fellow
- 2018 2020 Kristina Soursa-Johnson, PhD 2021 - Behzad Sorouri Khorashad, MD

# 2021 - Belizad Solodii Kilolasiiad, Wi

# **Dissertation Committees**

2012 – 2015 Tiffany Abrego PhD candidate, Clinical Psychology, Eastern Michigan University

# COMMITTEE, ORGANIZATIONAL, AND VOLUNTEER SERVICE

# University at Buffalo, State University of New York, School of Medicine & Biomedical Sciences

# **University Service**

1999 - 2001	Department of Psychiatry Representative to the Faculty Council
1999 - 2003	Faculty Council Continuing Medical Education Committee (Acting Chair, 2001-
	2002)
2000 - 2001	Member, Search Committee for Chief, Division of Pediatric Endocrinology
2001 - 2006	Health Sciences Institutional Review Board, Alternate
2000 - 2003	Ad hoc Committee for Promotions to Unqualified Ranks,
2004 - 2006	Ad hoc Committee for Promotions to Unqualified Ranks

## **Departmental Service (Psychiatry)**

1993 – 1994	Strategic Planning Task Force, Academic Management Issues
1993 – 1994	Research & Faculty Development Committee
1993 - 2006	Appointments, Promotions, Tenure and Privileges Committee (Chair, 1996-2006)
1993 - 2006	Research Subcommittee, Division of Child & Adolescent Psychiatry (Chair,
	1995-2006).
1993 – 1998	Promotions & Credentialing, Division of Child & Adolescent Psychiatry
1994 – 1999	Institutional Review Board, Children's Hospital of Buffalo
1995 - 2006	Selection Subcommittee for the Child & Adolescent Psychiatry Residency
	Training Program
1995 - 2006	Evaluation Subcommittee for the Child & Adolescent Psychiatry Residency
	Training Program
1995 - 2006	Residency Training Committee, Child & Adolescent Psychiatry
2004	Departmental Strategic Planning Retreat, Research Development Work Group.
2005 - 2006	Academic Affairs Steering Committee

# **University of Michigan Medical School**

# **University Service**

2008 – 2009 Member, Pediatric Clinical Research Committee, MICHR Clinical & Translational Science Award (CTSA)

# **Departmental Service (Pediatrics)**

2006 –	Member, Pediatric Directors' Advisory Council
2008 - 2009	Member, Grand Rounds Committee
2009 - 2010	Co-Chair, ad hoc Committee on Psychosocial Services for C.S. Mott Children's
	Hospital
2010 - 2013	Research Advisory Committee

# **Division Service (Pediatrics, Pediatric Psychology)**

2020 – Diversity, Equity, and Inclusion Committee

## **Professional Service**

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2001 - 2010	Member, ad hoc Disorders of Sex Development Committee (formerly the
	Committee on Intersexuality), Lawson Wilkins Pediatric Endocrine Society
2004 - 2006	Co-Chair, Society of Pediatric Psychology (APA, Div 54) Task Force on Access
	to Pediatric Psychology Services
2007 - 2008	Member, Ethics Committee of the Lawson Wilkins Pediatric Endocrine Society
2009	Member, World Professional Association for Transgender Health (WPATH,
	formerly known as the Harry Benjamin International Gender Dysphoria
	Association). Consensus Statement on DSM-V Gender Identity Disorders,
	workgroup co-leader, Disorders of Sex Development. Oslo, Norway, June 17-20,
	2009
2010 - 2019	Chair, Committee on Disorders of Sex Development, WPATH
2010 - 2011	NICHD, National Newborn Screening Translational Research Network,
	Endocrine Working Subgroup
2010 - 2013	Organization for the Study of Sex Differences, Program Planning Committee

- 2015 Association of American Medical Colleges (AAMC) Advisory Committee on Sexual Orientation, Gender Identity, and Sex Development (Axis) as Chair of the Differences of Sex Development Ad Hoc Committee
- 2016 2019 Member, National Institutes of Health (NIH) Sexual and Gender Minority Research Working Group (SGMRWG)
- 2019 American Psychological Association, Division 54 (Society of Pediatric Psychology): Co-Chair, Differences of Sex Development (DSD) Special Interest Group
- 2019 2020 Member, Diane Willis Award Committee; selection of outstanding article in the Journal of Pediatric Psychology

## Volunteer Service, Committee/Board Work

Children's Growth Foundation http://www.childsgrowth.org/

(Member Agency of the United Way of Buffalo & Erie County, NY)

1990 – 1995 Member, Medical Advisory Board

1995 – 2004 President

2004 – 2006 Member, Health Advisory Board

Buffalo Academy for Visual and Performing Arts

1993 – 1997 Member, Dance Advisory Board, Buffalo Public Schools

Human Growth Foundation <a href="http://www.hgfound.org/">http://www.hgfound.org/</a>

1994 – 1997 Director-at-Large

Turner Syndrome Society of the United States <a href="http://www.turnersyndrome.org/">http://www.turnersyndrome.org/</a>

2001 – Member, Professional Advisory Board

Consortium on Disorders of Sex Development <a href="http://www.dsdguidelines.org/">http://www.dsdguidelines.org/</a>

2005 Member

Intersex Society of North America <a href="http://www.isna.org/">http://www.isna.org/</a>

2006 – 2008 Medical Advisory Board

Accord Alliance (project of the Tides Center) http://www.accordalliance.org/

2007– Founding Member, Advisory Board

MAGIC (Major Aspects of Growth in Children) Foundation

http://www.magicfoundation.org/www

2001–2009 Member, Medical Advisory Board

CARES (Congenital Adrenal hyperplasia Research, Education and Support) Foundation

http://caresfoundation.org/symptoms.html

2007 – Member, Scientific & Medical Advisory Board

## **Community Lectures:**

- 1. Psychosocial aspects of short stature. Children's Growth Foundation supported talk given to parents of children receiving growth hormone therapy at Children's Hospital of Buffalo (November 7, 1990).
- 2. Are you male or female? Nichols Wellness Fair, Buffalo, NY (February 28, 1991) (workshop given jointly with T Mazur).

- 3. Psychosocial aspects of short stature. Children's Growth Foundation, Children's Hospital of Buffalo (November 16, 1991).
- 4. Psychosocial assessment and clinical management of Turner syndrome. Children's Growth Foundation, Buffalo, NY (March 14, 1992).
- 5. Teenage sexuality: a talk for parents. Buffalo Academy for Visual and Performing Arts, Buffalo, NY (February 19, 1992 and February 17, 1993).
- 6. Sexual orientation: potential biological contributions. Westminster Presbyterian Church Adult Program, Buffalo, NY (May 16, 1993).
- 7. Psychosocial aspects of short stature: early clinical and emerging research perspectives. Human Growth Foundation, Columbia, MD (November 6, 1993).
- 8. Psychosocial aspects of short stature: early clinical and emerging research perspectives. Human Growth Foundation, Montreal, Canada (March 5, 1994).
- 9. Short stature: psychosocial issues. Human Growth Foundation and Serono Symposia USA, Inc.'s Insights into Growth Disorders, Uniondale, NY (June 11, 1994).
- 10. Psychological, social, and emotional aspects of being short. Second Combined University of Toronto, McMaster University and the University of Western Ontario Growth Day, Toronto, Ontario (October 22, 1994).
- 11. Psychosocial aspects of short stature: early clinical and emerging research perspectives. Human Growth Foundation and Serono Symposia USA, Inc. Dayton, OH (September 17, 1995).
- 12. Psychosocial aspects of short stature: early clinical and emerging research perspectives. Human Growth Foundation and Serono Symposia USA, Inc. Atlanta, GA (November 12, 1995).
- 13. Short stature: psychosocial issues past experience and new directions. Human Growth Foundation and Serono Symposia USA, Inc. Rockville, MD (May 4, 1996).
- 14. Short stature: psychosocial issues past experience and new directions. Human Growth Foundation and Serono Symposia USA, Inc. Chicago, IL (October 26, 1996).
- 15. Short stature: psychosocial issues past experience and new directions. Human Growth Foundation and Serono Symposia USA, Inc. Denver, CO (April 5, 1997).
- 16. Formerly treated growth hormone deficient adults: How well are they doing? Human Growth Foundation, Annual Meeting, Memphis, TN (April 18, 1998).
- 17. Genital and reproductive anomalies in children. MAGIC (Major Aspects of Growth in Children) Foundation Annual Convention, Chicago, IL (July 18-21, 2002).
- 18. The psychology of short stature: Are our assumptions based on the scientific evidence? Turner Syndrome Society of the United States, 2002 Annual Convention, St. Louis, MO (August 9-11, 2002).
- 19. Career Day Program, Pediatric Psychology. West Seneca West High School, West Seneca, NY (November 20, 2002).
- 20. Psychosocial aspects of short stature and assumptions underlying its treatment with growth hormone therapy. Family Growth Day 2003, Winnipeg Children's Hospital, Winnipeg, Canada (March 22, 2003).
- 21. The psychology of short stature. Children's Growth Foundation Annual Family Meeting, Buffalo, NY (May 3, 2003).
- 22. Psychosocial aspects of short stature and assumptions underlying its treatment with growth hormone therapy. Turner Syndrome Support Group of Central New York, Syracuse, NY (June 13, 2003).

- 23. Invited testimony (with Anne Lockwood, Ph.D.) at the Public Hearing, Preventing Childhood Obesity at School, At Home and in the Community / Task Force on Food, Farm and Nutrition Policy; Chair, New York State Assemblyman Felix W. Ortiz. University at Buffalo (July 5, 2003).
- 24. MAGIC (Major Aspects of Growth in Children) Foundation Annual Convention, Chicago, IL (July 25-27, 2003).
  - Coping with a chronic illness how it affects the family
  - Psychosocial issues affecting girls/adolescents with Turner syndrome
  - Genital and reproductive anomalies in children: How can I support my child?
- 25. A Fair and Balanced Look at Short Stature: Myth and Reality. Family Growth Day, Hospital for Sick Children, Toronto, Canada (October 25, 2003).
- 26. MAGIC (Major Aspects of Growth in Children) Foundation Annual Convention, Chicago, IL (July 22-25, 2004).
  - Special challenges facing older children with CAH
  - Psychosexual issues in children born with genital or reproductive anomalies:
  - How can I best support my child?
  - Family matters: The affected child is not the only one affected
- 27. Family Matters. Children's Growth Foundation Annual Family Meeting, Buffalo, NY (March 13, 2004).
- 28. Coping with a Chronic Illness How It Affects the Family. Hemophilia Center of Western NY, Buffalo, NY (September 27, 2004).
- 29. CARES (Congenital Adrenal Hyperplasia Research Education and Support) Foundation, 2004 Conference on Congenital Adrenal Hyperplasia, Summit, NJ (October 24, 2004).
  - How can I best support my child and impact of CAH on siblings and families (with Sheri Berenbaum, PhD and Susan Baker, PhD)
  - Older kids with CAH: Discussion group for male teens
  - Younger kids with CAH: Discussion group for pre-teens
- 30. The Impact of Chronic Illness on the Family. Children's Growth Foundation Annual Family Meeting, Buffalo, NY (April 9, 2005).
- 31. MAGIC (Major Aspects of Growth in Children) Foundation Annual Convention, Chicago, IL (July 20-23, 2005).
  - Will they ever do it on their own? Discussion group with parents with teens with congenital adrenal hyperplasia (with Tom Mazur, PsyD)
  - Helping your child to positively manage a genital and reproductive difference: Parts 1 & 2 (with Tom Mazur, PsyD and Ellen Bean)
- 32. Coping with a Child's Chronic Illness -- How It Can Affect the Family. Western New York PKU Association, Buffalo, NY (February 4, 2006).
- 33. MAGIC (Major Aspects of Growth in Children) Foundation Annual Convention, Chicago, IL (July 23-26, 2006).
  - Strategies to get through those difficult times in raising a child with CAH
  - Parenting a child who has a genital or reproductive difference: What professionals have learned from 50 combined years of clinical experience that can help MAGIC parents (Parts 1 & 2) (with Tom Mazur, PsyD)
- 34. Hypospadias & Epispadias Association, New York, NY (July 29-31, 2006).
  - Childhood gender and psychosocial development in boys with hypospadias

