

# 2014 Conference on Holoprosencephaly

## October 2-5, 2014 Dallas, TX

Families for HoPE invites you to join us as we **'Find the HoPE'** at the 2014 Family Conference on Holoprosencephaly from Thursday, October 2 through Saturday, October 4, 2014 in Dallas, Texas.

The conference is for families of persons who are affected by HPE, their extended families and care-givers. We also welcome those who have loved and lost someone affected by HPE and will have special sessions dedicated to bereavement topics.

The three days of conference sessions will provide you with information you need to help you better deal with the day-to-day life issues you and your family face when caring for or missing a child with HPE.

Your family will benefit in so many ways! You will:

- Learn you are NOT alone.
- Share personal connections with others who understand.
- Meet others to exchange ideas, support and advice.
- Learn from stimulating round-table discussions, hands-on therapy time, and physician led sessions.
- Gain knowledge of helpful products and resources.
- Participate in research studies to advance understanding of HPE.
- Make and renew friendships with other families affected by HPE.
- Have a great time together as a family with other families who truly understand what it is like to love a child with HPE!



### About Dallas, TX

The Texas Scottish Rite Hospital is in the heart of Dallas, TX. The hotel where our attendees will be staying is just minutes from the Hospital, where the Carter Centers for Research in Holoprosencephaly is located.



The hotel is also just a few miles away from downtown Dallas. Dallas is full of many fun family outings including The Dallas World Aquarium, the 6<sup>th</sup> Floor Museum and The Dallas Zoo. If you enjoy shopping, restaurants or entertainment, you can find something fun to do here!

We encourage you to stay a few extra days to see what the area has to offer.

### Carter Centers

The majority of the conference activities will be held at the Conference Center at the Texas Scottish Rite Hospital and coordinated by the Carter Centers for Research in Holoprosencephaly. The hospital is a short drive from the hotel. Free parking is located on site at Texas Scottish Rite Hospital. Please note on your registration form if you will need transportation to and from the conference. (Please see the travel/lodging info sheet).





# Registration Details of Texas!

## How to Register

Read and complete the registration form carefully. Return your completed form and payment to Families for HoPE, Inc. no later than **August 18, 2014**.

- E-mail the completed e-form to: [conference2014@FamiliesforHoPE.org](mailto:conference2014@FamiliesforHoPE.org)
- You can then pay your deposit online at: [FamiliesforHoPE.org/donatenow](http://FamiliesforHoPE.org/donatenow).
- **OR** mail the completed printed form with your registration check to:

Families for HoPE, Inc. c/o Ramona Joyce,  
728 College Street, Moulton, AL 35650

## Registration Fees

All family members or caregivers who are participating in conference sessions, activities and/or meals must register for the conference.

- Adults (age 13 & up) - **\$75**
- Children (age 12 & under) - **\$50**
- Child with HPE - **FREE!**

## Early Bird Discount

If you pay in full before **June 27, 2014**, you can deduct \$25 per person from your registration fee.

## Deposits

You are free to make deposits towards your registration fees at any time. If you are paid **in full by June 27**, you will get the Early Bird Discount. If you do not complete your payment before then, you will owe the full registration fee.

## Cancellations

Families for HoPE **must** be informed of cancellations for any reason before Sept 1, 2014. We will keep 20% of your registration fee and return the balance to you. **No refunds will be issued after September 1, 2014!**

## Teen Days

Siblings ages 12 and up are encouraged to join in with other siblings for a day at “**Group Dynamix**” and a day at The Dallas World Aquarium and/or The George W. Bush Presidential Library. Please be sure to indicate on your registration if your child wishes to join in the fun. All expenses are included in the registration fee.

## What you Get

- **Thursday:** Starting at 10 AM, a full day of sessions, lunch and dinner. Followed by the balloon release.
- **Friday:** Full day of sessions, lunch and dinner, Plus a Vendor Fair!
- **Saturday:** ½ day of sessions and lunch
- ✓ All session materials, handouts, etc.
- ✓ T-shirt for each member of your family in attendance
- ✓ Various snacks, drinks & extras
- ✓ Breakfast is provided at the hotel (if you choose other lodging, you are on your own for breakfast).
- ✓ Free Genetic testing, by the NIH

## What you should bring

There are shopping options near the hotel if you forget anything, but you do want to bring these things...

