

PHACEing the Future

PHACE Syndrome Family Conference

September 16-17, 2010

Milwaukee, WI



Event Highlights:

PHACE Syndrome overview.

Imaging (radiology) information.

Neurological issues.

Treatment and management.

Social implications of facial differences.

Laser therapy for hemangiomas.

Research update.

Registration

Cost: Free.

How to register: E-mail Jennefer Lehman at

jlehman@mcw.edu or call Jennefer at (414) 955-2818.

Sponsored by Children's Hospital of Wisconsin, The Medical College of Wisconsin, National Organization of Vascular Anomalies and the Hemangioma Investigator Group



A member of Children's Hospital and Health System.

PHACE the Future

An educational conference for families about PHACE syndrome.

September 16-17

Children's Health Education Center

1533 N. RiverCenter Drive, Milwaukee, Wis.

PHACE syndrome is the combination of a large hemangioma, usually on the face or neck, with one or more other medical problems.

Conference participants will learn about PHACE syndrome, have opportunities to meet other families that have a child with this syndrome, and exchange ideas, support and advice. Educational materials will be available.

The conference is designed for families of children with PHACE syndrome or anyone who cares for a child with this syndrome, from new diagnosis to the latest research.

Schedule

Thursday, September 16

- | | |
|------------|--|
| 12:30 p.m. | Registration |
| 1 p.m. | Introduction and welcome
Adriane Baylis, PhD, CCC/SLP, Children's Hospital of Wisconsin |
| 1:15 p.m. | History of PHACE
Ilona Frieden, MD, University of California, San Francisco |
| 1:45 p.m. | Overview of medical intervention for hemangiomas: What's new
Beth Drolet, MD, Children's Hospital of Wisconsin, Milwaukee |
| 2:15 p.m. | Laser treatment for hemangiomas: Sorting through the myths
Maria Garzon, MD, Morgan Stanley Children's Hospital, New York |
| 2:45 p.m. | Question and answer period
Panel: Dr. Drolet; Dr. Frieden; Dr. Garzon; and John Jensen, MD,
Children's Hospital of Wisconsin |
| 3:15 p.m. | Parent-to-parent presentation
Stuff family |

Registration

Cost: Free.

How to register: E-mail Jennefer Lehman at jlehman@mcw.edu and request a registration form or call Jennefer at (414) 955-2818 to register by phone. **The registration deadline is Aug. 30.** For a map to Children's Health Education Center, visit chw.org/chec.

Child care, for children ages 2-8 years old, is available during educational sessions.

Event highlights

The PHACE syndrome conference will include:

- Syndrome overview.
- Imaging (radiology) information.
- Neurological issues that may challenge patients.
- Treatment and management guidelines.
- Social implications of facial differences.
- Laser therapy for hemangiomas.
- Research update.

Speakers and panelists

- Denise Adams, MD, Cincinnati Children's Hospital Medical Center, Ohio
- Beth Drolet, MD, Children's Hospital of Wisconsin, Milwaukee
- Jen Duncan, PHACE Syndrome Community
- Ilona Frieden, MD, University of California, San Francisco
- Maria Garzon, MD, Morgan Stanley Children's Hospital, New York
- Karla Hall, NOVA
- Christopher Hess, MD, PhD, University of California, San Francisco
- Jennifer Hoag, PhD, Children's Hospital of Wisconsin
- John Jensen, MD, Children's Hospital of Wisconsin
- Craig Johnson, DO, Children's Hospital of Wisconsin
- Patricia Marik, PsyD, Children's Hospital of Wisconsin
- Denise Metry, MD, Texas Children's Hospital, Houston
- Sunila O'Connor, MD, Children's Hospital of Wisconsin
- Darren Orbach, MD, PhD, Children's Hospital Boston, Mass.
- Dawn Siegel, MD, Children's Hospital of Wisconsin

Accommodations

Hotel options include:

Comfort Inn & Suites Downtown Lakeshore

916 East State Street, Milwaukee

(414) 276-8800

Rooms are \$79 plus tax. The hotel has a shuttle for conference participants, and a block of rooms is set aside. To receive the discounted room rate, be sure to tell reservation staff that you are with the PHACE conference. **The deadline for the rate discount is Aug. 15.**

Discounted passes for the Paradise Landing Indoor Waterpark, located in the Hilton Milwaukee City Center, are available for \$10 each. The passes may be used 3 p.m. to 10 p.m., Friday, September 17, and 9 a.m. to 10 p.m., Saturday. To receive the discounted rate, be sure to mention the PHACE conference and Children's Hospital when you purchase the water park passes. Reservations: (877) 543-7785.

For more information about Children's Hospital's Birthmarks & Vascular Anomalies Center, visit chw.org/birthmarks.

The conference is sponsored by Children's Hospital of Wisconsin, The Medical College of Wisconsin, the National Organization of Vascular Anomalies and the Hemangioma Investigator Group.