

# 2014 PHACE Family Conference - Conference Agenda

*All sessions and meals will be held in the Grand Pavilion*

## **Thursday June 19, 2014**

- 8:00 Check-in for Conference / Breakfast
- 8:45 Childcare begins
- 9:00 Welcome: Jen Meints, President, PHACE Syndrome Community
- 9:10 The PHACE Syndrome Community Journey: Janet and Andrew Ziffer
- 9:30 Overview of PHACE Syndrome and Current Diagnostic Protocols: Ilona Frieden, MD, University of California-San Francisco
- 10:15 Coffee Break (sponsored by Children's Hospital of Wisconsin)
- 10:30 PHACE Research and Genetics Updates: Dawn Siegel, MD, Children's Hospital of Wisconsin
- 11:15 Rick Guidotti, Founder and CEO, Positive Exposure
- 12:15 Family Lunch (sponsored by PHACE Syndrome Community)
- 1:15 Team Care for PHACE syndrome and Care Coordination:  
Marcia Seefeldt, RN, BSN, Children's Hospital of Wisconsin
- 1:45 Protecting your child's privacy and medical information in the era of social media: Travis Good, MD,  
Co-Founder, Catalyze
- 2:45 Coffee Break - (sponsored by Direct Supply Foundation)
- 3:00 Parent-Patient Panel: Jill Salas, Shannon Audette, Kimberly Nelson, Adriane Baylis, Natalka Haras
- 4:15 Adjourn
- 6:00 Family Dinner (sponsored by Boston Children's Hospital); face painting for children starts at  
5:30pm

## Friday June 20, 2014

- 7:30 Breakfast
- 8:15 Childcare begins
- 8:30 PHACE Research Meeting Update: Beth Drolet, MD, Children's Hospital of Wisconsin, plus other members of the 2014 PHACE Syndrome Research Workshop
- 9:30 Management of Headaches/Migraines in PHACE: Geoffrey Heyer, MD, Nationwide Children's Hospital
- 10:15 Coffee Break (sponsored by Culhane Meadows Law Firm)
- 10:30 Neuroimaging and Treatment of cerebrovascular Anomalies in PHACE: Darren Orbach, MD, Boston Children's Hospital
- 11:30 Panel Discussion on Guidelines for Neuroimaging: Dr. Heyer, Dr. Orbach
- 12:00 Lunch with the Researchers (sponsored by PHACE Syndrome Community)
- 1:30 Roundtable Discussions
- Introduction by Juliet N. Kersten, Vice President, Ambulatory, Regional Services and Service Lines, Children's Hospital of Wisconsin
- Cardiology/Cardiothoracic Surgery: Michael Mitchell, MD, Children's Hospital of Wisconsin
  - Plastic/Reconstructive Surgery: John Jensen, MD, Children's Hospital of Wisconsin
  - Feeding/swallowing difficulties and management: Joan Arvedson, PhD, CCC, Children's Hospital of Wisconsin
  - Psychological and developmental concerns/coping with facial difference/self-image: Patricia Marik, PsyD, Children's Hospital of Wisconsin
  - Management of Airway hemangiomas, and ear/hearing issues: Bob Chun, MD, Children's Hospital of Wisconsin
- 3:00 Coffee Break
- 3:15 Hemangioma Treatment: Current practices in the use of steroids, propranolol, and laser treatment for children with PHACE syndrome: Beth Drolet, MD, Children's Hospital of Wisconsin
- 4:00 PHACE Syndrome Community Annual Meeting and Future Directions: Jen Meints, Jill Salas
- 4:45 Closing Remarks and Open Discussion
- 5:00 Adjourn
- Dinner (on your own)

**Saturday June 21**

10:00 am – 4:00 pm PHACE Syndrome Community Family Social Event

Lunch and activities will be provided!

Grandview Park  
1001 Grandview Blvd  
Waukesha, WI 53188  
Grandview Park

**Directions from hotel to Grandview Park:**

1. Head east on Golf Rd toward Lake Country Recreation Trail for 1.2 miles
2. Turn right onto N Grandview Blvd. Destination will be on the left after 1.6 miles