- A psychoeducational treatment manual for families of newborns with congenital health problems: A pilot project
- 35. Congenital Adrenal Hyperplasia Family Education Day, Ann Arbor, MI (May 19, 2007)
  - Family coping with CAH
- 36. MAGIC (Major Aspects of Growth in Children) Foundation Annual Convention, Wheeling, IL (July 19-22, 2007).
  - CAH research: Putting it in perspective. (with Phyllis W. Speiser, MD)
  - What you need to know about genital and reproductive anomalies in 2007 (with Tom Mazur, PsyD)
  - What parents want to discuss about genital and reproductive anomalies
- 37. MAGIC (Major Aspects of Growth in Children) Foundation Annual Convention, Wheeling, IL (July 24-27, 2008).
  - Raising a medically responsible adolescent
  - Coping with a child's chronic illness -- how it can affect the family
  - Helping your child adjust to a Disorder of Sex Development (DSD)
- 38. Lake County Health Department and Community Health Center, Is It a Boy or a Girl? Understanding Clients with Disorders of Sex Development (DSD), Gurnee, IL (September 19, 2008).
  - Overview of Disorders of Sex Development
- 39. MAGIC (Major Aspects of Growth in Children) Foundation Annual Convention, Wheeling, IL (July 23-26, 2009).
  - Congenital Adrenal Hyperplasia: Vision for a new research agenda and improved model of care
  - Understanding Disorders of Sex Development: How We Can Help Our Children
- 40. Lake County Health Department and Community Health Center, Overview of Disorders of Sex Development (DSD), Schaumburg, Illinois (October 21, 2011).
- 41. Androgen Insensitivity Syndrome-Disorders of Sex Development Support Group for Women and Families. Oklahoma City, OK (June 21-24, 2012).
  - Getting to Know You Sharing Family Stories. Facilitators: Arlene Baratz MD, Mark Baratz MD, Charmian Quigley MD, David Sandberg PhD, Barbara Neilson MSW, Amy Wisniewski PhD
  - Informed Consent & Asserting Yourself in the Doctor's Office. Anne Tamar-Mattis JD, Suegee Tamar-Mattis MD, Arlene Baratz MD, Charmian Quigley MD, Lesley Breech MD, Samantha Pfeifer MD, David Sandberg PhD
  - Parenting Boys with DSD. William Reiner MD and David Sandberg PhD
  - Informational session regarding DSD-Translational Research Network and role for advocacy and support group representation. David Sandberg PhD, Eric Vilain MD PhD and Janet Green (Accord Alliance)
- 42. Turner Syndrome Society, Michigan Chapter, Social skills in girls with Turner syndrome: a neglected target for intervention? Livonia Civic Center Library (June 22, 2013).
- 43. Turner Syndrome Society of the United States, 27<sup>th</sup> Annual Conference. Giving your daughter tools for independence. Jacksonville, FL (July 11-13, 2014)
- 44. DSD (Disorders of Sex Development) Family Day. University of Michigan Program for Disorders of Sex Development (DSD) at C.S. Mott Children's Hospital. Communication with children and adolescents about their DSD. University of Michigan North Campus Research Complex, Ann Arbor, MI (March 5, 2016)

- 45. CARES Foundation, CAH Women's Support Call. Q&A Virtual meeting (April 22, 2021)
- 46. Accord Alliance and DSD Translational Research Network, Family Day (April 23, 2022). Peer support moderator.

# **CONSULTING POSITIONS**

2000 - 2001	American Psychological Association, Pediatric Endocrine Nursing Society, and
	Pharmacia Corporation Partners for Healthy Growth Project, Washington, DC
2003	Eli Lilly & Company, Humatrope Product Team. The psychosocial aspects of
	short stature. Indianapolis, IN
2007	American Psychological Association, Task Force on Gender Identity, Gender
	Variance, and Intersex Conditions, ad hoc consultant
2008	Pfizer Global Pharmaceuticals, Patient Reported Outcomes in Short Stature Youth
	(PROSSY). Gothenburg, Sweden
2011	Pfizer Global Pharmaceuticals, Quality of Life in Short Youth: The QoLISSY
	Study. New York, NY
2011	Ipsen Pharmaceuticals, ANTARES (Adequate Management of Transitional Age
	with Growth Deficiencies), Milan, Italy

# <u>VISITING PROFESSORSHIPS, SEMINARS, AND EXTRAMURAL</u> INVITED PRESENTATIONS

# University at Buffalo, State University of New York

- 1. Regional Conference on Recognition and Management of Growth Failure in Childhood. Psychosocial aspects of short stature (March 6, 1991).
- 2. Grand Rounds Presentation, Department of Pediatrics. Psychosocial aspects of short stature: early clinical and emerging research perspectives (February 12, 1993).
- 3. Grand Rounds Presentation, Department of Pediatrics. Children's Hospital of Buffalo, NY. Congenital hypothyroidism: treatment approaches (with SP Campos) (July 15, 1994).
- 4. Spring Seminar Series, Department of Social & Preventive Medicine. The developmental effects of sex hormones on human behavior, Buffalo, NY (February 10, 1995).
- 5. Grand Rounds Presentation, Department of Psychiatry. Short stature: A psychosocial burden requiring growth hormone therapy? (January 31, 1997).
- 6. Grand Rounds Presentation, Department of Pediatrics. The quality-of-life benefits of growth hormone-increased adult height: What's known (October 29, 1999).
- 7. National Heart, Lung, and Blood Institute, NIH, Summer Research Program. Endocrine disruptors and human sex-dimorphic development (July 14, 2002).
- 8. National Heart, Lung, and Blood Institute, NIH, Summer Research Program. Endocrine disruptors and human sex-dimorphic development (June 13, 2003).
- 9. National Heart, Lung, and Blood Institute, NIH, Summer Research Program. Stereotypes vs evidence: The example of 'short stature' and its clinical management (July 16, 2004).
- 10. National Heart, Lung, and Blood Institute, NIH, Summer Research Program. The psychosocial aspects of short stature: Are our assumptions evidence-based? (July 29, 2005).
- 11. Grand Rounds Presentation, Department of Pediatrics. Assessing patient centered communication at WCHOB. Discussant. (March 3, 2006).

#### University of Michigan

- 1. Pediatrics & Communicable Diseases, Alumni Association. Growth hormone treatment for short stature: Questioning assumptions and gauging success. (October 20, 2006).
- 2. Pediatrics & Communicable Diseases, Health Services Research Seminar. Psychoendocrine travel log and tour of future destinations. (October 24, 2006).
- 3. University of Michigan Medical School, LGBT Health Awareness Week. Disorders of sex development: Clinical decision-making in a state of flux. (March 16, 2007).
- 4. Pediatrics & Communicable Diseases, Grand Rounds. Newborn screen as a laboratory for service delivery research: optimizing health and quality of life outcomes in pediatric chronic illness. (May 29, 2007).
- 5. Department of Surgery, Michigan Interdisciplinary Committee on Disorders of Sex Development. Consensus Statement on Management of Disorders of Sex Development (DSD). (June 11, 2007).
- 6. Pediatrics & Communicable Diseases, Health Services Research Seminar. Variability in clinical management of disorders of sex development: reasons to be concerned, (October 30, 2007).
- 7. Pediatrics & Communicable Diseases, Grand Rounds. Management of disorders of sex development: The case for integrated team care. (January 22, 2008).
- 8. Bioethics Program, Grand Rounds. Psychosocial Aspects of Height and Its Management. (March 26, 2008).
- 9. Pediatric Surgery Didactic Lecture. Disorders of Sexual Development: Psychosocial factors and clinical management (June 4, 2009).
- 10. Pediatrics & Communicable Diseases, Health Services Research Seminar. Disorders of Sex Development: Report on a Research and Quality Improvement Symposium (June 23, 2009).
- 11. Department of Psychology (Woman Studies 407, Intersexualities). Psychoendocrine Travel Log -- The Thread Only Seen in Hindsight (September 29, 2009).
- 12. UMHS Center for Sexual Health, Addressing Sexual Health with Patients with Disorders of Sex Development: A Case for a Surgeon Sex Therapist Collaboration, Discussant (October 31, 2009).
- 13. University of Michigan (co-sponsored by OUTLAWS, BGLAM, The Michigan Journal of Gender & Law, SAGE, The University of Michigan Department of Psychology) Exploring Intersex. A panel discussion exploring the medical, legal & ethical issues that accompany disorders of sexual development & intersex conditions (March 11, 2010).
- 14. Pediatrics & Communicable Diseases, Health Services Research Seminar. Experiences vs memory: which drive our choices and reports of satisfaction? (June 22, 2010).
- 15. Department of Social Work, Staff Development Lecture Series. Disorders of Sex Development: More than New Nomenclature (August 19, 2010).
- 16. Pediatrics & Communicable Diseases, Health Services Research Seminar. Congenital Adrenal Hyperplasia: A systematic survey of studies employing psychological endpoints? (May 31, 2011).
- 17. Pediatrics & Communicable Diseases, Health Services Research Seminar. Management of disorders of sex development: Is there a consensus? (February 5, 2012).
- 18. Center for Bioethics and Social Sciences in Medicine, Winter 2013 Seminar Series. Management of disorders of sex development: Is there a consensus? (February 6, 2012).
- 19. Pediatrics & Communicable Diseases, Grand Rounds. Disorders of Sex Development (DSD): The Clinical Research Agenda. (June 22, 2014).

- 20. Center for Organogenesis Translational Cross Talk Series. Disorders of sex development, from biochemistry to behavior. (with Rich Auchus, MD, PhD) (December 18, 2014).
- 21. Department of Pediatrics, Grand Rounds. Shared decision making in pediatrics: Science and tools to facilitate involvement of parents and children in healthcare decisions (with Dawn Stacey, RN, PhD, CON(C)) (March 1, 2022) Virtual presentation.

