

Deciphering Beckwith-Wiedemann Syndrome

July 21 – 23, 2017

Sponsored by:
Children's Hospital of Philadelphia,
Orphan Disease Center,
Perelman School of Medicine at the University of Pennsylvania, and
Alex's Lemonade Stand Foundation

Ruth and Tristram Colket, Jr.
Translational Research Building

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GENERAL INFORMATION

The Division of Human Genetics and the Cancer Predisposition Program at Children’s Hospital of Philadelphia presents a conference on Diagnosis and Management of Beckwith-Wiedemann syndrome (BWS). The 2017 course will be held at Children’s Hospital of Philadelphia in the Ruth and Tristram Colket, Jr. Translational Research Building starting the evening of Friday, July 21, 2017, and running through lunch on Sunday, July 23.

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. Participants will receive current information on Beckwith-Wiedemann syndrome in neonates, children and adolescents. Parallel sessions are open to families and caregivers of children with BWS and adults with BWS.

COURSE OBJECTIVES

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

- Identify the clinical criteria to diagnose to Beckwith-Wiedemann syndrome
- Review the appropriate genetic testing to molecularly confirm BWS, including limitations and explanations of testing
- Identify current management guidelines for the common features of BWS
- Review recent clinical and scientific advancements in BWS

REGISTRATION FEES

The registration fee includes registration materials, opening reception, continental breakfasts, lunches, breaks and parking. As part of our green initiative, syllabus material will be available online up to one week prior and two weeks following the conference.

Physician	\$75
Other Health Care Providers	\$50
Family	\$10/adult

To register, please visit **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 11.5 *AMA PRA Category 1 credits™*. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

CONTINUING NURSING EDUCATION APPROVED PROVIDER STATEMENT

Children's Hospital of Philadelphia is an approved provider of continuing nursing education by the Pennsylvania State Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation. This program will provide 10.78 contact hours for the full-day program.

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.

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, less a service charge, 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 Wednesday, July 5, 2017. No refunds will be issued thereafter. Refunds will be issued for the amount of registration minus a \$50 service charge.

HOTEL ACCOMMODATIONS

A block of rooms with reduced rates has been reserved at the Sheraton University City Hotel, 36th and Chestnut streets, Philadelphia, PA 19104. The group rates are \$159 single and double occupancy, plus a 15.5 percent room tax. Participants are required to make their own hotel reservations by calling the Sheraton directly at 888-627-7071 or 215-387-8000.

An additional block of rooms has been reserved at the Homewood Suites University City, 4109 Walnut St., Philadelphia, PA 19104. The group rates are \$149 single and double occupancy, plus a 15.5 percent room tax. Participants are required to make their own hotel reservations by calling the Homewood Suites directly at 215-382-1111.

Please mention the CHOP Beckwith-Wiedemann Syndrome Conference when you call to make your reservations. The special room rates will be available until Wednesday, June 21, 2017. After that date, reservations will be accepted on a space and rate availability basis.

SERVICES FOR THE DISABLED

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.

PROGRAM — FRIDAY, JULY 21, 2017

6 p.m. **Registration**

6:30 p.m. **Opening Reception and Welcome**
Jennifer Kalish, MD, PhD
Liz Scott, Alex's Lemonade Stand Foundation

Ruth and Tristram Colket, Jr. Translational Research Building



Register online at
chop.cloud-cme.com

PROFESSIONAL PROGRAM — SATURDAY, JULY 22, 2017

8 a.m.	Registration and Continental Breakfast	12:45 p.m.	Lunch
8:15 a.m.	Welcome and Announcements	1:40 p.m.	Skin Findings and Management <i>James Treat, MD</i>
8:25 a.m.	Overview of BWS <i>Jennifer Kalish, MD, PhD</i>	2 p.m.	Hemihypertrophy and Leg Length Differences <i>Richard Davidson, MD</i>
8:50 a.m.	Clinical Features of BWS <i>Matthew Deardorff, MD, PhD</i>	2:20 p.m.	Break
9:15 a.m.	Macroglossia Management <i>Jesse Taylor, MD</i>	2:40 p.m.	The Genetics of BWS <i>Jessica Ebrahimzadeh, MS, LCGC</i>
9:40 a.m.	Sleep in BWS <i>Chris Cielo, DO</i>	3 p.m.	Molecular Diagnosis of BWS <i>Arupa Ganguly, PhD</i>
10:05 a.m.	Orthodontics and Jaw Shape <i>Hyun-Duck Nah-Cederquist, DMD, MSD, PhD</i>	3:20 p.m.	ART and BWS <i>Christos Coutifaris, MD, PhD</i>
10:30 a.m.	Coffee Break	3:40 p.m.	Mouse Models of BWS <i>Marisa Bartolomei, PhD</i>
10:50 a.m.	Recognizing the Neonate with BWS <i>Janet Lioy, MD</i>	4:05 p.m.	Emerging Technologies to Study BWS <i>Jennifer Kalish, MD, PhD</i>
11:15 a.m.	Hypoglycemia and Hyperinsulinism <i>Diva De León-Crutchlow, MD</i>	4:30 p.m.	BWS Over Time: A Family and Patient Panel
11:35 a.m.	Tumor Screening <i>Kristin Zelle, MS, LCGC</i>	5:45 p.m.	Summary of Key Features of BWS <i>Jennifer Kalish, MD, PhD</i>
11:55 a.m.	Radiology Findings <i>Lisa States, MD</i>	6 p.m.	Adjourn
12:15 p.m.	Feeding, Nutrition and Growth <i>Sherri Cohen, MD, MPH, FAAP</i>		

