



Hereditary Hemorrhagic  
Telangiectasia Foundation  
International, Inc.

*(Osler-Weber-Rendu Syndrome)*

# 15<sup>th</sup>

## Hereditary Hemorrhagic Telangiectasia (HHT) Foundation International

*(Osler-Weber-Rendu Syndrome)*

## Patient and Family Conference

St. Louis, MO

October 22-24, 2010



### CONFERENCE LOCATION:

Eric P. Newman Education Center (EPNEC)  
320 S. Euclid Avenue  
St. Louis, MO 63110

### HOTEL ACCOMODATIONS:

Parkway Hotel  
4550 Forest Park Avenue  
St. Louis, MO 63108  
[www.theparkwayhotel.com](http://www.theparkwayhotel.com)

### Hotel Reservations:

Phone: 314-256-7777  
Online: <http://bit.ly/9jLIBH>

### Conference Registration:

<http://www.hht.org>



# Meet Us In St. Louis...

## For The 15th HHT Foundation International Patient And Family Conference

You are invited to the latest installment of the inspirational and educational National HHT Patient and Family Conference. This conference commemorates the 20th anniversary of the HHT Foundation and will have something for everyone...

- Whether you're affected or know someone who is,
- Whether you're a child or an adult,
- Whether you're newly diagnosed or a long-time patient,
- Whether you have never attended or have been to prior conferences.

The Program Committee has compiled an outstanding roster of speakers from around the continent to cover an ambitious list of topics: genetics of HHT, organ-specific management, psychological impact of HHT, anti-angiogenic therapies, and much more. This conference is also spotlighting a new *Youth Track* and "Advanced" workshop topics geared especially for returning participants, in addition to a unique opportunity to enroll in the NIH-funded Brain AVM research registry.

October is a wonderful time to visit St. Louis. The weather is fabulous. The foliage is spectacular. And baseball fever is in the air! The area has much to offer families, including a world-renown zoo, the Gateway Arch, glorious Forest Park, the Missouri Botanical Gardens, and so much more.

So bring the whole family and meet us in St. Louis!!



**Murali Chakinala, MD**  
Co-Chair, Program Committee



**James Gossage, MD**  
Co-Chair, Program Committee

*"This conference was about people who are brought together by a shared challenge and who are, in turn, provided an opportunity to respond, excel, and truly make a difference to enrich their own and each others lives."*

— Thomas L., following the San Diego Conference 2006

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## HHT Foundation International, Inc.... Celebrating 20 years of advancing clinical and research solutions and educating HHT families!

For two decades, the HHT Foundation has been promoting the health of HHT families through the establishment of HHT Centers of Excellence, DNA testing, groundbreaking research, physician education, and relationships with National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC).

Our greatest achievement, however, is hosting fifteen national and five regional Patient and Family Conferences. It's all about **FAMILY**. Our children are our legacy and for the first time ever, this event is truly a **FAMILY CONFERENCE** with the introduction of a **YOUTH PROGRAM**. Over the years, more and more children have joined their parents at these conferences, and although they fully understand how HHT impacts their family, they don't understand the information being presented. Children need to learn about this disorder so they can advocate for themselves in school, at camp, at the doctor's office. Children need to be armed with knowledge so they can make others aware of their disorder, which will increase awareness and diagnosis, and ultimately, save lives! And, just like adults, it is important for children to network with one another and realize they are not alone in this battle.

## Join Us In St. Louis For A Family Affair!

HHT Foundation Board of Directors  
HHT Foundation Executive Director and Staff

The Washington University HHT Center of Excellence is a **FAMILY** Center with a full team of adult and pediatric specialists. What better place to host our first comprehensive Patient and FAMILY Conference. While the adults are attending lectures and workshops, the children will be participating in age appropriate discussions with HHT specialists — physicians, nurses, and psychologists — to better understand their family's medical history.



## You will not want to miss one of the most important educational opportunities organized by the HHT Foundation!

There have been significant treatment and management advances over time and it is crucial for your health & well-being to be informed of the latest recommendations.