# Regional

- 1. Queens Children's Psychiatric Center, Grand Rounds Presentation. Boys with congenital abnormalities of the sex organs, Queens, New York, NY (March 27, 1986).
- 2. Rockland Children's Psychiatric Center, Grand Rounds Presentation. Androgens and male development. Orangeburg, NY (January 6, 1987).
- 3. Villanova University chapter of PSI CHI (National Honor Society in Psychology). Paper presented at the Induction Ceremony. Androgens and Psychosocial Development of the Male. Villanova, PA (April 1, 1987).
- 4. Queens Children's Psychiatric Center, Grand Rounds Presentation. Boys with congenital anomalies of the sex organs: A research update. Queens, New York, NY (December 10, 1987).
- 5. North Shore University Hospital, Department of Psychiatry, Division of Child & Adolescent Psychiatry, Grand Rounds Presentation. Gender role and behavior problems of boys born with genital anomalies. Manhasset, NY (January 23, 1989).
- 6. North Shore University Hospital, Department of Pediatrics, Grand Rounds Presentation. Psychosocial aspects of short stature. Manhasset, NY (March 15, 1989).
- 7. North Dakota State University, Department of Psychology, Distinguished Speaker Series. Sex-dimorphic behavior and behavior problems in boys born with genital anomalies. Fargo, ND (February 16, 1990).
- 8. North Shore University Hospital-Cornell University Medical College, Department of Psychiatry (Division of Child & Adolescent Psychiatry), Grand Rounds Presentation. Short stature: a psychosocial burden requiring growth hormone therapy? Manhasset, NY (October 9, 1992).
- 9. Miami Children's Hospital, Noon Conference. Psychosocial aspects of short stature: early clinical and emerging research perspectives. Miami, FL (April 19, 1994).
- 10. Northwestern University, Children's Memorial Hospital, Department of Pediatrics. Consensus Statement on Management of Intersex Disorders. Event sponsored by Division of General Academic Pediatrics. Chicago, IL (July 24, 1996).
- 11. Erie Community College, State University of New York, Sexual orientation: potential biological contributions, Buffalo, NY (October 17, 1996).
- 12. Cardinal Glennon Children's Hospital, Department of Pediatrics (St. Louis University), Grand Rounds Presentation. Psychosocial stresses related to short stature: Does their presence imply psychiatric dysfunction? St. Louis, MO (September 23, 1998).
- 13. Indiana University School of Medicine & Riley Hospital for Children, Regional Pediatric Endocrinology Symposium for Nurses, Psychosocial aspects of short stature: considerations in clinical management. Indianapolis, IN (November 15, 1999).
- 14. Cardinal Glennon Children's Hospital, Department of Pediatrics (St. Louis University), Grand Rounds Presentation. Hormonally active chemicals in the environment: are children at risk? St. Louis, MO (May 2, 2001).

- 15. University of Miami, Department of Psychology, Colloquium Series. Developmental Psychoendocrinology: The Challenges of Integrating Science with Clinical Care. Miami, FL (February 4, 2002).
- 16. Great Lakes Regional Meeting on Child Health Psychology. Caring for children with ambiguous genitalia: Do psychologists have a role to play? Symposium organizer and Chair. Milwaukee, WI (April 19, 2002).
- 17. Robert Wood Johnson Medical School, Human Sexuality Week 2004. Piscataway, NJ (January 7, 2004).
  - Intersexuality: Clinical and personal perspectives, participant in panel discussion.
  - Are there more than two sexes? Current debates in intersexuality, workshop leader.
- 18. Baylor College of Medicine & Texas Children's Hospital, Gender Medicine Team. Disparate Viewpoints Regarding Clinical Management of Intersexuality: Findings from a Survey of Clinicians. Houston, TX (August 6, 2004).
- 19. Children's Psychiatric Center of Western New York. The psychosocial aspects of short stature and its clinical management: Are our assumptions evidence-based? West Seneca, NY (May 18, 2005).
- 20. University of Michigan Medical School, Division of Pediatric Endocrinology, Department of Pediatrics & Communicable Diseases. Ann Arbor, MI (October 11, 2005).
  - Psychosocial aspects of short stature and its clinical management
  - Clinical management of intersexuality: a survey of expert opinion.
- 21. Robert Wood Johnson Medical School, Human Sexuality Week 2006. Piscataway, NJ (January 4, 2006). Workshop leader:
  - Congenital Adrenal Hyperplasia
  - Assessing psychological outcomes in patients with disorders of sexual differentiation
- 22. Children's Hospital Los Angeles, The Center for Diabetes, Endocrinology and Metabolism. Los Angeles, CA (February 16, 2006).
  - Clinical decision-making and treatment models in a state of flux: findings from a North American survey
  - Psychosocial aspects of short stature: Are our assumptions evidence-based?
- 23. Upstate Medical University, College of Medicine, State University of New York. Psychosocial aspects of short stature: Are our assumptions evidence-based? Syracuse, NY (March 15, 2006).
- 24. University of Rochester Medical Center, Center for Palliative Care and Clinical Ethics, Interdisciplinary Clinical Ethics Rounds. Growth hormone for short kids: science and ethics. Rochester, NY (April 12, 2006).
- 25. Pediatric Endocrinology Society of Texas, Oklahoma, Louisiana and Arkansas, Oklahoma City, OK (September 22-23, 2006).
  - Psychosocial aspects of short stature and its clinical management: does the evidence support current practice?
  - A psychoeducational treatment manual for families of newborns with CAH: broadening the goals of our interventions
- 26. Wayne State University, Child Psychiatry Grand Rounds Presentation, Psychosocial aspects of short stature and its clinical management: Does the evidence support current practice? Detroit, MI (February, 13, 2007).

- 27. St. Joseph Mercy Hospital, Department of Psychiatry Grand Rounds, Psychosocial aspects of short stature and its clinical management: Does the evidence support current practice? Ann Arbor, MI (February 21, 2007).
- 28. St. Joseph Mercy Hospital, Department of Psychiatry Grand Rounds, Congenital disorders of sex development: Clinical care in a state of flux? Ann Arbor, MI (March 21, 2007).
- 29. Children's Hospital of Orange County. Orange, CA (October 16, 2007)
  - Care for families of newborns with congenital adrenal hyperplasia: A pilot psychoeducational project for newborn screen
  - Psychosocial aspects of short stature and its clinical management: Does the evidence support current practice?
- 30. Riley Children's Hospital, Indianapolis, IN, Pediatrics Grand Rounds Presentation, Clinical Management of Short Stature: In What Respect is it Evidence-Based? (January 9, 2008).
- 31. Riley Children's Hospital, Indianapolis, IN, Endocrinology Grand Rounds, Disorders of Sex Development: Clinical Decision-Making in a State of Flux? (January 9, 2008).
- 32. Mount Sinai School of Medicine, New York, NY, Reproductive Physiology module, M1 medical students. Disorders of Sex Development: Overview and Management. (March 17, 2009).
- 33. Schneider Children's Hospital (North Shore Long Island Jewish Health System), Hyde Park, NY, Child & Adolescent Psychiatry Grand Rounds, Medical management of short stature: questioning the assumptions. (December 3, 2009).
- 34. Schneider Children's Hospital (North Shore Long Island Jewish Health System), Hyde Park, NY, Pediatrics Grand Rounds, Growth hormone treatment for short stature: questioning assumptions and gauging success. (December 4, 2009).
- 35. Hackensack University Medical Center and The Joseph M. Sanzari Children's Hospital, Hackensack, NJ, Pediatric Grand Rounds, Psychosocial consequences of short stature and its endocrine management. (May 12, 2010).
- 36. Helen DeVos Children's Hospital, Grand Rapids, MI, Pediatric Grand Rounds, Psychological aspects of short stature and its endocrine management. (September 6, 2011).
- 37. Cincinnati Children's Hospital Medical Center, Visiting Professor. (January 10-11, 2013)
  - DSD-Translational Research Network
  - Outcomes in DSD: Expanding our focus beyond psychosexual differentiation
  - Management of Disorders of Sex Development: Is there a consensus?
- 38. Cincinnati Children's Hospital Medical Center, Visiting Professor. (April 30-May 1, 2015)
  - Decision Support for DSD
  - Outcomes in DSD: Expanding our focus beyond psychosexual differentiation
- 39. Best Practices in Clinical Care, Communication, and Research for Differences of Sex Development/ DSD, CME sponsored by Cincinnati Children's Hospital Medical Center, Update on the progress of the DSD-Translational Research Network and next Steps (with Meilan Rutter, MD). (July 30, 2015).
- 40. Western Michigan University School of Medicine, Kalamazoo, MI. Endocrine-Reproductive course, M2 students. Point-Counterpoint Debate on Growth Hormone Treatment. (with Ram Menon, MD) (November 19, 2015).
- 41. John R. Oishei Children's Hospital / Jacobs School of Medicine and Biomedical Sciences, University at Buffalo, Visiting Professor. (November 29-30, 2018).
  - Pediatrics Research Conference. Disorders/Differences of Sex Development (DSD): Evolution of a Research & QI Agenda

Pediatrics Grand Rounds. Disorders/Differences of Sex Development (DSD):
 Model of Care in a State of Flux

#### **National**

- 1. Serono Symposia, USA, A Current Review of Pediatric Endocrinology. Psychosocial aspects of short stature. Washington, DC (April 27, 1989).
- 2. Eli Lilly Pediatric Endocrinology Nursing Symposium. Turner syndrome: Psychosocial assessment and management. Indianapolis, IN (September 1, 1989).
- 3. Genentech's First Pediatric Nurse Preceptor Program. Short stature: Psychosocial issues. Scottsdale, AZ (September 10-13, 1992).
- 4. University of North Carolina School of Medicine. Growth, Stature and Adaptation: An International Symposium on the Behavioral, Social, and Cognitive Aspects of Growth Delay. Short stature in middle childhood: a survey of psychosocial functioning in a clinic-referred sample. Chapel Hill, NC (October 15, 1993).
- 5. Wingspread Symposium on Environmental Exposures that Affect the Endocrine System (sponsored by the Workgroup on Ecosystem Health, Science Advisory Board of the International Joint Commission on the Great Lakes and The Johnson Foundation). Hormonal Effects on Neurobehavioral Function in Humans Racine, WI (January 13-14, 1995).
- 6. Conference on Quality-of-Life Assessment in Children and Adolescents with Chronic Conditions. Psychosocial stresses related to short stature: Does their presence imply psychiatric dysfunction? Cleveland, OH (October 18-20, 1996).
- 7. Therapeutic Outcome of Endocrine Disorders: Efficacy, Innovation and Quality of Life, Serono Symposia USA. Quality of life among adults with childhood onset growth hormone deficiency: a comparison with siblings. Palm Beach Gardens, FL (November 13-16, 1997).
- 8. Conference on Adherence to Treatment in Childhood Chronic Illness: Interventions and Methods, Promoting Adherence in Growth Hormone Therapy among Children with Growth Failure? Cleveland, OH (October 30-31, 1998).
- 9. Conference on Ethical Issues in Growth Hormone Therapy: Where Are We Now? The Quality-of-Life Benefits of Growth Hormone-Increased Final Height: What Do We Know? Madison, WI (October 7-9, 1999).
- 10. National Institute of Child Health and Human Development Research Planning Workshop on Intersex. Agenda Planning Committee and Discussion Co-Leader for Session "Regarding Gender Assignment Where are we?" Tempe, AZ (May 19-20, 2002).
- 11. American Academy of Pediatrics. Critical Challenges in Developing and Applying Pediatric Health Status and Outcome Measures. Invited Participant. Chicago, IL (March 24-25, 2003).
- 12. NIH/NIDDK Workshop. Research Progress Report and Strategic Plan for Pediatric Urology. Adelphi, MD (February 2-4, 2005).
- 13. American College of Medical Genetics, 2005 Annual Meeting. Invited symposium participant, "Intersex" (moderator: Eric Vilain, M.D). Psychosexual differentiation in individuals born with intersex conditions. Dallas, TX (March 17, 2005).
- 14. A Current Review of Pediatric Endocrinology, Serono Symposia International. Psychosocial aspects of short stature. San Diego, CA (June 1, 2005).
- 15. The Hastings Center for Bioethics. The psychosocial aspects of short stature and its clinical management: are our assumptions evidence-based? Garrison, NY (January 5, 2006).

