

Invitation

We want you to join us at the 2020 Family Conference on Holoprosencephaly! This conference is for families and persons who are affected by HPE, their extended families and caregivers.

The conference is a collaboration among Families for HoPE, The Carter Centers for Brain Research in Holoprosencephaly and Related Malformations, and the National Institutes of Health. Utilizing world renowned subject-matter experts from each of these organizations, the HPE families are provided a well-rounded program addressing research, clinical and therapeutic management, and day-to-day living.

We welcome those who have loved and lost someone affected by HPE and will have special sessions dedicated to bereavement topics. The two days of conference sessions will provide you with information you need to help you better manage the day-to-day life issues you and your family face when caring for or missing a child with HPE. The final day of the conference will be to celebrate together at our HoPE PROM!

Siblings are invited and encouraged to attend! We will have special activities for siblings ages 13 and older which will include off-site field trips. We will have on-site childcare for children ages 12 and younger.

Lodging

Great Wolf Lodge

2501 Great Wolf Drive, Mason, OH 45040

Families for HoPE will coordinate the hotel reservations for you, so you **do not** need to contact Great Wolf Lodge for reservations.

Registration fee of \$845 includes 4-nights lodging in a Family Suite which sleeps up to 6 people (2 queen beds and a sofa sleeper) and includes up to 6 waterpark passes. This hotel features all suite rooms with a refrigerator and microwave in each room. Check-in is Sunday, June 14, 2020 at 4:00pm and check-out is Thursday, June 18, 2020 at 11am.

Families who wish to upgrade to a specialty room may incur an additional fee. A limited number of shoulder nights before and after our event are available. Additional nights are at your cost and must be arranged through Families for HoPE for our discounted rate. To upgrade or add nights please contact Roxanne Steele at Roxanne.Steele@FamiliesforHoPE.org.

Airports

Cincinnati/Northern Kentucky International Airport (CVG) is approximately 28 miles to Great Wolf Lodge.

Dayton International Airport (DAY) is approximately 38 miles to Great Wolf Lodge.



2020 Family Conference on Holoprosencephaly

June 14-17, 2020

**Great Wolf Lodge &
Conference Center**



Conference Agenda*

Sunday, June 14

Arrival, check in and visit our family lounge to meet other families. A memorial ceremony and conference kick-off to be held at approximately 7:30pm.

Monday, June 15

9am-5pm—Conference sessions and Teen activities. Lunch buffet included. Childcare open 8:30am-5pm with snacks and lunch included. 1:1 Consultations and gene screening. Vendor Fair. Ladies evening event.

Tuesday, June 16

9am-5pm—Conference sessions with lunch buffet included. Childcare open 8:30am-5pm with snacks and lunch included. Teens activity off-site with lunch provided. 1:1 Consultations and gene screening. Vendor Fair. Mens evening event.

Wednesday, June 17

The indoor waterpark will open 1 hour early to allow our group to swim and play before it opens to other lodge guests. Lunch is on your own. Then, powder your nose and shine your shoes because you will be getting ready for the **HoPE PROM!** In the evening, join us in the ballroom for dinner, dancing, and more.

Thursday, June 18

Check out time is 11am. After checking out of your room, you are welcome to stay throughout the day and enjoy the waterpark until it closes for the day.

Sibling Activities

Children 12 years old or 6th grade and younger

Childcare provided on-site by a professional childcare company and presented in a day-camp style program. All children who do not need nursing level of care may participate.

Children 13 years old or 7th grade and older

Adult-supervised fun, team-building and social activities to be held Monday and Tuesday. Teens will have some choices in activities and will receive snacks and meals at their designated activities.



Objectives

- Outline recent advances in the understanding of HPE
- Discuss the optimal clinical management of patients with HPE
- Provide for family networking and support
- Educate families on treatment options
- Expose families to therapeutic strategies
- Explore options for medical equipment

Presentations/Workshops*

NIH Research Update

Clinical Management

Seizure Management

OT/PT/Dietary

Caregiver Burnout/Self Care

Dentistry

Behavioral Issues

Transitioning from Adolescence to Adulthood

HPE from a Sibling Perspective

Fathers: Balancing Work and Home Life

Making Relationships Work

Making Difficult Decisions for Your Child

(*May be subject to change)

Instructions

To register, complete the registration form and scan to:

Roxanne@FamiliesforHoPE.org

Or return via mail to:

**Families for HoPE, Inc.
c/o Roxanne Steele
401 SW H Street
Richmond, IN 47374**

Registration fees may be paid via check payable to "Families for HoPE, Inc.", or paid via credit card utilizing the credit card info section on the back of this form.