This national conference takes place every two years and the program has been expanded to meet your needs and address the most important aspects of HHT including:

- **Most current information** on HHT research, diagnosis, management, and treatment
- **Talk one-on-one** with leaders in the field of HHT
- **Network with individuals and families affected by HHT**
- **50 workshops and presentations to choose from, including but not limited to:**
  - HHT Diagnosis, Treatment, and Management in Children and Adults
  - Management of Anemia
  - Medical Treatment and Management of Nosebleeds in Adults and Children
  - Nosebleed Home Remedies
  - Genetic Advances in HHT
  - Exciting Research Advances and Opportunities for Your Participation
  - Medical Insurance Issues and Benefits You Are Entitled to by Law
  - Emotional and Psychological Aspects of Living with HHT and Strategies to Help Overcome Denial, Grievance and Quality of Life Issues
- **Youth Track** – a program specially designed for children and teens 16 years of age and younger. HHT pediatric physicians, nurses, and psychologists will conduct age-appropriate sessions on the genetics of HHT, screening & treatment of HHT at a center of excellence, sports & exercise, nosebleed management and much, much, more...
- A special **Gala Dinner and a Live Auction** on Saturday, October 23rd. This is a time to celebrate FAMILY and 20 years of advancing HHT in the medical and public communities.

## PROGRAM AT A GLANCE

### ADULT PROGRAM

#### THURSDAY, OCTOBER 21st

4:00pm – 8:00pm Patient & Family Conference Registration

#### FRIDAY, OCTOBER 22, 2010

8:30am – 10:00am Registration  
10:00am – 5:30pm Lectures, Workshops, Q&A  
5:30pm – 7:00pm Welcome Reception

#### SATURDAY, OCTOBER 23, 2010

7:00am – 8:00am Breakfast  
8:00am – 12:00pm Lectures, Workshops, Q&A  
12:00pm – 1:00pm Lunch  
1:00pm – 4:00pm Workshops  
6:30pm – 10:00pm Gala Dinner & Live Auction

#### SUNDAY, OCTOBER 24, 2010

7:00am – 8:00am Breakfast  
8:00am – 1:00pm Lectures, Workshops, Q&A

### YOUTH PROGRAM

#### FRIDAY, OCTOBER 22, 2010

9:00am – 10:00am Registration  
10:00am – 11:30am Age Appropriate Workshops  
Q&A with HHT Specialists  
11:30am – 12:30pm Lunch  
12:30pm – 3:30pm Age Appropriate Workshops  
Q&A with HHT Specialists  
3:30pm – 5:30pm Activities / Games / Movie  
5:30pm – 7:00pm Welcome Reception with family

#### SATURDAY, OCTOBER 23, 2010

7:00am – 8:00am Breakfast with family  
8:00am – 10:00am Age Appropriate Workshops  
Q&A with HHT Specialists  
11:30am – 12:30pm Lunch  
1:00pm – 4:30pm St. Louis Field Trip  
6:30pm – 10:00pm Gala Dinner & Live Auction with family

#### SUNDAY, OCTOBER 24, 2010

7:00am – 8:00am Breakfast with family  
8:00am – 12:00pm Age Appropriate Workshops  
Q&A with HHT Specialists  
12:00pm – 1:00pm Activities / Games / Networking  
1:00pm Re-join family

*We look forward to seeing you in St. Louis...*



# ADULT PROGRAM SCHEDULE

## FRIDAY, OCTOBER 22ND

**10:00AM – 10:30AM**

### WELCOME TO THE 15TH HHT PATIENT & FAMILY CONFERENCE

A warm welcome from representatives of the HHT Foundation International, the Board of Directors, and HHT Treatment Centers.

**10:30AM – 11:00AM**

### AN OVERVIEW OF HHT

A brief introduction to Hereditary Hemorrhagic Telangiectasia (HHT), including its symptoms and treatment.

**11:00AM – 11:30AM**

### GENETIC ADVANCES IN HHT

Genetic concepts important for understanding the inheritance pattern of HHT will be discussed along with the “whys” and “hows” of genetic testing for HHT.

**11:30AM – 12:10PM**

### HHT FROM A PEDIATRICIAN'S PERSPECTIVE

This session will describe and discuss HHT from a pediatric perspective. It will include the frequency and utility of screening for AVMs, management of pulmonary (lung) and intracranial (brain) AVMs at different ages, exercise and physical education, and family support.