- 16. Disorders of Sex Development Symposium, Annual Conference of the Gay and Lesbian Medical Association, San Francisco, CA (October 11-14, 2006).
  - Report on Chicago consensus statement on management of intersex disorders
  - A psychoeducational treatment manual for families of newborns with CAH: broadening the goals of our interventions
- 17. Disorders of Sex Development (DSD): Research and Quality Improvement Symposium (sponsored by the Office of the Vice-President for Research, University of Michigan), symposium organizer: David E. Sandberg, Ann Arbor, MI (April 1-3, 2009).
- 18. NICHD & Newborn Screening Translational Research Network, Disease-Specific Workgroup, Bethesda, MD (February 25-26, 2010).
  - An Integrated Strategy for Long-Term Follow Up: Perspective from Disorders of Sex Development (with Eric Vilain, MD PhD)
- 19. American College of Medical Genetics, 2011 Annual Meeting. Invited symposium participant, "Disorders of Sex Development: From Genetic Testing to Healthcare Delivery" (convener: Eric Vilain, MD, PhD). An Alternative Paradigm for the Psychosocial Management of Patients with DSD. Vancouver, Canada (March 19, 2011).
- 20. UCLA, Department of Pediatrics Grand Rounds. The psychological aspects of short stature and its endocrine management. Los Angeles, CA (June 10, 2011).
- 21. Phoenix Children's Hospital. Cracking the Code: Tools for Patients and Families Dealing with Disorders of Sex Development (CME). Uncovering the benefits of integrated psychosocial and medical care for the DSD patient and family. Phoenix, AZ (March 22, 2012).
- 22. Pediatric Academic Societies Annual Meeting. Social skills in girls with Turner syndrome: a neglected target for intervention? In symposium Turner Syndrome: Update and Controversial Issues. Washington, DC (May 5, 2013).
- 23. NICHD Scientific Research Workshop: Growing up with DSD. Critical developmental issues for children and families affected by disorders of sex development. A noncategorical approach to the care of persons with DSD and their families. NIH Campus, Bethesda, MD (March 26-27, 2014).
- 24. NICHD Scientific Research Workshop Turner Syndrome Health and Wellness in the 21st Century: Crossroads of Health Care Research and Health Care Delivery. Health care access for Turner syndrome patients. Jacksonville, FL (July 13-14, 2014).
- 25. American College of Medical Genetics, 2015 Annual Meeting. Symposium co-moderator, March of Dimes Clinical Genetics Conference Interdisciplinary Approach to Disorders of Sex Development: From Genes to Quality of Life. Salt Lake City, UT (March 26, 2015).
- 26. American College of Medical Genetics, 2015 Annual Meeting. March of Dimes Clinical Genetics Conference Interdisciplinary Approach to Disorders of Sex Development: From Genes to Quality of Life. Clinical management in DSD: what's genes got to do with it? Salt Lake City, UT (March 26, 2015).
- 27. North American Society for Pediatric and Adolescent Gynecology. 29th Annual Clinical and Research Meeting. Shared decision making and disorders of sex development: Strategies to optimize patient and family satisfaction and decrease decisional regret. (Workshop, with co-leader Anne-Marie Amies-Oelschalger) Orlando, FL (April 17, 2015).
- 28. 2018 National Birth Defects Prevention Network (NBDPN) Annual Meeting. The experience of disorders (or differences) of sex development (DSD). (Plenary Clinical

- Session: Disorders of Sex Development (DSD): Embryology, Etiology, Epidemiology) Atlanta, GA (March 11-14, 2018).
- 29. Society for Pediatric Psychology 2018 Annual Meeting. Advancing understanding of psychosocial implications of disorders/differences of sex development (DSD) (Symposium discussant) Orlando, FL (April 5-7, 2018).
- 30. Pediatric Academic Societies 2019 Meeting. Interdisciplinary care in DSD: psychosocial component (in Symposium Disorders/Differences of Sex Development (DSD) Update) Baltimore, MD (April 24 May 1, 2019).
- 31. 2020 Pediatric Endocrine Society Annual Meeting. Improving neuropsychological screening and care for girls with TS (with S Davis) Fort Worth, TX (April 24-27, 2020) [Conference canceled COVID-19].
- 32. 14th Annual Meeting of the Organization for the Study of Sex Differences (OSSD). Symposium: Differences of sex development: A window into sex and gender development. Psychosocial outcomes in DSD and the impact of sex steroids on the brain. Marina del Rey, CA (May 4-7, 2020) [Conference canceled COVID-19].
- 33. Pediatric Endocrine Society State of the Art Education Series (webinar; 106 participants), Behavioral health risks in Turner Syndrome: The role of the pediatric endocrinologist (David E Sandberg, PhD and Shanlee Davis, MD, MSCS) (February 26, 2021).
- 34. Pediatric Endocrine Society, DSD Special Interest Group. 17β-hydroxysteroid dehydrogenase type 3 deficiency: Decision Making. Annual Pediatric Endocrine Society Meeting Virtual (April 29, 2021).
- 35. Society for Pediatric Psychology, DSD Special Interest Group. Shared decision making in differences of sex development. Virtual (May 18, 2021).
- 36. Combined meeting of the Society for Pediatric Psychology, DSD Special Interest Group and Psychosocial Workgroup of the DSD Translational Research Network. Shared decision making in differences of sex development. Virtual Clinical care in DSD: Recommendations of pediatric endocrinologist and urologists spanning 2002 to 2020 (May 25, 2022).

#### **International**

- 1. Behavioral Sciences Research Group, The Hospital for Sick Children, Special Guest Lecture. Short stature: a psychosocial burden requiring growth hormone therapy? Toronto (April 16, 1993).
- 2. Center for Research in Human Development, Concordia University. Is short stature a psychosocial burden requiring growth hormone therapy? Montreal (March 4, 1994).
- 3. Canadian Pediatric Endocrine Nurses Conference. Meeting the needs of the adolescent with an endocrine disorder: some unexpected considerations Niagara-on-the-Lake, Canada (June 19, 1994).
- 4. Invited Lecture to Senior Registrar's (Child & Adolescent Psychiatry), Royal Manchester Children's Hospital. The potential role of prenatal sex hormones in the sexual differentiation of human behavior. Manchester, England (July 4, 1994).
- 5. Guest Lecture, Royal Manchester Children's Hospital. The psychological aspects of short stature Manchester, England (July 5, 1994).
- 6. Guest Lecture, Institute of Child Health, Great Ormond Street Hospital for Sick Children. Prenatal sex hormones and gender-role behavior in humans London, England (July 6, 1994).
- 7. Guest Lecture, Department of Pediatrics, Southampton General Hospital. Sex, hormones, and behavior. Southampton, England (July 7, 1994).

- 8. Guest Lecture, Plymouth Hospitals NHS Trust (Child Health Directorate). Psychosocial aspects of short stature. Plymouth, England (July 8, 1994).
- 9. 19th International Symposium: Growth Hormone and Growth Factors in Endocrinology and Metabolism. Short Stature: Does Psychosocial Stress Imply Psychiatric Dysfunction? Prague, Czech Republic (April 21-22, 1995).
- 10. International Symposium on Developmental Issues in Paediatric Endocrinology. Does short stature lead to psychosocial sequelae? Hamburg, Germany (October 6-8, 1995).
- 11. Symposium on Growth and Psyche. Psychosocial experiences of being short: Should we expect any problems? Zurich, Switzerland (October 27-28, 1995).
- 12. Allan Memorial Institute, Psychiatry Academic Grand Rounds. Is short stature a psychosocial burden requiring growth hormone therapy? Montreal, Canada (November 30, 1995).
- 13. The Montreal Children's Hospital, Division of Endocrinology, Psychosocial aspects of short stature: early clinical and emerging research perspectives, Montreal, Canada (July 10, 1996).
- 14. Eli Lilly 9th Annual Humatrope Symposium. Psychosocial problems of being short: should we expect significant problems of adjustment? The Lodge at Kananaskis, Alberta, Canada (February 20-21, 1997).
- 15. GH and Growth Factors in Endocrinology and Metabolism. How to measure quality of life in children, workshop organizer and chair. Istanbul, Turkey (April 24-25, 1998).
- 16. Institute of Pediatric Endocrinology and Diabetes, Schneider Children's Medical Center. Are the social pressures of short stature associated with significant psychosocial dysfunction during childhood? Petah-Tikvah, Israel (April 27, 1998).
- 17. Workshop on Idiopathic Short Stature, The Psychological Adjustment of Children and Adolescents with Short Stature: A Questioning of Assumptions. Le Mas d'Artigny, Saint Paul, France (April 18-19, 1999).
- 18. Pediatric Endocrinology, Karolinska Hospital. The Psychological Adjustment of Children and Adolescents with Short Stature: A Questioning of Assumptions. Stockholm, Sweden (June 18, 1999).
- 19. Institute of Pediatric Endocrinology and Diabetes, Schneider Children's Medical Center. The Psychological Adjustment of Children and Adolescents with Short Stature: A Questioning of Assumptions. Petah-Tikvah, Israel (January 25, 2000).
- 20. 5th International Turner Symposium Optimizing Health Care for Turner Patients in the 21st Century. Brain Function in Turner Syndrome, Session Co-Chair. Naples, Italy (March 24, 2000).
- 21. Lawson Wilkins Pediatric Endocrine Society/European Society of Pædiatric Endocrinology 6th Joint Meeting. (Mis)perceptions of Height and Psychological Adaptation, Symposium organizer and co-chair. Montreal, Canada (July 6-10, 2001).
- 22. 12th Advanced Postgraduate Course on Growth and Growth Disorders. The Psychosocial Aspects of Short Stature and Its Clinical Management: Are Our Assumptions Evidence-based? Stockholm, Sweden (September 24-28, 2001).
- 23. Manitoba Pediatric Society. The Psychosocial Aspects of Short Stature and Its Clinical Management: Are Our Assumptions Evidenced Based? Winnipeg, Canada (March 20, 2003)
- 24. Department of Clinical Health Psychology, University of Manitoba, Colloquium Series. Developmental Psychoendocrinology: The Challenges of Integrating Science with Clinical Care. Winnipeg, Canada (March 21, 2003).

- 25. Hospital for Sick Children Research Rounds. A Survey of Clinical Management of Intersexuality: An Early Glimpse of Findings. Toronto, Canada (October 24, 2003).
- 26. 16th Advanced Postgraduate Course on Growth and Growth Disorders, sponsored by the Karolinska Institute. Quality of life and short stature. Stockholm, Sweden (June 13-17, 2005).
- 27. 17th World Congress of Sexology, Clinical decision-making and treatment models in a state of flux: Findings from a North American survey (invited participant in symposium Clinical Care of Intersexuality-Emerging Solutions of the Controversy, Montreal, Canada (July 12, 2005).
- 28. European Society of Pædiatric Endocrinology/Lawson Wilkins Pediatric Endocrine Society 7th Joint Meeting, Psychological aspects of short stature (invited participant in symposium Genetics and Treatment of Short Stature), Lyon, France (September 24, 2005).
- 29. Canadian Pediatric Endocrinology Group. Growth hormone therapy for short stature: Added inches versus quality of life as the measure of treatment success (invited participant to annual meeting), London, Ontario, Canada (April 20, 2007).
- 30. Consensus Conference for the Diagnosis and Treatment of Children with Idiopathic Short Stature. Lawson Wilkins Pediatric Endocrine Society and the European Society for Pædiatric Endocrinology, Psychosocial aspects of short stature and its management with growth hormone, Santa Monica, CA (October 17-20, 2007).
- 31. 2008 Jacques R. Ducharme Lecture. University of Montreal/Sainte-Justine Hospital. Short stature and growth hormone therapy: What's the problem and where's the evidence? Montreal, Canada (September 10, 2008).
- 32. 18th Advanced Postgraduate Course on Growth and Growth Disorders, sponsored by the Karolinska Institute. Stockholm, Sweden (May 25-29, 2009).
  - Psychosocial consequence of short stature and its management
  - Informed consent for treatment with growth-enhancing or suppressing treatments.
- 33. Emerging Clinical Paradigms: Exploring the Relationship between Idiopathic Short Stature and Growth Hormone, CME symposium sponsored by Mount Sinai School of Medicine at the Lawson Wilkins Pediatric Endocrine Society / European Society of Pædiatric Endocrinology 8th Joint Meeting, Psychosocial aspects of short stature and its management with growth hormone. New York, NY (September 10, 2009).
- 34. Expert Conference on Developments in Idiopathic Short Stature, Barcelona, Spain (October 23-24, 2009).
  - Treatment options: psychological interventions
  - Round-table discussion: Considerations from quality of life research
- 35. III World Congress on Hypospadias and Disorders of Sex Development, Toronto, Canada (November 12-15, 2009).
  - Congenital adrenal hyperplasia: A systematic survey of studies employing psychological endpoints
  - Shared decision making in disorders of sex development
  - Developing a measure of health-related quality of life in disorders of sex development: Phase I Item generation
  - Disorders of sex development research and health care quality improvement: proceedings of a symposium of key stakeholders
- 36. International Symposium of the Pediatric Endocrinology Foundation, 50-Year Anniversary, Buenos Aires, Argentina (May 6-7, 2010).

