The National Organization of Vascular Anomalies & Texas Children’s Hospital Texas Medical Center
Presents the
2008 PHACES Family Conference

Wednesday November 5, 2008 – Friday November 7, 2008
Texas Medical Center, Houston TX & The Marriott Hotel & Conference Center

The National Organization of Vascular Anomalies & Texas Children’s Hospital have joined together to host a unique medical and research conference for individuals affected by PHACES.

Internationally renowned physicians will present a medical seminar on the current approaches in the care and management of PHACES. Leading research scientists in the field will provide information on the latest advances in understanding PHACES and the potential for the application of basic science for the development of treatment modalities. The opportunity to join the PHACES patient registry sponsored by TCH will be made available to all conference participants.

Faculty:

Denise W. Metry, M.D., Associate Professor of Dermatology and Pediatrics, Baylor College of Medicine
Ilona Frieden, M.D., Clinical Professor of Dermatology and Pediatrics, University of California-San Francisco
Dawn Siegel, M.D., Assistant Professor of Dermatology and Pediatrics, Oregon Health Science Center-Portland
Maria Garzon, M.D., Associate Professor of Dermatology and Pediatrics, Columbia University Medical Center
Geoffrey Heyer, M.D., Associate Professor, Division of Pediatric Neurology, Columbia University Medical Center
Christopher Hess, M.D., Fellow, Pediatric Neurology, University of California-San Francisco
Beth A. Drolet, M.D., Associate Professor of Dermatology and Pediatrics, Medical College of Wisconsin
Peter C. Frommelt, MD, Professor of Pediatric Cardiology, Medical College of Wisconsin, Children’s Hospital of Wisconsin

National Organization of Vascular Anomalies:

Denise Adams, MD, Clinical Director, Division of Hematology/Oncology Medical Director Comprehensive Hemangioma and Vascular Malformation Clinic, Cincinnati Children’s Hospital, Associate Professor of Pediatrics, Medical Director NOVA,
John S. DuBiel NOVA President,
Karla L. Hall, NOVA Executive Director,
Roy Clemens NOVA PHACES Family Coordinator

Agenda:

Wednesday 11/5/08: Families arrive; Marriot Hotel, Texas Medical Center
5:00pm- 7:00pm  Registration Marriot Hotel
5:00pm-8:00pm  Welcome Reception Marriot Hotel:

Thursday 11/6/08:  PHACES Conference , Marriott Hotel, Texas Medical Center
7:00am  Breakfast
8:00am  PHACES Conference Session I
11:00am  Panel Discussion
12:00pm  Lunch
12:30 -4:00pm  PHACES Conference Session II

5:30 pm  Buses Leave for Dinner with Families & Professors
Houston Zoo: Natural Encounters Building
Friday 11/7/08
7:00am -10:00am Continental Breakfast for Families Marriot Hotel
NOVA Board of Directors- Closing Remarks

Hotel Accommodations: Marriot Hotel: Houston Medical Center 6580 Fannin Street, Houston TX 713-796-0080
A room block has been reserved with a rate of $139 Double or Single Occupancy. Make sure you reserve your room under the TCH PHACES Meeting. Typical room rates at this hotel are $249. The hotel is a 26 story hotel in Houston located in the Texas Medical Center, connected via skywalks to the hospitals. All 386 guestrooms provide refrigerators, coffee/tea makers, cable and high speed internet access. There is a parking garage at a daily rate of $9. The Hotel is entirely smoke free. Rollaway beds and cribs area available upon request. The indoor pool is open each day. There is a fitness center for all guests. The hotel is ½ mile from the 18 hole Hermann Golf Course. Jogging paths are within a ½ mile of the hotel and tennis courts, bowling allies and mountain bike paths are 5 miles from the hotel. Visit the web site at: http://www.marriott.com/hotels/travel/houmc-houston-marriott-medical-center/ We encourage you to make reservations by telephone to ensure you get the group rate.

Travel:

Air Transportation: Transportation to Houston can be arranged through the Houston Airport System. George Bush International Airport 1-281-230-3000 or Houston/William P. Hobby Airport 1-713-640-3000 hosts flights from all major airlines.

Ground Transportation: Reservations for ground transportation to the hotel can be made by calling 1-888-261-8841 $30 Round trip.

Shuttle Service: Super Shuttle Services, Reservations to and from hotel and airport can be made by calling 1-800-258-3826. George Bush Intercontinental Airport $24.00 one-way, per person. Estimate taxi fare $45.00 one-way; William P. Hobby Airport $19.00 one-way, per person. Estimate taxi fare $25.00 one-way.

Houston MetroRail System: Travels between Downtown, Midtown, the Museum District, the Texas Medical Center, and Reliant Park. For more information, call MetroLine at 713-635-4000. $1.00 one-way.

Hotel Parking: The Houston Marriott Medical Center on-site parking $4.00 per hour, $9.00 daily. Valet parking $19.95 daily.

Top Attractions:

Houston Zoo: Located in Texas Medical Center and the Museum District. Houston Zoo address is 6200 Golf Course Drive, 713-533-6500. Hours of operation 9:00 a.m. to 6:00 p.m.

