

# Deciphering Beckwith-Wiedemann Spectrum

Saturday and Sunday • July 24 and 25, 2021

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#### **COURSE OVERVIEW**

Deciphering Beckwith-Wiedemann Spectrum (BWSp) will provide current diagnostic and clinical management information to clinicians and caregivers with patients affected by BWSp. Conference attendees will be educated on the vast spectrum of presenting clinical features, current clinical management practices, and common medical procedures. Understanding this information is crucial in providing optimal care to patients with BWSp. The audience will be encouraged to further educate other clinicians and caregivers at their home institutions.

#### TARGET AUDIENCE

This course is intended for practicing clinicians who care for children, including, but not limited to, pediatricians, family practitioners, general practitioners, genetic counselors, nurse practitioners, nurses, physician assistants, physicians-in-training and other allied healthcare professionals. Other specialists are welcome to attend.

#### COURSE OBJECTIVES

Upon completion of this course, participants should be able to:

- · More accurately diagnose patients with BWSp
- · Improve their management of individuals with BWSp
- · Share educational materials with other providers at their home institution

#### GENERAL INFORMATION AND COURSE FEE

The registration fee includes course registration, livestream access to the conference and access to view presentations online. For questions, please email **CMEoffice@chop.edu**.

Healthcare Providers	\$40
Family	\$10/adult

**REGISTER ONLINE: CHOP.CLOUD-CME.COM** 



#### ACCME ACCREDITATION STATEMENT

Children's Hospital of Philadelphia is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

#### AMA CREDIT DESIGNATION STATEMENT

Children's Hospital of Philadelphia designates this live activity for a maximum of 7.25 AMA PRA Category 1 credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Nurses will receive a CME certificate of completion. Nurses may use CME category 1 credits for re-licensure in many states, as well as most re-certifications. Please check your state board and certifying body for re-licensure and re-certification requirements.

#### CONTINUING GENETIC COUNSELOR APPROVED PROVIDER STATEMENT

This event has been submitted to the National Society of Genetic Counselors (NSGC) for approval of Category 1 CEUs. The American Board of Genetic Counseling accepts CEUs approval by NSGC for purposes of recertification. Approval for the requested CEUs and Contact Hours is currently pending.

#### REFUND AND CANCELLATION POLICY

Children's Hospital of Philadelphia reserves the right to cancel or postpone any course due to any unforeseen circumstances. In the event of cancellation or postponement, Children's Hospital of Philadelphia will refund any registration fees. In order to process refunds for course withdrawals, cancellations must be received in writing by Friday, July 9, 2021. No refunds will be issued thereafter.



# PROGRAM • SATURDAY, JULY 24, 2021

11 a.m. Welcome and Opening Remarks

Beckwith-Wiedemann Spectrum (BWSp) Through the Years

11:15 a.m. Parents' Perspectives

11:35 a.m. Q & A

Moderators: Kelly A. Duffy, MPH; Evan R. Hathaway, MS, LCGC

11:50 a.m. Break

Noon Parents' Perspectives

12:20 p.m. Q & A

Moderators: Kelly A. Duffy, MPH; Evan R. Hathaway, MS, LCGC

12:35 p.m. Break

12:45 p.m. Teens' and Adults' Perspectives

1:05 p.m. Q & A

Moderators: Kelly A. Duffy, MPH; Evan R. Hathaway, MS, LCGC

1:20 p.m. Lunch Break

2 p.m. Grandparents' Perspectives

2:20 p.m. Q & A

Moderators: Kelly A. Duffy, MPH; Evan R. Hathaway, MS, LCGC

2:35 p.m. Break

**BWSp Resources for Families and Professionals** 

2:45 p.m. Information and Support for BWSp

Evan R. Hathaway, MS, LCGC

2:55 p.m. Lessons Learned Advocating for a Child with BWSp in the Healthcare System

Cathy Clarkin, MS

3:10 p.m. Overview of the BWSp Registry and Research

Kelly A. Duffy, MPH

3:20 p.m. Q & A

Moderators: Kelly A. Duffy, MPH; Evan R. Hathaway, MS, LCGC

3:40 p.m. Adjourn



# PROGRAM • SUNDAY, JULY 25, 2021

Basics of Beckwith-Wiedemann Spectrum (BWSp)