- Medical management of children with short stature: What are the objectives and are they achieved?
- Disorders of sexual differentiation, beyond a change in nomenclature
- 37. Endocrine Society, 92nd Annual Meeting, San Diego, CA (June 19-22, 2010). Invited participant to symposium Concepts & Controversies in the Management of Short Stature. Endocrine management of short stature: Assumptions and evidence regarding the quality-of-life benefits.
- 38. Excellence in Pædiatrics, London, UK (December 2-4, 2010). Debate: Short stature is a serious handicap and should be treated with growth hormone (Con).
- 39. 19th Advanced Postgraduate Course on Growth and Growth Disorders, sponsored by the Karolinska Institute. Stockholm, Sweden (May 23-27, 2011).
  - The psychological aspects of short stature and its endocrine management
  - Informed consent for treatment with growth-enhancing or suppressing treatments.
- 40. IV World Congress on Hypospadias and Disorders of Sex Development, London, England (September 17-19-2011).
  - Symposium: Timing issues in DSD management: diagnostic, surgical and psychosocial considerations (**Sandberg**, symposium organizer)
    - o Sandberg DE. "Timing" in DSD care: psychosocial considerations
    - Rolston AM, Vilain E, Rock J, Gardner M, Sandberg DE. Disorders of sex development: an investigation of the psychosocial adaptation to diagnosis and treatment
    - Oyesanya T, Sandberg DE, Gardner M, Anderson D, Szmal P, Kogan B. Surgical management of disorders of sex development (DSD): shifts in recommendations post-Chicago consensus conference
- 41. World Professional Association of Transgender Health Biennial International Symposium, Atlanta, GA (September 24-28, 2011). Advancing translational science to improve human welfare.
- 42. 4th I-DSD (Disorders of Sex Development) Symposium, University of Glasgow, Scotland (June 7-9, 2013).
  - DSD training workshop for new investigators communication workstation (with Tom Mazur, PsyD)
  - Strengths and weaknesses of current research and future directions
  - A multicenter, interdisciplinary disorder of sex development registry (with PY Fechner and E Vilain)
- 43. DSD care and outcomes: An agenda beyond gender. World Professional Association of Transgender Health Biennial International Symposium, Bangkok, Thailand (February 14-18, 2014).
- 44. 5th I-DSD Symposium. Ghent, Belgium (June 11-13, 2015).
  - Délot EC, Sandberg DE, Vilain E. The Disorders of Sex Development Translational Research Network (DSD-TRN)
  - Green J, Muscarella M, Délot E, Vilain E, Sandberg DE. Incorporating support and advocacy into the Disorders of Sex Development Translational Research Network (DSD—TRN): Building relationships and resources for patients, families, and healthcare providers

- Callens N, Siminoff, LA, Gardner M, Sharp M, Green J, Muscarella M, Fechner P, Shnorhavorian M, Keegan C, Yashar B, Vilain E, Sandberg DE. A Web-based tool for shared decision-making in DSD
- Quint EH, Alaniz VI, Auchus RJ, Chen M, Keegan C, Ivancic V, Rabah R,
   Sandberg DE, Teitelbaum D. Gonadectomy outcomes in patients with 46, XY
- 45. Université Paris Diderot, Sorbonne Paris Cité Service d'Endocrinologie Diabétologie Pédiatrique & INSERM U1141, Hôpital Universitaire Robert-Debré, Paris, France. Decision support for Disorders of Sex Development (June 19, 2015).
- 46. European Society of Paediatric Endocrinology, 54th Annual Meeting, Barcelona, Spain. (October 1-3, 2015). Decision making in DSD: development of a decision support tool.
- 47. Gender, Typicality and Development: A multidisciplinary conference and webinar. Centre for Research in Human Development, Concordia University, Montreal, Canada. A Noncategorical approach to the care of people with DSD and their families (October 16, 2015).
- 48. International Turner Syndrome Clinical Care Guidelines Consensus Meeting. Co-lead (with Jänielle van Alfen–van der Velden) of the Neurocognition and Behavior workgroup. Cincinnati, OH (July 24-26, 2016).
- 49. Annual Meeting of the Endocrine Society, ENDO 2017. The Psychology of Transition, In Symposium: Growing up Is Hard to Do: Transition of the Pediatric Patient to the Adult World. Orlando, Florida (April 4, 2017).
- 50. 6th I-DSD Symposium. Chair, Defining Outcome in DSD. Copenhagen, Denmark (June 29-July 1, 2017).
- 51. 10<sup>th</sup> International Meeting of Pediatric Endocrinology. Disorders of Sex Development, Special Interest Group. Disorders/Differences of Sex Development Translational Research Network (DSD-TRN). Washington, DC (September 14, 2017).
- 52. 10<sup>th</sup> International Meeting of Pediatric Endocrinology. Turner Syndrome, Special Interest Group. Neurocognitive aspects. Washington, DC (September 14, 2017).
- 53. The Hospital for Sick Children, Department of Pediatrics Visiting Professor, Toronto, Canada (October 4, 2017).
  - Grand Rounds: Short Stature: When Beliefs and Evidence Clash.
  - Multidisciplinary Urogenital (MUG) Clinic Team Meeting: Decision making in DSD
  - Endocrinology Rounds Presentation: DSD Clinical Care: Are we moving forward?
- 54. 7th I-DSD Symposium. Sao Paulo, Brazil (July 4 6, 2019)
  - Impact of collaboration in North America. Platform session: The impact of collaboration
  - Challenging case discussions in DSD cases, Moderator (with Rodolfo Rey)
  - A health-related quality of life tool for parents of young children with disorders of sex development. Platform session: Ali SR, Macqueen Z, Gardner M, Kyriakou A, Mason A, Shaikh MG, Wong SC, **Sandberg DE**, Ahmed SF
- 55. European/USA DSD 2020 (face-to-face, Ghent, Belgium, rescheduled as virtual, September 17-18, 2020). Inter-professional best practices in DSD care.
- 56. UK Psychologists in DSD Healthcare Pædiatric Service Pathway Planning Meeting (virtual November 25, 2020). Decision aids in DSD care (with Melissa Gardner)

- 57. Organization for Study of Sex Differences Virtual. Psychosocial outcomes in DSD and the impact of sex steroids on the brain (in Symposium: Differences of Sex Development: A window into sex and gender development). (May 6, 2021)
- 58. UK National Health Service, South-West Region, DSD Clinical Network Annual Meeting. Decision support in disorders/differences of sex development (DSD): Tools and teams. (December 10, 2021) Virtual presentation.
- 59. London Pediatric Urology Group. Shared decision making in (elective?) urogenital surgery. (March 9, 2022) Virtual presentation.
- 60. Digital Network for Providers of Psychosocial Care in DSD. Shared decision making in DSD. (December 2, 2022) Virtual presentation.
- 61. 9th I-DSD Symposium, Bern, Switzerland. Debate (Against): "This house believes that clinical psychology care should be provided proactively in every case of atypical genitalia". (July 15, 2022).
- 62. Annual Conference of the Israeli Association of Pediatric Endocrinology, Dead Sea, Israel (October 27-29, 2022)
  - Short stature: Is it a psychosocial problem and does changing height matter?
  - Controversy in DSD care: Trends in clinical recommendations and the role for shared decision making

## MEDIA COVERAGE RELATED TO RESEARCH

More than 100 interviews, including television (eg, ABC 20/20, MSNBC), radio (eg, National Public Radio, Voice of America, BBC World Service), quotations in major newspapers and magazines (eg, Chicago Tribune, New York Times, New York Times Magazine, Los Angeles Times, Washington Post, Washington Post Magazine, London Times, NewScientist), science journals (eg Nature), general interest magazines (eg, Time Magazine, People), print/web new magazines (eg, CNN Health, Proto – Massachusetts General Hospital, Men's Health, VICE, Buzzfeed, TeenVogue), and LGBT+ reporting platforms (eg, *OPENLY* of Thomson Reuters Foundation)

## **BIBLIOGRAPHY**

**Peer Reviewed Journals and Publications** (\*denotes psychology/medical student, resident, or fellow supervised by Sandberg):

## (A) Refereed Journals

- Segal, M., & Sandberg, D. (1977). Analgesia produced by electrical stimulation of catecholamine nuclei in the rat brain. *Brain Res*, 123(2), 369-372. https://doi.org/10.1016/0006-8993(77)90488-7
- 2. **Sandberg, D. E.**, & Segal, M. (1978). Pharmacological analysis of analgesia and self-stimulation elicited by electrical stimulation of catecholamine nuclei in the rat brain. *Brain Res*, 152(3), 529-542. https://doi.org/10.1016/0006-8993(78)91108-3
- 3. **Sandberg, D.**, David, S., & Stewart, J. (1982). Effects of estradiol benzoate on the pattern of eating and ethanol consumption. *Physiol Behav*, *29*(1), 61-65. https://doi.org/10.1016/0031-9384(82)90366-3

- 4. **Sandberg, D.**, Stewart, J., & Amit, Z. (1982). Changes in ethanol consumption during pregnancy of the rat. *J Stud Alcohol*, 43(1), 137-145. <a href="https://doi.org/10.15288/jsa.1982.43.137">https://doi.org/10.15288/jsa.1982.43.137</a>
- 5. **Sandberg, D.**, & Stewart, J. (1982). Effects of estradiol benzoate and mer-25 on ethanol consumption in the ovariectomized rat. *J Comp Physiol Psychol*, 96(4), 635-648. https://doi.org/10.1037/h0077913
- 6. Field, T., **Sandberg, D.**, Garcia, R., Vegalahr, N., Goldstein, S., & Guy, L. (1985). Pregnancy problems, postpartum depression, and early mother infant interactions. *Developmental Psychology*, *21*(6), 1152-1156. https://doi.org/Doi 10.1037/0012-1649.21.6.1152
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- 8. Field, T. M., **Sandberg, D.**, Goldstein, S., Garcia, R., Vegalahr, N., Porter, K., & Dowling, M. (1987). Play interactions and interviews of depressed and conduct disorder children and their mothers. *Child Psychiatry & Human Development*, *17*(4), 213-234. https://doi.org/Doi 10.1007/Bf00706447
- 9. **Sandberg, D. E.**, Ehrhardt, A. A., Mellins, C. A., Ince, S. E., & Meyer-Bahlburg, H. F. L. (1987). The influence of individual and family characteristics upon career aspirations of girls during childhood and adolescence. *Sex Roles*, *16*(11-12), 649-668. https://doi.org/Doi 10.1007/Bf00300379
- 10. **Sandberg, D. E.**, Rotheram-Borus, M. J., Bradley, J., & Martin, J. (1988). Methodological issues in assessing aids prevention programs. *Journal of Adolescent Research*, *3*(3-4), 413-418. https://doi.org/10.1177/074355488833013
- 11. **Sandberg, D. E.**, Meyer-Bahlburg, H. F., Aranoff, G. S., Sconzo, J. M., & Hensle, T. W. (1989). Boys with hypospadias: A survey of behavioral difficulties. *J Pediatr Psychol*, *14*(4), 491-514. https://doi.org/10.1093/jpepsy/14.4.491
- 12. **Sandberg, D. E.**, Meyer-Bahlburg, H. F., Rosen, T. S., & Johnson, H. L. (1990). Effects of prenatal methadone exposure on sex-dimorphic behavior in early school-age children. *Psychoneuroendocrinology*, *15*(1), 77-82. https://doi.org/10.1016/0306-4530(90)90049-f
- 13. **Sandberg, D. E.**, Meyer-Bahlburg, H. F., & Yager, T. J. (1991). The child behavior checklist nonclinical standardization samples: Should they be utilized as norms? *J Am Acad Child Adolesc Psychiatry*, *30*(1), 124-134. https://doi.org/10.1097/00004583-199101000-00019
- 14. **Sandberg, D. E.**, Smith, M. M., Fornari, V., Goldstein, M., & Lifshitz, F. (1991). Nutritional dwarfing: Is it a consequence of disturbed psychosocial functioning? *Pediatrics*, 88(5), 926-933. https://www.ncbi.nlm.nih.gov/pubmed/1945633

