

## Invitation

We want you to join us as A Family of HoPE at the 2016 Family Conference on Holoprosencephaly.

This conference is for families and persons who are affected by HPE, their extended families and caregivers. 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 first-ever 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 childcare on site for children ages 12 and younger and special activities for our children with HPE.

## Airports

Dallas/Fort Worth International (DFW) is approximately 18 miles from the hotel.

Dallas Love Field is approximately 3 miles from the hotel. If you arrive during the day, the hotel will provide shuttle service to and from Love Field at no additional charge. (Shuttle is not handicap accessible.)

## Lodging

Families are encouraged to stay at:

**Homewood Suites by Hilton  
Dallas-Market Center  
2747 North Stemmons Freeway  
Dallas, Texas 75207**

Group rates of \$119 for a 1-bedroom king bed suite or \$139 for a 1-bedroom double bed suite have been secured. This hotel features all suite rooms with refrigerators, a complimentary full hot breakfast daily and complimentary evening hot snacks and beverages. The hotel has an outdoor pool and large areas for families to gather and socialize.

**The time at the hotel is often one of the favorite social opportunities for families. Therefore, we encourage you to call the hotel and reserve your room today!**

To make reservations:

1. Call the hotel directly at 214-819-9700, ask for “reservations” and reference our group code “FFH”
2. [www.dallasmarketcenter.homewoodsuites.com](http://www.dallasmarketcenter.homewoodsuites.com)  
After selecting dates, enter the group code “FFH” under the group/convention code section.

In an effort to help our conference better fit into your budget, Families for HoPE has funds available to assist HPE families with up to 4 nights in a suite at Homewood Suites by Hilton/Dallas-Market Center (Tuesday-Friday). Please indicate the number of nights you are requesting on the attached registration form.



## 2016 Family Conference on Holoprosencephaly (HPE)

**July 12-15  
Dallas, Texas**

Presented by:  
Families for HoPE, Inc.  
and Carter Centers for Brain  
Research in Holoprosencephaly  
and Related Malformations

To be held at the  
T. Boone Pickens Training and  
Conference Center at Texas Scottish  
Rite Hospital for Children

## Agenda

### Tuesday, July 12

Arrival and evening social time at the hotel including “Moms’ Night” activity. Complimentary beverages and “small plate” food offerings from 5-7pm. Please plan to sign your release forms and pick up your conference materials and t-shirts.

### Wednesday, July 13

9am-5pm Conference sessions and catered lunch at Texas Scottish Rite Hospital. *If you are not staying at the Homewood Suites, please arrive early to sign your release forms and pick up conference materials and t-shirts.*

Complimentary beverages and “small plate” food offerings at the hotel from 5-7pm. Special vendors at the hotel from 5-8pm. Socializing and swimming.

### Thursday, July 14

9am-5pm Conference sessions and catered lunch at Texas Scottish Rite Hospital. Complimentary beverages and “small plate” food offerings at the hotel from 5-7pm. Special vendors at the hotel from 5-8pm. “PJs and Movies” for the kids. Dads’ activity to be held.

### Friday, July 15

Sleep in/swim/socialize. Light lunch provided by Families for HoPE. Then, powder your nose and shine your shoes because you will be getting ready for the first-ever **HoPE PROM!** Join us in the evening at the Dallas World Aquarium for dinner, dancing, and more.

## Sibling Activities

### Children 12 years-old or 6th grade and younger:

Childcare at the conference site provided by Texas Scottish Rite employees and volunteers. Arts and crafts, music, movies, playground time, snacks and more!

### Children 13 years-old or 7th grade and older:

Adult-supervised fun, team-building and social activities to be held off-site on Wednesday and Thursday. Lunch and snacks will be provided. Adult siblings are welcome to attend some or all 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 to improve quality of life

## Presentations/Workshops\*

NIH Research Update

Seizure Management

OT/PT/Dietary

Caregiver Burnout/Self Care

Vehicle and Home Modifications

Do-It-Yourself Sensory Ideas

HPE from a Sibling Perspective

Dads with HoPE

HoPE, Grief & Beyond

(\*May be subject to change)



## Instructions

The 2016 registration fee is **\$125 per family**. If your family requires assistance with the registration fee, please contact Roxanne@FamiliesforHoPE.org.

Please register prior to June 1, 2016. You may register online at www.FamiliesforHoPE.org or complete this form and mail with your \$125 registration fee to:

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

## Child with HPE

_____	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Deceased
Child With HPE's Name	Attending
Age _____	Lives With _____
Favorite Song _____	
Food Allergies _____	
Eats by Mouth	<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 activities:	
<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... _____	
Siblings Food Allergies _____	
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... _____	
Siblings Food Allergies _____	
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... _____	
Siblings Food Allergies _____	
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 _____	
Food Allergies _____	
E-mail _____	
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 _____	
Food Allergies _____	
E-mail _____	
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"/>	

If your child is 13 or older and has his/her own cell phone, e-mail or Facebook/Twitter account, please include all the info you can share. We would like to contact the siblings in advance for ideas and input on the teen and adult sibling activities.

Also, if your teen sibling would like to help with the PROM, please indicate the activities they have an interest in:

- Pre-PROM decorating
- Pre-PROM beauty (hair/nails/makeup)
- Roving photographer
- Serve as an escort/date
- Other duties as needed

Please register online at [www.FamiliesforHoPE.org](http://www.FamiliesforHoPE.org) or complete this form and mail with the \$125 registration fee to:

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



## Fees

Registration deadline is June 1, 2016.

The 2016 registration fee is \$125 per HPE family which includes but is not limited to t-shirts for attendees and conference materials. If your family requires assistance with the registration fee, please indicate that here: \_\_\_\_\_

In an effort to help our conference better fit into your budget, Families for HoPE has funds available to assist HPE families with up to 4 nights in a suite at Homewood Suites by Hilton/Dallas-Market Center. If you would like to utilize this funding, please indicate the number of nights you are requesting: \_\_\_\_\_