Houston Museum District: Includes 18 museums. For information call 713-715-1939 or visit www.houstonmuseumdistrict.org

Minute Maid Park: Located on the east side of downtown Houston at 501 Crawford and Texas Street. For more information, call 713-259-8500. MetroRail and Downtown Trolley line available.

Johnson Space Center: Located at 1601 NASA Parkway, approximately 25 miles South of Downtown Houston in the NASA/Clear Lake area. For more information, please call 281-244-2100. Hours of operation: Monday-Friday 10:00 a.m. to 5:00 p.m, & Saturdays 10:00 a.m. – 6:00 p.m.

Moody Gardens Galveston Island: Located at One Hope Boulevard, Galveston, Texas. Hours of operation: Monday-Sunday 10:00 a.m. to 6:00 p.m. For more information, call -1-800-582-4673.

Child Care: NOVA & Texas Children’s Hospital will not be offering Child Care for the Conference. Child Life Specialists from TCH will have some activities for the Children in the Clinic area.

Young Children will not be allowed into the Main Auditorium on Saturday Morning. A meeting room will be available with audio-visual of the conference live feed for those wanting to bring children to the seminar.

For more information contact NOVA at admin@mail.novanews.org or PO Box 0358 Findlay, OH 45840

National Organization of Vascular Anomalies
Name of Family Registering: ________________________________________________________
Name of Person Diagnosed with PHACES: ____________________________________________
Telephone: __________________________ Email: _______________________________________
Address: _______________________________________________________________________
State __________________________ Zip ______________
Number of People to attend conference ______________________________________________

Please list the names of those attending the conference include date of birth if under 18:

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- A Registration Processing fee is accessed at $25/registered family.
- Advance registration is required. The seminar is open to all registered guests 16 years old and older. Special consideration will be given to younger teens wishing to attend the seminars with parental permission. The material presented in these seminars is medically graphic.

Please Return Registration along with a $25 Registration fee to:

NOVA
PO Box 0358 Findlay OH 45840
Email: admin@mail.novanews.org
Patient Registration

Name of Individual with PHACES:__________________________

Date of Birth________
Telephone:_________________________Email:____________________________
Address:____________________________________________________________
Name of Parent or Guardian if
minor:______________________________________________________________
Diagnosis given to patient:______________________________________________
List Associated Symptoms of PHACES:___________________________________
__________________________________________________________________
Name & Address of Primary Care
Physician:__________________________________________________________
___________________________________________________________________
Is the patient included in the PHACES Patient Data Registry___________________
Is the patient a participant in any research study_____________ If yes which ones.
___________________________________________________________________
___________________________________________________________________
___________________________________________________________________

On a separate sheet of paper please provide a brief history and all treatment to
date,
Please read the attached NOVA Privacy Policy

I have read the NOVA Privacy Policy and agree to the policy as set forth by NOVA.

Signed by patient or legal guardian ___________________________ Date ________________

Signed by patient or legal guardian ___________________________ Date ________________

Return to: NOVA PO Box 0358 Findlay, OH 45840 Email admin@mail.novanews.org
NOVA Privacy Policy

The Health Insurance Portability Act of 1996 (HIPPA) is a federal program that requires that all medical records and other individually identifiable health information used or disclosed by NOVA in any form, whether electronically, on paper or orally be kept properly confidential. HIPPA provides penalties for covered entities that misuse personal health information.

As required by HIPPA we have prepared this explanation of how the National Organization of Vascular Anomalies will maintain the privacy of all health information and how we may use and disclose health information. NOVA will ask you to sign a Privacy Agreement at the Conference.

NOVA may create and distribute de-identified health information by removing all references to individually identifiable information. We may do this in one of the following but not limited to ways.

- NOVA may decide to compile data for our organizational report on the NOVA Family Conference
- NOVA may produce a report or update in the paper or electronic newsletter.
- NOVA may use de-identified information for other aspects of running our business.

Any other uses and disclosures will be made only with prior written authorization of the patient or parent/legal guardian of a minor child. Patients or the parent or legal guardian of a minor child may revoke such authorization in writing and NOVA is required to honor and abide by that request except to the extent that we have already taken actions on the original authorization.

Patients and or the parent/legal guardian of a minor child have the right to:

- Review and inspect your protected health information.
- To copy your protected health information.
- To a paper copy of this notice upon request.

We are required by law to maintain the privacy of protected health information and to provide patients and or the parent/legal guardian of a minor child with notice of our legal duties and privacy practices with respect to protected health information.

All individuals affiliated with the National Organization of Vascular Anomalies must agree to maintain the privacy of all protected health information, as stated in the above policy.

All medical information obtained by NOVA through our patient or parent/legal guardian contacts is to be used only by NOVA and is to be protected by the NOVA Privacy Policy in accordance with the law governing protected medical information.

No volunteer, contractor or other individual or organization having access to this information may use, or disclose any protected medical information for purposes outside of official NOVA business. This includes but is not limited to physicians and medical personnel using patient medical information obtained in the NOVA Family Medical Conference & Clinic for their private medical practices, research or institutions. Any such use must first be approved and expressed in writing by the Executive Board of the National Organization of Vascular Anomalies and the patient or parent/legal guardian of the minor child to whom the information is related.

Questions concerning the NOVA Privacy Policy should be directed to the Executive Director, Karla L. Hall. admin@mail.novanews.org