FAMILY PROGRAM — SATURDAY, JULY 22, 2017
WILL RUN CONCURRENTLY WITH PROFESSIONAL PROGRAM

- 8 a.m.** **Breakfast/Meet and Greet**
- 9:10 a.m.** **Welcome and Overview of BWS**
Jennifer Kalish, MD, PhD
- 10 a.m.** **Clinical Features of BWS**
Matthew Deardorff, MD, PhD
- 10:30 a.m.** **The Genetics of BWS**
Kristin Zelle, MS, LCGC
Jessica Ebrahimzadeh, MS, LCGC
- 11 a.m.** **Coffee Break**
- 11:15 a.m.** **Diagnosing and Managing Macroglossia**
Jesse Taylor, MD
Chris Cielo, DO
Hyun-Duck Nuh-Cederquist, DMD, MSD, PhD
- 11:55 a.m.** **Tumor Screening in BWS**
Jennifer Kalish, MD, PhD
- 12:25 p.m.** **Radiology Findings**
Lisa States, MD
- 12:45 p.m.** **Lunch • Discussion Groups by Child's Age**
- 2:15 p.m.** **ART and BWS: A Panel Discussion**
Marisa Bartolomei, PhD
Christos Coutifaris, MD, PhD
Monica Mainigi, MD
- 3 p.m.** **Break**
- 3:30 p.m.** **Common Concerns in BWS: A Panel Discussion**
Sherri Cohen, MD, MPH, FAAP
Richard Davidson, MD
Diva De León-Crutchlow, MD
James Treat, MD
- 4:30 p.m.** **BWS Over Time: A Family and Patient Panel**
- 5:45 p.m.** **Summary of Key Features of BWS**
Jennifer Kalish, MD, PhD
- 6 p.m.** **Dinner and Adjourn**

PROGRAM — SUNDAY, JULY 23, 2017

- 8 a.m.** **Registration and Continental Breakfast**
- 8:30 a.m.** **Findings from the BWS Registry**
Jennifer Kalish, MD, PhD
Kelly Duffy, MPH
- 9:30 a.m.** **BWS Resources for Healthcare Professionals and Families**
Kristin Zelle, MS, LCGC
Evan Hathaway, MS
- 10 a.m.** **Navigating the Healthcare System with BWS**
Caren Kelman, MS, LCSW
Joan Jenaway
Michele Hillman, MSN, RN-CCM
- 10:30 a.m.** **Adults with BWS: A Panel Discussion**
- 11:30 a.m.** **Closing Remarks**
- Noon** **Lunch and Adjourn**

 Register online at
chop.cloud-cme.com

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

COURSE DIRECTORS

Jennifer Kalish, MD, PhD

*Attending Physician, Human Genetics
Assistant Professor of Pediatrics*

Garrett Brodeur, MD

*Attending Physician, Oncology
Professor of Pediatrics
Director of the Cancer Predisposition Program at CHOP
Associate Director of the Abramson Cancer Center at Penn*

CONTINUING NURSING EDUCATION PLANNERS

Kathleen Monforto, MSN, RN, CPN

Education Nurse Specialist, Department of Nursing Education

Ray Wildes, MSN, RN

Education Nurse Specialist, Department of Nursing Education

CONTINUING GENETIC COUNSELOR EDUCATION PLANNER

Kristin Zelle, MS, LCGC

*Senior Genetic Counselor
Cancer Predisposition Program*

COURSE FACULTY

Marisa Bartolomei, PhD

*Professor of Cell and Developmental Biology
Co-director of the Epigenetics Program*

Christopher Cielo, DO

*Attending Physician, Pulmonary Medicine
Assistant Professor of Pediatrics*

Christos Coutifaris, MD, PhD

*Attending Physician, Obstetrics and Gynecology
Chief, Division of Reproductive Endocrinology and Infertility
Penn Medicine
Celso-Ramon Garcia Professor*

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

Richard Davidson, MD

*Attending Surgeon, Orthopaedic Surgery
Professor of Orthopaedic Surgery*

Matthew Deardorff, MD, PhD

*Attending Physician, Human Genetics
Assistant Professor of Pediatrics
Associate Medical Director, Roberts Individualized Medical Genetics Center*

Diva De León-Crutchlow, MD, MSCE

*Attending Physician, Endocrinology
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Associate Professor of Pediatrics*

Kelly Duffy, MPH

Coordinator, BWS Registry

continued >

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Genetic Counselor
Genetics Diagnostic Laboratory

Arupa Ganguly, PhD
Professor of Genetics
Director, Genetic Diagnostic Laboratory

Evan Hathaway, MS
Genetic Counselor, Human Genetics

Michele Hillman, MSN, RN-CCM
Senior Director, Case Management

Joan P. Jenaway
Director, Payor Relations
Managed Care and Reimbursement Strategy

Caren Kelman, MS, LCSW
Licensed Clinical Social Worker, Human Genetics

Janet Lioy, MD
Attending Physician
Director, Neonatal Outreach Program
Medical Director, Neonatal Airway Program
Professor of Pediatrics

Monica Mainigi, MD
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Assistant Professor of Obstetrics and Gynecology

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Orthodontist
Director, Craniofacial Research Laboratory
Research Associate Professor of Surgery
Clinical Associate Professor
University of Pennsylvania School of Dental Medicine

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Division Chief, Human Genetics
Chair, Department of Genetics
Professor of Molecular Medicine

Arjun Raj, PhD
Associate Professor, Bioengineering

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

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

James Treat, MD
Attending Physician, Dermatology
Fellowship Director, Pediatric Dermatology
Associate Professor of Pediatrics