**12:10PM – 12:40PM**

### BREAK WITH SNACK

**12:40PM – 1:00PM**

### QUESTION & ANSWER PERIOD FROM MORNING PRESENTATIONS

**1:00PM – 1:20PM**

### SCREENING AND MANAGEMENT OF PULMONARY AVMs

Pulmonary AVMs represent one of the most important manifestations of HHT. This session will discuss the manifestations and therapeutic approaches to AVMs in the lung.

**1:20PM – 1:40PM**

### SCREENING AND MANAGEMENT OF THE BRAIN

The multiple ways that HHT can affect the brain will be covered. Symptoms, diagnosis, screening, and treatment of HHT brain manifestations will be presented.

**1:40PM – 2:00PM**

### NIH RESEARCH - BRAIN AVM REGISTRY

As part of a Rare Disease Clinical Research Consortium, a team of researchers studying HHT and related vascular disorders was awarded a five-year grant to study brain AVMs in HHT. A lead researcher will discuss the study's objective to determine what genetic and clinical factors signal high risk for hemorrhage from brain AVMs and why this research is important to all HHT patients.

**2:00PM – 2:15PM**

### QUESTION & ANSWER PERIOD FROM AFTERNOON PRESENTATIONS

**2:30PM – 5:25PM**

### AFTERNOON WORKSHOPS

(CHOOSE ONE IN EACH SESSION)

| Session I<br>2:30pm – 3:25pm                         | Session II<br>3:30pm – 4:25pm                                   | Session III<br>4:30pm – 5:25pm   |
|--|---|--|
| (A) Understanding HHT: The Basics                    | (F) Screening Evaluation in Children                            | (I) Screening Evaluation in Adults   |
| (B1) Genetic Testing: Benefits and Implications      | (B2) Genetic Testing: Benefits and Implications                 | (J) The “At Risk” Individual / Genetic Information Non-Discrimination Act (GINA) |
| (C) Evaluation and Management of Brain AVMs          | (G) Migraine Headache Management (ADVANCED)                     | (K) Overcoming a Stroke  |
| (D1) Basics of Pulmonary AVMs                        | (D2) Basics of Pulmonary AVMs                                   | (L) Management and Long-Term Monitoring of Pulmonary AVMs (ADVANCED)             |
| (E1) Overcoming Denial: Becoming a Family Ambassador | (H) Bereavement: Loss of Your Health, Friend, Family, Loved One | (M1) Psychological effects of HHT on Partner Relationships                       |

**5:30PM – 6:45PM**

### WELCOME RECEPTION

## SATURDAY, OCTOBER 23RD

**7:00AM – 8:00AM**

### BREAKFAST

**8:00AM – 8:15AM**

### DEVELOPMENT OF THE EPISTAXIS SEVERITY SCORE

This session will review the development of the widely used Epistaxis Severity Score (ESS) which is standardizing the evaluation of nosebleeds.

**8:15AM – 8:45AM**

### NOSEBLEED EVALUATION AND MANAGEMENT: STATE OF ART

Nosebleeds are the most troublesome symptom for many HHT patients. This session will describe effective medical therapies and treatments and “at home” management techniques.

**8:45AM – 9:15AM**

### EVALUATION AND MANAGEMENT OF GASTROINTESTINAL TELANGIECTASIA

This session is designed to provide awareness of symptoms related to HHT of the intestines. The diagnosis and treatment of HHT of the GI tract will be described.

**9:15AM – 9:45AM**

### IRON DEFICIENT ANEMIA: MANAGEMENT AND LONG-TERM IMPLICATIONS

Anemia is commonly experienced by those affected with HHT and it frequently results from bleeding from the nose and/or gastrointestinal tract. This session will discuss the most effective ways to manage anemia in HHT patients.

**9:45AM – 10:00AM**

### BREAK

**10:00AM – 10:45AM**

### CARDIAC MANIFESTATIONS OF HHT: THE ‘HEART OF THE MATTER’

This session will cover various ways that the heart can be affected in HHT, including heart failure due to liver AVMs and pulmonary hypertension.

**10:45AM – 11:45AM**

### INSPIRING ADVANCES IN HHT RESEARCH

Current HHT Foundation Research Grant recipients present their preliminary findings.

