

The Hemispherectomy Foundation Conference and Family Reunion
July 5th – 8th (Thursday – Sunday), 2012
BWI, DoubleTree Hilton

Thursday, July 5th

3:00 – 8:00 : **Registration and Reception** (Conference Room Reception Area)
Check-In, Pick-Up Notebook, Nametags
Individual Family Pictures – Diana Waguespack
Chance for Families to get together, Talk, Catch-up

Friday, July 6th

8:00 – 9:00 **Breakfast**
Kid's Camp – Check in begins @ 7:30 AM (All Kids should be checked in by 8:45 AM)
Individual Family Pictures – Diana Waguespack

9:00 – 9:15 **Welcome by Hemispherectomy Foundation Founders**
Cris and Kristi Hall
Co-Founders, The Hemispherectomy Foundation

9:15 – 9:30 *Short Break for Set-Up*

9:30 – 10:30 **Hemispherectomy Recovery of Function – Cognitive/Physical/Long-Term**
Stella de Bode, Ph. D.
The Brain Recovery Project

10:30 – 11:30 **Effectiveness of Pediatric CI Therapy of Children after Hemispherectomy**
Edward Taub, Ph.D.
The University of Alabama at Birmingham

11:30 – 1:00 **Lunch with Other Hemi Families**
Lunch Speakers
11:40 **Jody Miller** – “College, Life, and Dance”
12:05 **Dylan Norwood** – “Dylan and Driving”
12:30 **Lisa & Diana Waguespack** – “Horizon School and other Post-High School Options”

1:00 – 2:00 **Veterans / Young Adult / Teen : Question/Answer Panel**
Lynn and Jody Miller
Joan and Emily Olsen
Mary Beth and Dylan Norwood
Diana and Lisa Waguespack
Lisa Segreson
**Please contact Cris@HemiFoundation.org if you would like to be on this panel.

2:00 – 3:00 **One Handed Gadget Presentation**
Joan and Emily Olsen

Also, we encourage families to bring their own gadgets, equipment, and orthotics. Show, Share, or Trade with other families during the conference.

- 3:00 – 4:00 **Organization Presentations**
20 Minutes : **HME Family Support Network** – Holly Pauwee
20 Minutes : **RE Children’s Project** – Seth Wohlberg
20 Minutes : **The Brain Recovery Project** – Monika Jones
- 4:00 – 5:00 **Regional Breakouts** – In main conference room
Central Region – Roxanne Cogil
Northeastern Region – Jane Stefanik
Eastern Region – Nicole Fuller
Western Region - TBD
- 5:00 – 6:00 **Informal Family Mixing / Rest Time** (Bar Area, Pool, Conf. Rooms)
Individual Family Pictures – Diana Waguespack
- 6:30 – 8:00 **Dinner and Mingle**

Saturday, July 7th

- 8:00 – 9:00 **Breakfast**
Kid’s Camp – Check in begins @ 7:30 AM (All Kids should be checked in by 8:45 AM)
- 9:00 – 11:30 **Johns Hopkins and KKI Presentations**
Bastian: Split-belt Treadmill Studies
Salorio: Behavior Outcomes after Hemispherectomy
Hartman: Quality of Life after Hemispherectomy
Kossoff: Nonsurgical Options for Hemispherectomy Candidates
Kelley: Headaches after Hemispherectomy
Comi: Sturge-Weber
Anderson: Surgical Topic
- 11:30 – 1:00 **Lunch with Other Hemi Families**
Lunch Speakers
11:40 **Beth Usher** – “Enjoying Life and Clowning Around”
12:05 **Lisa Segreson** – “Being a Mommie”
- 1:00 – 2:00 **Johns Hopkins and KKI Doctors Panel Discussion** - Questions from Hemi Families
- 2:00 – 2:30 **Doctor’s Awards**
- 2:30 – 3:00 **Break**
- 3:00 – 4:00 **Hemi Foundation Presentation and Awards and Conclusion**
- 4:00 – 4:30 **Hemi Kids and Hemi Family Group Photo**

Outside near pool / basketball courts
Diana Waguespack

- 4:30 – 5:30 **Specialty Breakouts** (Rasmussen's, Stroke, HME, Cortical Dysplasia, SWS)
RE Children's Project / Hopkins – DNA Collection for study
SWS – Meet with Drs. Kossoff and Comi of Johns Hopkins
HME/CD – Holly Pauwee, Hemi Foundation Specialty Director HME/CD
Stroke – Barb Frazier, Hemi Foundation Specialty Director Pediatric Stroke
- 5:30 – 6:30 **Informal Family Mixing / Rest Time** (Bar Area, Pool, Conf. Rooms)
- 6:30 – 8:00 **Pizza Party**

Sunday, July 8th

8:00 – 9:00 **Breakfast on your own**

9:00 - **Hugs, Tears, and Goodbyes**

Monday, July 9th

Don't forget to schedule your clinic appointments for this day at Johns Hopkins.