- ✓ All items needed by your child and family for an extended vacation
- ✓ Special food or snacks for your children
- ✓ Any medications and equipment that your child with HPE will need
- ✓ Your camera, video camera, phone, etc.
- ✓ Extra money for buying additional Families for HoPE apparel and gift items
- ✓ An open mind and an open **Heart!**

## Attire

The weather in Dallas in October is typically quite warm. Casual attire is appropriate for the entire conference. Please dress your children for play. **Please wear your conference shirts on Friday!**

**QUESTIONS**, email Molly Johnson at [conference2014@familiesforhope.org](mailto:conference2014@familiesforhope.org)



# Travel/Lodging details

**Lodging:** Families for HoPE has saved a block of room at The Homewood Suites Dallas/Market Center. The address is 2747 N. Stemmons Freeway, Dallas, TX. The group rates are \$114 for a 1 bedroom King Suite and \$134 for a 1 bedroom double bed suite. **Be sure to make your reservation early, the blocked rooms are limited.**

To make reservations:

1. Call the Hotel Directly at (214) 819.9700, ask for "Reservations" and reference your Group Code **FFH**
2. Book Online at [www.dallasmarketcenter.homewoodsuites.com](http://www.dallasmarketcenter.homewoodsuites.com) After selecting dates, enter the Group Code under the Group/Convention Code section.
3. Go to your Personalized Booking Page. We have created a special booking! [http://homewoodsuites.hilton.com/en/hw/groups/personalized/D/DALMCHW-FFH-20141001/index.jhtml?WT.mc\\_id=POG](http://homewoodsuites.hilton.com/en/hw/groups/personalized/D/DALMCHW-FFH-20141001/index.jhtml?WT.mc_id=POG)

**Other local hotels:**

Embassy Suites, 214-630-5332  
Holiday Inn Express, 214-905-1400

**Flights:** There are two airports in Dallas.

1. Dallas/Fort Worth International (DFW). It is about an 18 mile/30 minute drive to the hotel.
2. Dallas/Love Field. It is about a 3 mile/10 minute drive. Dallas Love Field is a small airport, and flights typically cost more.

**Transportation:** There are a number of car rental locations at both airports. Listed below are a few Wheelchair accessible van rental companies. Rates for van rentals range between \$90 and \$99 a day.

- Dallas Wheelchair Transport LLC-469-363-1103
- Medical Transportation Solutions-866-755-1901
- Premier Accessible Van Rentals-866-755-8267

We are currently attempting to secure a wheelchair shuttle service, but we will not know until late July. So please be sure to check the box on the registration form.



## **MORE INFORMATION**

### **Topics to be discussed:**

- Dental/Biting
- DI/SIADH
- Multiple therapy sessions
- Grief
- GI issues
- Moms' group
- Dads' group
- Transitioning to teens/adulthood
- Writing/understanding an IEP
- Seizures
- Traveling with a child with HPE
- Marital issues/strengthening relationships
- Behavior issues
- Coping with stress
- Pulmonary
- Fundraising

*\*\*\*Topics are subject to change\*\*\**

### **Genetic Testing**

The NIH is offering free genetic testing for both parents and child with HPE during the conference.

There are a number of causes of HPE including exposure to chemicals, alcohol, or drugs. Some risk factors are unknown. The NIH is interested in studying if genetic factors are important in HPE. Genes contain the instructions for building body cells and reside in all cells as DNA. Mis-spellings in genes (called mutations) can alter the building instructions and lead to problems

with the way that the brain is built. The NIH is interested in understanding how genes build the brain and just how this can go wrong to cause HPE. Because a child gets his or her genes from both parents, the NIH is also interested in checking the parents' genes.

If you wish to participate, please fill out both the "2008 Checklist" and bring that with you to the conference, and fill out the "Request for Research" form and mail it to:

**Nancy Clegg, RN, CNS, PhD**  
**National Holoprosencephaly Project Director**  
**Texas Scottish Rite Hospital for Children**  
**Department of Neurology**  
**2222 Welborn St.**  
**Dallas, TX 75219**

*\*\*Please mail this form ASAP, it takes time for you and your family to be placed in the system.\*\**

You may choose not to take part, or withdraw at any time.



Patient Name: \_\_\_\_\_

## GENETIC ANALYSIS OF BRAIN DISORDERS CHECKLIST

Laboratory Accession Number: \_\_\_\_\_

Date received: \_\_\_/\_\_\_/\_\_\_

DOB or Age: \_\_\_\_\_ Sex: \_\_\_\_\_

Referring Physician: \_\_\_\_\_

Institution: \_\_\_\_\_

Address: \_\_\_\_\_

Phone number: \_\_\_\_\_ Fax number: \_\_\_\_\_

E-mail address: \_\_\_\_\_

### Pregnancy and Maternal History:

\_\_\_ diabetes                      \_\_\_ low cholesterol                      \_\_\_ viral infections  
\_\_\_ alcohol consumption                      \_\_\_ drugs/teratogens: \_\_\_\_\_  
\_\_\_ prenatal  
ultrasound: \_\_\_\_\_  
\_\_\_ chromosome study: \_\_\_ normal                      \_\_\_ abnormal : \_\_\_\_\_

