

The Beckwith-Wiedemann Spectrum Symposium: Bridging Research and Care

Friday, July 18 - Sunday, July 20, 2025

Children's Hospital of Philadelphia HUB for Clinical Collaboration or Live Stream

Learn more: chop.cloud-cme.com



Course Overview

This years Beckwith-Wiedemann Spectrum (BWSp) Symposium will provide updates on the current diagnostic and clinical management information and the latest research findings on the condition. Conference attendees will be educated on the vast spectrum of presenting clinical features, current clinical management practices, and common medical procedures. Researchers from Children's Hospital of Philadelphia will be joined by collaborators from around the world to present ongoing BWSp research topics as well. Understanding this information is crucial in providing optimal care to patients with BWSp. This conference is designed for clinicians, families with children who have BWSp, and adults with BWSp. The audience will be encouraged to further educate other clinicians and caregivers at their home institution.

Course Objectives

- Describe the (epi)genetics and clinical features of BWSp
- More accurately diagnose patients with BWSp
- Improve clinical care of individuals with BWSp
- Provide educational materials with providers at their home institution
- · Share the latest updates on BWSp research

General Information and Course Registration Fees

In-Person Registration Fees

Physicians: \$75 Other Healthcare Providers: \$50 Family: \$10/adult

Attending the conference in person includes continental breakfast, refreshments, lunch, and course materials.

Virtual Registration Fees

Healthcare Providers: \$40 **Family:** \$20/family

Attending the conference virtually includes livestream access to the conference and access to view online course materials.

Accreditation



In support of improving patient care, this activity has been planned and implemented by Children's Hospital of Phila. Children's Hospital of Philadelphia is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME), the Accreditation Countil for Pharmacy Education (ACPE), and the American Nurses Credentialing Center (ANCC), to provide continuing education for the healthcare team.

Designation of Credit

Physicians: Children's Hospital of Philadelphia designates this live activity for a maximum of 9.25 *AMA PRA Category 1 Credits™*. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Nurses: This program provides 9.25 ANCC contact hours.



Joint Accreditation



This activity was planned by and for the healthcare team, and learners will receive 9.25 Interprofessional Continuing Education (IPCE) credit for IPCE CREDIT™ learning and change.

Continuing Genetic Counselor Credits

Genetic counselors may apply directly for Category 2 CEUs after they have attended the CHOP BWSp Conference. This event meets the criteria to be applicable for Category 2 CEUs. For more information on how to apply: nsgc.org

Hotel Accommodations

A block of rooms has been reserved at reduced rates at The Study at University City, 20 S 33rd St, Philadelphia, PA 19104, located just a few blocks from Children's Hospital. The group overnight rate is \$219 single and double occupancy plus a 16.25% room tax. Participants are required to make their own hotel reservations by calling The Study directly at 215-387-1400. Please mention the name of the conference when making your reservation. The special room rate will be available until Friday, May 9, 2025. After that date, reservations will be accepted on a space and rate availability basis.

Cancellation and Refund 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 but is not responsible for any related costs, charges or expenses to participants, including cancellation charges assessed by airlines/travel agencies. In order to process refunds for course withdrawals, cancellations must be received in writing by Monday, July 7, 2025. No refunds will be issued thereafter.

Services for People With Disabilities

If special arrangements are required for an individual with a disability to attend this meeting, please contact the Continuing Medical Education Department at 215-590-5263.





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PROGRAM

Friday, July 18, 2025

5:00 p.m. Registration

6:00 p.m. **Opening Reception and Welcome Remarks**

Jennifer M. Kalish, MD, PhD

Dinner 6:30 p.m.

Saturday, July 19, 2025

Registration and Breakfast 8:00 a.m.

An Introduction to BWSp

9:00 a.m. Introduction to BWSp and Clinical Features

Jennifer M. Kalish, MD, PhD

A Historic Case Review: The Original BWSp Slides 9:30 a.m.