**11:45AM – 12:00PM**

### QUESTION & ANSWER PERIOD FROM MORNING PRESENTATIONS

**12:00PM – 1:00PM**

### LUNCH

**1:15PM – 4:10PM**

### AFTERNOON WORKSHOPS

(CHOOSE ONE IN EACH SESSION)

| Session I<br>1:15pm – 2:10pm   | Session II<br>2:15pm – 3:10pm  | Session III<br>3:15pm – 4:10pm                                |
|--|--|---|
| (N1) Nosebleed Management: Nasal Hygiene, Medical Mgmt., and Home Remedies       | (N2) Nosebleed Management: Nasal Hygiene, Medical Mgmt., and Home Remedies | (X) Blood Thinners & Alternative Herbal Medicines (ADVANCED)  |
| (O) My Parent / Sibling / Child has HHT: A Session for Unaffected Family Members | (T1) Nosebleed Treatments: Therapeutics to Surgery (ADVANCED)              | (T2) Nosebleed Treatments: Therapeutics to Surgery (ADVANCED) |
| (P) Nosebleeds in Kids   | (U) Ask the Pediatrician (Parents Only)                                    | (Y1) Parenting a Child with HHT                               |
| (Q) Gastrointestinal (GI) Telangiectasia   | (V1) Health Insurance & Disability Determination                           | (Z) Advancing the Cure by Being a Research Participant        |
| (R1) Managing Anemia and Iron Replacement  | (R2) Managing Anemia and Iron Replacement                                  | (R3) Managing Anemia and Iron Replacement                     |
| (S) Pulmonary Hypertension (ADVANCED)  | (W) Heart Failure in HHT: The Overworked Heart (ADVANCED)                  | (AA) Liver AVMs & Liver Transplantation                       |

**6:30PM – 10:00PM**

### GALA DINNER & LIVE AUCTION

## SUNDAY, OCTOBER 24TH

7:00AM – 8:00AM

**BREAKFAST**

8:00AM – 8:30AM

### HOPE OF ANTI-ANGIOGENIC THERAPIES IN HHT

Angiogenesis — the process that results in blood vessel growth — is believed to be partially responsible for AVMs in HHT. This lecture will discuss therapies aimed at stopping or even reversing this process, including thalidomide and bevacizumab (Avastin).

8:30AM – 9:00AM

### PSYCHOLOGICAL ASPECTS OF HHT

Explore the emotional and social aspects of living with HHT and learn how to better cope with the emotional impact of the disorder.

9:00AM – 9:15AM

### QUESTION & ANSWER PERIOD FROM MORNING PRESENTATIONS

9:30AM – 12:45PM

### MORNING WORKSHOPS (CHOOSE ONE IN EACH SESSION)

| Session I<br>9:30am – 10:25am                        | Session II<br>10:30am – 11:25pm   | Session III<br>11:30am-12:45pm   |
|--|---|--|
| (AB) Planning for a Family: Issues and Options       | (AE) Pregnancy and HHT  | Skill Building Workshop: (SB1) Support Groups / Networking                       |
| (Y2) Parenting a Child with HHT                      | (AF) The SMAD4 Gene – Cause of Juvenile Polyposis/HHT Syndrome (ADVANCED) | Skill Building Workshop: (SB2) Become Your Own Advocate                          |
| (AC1) Aging and HHT                                  | (AC2) Aging and HHT   | Skill Building Workshop: (SB3) Spread the Word Through Fundraising and Awareness |
| (AD) Using the Epistaxis Severity Scoring Tool       | (V2) Health Insurance & Disability Determination                          |  |
| (E2) Overcoming Denial: Becoming a Family Ambassador | (M2) Psychological Effects of HHT on Partner Relationships                |  |

12:15PM – 1:00PM

### CLOSING REMARKS

## YOUTH PROGRAM SCHEDULE

*HHT is a Family Affair...  
The national conference should be too!*

For the first time, the HHT Foundation is offering a **YOUTH PROGRAM** in addition to the adult program. Children have a desire to understand the world around them and HHT can be scary if you don't understand it. We want to take the fear and uncertainty out of HHT and, in turn, provide children and teens the tools they need to overcome the challenges that this disorder can sometimes present.

The **Washington University HHT Center of Excellence** is a **FAMILY Center** with a full team of adult and pediatric specialists. What better place to host our first comprehensive Patient and **FAMILY** Conference. While the adults are attending lectures and workshops, the children will be participating in age appropriate discussions with HHT specialists – physicians, nurses, and psychologists – to better understand their family's medical history and learn how to care for themselves, while making new friends and having fun.