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  - **(B)** Letters to the Editor \*denotes psychology/medical student, resident, or fellow supervised by Sandberg) ‡denotes peer reviewed
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- (C) Book Chapters \*denotes psychology/medical student, resident, or fellow supervised by Sandberg) ‡denotes peer reviewed
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  - b. Wiech T,\* Sandberg DE. Gigantism and Acromegaly, 261-262.
  - c. Zurenda L,\* Sandberg DE. Noonan syndrome, 416-418.
  - d. Zurenda L,\* Sandberg DE. Hypoparathyroidism, 298-299.
  - e. Zurenda L,\* Sandberg DE. Prader-Willi syndrome, 491-493.
  - f. Zurenda L,\* Sandberg DE. Klinefelter syndrome, 331-333.
  - g. Zurenda L,\* Sandberg DE. Congenital adrenal hyperplasia, 134-136.
  - h. Zurenda L,\* Sandberg DE. Puberty, delayed, 526-527.
  - i. Zurenda L,\* Sandberg DE. Puberty, precocious, 530-532.
  - j. Zurenda L,\* Sandberg DE. Puberty, normal, 527-530.
  - k. Sandberg DE. Short stature: Psychological aspects, 606-608.
  - 1. Wiech T,\* Mazur T, Sandberg DE. Gynecomastia, 269-270.
  - m. Zurenda L,\* Sandberg DE. Hypothyroidism, congenital, 300-302.
  - n. Zurenda L,\* Sandberg DE. Hypothyroidism, acquired, 299-300.
  - o. Zurenda L,\* Sandberg DE. Hyperthyroidism, acquired, 294-295.
  - p. Wiech T,\* Sandberg DE. Diabetes mellitus, type 1, 172-174.
  - q. Mazur T, **Sandberg DE**. Sexual differentiation: Disorders and clinical management, 594-599.
- 11. \*Sandberg DE, Colsman M\*, Voss LD. Short Stature and Quality of Life: A Review of Assumptions and Evidence. In: Pescovitz OH, Eugster E, eds. *Pediatric Endocrinology: Mechanisms, Manifestations, and Management*. Philadelphia, PA; Lippincourt, Williams & Wilkins; 2004:191-202.
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- 24. <sup>‡</sup>Health-Related Disorders in Children and Adolescents: A Guidebook for Educators and Service Providers, Second Edition, Perfect MM, Riccio CA, Bray MA (eds). American Psychological Assn, 2023.
  - Chapter 33. **Sandberg DE**, Suorsa Johnson KI\*. Conditions associated with growth failure and short stature.
  - Chapter 35. Suorsa Johnson KI\*, **Sandberg DE.** Klinefelter syndrome.
  - Chapter 37. Suorsa Johnson KI\*, **Sandberg DE.** Turner syndrome.

### (D) Invited Articles/Commentaries

- 1. **Sandberg DE**. Caring for the short, endocrinologically normal child. *Current Problems in Pediatrics*. 1995;25:163-170.
- 2. Colsman MD\*, **Sandberg DE**. Treating short stature with growth hormones. *Virtual Mentor*. *Ethics Journal of the American Medical Association*. 2005;11. Available at: http://www.ama-assn.org/ama1/pub/upload/mm/384/cc2-short15623.pdf
- 3. **Sandberg DE**. Health-related quality of life as a primary endpoint for growth hormone therapy. *Hormone Research*. 2006;65:250-252.
- 4. **Sandberg DE**. Growth hormone treatment for short stature: Inferences from FDA decisions and clinical practice. *Atrium. The Report of the Northwestern Medical Humanities and Bioethics Program.* 2006;3:15-17. Available at: <a href="http://www.ama-assn.org/ama1/pub/upload/mm/384/cc2-short15623.pdf">http://www.ama-assn.org/ama1/pub/upload/mm/384/cc2-short15623.pdf</a>
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- 7. Gardner M, **Sandberg DE.** Addressing controversy in surgical intervention. European Society for Paediatric Endocrinology Newsletter, Issue 44 / Summer 2019, Special Issue: Understanding DSD. P7, ISSN 2045-5003 (https://www.eurospe.org/media/1932/espe\_newsletter\_issue-44.pdf).

#### (E) Book Reviews

- 1. <u>Handbook of sexology. Volume VI. The pharmacology and endocrinology of sexual function</u>, edited by JMA Sitsen. (J Money, H Musaph, series editors). Reviewed by **DE Sandberg**. *Archives of Sexual Behavior*. 1991;26:599-604.
- 2. Arndt, William B Jr Gender disorders and the paraphilias, Reviewed by **DE Sandberg**. *Journal of Nervous and Mental Disease*. 1993;181:68.

- 3. Perri MG, Nezu AM, Viegener BJ. Improving the long-term management of obesity-theory, research and clinical guidelines, Reviewed by **DE Sandberg**. *Journal of Developmental and Behavioral Pediatrics*. 1994;15:140-141.
- 4. Sexual Precocity: Etiology, diagnosis, and management, edited by GD Grave and GB Cutler. Reviewed by Susana P Campos and **DE Sandberg**. *Archives of Sexual Behavior*. 1998;27:112-116.
- 5. Dwarfism: Medical and psychosocial aspects of profound short stature, Betty M Adelson. Reviewed by **DE Sandberg**. *American Journal of Human Biology*. 2006;18(4):561-563.
- 6. Samaras TT, ed. Human body size and the laws of scaling: physiological, performance, growth, longevity and ecological ramifications. New York: Nova Science Publishers, Inc.; 2007. Reviewed by **DE Sandberg**. *Quarterly Review of Biology*. 2008;83(2):213.

#### (F) Published Protocols

- 1. Crerand CE, Suorsa-Johnson KI, Hansen-Moore J, Ernst M, Pennesi C, DeLozier A, Fei F, Johnson J, Jewell T, Lanphier E, Jaffal N, Umbaugh H, James LN, Saylor KM, **Sandberg DE.** Stigma and differences of sex development: A scoping review protocol. 2021. <a href="http://dx.doi.org/10.7302/1232">http://dx.doi.org/10.7302/1232</a>
- 2. Suorsa-Johnson KI, Poquiz JL, Papadakis J, James LN, Saylor KM, **Sandberg DE.** How is psychosocial adaptation and cognitive function assessed in differences/disorders of sex development? A scoping review protocol. 2021. <a href="http://dx.doi.org/10.7302/241">http://dx.doi.org/10.7302/241</a>

#### (G) Editorial Commentaries

## G.1. for Growth, Genetics and Hormones (http://www.gghjournal.com)

- 1. **Sandberg DE**. Growth hormone effects on quality of life of young adults. *Growth, Genetics and Hormones*. 2004;20(1):12-13.
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- 3. **Sandberg DE**, Williams N. Sexual outlook for post-surgical ambiguous genitalia patients. *Growth, Genetics and Hormones*. 2004;20(2):24.
- 4. **Sandberg DE**. Klinefelter syndrome: Phenotype and new research. Growth, Genetics and Hormones. 2004;20(2):31.
- 5. **Sandberg DE.** Attitudes toward clinical management of intersexuality: The voices of 46,XY adult patients. *Growth, Genetics and Hormones*. 2004;20(3):42.
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- 146. Ernst MM, Gardner M, Mara C, **Sandberg DE**, and in collaboration with the DSD-TRN Leadership Group and the DSD-TRN Psychosocial Workgroup. Psychosocial screening in DSD: Psychometric evaluation of the Psychosocial Assessment Tool. 6th I-DSD Symposium Programme. Copenhagen, Denmark (June 29-July 1, 2017), oral presentation, p.6.
- 147. Ernst MM, Baratz AB, **Sandberg DE**, Liao, LM. Creating a viable alternative to early elective genital surgery in DSD: Exploration of a psychosocial option. 6th I-DSD Symposium Programme. Copenhagen, Denmark (June 29-July 1, 2017), oral presentation, p.30.
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- 157. Macqueen Z\*, Gardner M, **Sandberg DE**, Kyriakou A, Mason A, Shaikh MG, Wong, JSC, Ahmed F. The assessment of parent-reported outcomes in conditions affecting sex development in the routine clinic setting. 100th Annual Meeting of the Endocrine Society 2018, Chicago, IL (March 17-20).
- 158. **Sandberg DE**, Symposium discussant: Advancing understanding of psychosocial implications of Disorders/Differences of Sex Development (DSD). Society of Pediatric Psychology Annual Conference, Orlando, FL (April 5-7, 2018).