Child with HPE

_____	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Deceased
Child With HPE's Name	Attending
Age _____	Lives With _____
Food Allergies _____	
Order meals <input type="checkbox"/> Yes <input type="checkbox"/> No	
Wheelchair <input type="checkbox"/> Yes <input type="checkbox"/> No	
Other Allergies or Special Needs _____	
Youth S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/>	
Adult S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/> XL <input type="checkbox"/> 2XL <input type="checkbox"/> 3X <input type="checkbox"/> 4X <input type="checkbox"/>	
Will participate in on-site childcare? <input type="checkbox"/> Yes <input type="checkbox"/> No	

Mother of child with HPE

_____	<input type="checkbox"/> Yes <input type="checkbox"/> No
Mother's Name	Attending
Mother's Cell _____	
Mother's Address _____	
City, State, Zip _____	
Food Allergies _____	
Mother's E-mail _____	
Mother's Special Needs _____	
Youth S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/>	
Adult S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/> XL <input type="checkbox"/> 2XL <input type="checkbox"/> 3X <input type="checkbox"/> 4X <input type="checkbox"/>	

Father of child with HPE

_____	<input type="checkbox"/> Yes <input type="checkbox"/> No
Father's Name	Attending
Father's Cell _____	
Father's Address _____	
City, State, Zip _____	
Food Allergies _____	
Father's E-mail _____	
Father's Special Needs _____	
Youth S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/>	
Adult S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/> XL <input type="checkbox"/> 2XL <input type="checkbox"/> 3X <input type="checkbox"/> 4X <input type="checkbox"/>	

Siblings

_____	_____
Sibling's Name	Age
Siblings E-mail, cell, Facebook, Twitter, etc... _____	
Food Allergies _____	
Youth S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/>	
Adult S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/> XL <input type="checkbox"/> 2XL <input type="checkbox"/> 3X <input type="checkbox"/> 4X <input type="checkbox"/>	
Will participate in age-appropriate sibling activities <input type="checkbox"/> Yes <input type="checkbox"/> No	

_____	_____
Sibling's Name	Age
Siblings E-mail, cell, Facebook, Twitter, etc... _____	
Food Allergies _____	
Youth S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/>	
Adult S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/> XL <input type="checkbox"/> 2XL <input type="checkbox"/> 3X <input type="checkbox"/> 4X <input type="checkbox"/>	
Will participate in age-appropriate sibling activities <input type="checkbox"/> Yes <input type="checkbox"/> No	

_____	_____
Sibling's Name	Age
Siblings E-mail, cell, Facebook, Twitter, etc... _____	
Food Allergies _____	
Youth S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/>	
Adult S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/> XL <input type="checkbox"/> 2XL <input type="checkbox"/> 3X <input type="checkbox"/> 4X <input type="checkbox"/>	
Will participate in age-appropriate sibling activities <input type="checkbox"/> Yes <input type="checkbox"/> No	

Other Attendees

Name _____	Relationship _____
Cell Phone _____	
Address _____	
City, State, Zip _____	
E-mail _____	
Food Allergies _____	
Special Needs _____	
Youth S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/> Adult S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/> XL <input type="checkbox"/> 2XL <input type="checkbox"/> 3X <input type="checkbox"/> 4X <input type="checkbox"/>	

Name _____	Relationship _____
Cell Phone _____	
Address _____	
City, State, Zip _____	
E-mail _____	
Food Allergies _____	
Special Needs _____	
Youth S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/> Adult S <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/> XL <input type="checkbox"/> 2XL <input type="checkbox"/> 3X <input type="checkbox"/> 4X <input type="checkbox"/>	

Families for HoPE is pleased to offer families the option to pay registration fees utilizing monthly payments via credit card (MC/Visa/AMEX/DIS).

Name on card: _____

Card number: _____

Exp. date: _____ CSC Code: _____

Month to begin payments: _____

Amount to be charged each month: _____

Day of month you want to be charged: _____

Signature: _____

Month to begin payments	Monthly Payment
April 2019	\$65
May 2019	\$70.50
June 2019	\$77
July 2019	\$84.50
August 2019	\$94
September 2019	\$106
October 2019	\$121
November 2019	\$141
December 2019	\$169
January 2020	\$211.50
February 2020	\$282
March 2020	\$422.50
April 2020	\$845

Registration Fees

Registration deadline is April 30, 2020.

Registration Fee: \$845 per family which includes:

- 1 Family Suite* for the nights of June 14, 15, 16 and 17. A Family Suite sleeps a maximum of 6 people with 2 queen beds and a sofa sleeper.
- Indoor waterpark passes for your family
- Childcare (if needed)
- Activities for ladies, men, teens, bereaved
- Exclusive admission to the waterpark one hour earlier than other GWL guests on Wednesday, June 17
- Welcome reception on June 14
- Lunch buffets on June 15 and 16
- Buffet dinner and entertainment on June 17

*Families that require a larger suite or a second suite will incur additional charges based upon the room type needed. Check with the conference chair-persons for details.

For those not requiring overnight lodging at Great Wolf Lodge, the registration fee is \$100 per person.

If attending the Prom only, tickets are \$25 per person.