The **Youth Program** is designed for children and teens **16 years of age and younger who have HHT in their family**. HHT impacts those who inherited the disease as well as those who did not. This program will educate and address issues for both groups of children.

The **program will be fully supervised** by the HHT Foundation and its Board of Directors, along with HHT specialists from the Washington University HHT Center. There will be hands on interaction as well as a variety of games and activities. Everything is included for one low fee, including a t-shirt and a field trip to either the St. Louis Zoo, Science Center or the City Museum. (The field trip location is within one mile of the conference and the children will be transported with chaperones on the hotel shuttle bus.) The only additional cost is Saturday night's dinner.

Check out the program and we hope to see the whole **FAMILY** in St. Louis!

### FRIDAY, OCTOBER 22nd

9:00AM – 10:00AM **REGISTRATION**  
10:00AM – 10:15AM **PROGRAM OVERVIEW**  
10:15AM – 11:15AM **WHAT IS HHT? (ORGAN OVERVIEW, GENETICS)**  
11:15AM – 11:30AM **Q&A**  
11:30PM – 12:15PM **LUNCH**  
12:30PM – 1:30PM **SCREENING & TREATMENT AT AN HHT CENTER**  
1:30PM – 1:45PM **Q&A**  
1:45PM – 2:45PM **SPORTS AND EXERCISE**  
2:45PM – 3:00PM **Q&A**  
3:00PM – 3:30PM **BREAK (WITH SNACKS)**  
3:30PM – 5:30PM **ACTIVITIES / GAMES / MOVIE**  
5:30PM – 7:00PM **WELCOME RECEPTION**

### SATURDAY, OCTOBER 23rd

7:00AM – 8:00AM **BREAKFAST**  
8:00AM – 8:30AM **ACTIVITIES / GAMES**  
8:30AM – 9:30AM **NOSEBLEED MANAGEMENT**  
9:30AM – 9:45AM **TALKING TO YOUR SCHOOL NURSE**  
9:45AM – 10:00AM **Q&A**  
10:00AM – 11:30AM **CONCURRENT SESSIONS:**  
(1) I HAVE HHT OR  
(2) MY PARENT / SIBLING HAS HHT  
11:45AM – 12:30PM **LUNCH**  
1:00PM – 4:30PM **FIELD TRIP**  
6:30PM – 10:00PM **GALA DINNER / LIVE AUCTION**

### SUNDAY, OCTOBER 24th

7:00AM – 8:00AM **BREAKFAST**  
8:00AM – 9:00AM **ACTIVITIES / GAMES**  
9:00AM – 10:30AM **EMPOWERING YOURSELF: INCREASING AWARENESS OF HHT**  
10:30AM – 10:45 AM **BREAK (WITH SNACKS)**  
10:45AM – 12:15PM **MAKING A DIFFERENCE: LEARN HOW TO GET INVOLVED**  
12:15PM – 1:00PM **ACTIVITIES / GAMES / MOVIE**

# Join us for a Gala Dinner and Live Auction

This year begins The HHT Foundation's 20th year of educating, advocating for, and supporting our HHT Families. We want to celebrate with you at the Gala Dinner twenty years of advancing clinical and research solutions, educating patients and physicians, developing partnerships with institutions like NIH and CDC, and caring for families around the world.

On Saturday evening, after attending two full days of HHT presentations and workshops, we will gather for a relaxing, yet fun-filled Gala Dinner and Auction. This is a great time to socialize and make new friends. In the past, guests have enjoyed dressing up for dinner and others preferred to come in casual attire. How you dress isn't important. . . just come join in the fun!

## Do I hear \$500 .... Going Once ... Going Twice...

The live auction is always a highlight of the Gala Dinner. Auctions, in general, are lively and fun. But this year, we are really excited to have Chuck Abbott, past president of the HHT Foundation, return as our Auctioneer. With his humor and finesse, Chuck is always fun to watch! The auction is one of the Foundation's largest fundraising events so be prepared to be amazed by the fabulous vacations, jewelry, art, and specialty items. You will not want to miss this event!

## A Family Affair...

With the addition of a Youth Program, we anticipate more children at this year's Gala Dinner. Therefore, we will be offering a special meal for children (chicken tenders) at a reduced rate, however, any child can purchase an adult meal if they prefer. The Gala Dinner is not included in the Youth Program registration fees, you must sign up for this event separately. This is also a wonderful opportunity to reach out to family and friends not attending the conference and bring them into our HHT Family. The dinner is included in the adult conference registration fees; guests can pay for their dinner separately.