- 159. Ernst M, Chen D, Gardner M, **Sandberg DE**. Multidimensional exploration of the self-concept of youth with DSD. Society of Pediatric Psychology Annual Conference, Orlando, FL (April 5-7, 2018). Platform session.
- 160. **Sandberg DE**, Callens N\*, Fechner P, Gardner M, Green J; Keegan C, Rosen E, Sharp M, Shnorhavorian M, Siminoff L, Vilain E, Yashar B. A decision-support workbook for parents of children with disorders of sex development. Pediatric Academic Societies (PAS) 2018 Meeting, Toronto, Canada (May 5-8, 2018).
- 161. Goodman M, Cromwell L, Bradlyn A, Contreras R, Gardner M, Getahun D, Im T, Lash T, Lee P, Nash R, Robinson B, Roblin D, Truong C, Vupputuri S, Sandberg DE. Identification of persons with disorders of sex development in electronic medical records: methodology and early results. WPATH Scientific Symposium, Buenos Aires, Argentina (November 2-6, 2018) Platform presentation.
- Wiryaman S\*, Williams L\*, Mohnach L, Fitzgerald JT, **Sandberg D**, Yashar B. Assessing family perceptions of diagnostic terminology for disorders of sex development (DSDs). National Society of Genetic Counselors (NSGC) Annual Conference, Atlanta, GA (November 14-17, 2018) B-263, Poster.
- 163. Speiser PW, Chawla R, Chen M, Delot EC, Diaz Thomas A, Finlayson CA, Hollander AS, Lowell M, Rutter MM, **Sandberg DE**, Shimy K, Vilain E. Congenital adrenal hyperplasia newborn screening protocols differ widely in the US: A survey by the Differences/Disorders of Sex Development Translational Research Network (DSD-TRN). Endocrine Society 2019, New Orleans, LA (March 23-26, 2019) SAT-LB050.
- Baskin AS\*, Suorsa KI\*, Gardner M, Schafer-Kalkhoff T, Baimbridge E, Rutter, MM, van Leeuwen K, **Sandberg DE**. DSD education for patients and parents: are principles alone adequate? Society of Pediatric Psychology Annual Conference, New Orleans, LA (April 4-6, 2019) Platform presentation.
- 165. Suorsa KI\*, Ernst M, Gardner M, **Sandberg DE**. Decisional conflict in differences/disorders of sex development (DSD). Society of Pediatric Psychology Annual Conference, New Orleans, LA (April 4-6, 2019) Platform presentation.
- 166. Rutter M, Schafer-Kalkhoff T, Gardner M, Baskin A\*, Suorsa K\*, Weidler E, van Leeuwen K, **Sandberg DE.** Optimal models of delivering care for patients with DSD: Opinions of different stakeholders. Pediatric Academic Societies Meeting, Baltimore, MD (April 27-30, 2019) Poster 616.
- Rutter M, Schafer-Kalkhoff T, Gardner M, Baskin A\*, Suorsa K\*, Weidler E, van Leeuwen K, **Sandberg DE.** Defining successful outcomes in people with differences/disorders of sex development: Perspectives and priorities of different stakeholders. Pediatric Academic Societies Meeting, Baltimore, MD (April 27-30, 2019) Poster 625.
- 168. **Sandberg DE.** Interdisciplinary care in DSD: psychosocial component. In invited symposium, Disorders/Differences of Sex Development (DSD) Update. Pediatric Academic Societies Meeting, Baltimore, MD (April 27-30, 2019) Platform presentation.
- 169. Streur C, Schafer C, **Sandberg D**, Quint E, Wittmann D. (2019). PD39-03 "We can set you up for an abortion": The importance of reproductive health to young women with spina bifida and the lack of support from their doctors. American Urological Association Annual Meeting, Chicago, IL (May 3-6, 2019) Program Abstracts. Journal of Urology, 201(Supplement 4), e732-e733. doi:10.1097/01.JU.0000556453.37226.ec
- 170. Streur C, Schafer C, **Sandberg D**, Quint E, Wittmann D. (2019). PD39-02 "If everyone else is having this talk with their doctor, why am I not having this talk with mine?": The

- experiences of sexuality and sexual health education of young women with spina bifida. American Urological Association Annual Meeting, Chicago, IL (May 3-6, 2019) Program Abstracts. Journal of Urology, 201(Supplement 4), e732-e732. doi:10.1097/01.JU.0000556451.29602.9e
- 171. van Leeuwen K, Weidler E, Gardner M, Schafer-Kalkhoff T, Baskin AS\*, Suorsa KI\*, M. Rutter M, **Sandberg DE.** Timing of reconstructive surgery for patients with disorders/differences of sex development (DSD): Preliminary analysis of stakeholder views on successful outcomes. American Pediatric Surgical Association 2019 Annual Meeting, Boston, MA (May 19-22, 2019) Platform presentation, S81.
- 172. **Sandberg DE**, Bradlyn A, Cromwell L, Gardner M, Getahun D, Hoffman T, Jung HL, Kim J, Lash T, Lee P, Nash R, Rechler W, Roblin D, Voss A, Vupputuri S, Yacoub R, Goodman M. Identification of an unbiased sample of persons with disorders (differences) of sex development in electronic medical records. 7th I-DSD Symposium Programme. Sao Paulo, Brazil (July 4 7, 2019).
- 173. **Sandberg DE**, Suorsa Johnson KI\*, Gardner M, Schafer-Kalkhoff T, Weidler EM, Rutter MM, van Leeuwen, K, Baskin AS\*. DSD education for patients and parents: are principles alone adequate? 7th I-DSD Symposium Programme. Sao Paulo, Brazil (July 4 7, 2019).
- 174. **Sandberg DE**, Schafer-Kalkhoff T, Gardner M, Baskin AS\*, Suorsa Johnson KI\*, Weidler EM, van Leeuwen K, Rutter MM. Optimal models of delivering care for patients with DSD: Opinions of different stakeholders. 7th I-DSD Symposium Programme. Sao Paulo, Brazil (July 4 7, 2019).
- 175. **Sandberg DE**, Gardner M, Schafer-Kalkhoff T, Baskin AS\*, Suorsa Johnson KI\*, Rutter MM, van Leeuwen K, Weidler EM. Timing of reconstructive surgery for patients with disorders/differences of sex development (DSD): Preliminary analysis of stakeholder views on successful outcomes. 7th I-DSD Symposium Programme. Sao Paulo, Brazil (July 4 7, 2019).
- 176. **Sandberg DE**, Schafer-Kalkhoff T, Gardner M, Baskin AS\*, Suorsa Johnson KI\*, Weidler EM, van Leeuwen K, Rutter MM. Defining successful outcomes in people with differences / disorders of sex development: perspectives and priorities of different stakeholders. 7th I-DSD Symposium Programme. Sao Paulo, Brazil (July 4 7, 2019).
- 177. **Sandberg DE**, Ernst MM, Gardner M, Suorsa Johnson KI\*. Decisional conflict in differences/disorders of sex development (DSD). 7th I-DSD Symposium Programme. Sao Paulo, Brazil (July 4 7, 2019).
- 178. Suorsa Johnson KI\*, Gardner M, Schafer-Kalkhoff T, Weidler EM, Rutter MM, van Leeuwen, K, Baskin AS\*, **Sandberg DE**. Decisional conflict in differences/disorders of sex development. International Academy of Sex Research. Mexico City, Mexico (July 24-27, 2019
- 179. Suorsa Johnson KI\*, Gardner M, Schafer-Kalkhoff T, Weidler EM, Rutter MM, van Leeuwen, K, Baskin AS\*, **Sandberg DE**. DSD education for patients and parents. International Academy of Sex Research. Mexico City, Mexico (July 24-27, 2019).
- 180. Crerand C, Hansen-Moore J, Heppner C, **Sandberg DE**. Ethics in clinical decision making: practical application of decision aids to facilitate shared decision making in pediatric populations. Society of Pediatric Psychology Annual Conference, Dallas, TX (March 19 21, 2020) [Conference workshop canceled COVID-19].
- Rutter, MM, Muscarella M, Green J, Indig G, von Klan A, Weidler EM, Barrett M, Kennedy K, **Sandberg DE** in collaboration with the DSD-Translational Research Network.

- Creation of an electronic resource repository for differences of sex development (DSD): Collaboration between clinicians and advocates in the DSD-Translational Research Network. Society of Pediatric Psychology Annual Conference, Dallas, TX (March 19 21, 2020) <a href="https://societyofpediatricpsychology.org/node/726">https://societyofpediatricpsychology.org/node/726</a>
- Suorsa KI\*, Ernst, MM, Gardner, M, **Sandberg DE**. Differences/disorders of sex development (DSD): Healthcare and trust in providers. Society of Pediatric Psychology Annual Conference, Dallas, TX (March 19 21, 2020) <a href="https://societyofpediatricpsychology.org/node/726">https://societyofpediatricpsychology.org/node/726</a>
- 183. Suorsa-Johnson KI\*, Gardner M, Lee P, Kogan BA, Berenbaum SA, **Sandberg DE.** Informed consent for urogenital surgery in pediatric differences of sex development: a provider perspective. 2021 Virtual Society of Pediatric Psychology Annual Conference (April 8-9, 2021) (oral presentation, virtual).
- 184. Crerand CE, Heppner C, Hansen-Moore J, **Sandberg DE.** Shared decision making in craniofacial care. American Cleft Palate-Craniofacial Association's (ACPA) 78th Annual Meeting, April 29-May 1 (virtual).
- 185. Streich-Tilles T, Schafer-Kalkhoff T, Gardner M, Suorsa-Johnson K\*, Baskin AS\*, Weidler E, van Leeuwen K, **Sandberg DE**, Rutter MM. Defining success in the delivery of fertility-related care for patients with differences of sex development. Pediatric Endocrine Society Annual Meeting 2021, poster (April 30-May 3, 2021, virtual).
- 186. Suorsa-Johnson KI\*, Gebremariam A, Ernst, MM, Gardner M, **Sandberg DE**. Trust and conflict: the double-edged sword of decision-making in differences/disorders of sex development. Societies for Pediatric Urology 68<sup>th</sup> Annual Meeting, Washington, DC (May 15-17, 2020) [Conference canceled COVID-19]
- 187. Streich-Tilles T, Schafer-Kalkhoff T, Gardner M, Suorsa-Johnson KI\*, Baskin AS\*, Weidler, EM, van Leeuwen K, **Sandberg DE**, Rutter MM. Defining success in the delivery of fertility-related care for patients with differences of sex development. Poster presented virtually at the annual meeting of the Pediatric Endocrine Society. (2021, April-May).
- 188. Gruppen L, Carley M, Gardner M, Stacey D, **Sandberg DE**. Parental decision-making in pediatrics: healthcare providers' perspectives & roles. 2021 Virtual Annual Pediatric Research Symposium, Ann Arbor, MI (May 11, 2021).
- 189. Suorsa-Johnson K\*, Gardner M, Lee P, Kogan BA, Berenbaum SA, **Sandberg DE**. Informed consent for urogenital surgery in pediatric differences of sex development: a provider perspective. Virtual Annual Pediatric Research Symposium, Ann Arbor, MI (May 11, 2021).
- 190. **Sandberg DE.** Research addressing the challenges of differences in sex development (DSD). European Pediatric Psychology Conference, Virtual. Symposium moderator. (October 4-6, 2021).
- 191. Suorsa-Johnson KI\*, Brinkman W, Carle M, Gardner MD, Gruppen L, Lightfoot S, Speiser PW, **Sandberg DE**, & Stacey D. Clinical management pathways and parental decisions in disorders/differences of sex development: a survey of healthcare professionals. Societies for Pediatric Urology Fall Congress Meeting (Podium Presentation), Miami, FL (Dec 2-5, 2021).
- 192. Suorsa-Johnson KI\*, Brinkman W, Carle M, Gardner MD, Gruppen L, Lightfoot S, Speiser PW, **Sandberg DE**, & Stacey D. Decisional needs of parents facing decisions for their infant born with a disorder/difference of sex development: a survey of healthcare