Bruce Pawel, MD

9:45 a.m. Molecular Aspects of BWSp

Arupa Ganguly, PhD

Tumor Screening in BWSp 10:00 a.m.

> Suzanne MacFarland, MD Kristin Zelley, MS, LCGC

10:15 a.m. 0&A

10:30 a.m. **Break**

BWSp Experts Panel Discussion

*This session is not eligible for CE credit

11:00 a.m. Understanding Macroglossia in BWSp

Jesse A. Taylor, MD

Cassandra Ligh, MD

BWSp and Sleep

Christopher M. Cielo, DO



11:00 a.m. Orthodontics and Jaw Development in BWSp Hyun-Duck Nah-Cederquist, DMD, MSD, PhD

Management of Hypoglycemia and Hyperinsulinism in BWSp

Diva De Leon-Crutchlow, MD, MSCE

BWSp and Lateralized Overgrowth Michela Mansfield, MSN, CRNP Richard S. Davidson, MD

12:00 p.m. Lunch

Development in BWSp and Resources

1:00 p.m. Speech Development in BWSp Makaela Somma, MS, CCC-SLP

1:15 p.m. BWSp and Development

Carlyn Glatts, MD

1:30 p.m. Post-traumatic Stress and Post-traumatic Growth in Caregivers of Children

with Beckwith-Wiedemann Spectrum: The Roles of Appraisal and Coping

Rachel Ottman, PsyD, BCB

1:45 p.m. Resources for Families

Karen Kilson, MSW, LSW and Cynthia Kropp, MSS, LCSW

2:00 p.m. Q&A

2:15 p.m. Break

Research Updates and Ongoing Projects

2:30 p.m. Allele-Specific Methylation Analysis Using Oxford Nanopore Sequencing

Mian Umair Ashan, MPhil

2:45 p.m. Updates on Macroglossia Research

Andrew George, Aravind Viswanathan, and Jennifer M. Kalish, MD, PhD;

Allison Hu, MD and Dominic Romeo, MD

3:00 p.m. Growth Charts for BWSp

Jennifer M. Kalish, MD, PhD

3:15 p.m. An Approach to Lateralized Overgrowth

Allessandro Mussa, MD, PhD

3:30 p.m. Updates on Tumor Screening Guidelines

Zachary Berlant, MD and Jennifer M. Kalish, MD, PhD

3:45 p.m. The Use of Total Body Densitometry in the Study of Body Composition in BWSp

Giuseppe Reynolds, MD

4:00 p.m. Distinctive Clinical and Biological Features of Adrenocortical Tumors in BWSp

Diana Carli, MD, PhD

4:15 p.m. Q&A

4:30 p.m. Blood Tests for Wilms Tumor Surveillance in Children with BWSp

Jack Brzezinski, MD

4:45 p.m. BWSp in Animal Models

Marisa S. Bartolomei, PhD



5:00 p.m. The Placenta in BWS: Clinical Associations and Molecular Mechanisms

Sanam Kavari, MD-PhD Candidate

5:15 p.m. Single-nuclei Sequencing Reveals Metabolic Nature of BWSp Liver

Snehal Nirgude, PhD

5:30 p.m. A Taste of Tongue Overgrowth in BWSp

Elisia Tichy, PhD

5:45 p.m. Assessing Focal Liver Lesions in Beckwith-Wiedemann Syndrome

Laura Davis, MD

6:00 p.m. Q&A

6:15 p.m. Closing Remarks

Jennifer M. Kalish, MD, PhD

6:30 p.m. Dinner

Sunday, July 20, 2025

8:00 a.m. Breakfast

9:00 a.m. BWSp Through the Years: Parent Perspectives

9:40 a.m. Q&A

Breakout Discussions

10:00 a.m. Macroglossia

BWSp and Development

BWSp in Adults

Tumor Screening in BWSp

11:00 a.m. Break

11:30 a.m. American Beckwith-Wiedemann Spectrum Family Foundation

Christopher Eskew; Introduction by Monica Bertoletti

12:15 p.m. Next Steps in BWSp Research

Jennifer M. Kalish, MD, PhD

12:30 p.m. Leave for Phillies Game (pre-registration required)