## HOW TO DONATE

It is important to contact the HHT Foundation to make us aware of the item, the donor, and its estimated value. The donor will receive a tax receipt for income tax purposes. If you have an item to donate, please mail, fax, or email the auction item information, via the attached form, to the HHT Foundation office. All donated items must be physically received by the HHT Foundation no later than September 15, 2010. WE WILL NOT ACCEPT DONATIONS AT THE CONFERENCE!

## CONTACT INFORMATION

HHT Foundation International, Inc.,  
P.O.Box 329, Monkton, Maryland 21111  
Tel: 410-357-9932 / Fax: 410-357-0655

# RAFFLE!!!

## The grand prize is ... an Apple iPad!

You can support the HHT Foundation, whether or not you are attending the conference, by purchasing raffle tickets for yourself or to sell to others.

You could be one of the lucky winners who take home one of three valuable prizes. The prize drawings will take place during the auction on Saturday night. However, you do not need to be present to win!

**1st Prize - IPAD**

**2nd Prize - Kindle**

**3rd Prize - \$100 Cash**

**1 ticket for \$5.00 or  
6 tickets for \$25.00**

### Pre-pay for raffle tickets by:

- Sending a check, along with the completed raffle section of the conference registration form, to the HHT Foundation Office
- Calling the HHT Foundation Office at 800-448-6389 (U.S.) or 410-357-9932 (International) to purchase tickets with a credit card over the phone
- Faxing the conference registration form with your credit card and expiration date, along with the number of tickets desired, to 410-357-0655
- Purchasing online at [www.hht.org](http://www.hht.org).

**Remember . . .** If you are attending the conference, you can bring your ticket stubs with you and hand them in at registration. You can also purchase raffle tickets at the conference. However, if you cannot join us in St. Louis, then you must return the ticket stub for each ticket with your name and phone number to the HHT Foundation Office by October 15th.



## AUCTION DONATION FORM

ITEM description: \_\_\_\_\_

VALUE as stated by donor: \$ \_\_\_\_\_ (Tax ID: 22-3115041. You will receive a receipt letter for income tax purposes. Donations are tax deductible as allowed by law.)

Donor Name: \_\_\_\_\_

Company (if applicable): \_\_\_\_\_

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

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

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

Contact person if different from above: \_\_\_\_\_

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

### Please mail, fax, or email the information to:

HHT Foundation, PO Box 329, Monkton, MD 21111

Fax: 410-357-0655 Email: [christine.auro@hht.org](mailto:christine.auro@hht.org)

Questions: Call Christine Auro at 800-448-6389 (US) or 410-357-9932 (Intl)

**All donations need to be received by the HHT Foundation by September 15, 2010.** Donations will not be accepted at the conference. The shipping address will be given to you upon receipt of this form.

*Thank you very much for your support!*



# Hotel And Travel Information

## LOCATION

The 15th HHT Patient & Family Conference will take place in the Gateway City... **ST. LOUIS.** The Eric P. Newman Education Center (EPNEC), our conference location, is situated on the Washington University Medical Campus, within minutes of downtown St. Louis and many sightseeing and shopping attractions.

### Points of Interest include:

- Gateway Arch
- Art Museums
- St. Louis Zoo
- Anheuser-Busch Brewery
- NFL St. Louis Rams
- Science Center
- Cathedral Basilica
- Six Flags Amusement Park
- Cruise the Mississippi River on a paddle wheel boat
- Much, much more...

In addition, MetroLink, the region's light rail system, connects downtown to the airport and many popular attractions and neighborhoods, while MetroBus can get you almost anywhere you need to go.

## CONFERENCE LOCATION ON WASHINGTON UNIVERSITY MEDICAL CAMPUS

### Eric P. Newman Education Center (EPNEC)

320 S. Euclid  
St. Louis, MO 63110

## HOTEL

The Parkway Hotel is a non-smoking facility located in Midtown St. Louis within the historic Central West End (CWE) and is less than four miles from the heart of downtown.