- professionals. Societies for Pediatric Urology Fall Congress Meeting (Podium presentation), Miami, FL (Dec 2-5, 2021).
- 193. Imel S, Dougherty D, Speck E, **Sandberg DE**, Sack B, Quint E, Ralls M. Patients with cloaca and their families can benefit from the same health care model as those with differences of sex development (DSD). American College of Surgeons, Michigan Chapter, 68<sup>th</sup> Annual Meeting (Podium presentation), Traverse City, MI (May 18-20, 2022).
- 194. Suorsa-Johnson K, Lightfoot S, Gardner M, Carley M, Gruppen L, Mohnach L, Johnson J, Stacey D, **Sandberg DE**. Supporting shared decision making for parents of infants/young children with disorders/differences of sex development: Creation of a genetic testing decision aid. 5th ELSI Congress (Podium presentation), Virtual, (May 31-June 3, 2022).
- 195. Weidler EM, van Leeuwen K, Gardner M, Mykolajtchuk C, Suorsa-Johnson KI, Schafer-Kalkhoff T, Rutter MM, **Sandberg DE.** (2022, April). Timing of reconstructive surgery for individuals with differences of sex development (DSD): Stakeholder views on successful outcomes. Poster presented at the Society for Pediatric Psychology Annual Conference, Phoenix, AZ.
- 196. Suorsa-Johnson KI, Gardner MD, Avanceña ALV, Baskin A\*, Khorashad BS\*, Gruppen LD, Lightfoot S, Prosser L, Rose A, Rutter MM, Schafer-Kalkhoff T, Stacey D, van Leeuwen, K, Weidler EM, **Sandberg, DE**. (2022, April). Defining successful outcomes and trade-offs in differences of sex development: Parlaying stakeholder valuations into educational resources for healthcare providers. Poster presented at the Society for Pediatric Psychology Annual Conference, Phoenix, AZ.
- 197. Rutter MM, Britt AK, Schafer-Kalkhoff T, Suorsa-Johnson KI, Gardner MD, Baskin AS\*, Weidler EM, van Leeuwen K, **Sandberg DE**. (2022, April). Optimizing delivery of care for patients with differences of sex development (DSD): Perspectives of patients, parents, providers, and other professionals. Poster presented at the Society for Pediatric Psychology Annual Conference, Phoenix, AZ.
- 198. Weidler EM, Barrett M, Muscarella M, Green J, Indig G, von Klan A, **Sandberg DE**, Rutter M. (2022, April). An electronic resource repository for differences of sex development (DSD): A tool to assist patients, parents and providers. Poster presented at the Society for Pediatric Psychology Annual Conference, Phoenix, AZ.
- 199. Suorsa-Johnson KI, Rutter MM, Weidler EM, **Sandberg DE**. (2022, April). *Defining Successful Outcomes and Trade-offs (DSOT) for Clinical Management in Differences of Sex Development: A Mixed-Methods Approach to Inform Curriculum Development*. Symposium presented at the Society of Pediatric Psychology Annual Conference, Phoenix, Arizona.
- 200. Papadakis J, Whitehead J, Chen D, Finlayson C, Johnson E, Keegan C, Mohnach L, **Sandberg DE**. (2022, April). Psychosocial adjustment in youth with 17-beta hydroxysteroid dehydrogenase 3 deficiency: A case series. Poster presented at the Society for Pediatric Psychology Annual Conference, Phoenix, AZ.
- 201. Sorouri Khorashad B\*, Ernst M, Chen D, Gardner M, **Sandberg DE**. (2022, April). Gender identity in disorders of sex development: Multidimensional exploration. Poster presented at the Society for Pediatric Psychology Annual Conference, Phoenix, AZ.
- 202. Ali SR, Gardner M, Xin Y, O'Toole S, Flett M, Lee B, Steven M, **Sandberg DE**, Ahmed SF. (June 11-14, 2022) Development and validation of a short version of the Quality-of-Life DSD Questionnaire (QoL-DSD) for parents of young children with disorders/differences of sex development. Oral Presentation (OR05) ENDO 2022 (Annual Meeting of the Endocrine Society), Atlanta, GA.

- 203. Lee PA, Gardner M, Kogan B, Suorsa-Johnson K, Khorashad BS\*, **Sandberg DE**. (June 11-14, 2022) Changes in perceptions of pediatric endocrinologists (PE) and urologists (PU) to infants and children regarding care of individuals with 46,XY DSD. e-Poster on Demand Presentation (ODP381) ENDO 2022 (Annual Meeting of the Endocrine Society), Atlanta, GA.
- 204. Suorsa-Johnson KI, Brinkman W, Carley M, Gardner MD, Gruppen L, Lightfoot S, Speiser PW, Khorashad BS\*, **Sandberg DE**, Stacey D. (June 19-22, 2022) Decisional needs of parents of infant born with a disorder/difference of sex development: A survey of parents and healthcare professionals. Oral Presentation, ISDM (International Shared Decision–Making Conference) 2022, Kolding, Denmark.
- 205. **Sandberg DE**, Gardner M, Getahun D, Vupputuri S, McKracken C, Goodman M. (July 14-16, 2022) Pathway to care among people with disorders of sex development: Cohort profile. 9th I-DSD Symposium, Bern, Switzerland. *Sex Dev* 2022;16(suppl 1): Oral Communication 1.4, p.24 DOI: 10.1159/000525564
- 206. Weidler E, Avanceña ALV, Gardner M, Rose A, Rutter MM, Schafer-Kalkhof T, Suorsa-Johnson KI, van Leeuwen K, Prosser LA, **Sandberg DE**. (July 14-16, 2022) Designing a best-worst scaling survey for defining successful outcomes and trade-offs in DSD care. 9th I-DSD Symposium, Bern, Switzerland. *Sex Dev* 2022;16(suppl 1): Oral Communication 1.5, p.25 DOI: 10.1159/000525564
- 207. van Leeuwen K, Weidler EM, Gardner MD, Mykolajtchuk C\*, Suorsa-Johnson KI, Schafer-Kalkhoff T, Rutter MM, Sandberg DE. (July 14-16, 2022) Timing of reconstructive surgery for individuals with differences of sex development (DSD): Stakeholder views on successful outcomes. 9th I-DSD Symposium, Bern, Switzerland. Sex Dev 2022;16(suppl 1): Oral Communication 1.7, p.27 DOI: 10.1159/000525564
- 208. Suorsa-Johnson KI, Lapham ZK, Gardner MD, **Sandberg DE**, Fagerlin A. (July 14-16, 2022) Caregiver perceptions of stigma associated with their child's difference of sex development. 9th I-DSD Symposium, Bern, Switzerland. *Sex Dev* 2022;16(suppl 1): Oral Communication 2.1, p.28 DOI: 10.1159/000525564
- 209. Rutter M, Gardner MD, Dulo N\*, Suorsa-Johnson KI, Britt AK, Schafer-Kalkhoff T, Weidler EM, van Leeuwen K, **Sandberg DE**. (July 14-16, 2022) "I believe God doesn't make mistakes, and I am wonderfully made in His image": The intersection of religion/faith and clinical care in differences of sex development. 9th I-DSD Symposium, Bern, Switzerland. *Sex Dev* 2022;16(suppl 1): Oral Communication 2.3, p.31 DOI: 10.1159/000525564
- 210. Suorsa-Johnson KI, Gardner MD, Avanceña ALV, Baskin A, Gruppen LD, Khorashad BS\*, Lightfoot S, Prosser L, Rose A, Rutter MM, Schafer-Kalkhoff T, Stacey D, van Leeuwen KD, Weidler EM, Sandberg DE. (July 14-16, 2022). Defining successful outcomes and trade-offs (DSOT) in differences of sex development: Parlaying stakeholder valuations into educational resources for healthcare providers. Poster presented at the 9th I-DSD Symposium, Bern, Switzerland. Sex Dev 2022;16(suppl 1): Poster 5, p.42 DOI: 10.1159/000525564
- 211. Délot E, Weidler EM, Vilain E, **Sandberg DE**. (July 14-16, 2022) The DSD Translational Research Network: A platform for discovery and improved clinical care. 9th I-DSD Symposium, Bern, Switzerland. *Sex Dev* 2022;16(suppl 1): Poster 39, p.76 DOI: 10.1159/000525564

- 212. Papadakis JL, Whitehead J, Chen D, Finlayson C, Johnson EK, Keegan C, Mohnach L, **Sandberg DE**. (July 14-16, 2022) Psychosocial adjustment in youth with 17-beta hydroxysteroid dehydrogenase 3 deficiency: A case series. 9th I-DSD Symposium, Bern, Switzerland. *Sex Dev* 2022;16(suppl 1): Poster 40, p.77 DOI: 10.1159/000525564
- 213. Ali SR, Gardner M, Xin Y, O'Toole S, Flett M, Lee B, Steven M, **Sandberg DE**, Ahmed SF. (July 14-16, 2022) Development and validation of a short version of the Quality-of-Life DSD Questionnaire (QoL-DSD) for parents of young children with disorders/differences of sex development. 9th I-DSD Symposium, Bern, Switzerland. *Sex Dev* 2022;16(suppl 1): Poster 48, p.84 DOI: 10.1159/000525564
- Fen Chen H, Rose AM, Mercon K, Cousino MK, Adler J, Gadepalli S, Odetola FO, **Sandberg DE**, Streur C, Prosser LA. (October 23-26, 2022) A best-worst scaling survey for measuring family spillover effects for children with complex chronic conditions: a pilot study. Society for Medical Decision Making, 44<sup>th</sup> Annual Meeting, Seattle, WA.
- 215. Britt A, Suorsa-Johnson K, Gardner M, Rutter M, Schafer-Kalkhoff T, van Leeuwen K, Fagerlin A, **Sandberg DE**, Weidler E. "Love, man, it's part of life": Psychosexual health within differences of sex development. Poster presented at the Society for Pediatric Psychology Annual Conference, 30 March-1 April 2023, Chicago, IL. *Journal of Pediatric Psychology*, Volume 48, Supplement 1, Abstract ID: 3363 <a href="https://www.ncbi.nlm.nih.gov/pubmed/37071850">https://www.ncbi.nlm.nih.gov/pubmed/37071850</a>
- 216. Khorashad BS,\* Colsman M, Lee PA, **Sandberg DE**, Kogan B. Changes in management of 46 XX CAH over 17 years. (April 19-22, 2023) Platform presentation. European Society for Pediatric Urology, Lisbon, Portugal. Abstract S05-6 (OP).
- 217. Suorsa-Johnson KI, Britt A, **Sandberg DE**, Fagerlin A. Decision making for adolescents and young adults with differences of sex development. (May 21-23, 2023) 18th Biennial European Conference of the Society for Medical Decision Making (SMDM), Berlin, Germany. Poster PP-078.
- 218. Ali S, Gardner M, Xin Y, O'Toole S, Flett M, Lee B, Steven M, **Sandberg DE**, Ahmed F. Development and validation of short versions of quality of life questionnaires for parents of children with disorders/differences of sex development. Royal College of Paediatrics and Child Health, Abstracts of the RCPCH Conference, 522. Glasgow, 23–25 May 2023. DOI: 10.1136/archdischild-2023-rcpch.403

## (I) Republications

- 1. **Sandberg DE**, Meyer-Bahlburg HFL, Ehrhardt AA, Yager TJ. The prevalence of genderatypical behavior in elementary school children. In: Hertzig ME, Farber EA eds. Annual Progress in Child Psychiatry and Child Development, New York: Brunner/Mazel;1994:172-190.
- 2. Meyer-Bahlburg HFL, Dolezal C, **Sandberg DE**. The association of sexual behavior with externalizing behaviors in a community sample of prepubertal children. In: Sandfort TGM, Rademakers J eds. *Childhood Sexuality: Normal Sexual Behavior and Development*, New York: Haworth Press; 2000:61-79.
- 3. Stein M T, **Sandberg DE**, Mazur T, Eugster E, Daaboul J. A newborn infant with a disorder of sexual differentiation. *Pediatrics*. 2004;114:1473-1477.
- 4. Mazur T, **Sandberg DE**, Perrin MA, Gallagher JA, MacGillivray MH. Male pseudohermaphroditism: long-term quality of life outcome in five 46,XY individuals reared female. *Journal of Pediatric Endocrinology & Metabolism*. 2007;20(Suppl 3):S37-51.

# (J) Unpublished Documents

- 1. Callens N, Sharp M, **Sandberg DE.** DSD Support Tool: A Guide for Parents. University of Michigan; 2018. p. 175. <a href="https://dx.doi.org/10.7302/4204">https://dx.doi.org/10.7302/4204</a>
- 2. Gardner M, Floody E, **Sandberg DE.** Support Information for Parents: Thinking About Your Child's Sex Development. Deep Blue Documents: University of Michigan; 2022. p. 185. <a href="https://dx.doi.org/10.7302/4203">https://dx.doi.org/10.7302/4203</a>