### Pertinent Family History:

\_\_\_ cleft lip or palate                      \_\_\_ single central incisor                      \_\_\_ hypertelorism  
\_\_\_ hypotelorism                      \_\_\_ deafness                      \_\_\_ brain abnormalities  
\_\_\_ limb abnormalities                      \_\_\_ seizures                      \_\_\_ endocrinologic problems  
\_\_\_ pregnancy losses/ miscarriages                      \_\_\_ learning disabilities or mental retardation  
\_\_\_ other brain abnormalities, if any: \_\_\_\_\_

### Review of Systems:

\_\_\_ microcephaly                      \_\_\_ macrocephaly                      \_\_\_ hydrocephalus                      \_\_\_ proboscis  
\_\_\_ hypotelorism                      \_\_\_ hypertelorism                      \_\_\_ colobomas                      \_\_\_ cyclopia  
\_\_\_ low-set ears                      \_\_\_ dysplastic                      \_\_\_ ear abnormality: \_\_\_\_\_  
\_\_\_ notched nose                      \_\_\_ bifid nose                      \_\_\_ anosmia/hyposmia                      \_\_\_ maxillary hypoplasia  
\_\_\_ nasal pyriform aperture stenosis                      \_\_\_ absent nasal bone                      \_\_\_ choanal stenosis  
\_\_\_ bifid uvula                      \_\_\_ absent superior labial frenulum  
\_\_\_ cleft lip:                      \_\_\_ midline                      \_\_\_ unilateral                      \_\_\_ bilateral  
\_\_\_ cleft palate:                      \_\_\_ midline                      \_\_\_ unilateral                      \_\_\_ bilateral  
\_\_\_ single central incisor                      \_\_\_ other features: \_\_\_\_\_  
\_\_\_ laterality defects: \_\_\_\_\_

\_\_\_ dextrocardia                      \_\_\_ situs inversus                      Other congenital heart disease: \_\_\_\_\_  
\_\_\_ hypospadias                      \_\_\_ cryptorchidism                      \_\_\_ polydactyly                      \_\_\_ oligodactyly  
\_\_\_ syndactyly                      Other limb abnormalities: \_\_\_\_\_  
\_\_\_ seizures:                      \_\_\_ mild                      \_\_\_ moderate                      \_\_\_ severe  
\_\_\_ spasticity                      \_\_\_ hypotonia                      \_\_\_ dystonia                      \_\_\_ choreoathetosis  
\_\_\_ temperature dysregulation                      \_\_\_ mental retardation/developmental delay  
\_\_\_ self-abusive                      \_\_\_ sleep disturbances                      \_\_\_ hypopituitarism                      \_\_\_ diabetes insipidus

### Brain Imaging:

\_\_\_ MRI                      \_\_\_ CT Scan                      \_\_\_ Head Ultrasound  
\_\_\_ lobar HPE                      \_\_\_ semilobar HPE                      \_\_\_ alobar HPE  
\_\_\_ MIHF(midline interhemispheric fusion)                      \_\_\_ hydrocephalus                      \_\_\_ dorsal cyst  
\_\_\_ migration defects                      \_\_\_ cortical malformations  
\_\_\_ nonseparation of deep gray nuclei                      \_\_\_ corpus callosum agenesis/dysgenesis  
\_\_\_ others: \_\_\_\_\_

T E X A S  
**SCOTTISH RITE HOSPITAL**



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**REQUEST FOR RESEARCH NUMBER ASSIGNMENT**

Date: \_\_\_\_\_

First Name: \_\_\_\_\_ Last Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ Gender: \_\_\_\_\_ Ethnicity: \_\_\_\_\_

IF individual is a MINOR (under 18 yrs of age) we require Parent/Guardian Name:

\_\_\_\_\_

Street Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Telephone #: \_\_\_\_\_ Alternate #: \_\_\_\_\_

IRB#: \_\_\_\_\_ Staff Physician: \_\_\_\_\_

IF this person is a FORMER TSRHC patient and has had a name change First & Last Name patient was treated under:

First Name: \_\_\_\_\_ Last Name: \_\_\_\_\_

TSRHC#: \_\_\_\_\_

Upon receipt, Research encounter or research number will be assigned in  
Siemens and emailed to requestor.

**\*\*Please print a copy for your records.\*\***

Click below to email this form to Medical Records.