9 a.m. Introduction to BWSp and Clinical Features

Jennifer M. Kalish, MD, PhD

9:10 a.m. (Epi) Genetics of BWSp

Evan R. Hathaway, MS, LCGC

9:20 a.m. Molecular Aspects of BWSp

Arupa Ganguly, PhD

9:30 a.m. Tumor Screening in BWSp

Kristin Zelley, MS, LCGC

9:40 a.m. Q & A for Family Attendees

10 a.m. Q & A for Professional Attendees

**Macroglossia Implications and Management** 

10:30 a.m. Understanding Macroglossia in BWSp

Jesse A. Taylor, MD

10:40 a.m. BWSp and Sleep

Christopher M. Cielo, DO

10:50 a.m. Orthodontics and Jaw Development in BWSp

Hyun-Duck Nah-Cederquist, DMD, MSD, PhD

11 a.m. Speech Development in BWSp

Cynthia B. Solot, MA, CCC-SLP

11:10 a.m. Nutrition and Feeding in BWSp

Sherri S. Cohen, MD, MPH

11:20 a.m.  $\,\,$  Q & A for Family Attendees

11:40 a.m. Q & A for Professional Attendees

Noon Lunch Break

Aspects of BWSp Medical Management

1 p.m. Management of Hypoglycemia and Hyperinsulinism in BWSp

Diva D. De León-Crutchlow, MD, MSCE

1:10 p.m. BWSp and Lateralized Overgrowth

Richard S. Davidson, MD

1:20 p.m. Leg Length Difference over Time in BWSp

Alessandro Mussa, MD, PhD



## **PROGRAM** CONTINUED

1:30 p.m. BWSp in Neonates

Janet Lioy, MD

1:40 p.m. Prenatal Features in BWSp

Diana Carli, MD

1:50 p.m. Q & A for Family Attendees

2:10 p.m. Q & A for Professional Attendees

Radiology and Pathology in BWSp

2:30 p.m. Radiology Findings in BWSp

Lisa J. States, MD

2:50 p.m. Pathology Findings in BWSp

Tricia R. Bhatti, MD

2:50 p.m. Placenta Findings in BWSp

Rebecca L. Linn, MD

3 p.m. Q & A for Family Attendees

3:20 p.m. Q & A for Professional Attendees

Research Updates and Ongoing Projects

3:50 p.m. Diagnosis and Management of Twins in BWSp

Jennifer L. Cohen, MD

4 p.m. Behavior and Development in BWSp

Kelly A. Duffy, MPH

4:10 p.m. Health Issues in Adolescents and Adults with BWSp

Giovanni Battista Ferrero, MD, PhD

4:20 p.m. Human Cell Models of BWSp

Natali Sobel Naveh, PhD

4:30 p.m. Lessons from Mouse Models

Marisa S. Bartolomei, PhD

4:40 p.m. Q & A for Family Attendees

5 p.m. Q & A for Professional Attendees

5:20 p.m. Closing Remarks



Unless otherwise noted, faculty is from Children's Hospital of Philadelphia and the Perelman School of Medicine at the University of Pennsylvania.

### **COURSE DIRECTOR**

Jennifer M. Kalish, MD, PhD Attending Physician, Human Genetics Director, Beckwith-Wiedemann Syndrome Program of Excellence Assistant Professor of Pediatrics

# CONTINUING GENETIC COUNSELOR EDUCATION PLANNERS

Evan R. Hathaway, MS, LCGC Genetic Counselor, BWS Clinic

#### COURSE FACULTY

#### Marisa S. Bartolomei, PhD

Co-director, Epigenetics Program Professor of Cell and Developmental Biology

#### Tricia R. Bhatti, MD

Attending Physician, Anatomic Pathology Assistant Professor of Clinical Pathology and Laboratory Medicine

#### Diana Carli, MD

Attending Physician, Department of Public Health and Pediatrics University of Torino, Italy

#### Christopher M. Cielo, DO

Attending Physician, Pulmonary Medicine Assistant Professor of Pediatrics

#### Cathy Clarkin, MS

Parent Advocate

#### Jennifer L. Cohen, MD

Attending Physician Assistant Professor of Pediatrics Division of Medical Genetics Duke University Medical Center

#### Sherri S. Cohen, MD, MPH

Attending Physician, Gastroenterology, Hepatology and Nutrition Medical Director, Pediatric Feeding and Swallowing Center Program Director, Nutrition Fellowship Program Clinical Associate Professor

#### Richard S. Davidson, MD

Attending Surgeon, Orthopaedic Surgery

Professor of Orthopaedic Surgery

#### Diva D. De León-Crutchlow, MD, MSCE

Attending Physician, Endocrinology Chief, Endocrinology and Diabetes Director, Congenital Hyperinsulinism Center

#### Kelly A. Duffy, MPH

Project Manager Beckwith-Wiedemann Syndrome Program of Excellence

#### Giovanni Battista Ferrero, MD, PhD

Professor of Pediatrics
Department of Clinical and
Biological Sciences
School of Medicine, University of
Torino

Thalassemia and Hemoglobinopathies Reference Centre

San Luigi Gonzaga University Hospital

#### Arupa Ganguly, PhD

Director, Genetic Diagnostic Laboratory Professor of Genetics

#### Rebecca L. Linn, MD

Attending Physician, Anatomic Pathology

Assistant Professor of Clinical Pathology and Laboratory Medicine

#### Janet Lioy, MD

Attending Neonatologist Director, Neonatal Outreach Program Medical Director, Neonatal Airway Program Professor of Pediatrics

#### Alessandro Mussa, MD, PhD

Attending Physician, Department of Public Health and Pediatrics University of Torino, Italy Scientific Committee of the Italian Beckwith-Wiedemann Syndrome Association

#### Hyun-Duck Nah-Cederquist, DMD, MSD, PhD

Orthodontist

Director, Craniofacial Research Laboratory

Clinical Associate Professor, University of Pennsylvania School of Dental Medicine

Adjunct Associate Professor of Surgery

#### Natali Sobel Naveh, PhD

Research Postdoc Fellow Kalish Laboratory

#### Cynthia B. Solot, MA, CCC-SLP

Senior Speech-Language Pathologist Co-director, Velopharyngeal Dysfunction Program

#### Lisa J. States, MD

Attending Physician, Radiology Director, Outpatient Satellite Imaging Principal Investigator, 18F-DOPA PET Research Studies Associate Professor of Clinical Radiology

#### Jesse A. Taylor, MD

Chief and Attending Physician, Plastic and Reconstructive Surgery

Co-director, Cleft Lip and Palate Program

Associate Professor of Surgery

#### Kristin Zelley, MS, LCGC

Senior Genetic Counselor, Cancer Predisposition Program