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

Course Director

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

Conference Planning Committee

Abigail Casalnova, MSN, RN, CRNP, CPNP-PC Nurse Practitioner, BWS Clinic

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

Alexander Kaplan, MHA
Program Coordinator, Division of Oncology

Salima Nesbitt, RN, BSN Nurse Practitioner, BWS Clinic

Course Faculty

Mian Umair Ashan, M.Phil. Research Lab Manager Pathology and Lab Medicine

Marisa S. Bartolomei, PhD Co-director, Epigenetics Program Professor of Cell and Developmental Biology

Zachary Berlant, MDFellow
Division of Oncology

Monica Bertoletti AIBWS ODV Italy

Jack Brzezinski, MD Paediatric Oncologist, Division of Haematology/Oncology The Hospital for Sick Children, Toronto, Canada

Diana Carli, MD, PhD Assistant Professor (RTDB) in Medical Genetics Department of Medical Sciences University of Torino, Italy

Christopher M. Cielo, DO Attending Physician, Pulmonary Medicine Assistant Professor of Pediatrics

Richard S. Davidson, MD Attending Surgeon, Orthopaedic Surgery Professor of Orthopaedic Surgery

Laura Davis, MDRadiology Research Fellow
Department of Radiology



Course Faculty (continued)

Diva D. De León-Crutchlow, MD, MSCE

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

Christopher Eskew

Founder, American Beckwith-Wiedemann Spectrum Family Foundation

Arupa Ganguly, PhD

Director, Genetic Diagnostic Laboratory Professor of Genetics

Andrew George

Clinical Research Assistant BWS Registry

Carlyn Glatts, MD

Attending Physician
Developmental and Behavioral Pediatrics

Allison Hu, MD

Craniofacial Clinical Research Fellow Division of Plastic, Reconstructive and Oral Surgery

Sanam Kavari

MD-PhD Candidate

Karen Kilson, MSW, LSW

Advanced Practice Level 1, Social Worker CHOP Delaware County Primary Care Network

Cynthia Kropp, MSS, LCSW

Social Worker CHOP Primary Care

Cassandra Ligh, MD, FACS

Attending Physician

Division of Plastic, Reconstructive and Oral Surgery

Suzanne MacFarland, MD

Attending Physician

Cancer Predisposition Program, Division of Oncology

Michela Mansfield, MSN, CRNP

Nurse Practitioner

Orthopedic Center

Alessandro Mussa, MD, PhD

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

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

Director, Craniofacial Research Laboratory

Orthodontist

Clinical Associate Professor, University of Pennsylvania School of Dental Medicine

Snehal Nirgude, PhD

Postdoctoral Research Fellow Department of Human Genetics



Course Faculty (continued)

Rachel Ottman, PsyD, BCB

Postdoctoral Psychology Fellow LifeStance Health

Bruce Pawel, MD

Chief of Anatomic Pathology Attending Physician Professor of Clinical Pathology, Keck School of Medicine of USC

Giuseppe Reynolds, MD

Pediatric Resident, Department of Public Health and Pediatric Sciences University of Torino, Italy

Dominic Romeo, MD

First Year Resident Division of Plastic & Reconstructive Surgery Stanford University

Makaela Somma, MS, CCC-SLP

Speech-Language Pathologist Department of Speech-Language Pathology

Jesse A. Taylor, MD

Co-director, Cleft Lip and Palate Program Chief and Attending Physician Plastic and Reconstructive Surgery Associate Professor of Surgery

Elisia Tichy, PhD

Staff Scientist
Department of Human Genetics

Aravind Viswanathan

Clinical Research Assistant BWS Registry

Kristin Zelley, MS, LCGC

Genetic Counseling Manager, Cancer Predisposition Program



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