### The Parkway Hotel

4550 Forest Park Avenue  
St. Louis, MO 63108  
(314) 256-7777  
www.theparkwayhotel.com

## Hotel Amenities

Free high speed internet access in every guestroom (Ethernet); free Wi-Fi in hotel lobby; free shuttle within a 5 mile radius (6am-10pm); microwave, refrigerator and coffeemaker in every guestroom; exercise room; covered parking for \$5/day which includes twenty-four (24) hour in and out privileges.

### Additional Information:

- This is a non-smoking facility. Smoking in the hotel will incur a cleaning charge.
- 1 block from CWE Metro Link Station
- 2 blocks from the world famous Forest Park
- **Connected to EPNEC facility** (location of conference) by a covered walkway

## HOTEL ROOM RATES

The conference guest room rate is **\$103/night** (up to 4 people). This special rate is available only for reservations made on or before September 3, 2010. (Please note that this rate does not include applicable state and city taxes, which are currently 15.491%, and are subject to change)

## HOTEL RESERVATIONS

All conference attendees need to contact the Parkway Hotel directly for room reservations by calling **314-256-7777** or online at <http://bit.ly/9jLIBH>. You will need to guarantee your room with a major credit card by September 3, 2010 to receive the conference rate. Any requests after that date are on a space and rate available basis. A deposit equal to one night's room and tax is due with each reservation request and will become non-refundable if the guest does not arrive or cancels less than twenty-four (24) hours prior to the date of arrival.

## CHECK-IN TIME

The hotel's check-in time is 4:00pm. Guests arriving prior to 4:00pm will be able to store their luggage until rooms become available.



## CHECKOUT TIME

The hotel's checkout time is 12:00 noon. Guests departing after 12:00 noon should arrange to store their luggage with the hotel bell staff.

## CANCELLATION POLICY

All deposits for individual room reservations are fully refundable if a room is canceled twenty-four (24) hours prior to the arrival date.

## CONFERENCE ATTIRE

Casual attire is appropriate for the entire conference. Dressier attire is frequently chosen, but is not required, for the Saturday Night Gala Dinner and Live Auction.

# CONFERENCE REGISTRATION

You will not want to miss this HHT Patient & Family Conference! Come and learn about HHT from world renowned physicians and researchers while networking with other individuals and families affected by HHT every day.

## HOW TO COMPLETE YOUR CONFERENCE REGISTRATION:

1. Register for the HHT Conference
  - Online at our website, [www.hht.org](http://www.hht.org)
  - By mailing or faxing the conference registration form enclosed in this mailer
2. Completely fill out the conference registration form, whether online or on paper. **Early Bird Rates apply to conference registrations, as well as hotel reservations, made by September 3, 2010.**

3. Provide payment in one of the following ways:

- Paypal or Authorize.net, secure internet payment services. You will be linked to either service when you register online at our website, [www.hht.org](http://www.hht.org).
- Mail a check, money order, or credit card information with your paper conference registration form to:  
**HHT Foundation International, Inc.**  
**P.O. Box 329**  
**Monkton, MD 21111 USA**
- Fax credit card information on your paper conference registration form to: 410-357-0655
- Call in your conference registration information and credit card number to the HHT Foundation Office at 800-448-6389 (U.S.) or 410-357-9932 (International)

## PARENTS OF CHILDREN WITH HHT

- To participate in the Youth Program, you must complete a separate registration form for each child.
- There is an IRS ruling that permits parents to deduct "expenses of admission and transportation to a medical conference relating to the chronic disease of the individual's dependent". (See IRS Bulletin No. 2000-19, May 8, 2000)



**HHT Foundation International Inc.**

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U.S.A.

# 15<sup>th</sup>

## **HHT Patient and Family Conference**

October 22-24, 2010

**Reasons Why Your Peers Think You Should Come To St. Louis –**  
Conference Attendees from Chicago, 2008

**"I like the scientific nature of the talks...the physicians talk to lay people as though we are intelligent and well-informed. Just like we are!"**

**"I am thankful for the up-to-date information in order to be the best advocate I can be for my family. This information provides hope, reassurance and HOPE!"**

**"This was my first HHT Conference... I was quite overwhelmed with all of the information, but I learned so much from the discussions – both through groups and on an individual basis. I really appreciate all of the doctors that took their time to speak about HHT at a layman's level."**

***All in the Gateway City... Spectacular St. Louis, MO!***