



Hereditary Hemorrhagic
Telangiectasia Foundation
International, Inc.
(Osler-Weber-Rendu Syndrome)

DIRECT CONNECTION

Volume 3 • 2012

For Family, Friends and Supporters

SYMPOSIUM ON NOSEBLEED MANAGEMENT

A Highlight of this year's National Conference

Recurring nosebleeds can, and does, significantly impact a person's quality of life. In fact, they are the number one complaint from HHT patients around the world. Other than telangiectasias on the skin and in the mouth, nosebleeds are the most visible symptom of HHT. Most people think of nosebleeds as part of their HHT life but the reality is that they can become life threatening and should be managed by an otolaryngologist (ENT) who is familiar with HHT.

The challenge with managing and treating nosebleeds is that no one treatment is effective for everyone. Some people respond to topical ointments; other people don't. Some patients have experienced success with septodermoplasty while others prefer sclerotherapy. Still other individuals have resorted to the Young's Procedure or injections of Avastin for relief from their chronic nosebleeds. So what is right for you?

This year at the national patient and family conference we tried to unravel this mystery question by bringing together a distinguished panel of otolaryngologists from four of our North American HHT Treatment Centers. Dr. Marie Faughnan, HHT Foundation Scientific Director and Medical Director of the HHT Center at St. Michael's Hospital/University of Toronto, led the panel through a series of patient scenarios ranging from the individual who has an occasional nosebleed, is not anemic, but has social concerns to the person who bleeds often, takes oral iron and is still anemic. Surprisingly, there was consensus among the panelists on the level of treatment an individual patient should receive, however, the discussion became lively as the presenters debated the actual method of treatment.



Dr. Marie Faughnan moderated the distinguished panel of Otolaryngologists (from left to right): Dr. Terence Davidson (UCSD), Dr. Jay Piccirillo (Washington University), Dr. Douglas Ross (St. Vincent's Hospital/Yale), and Dr. Nathan Sautter (Oregon Health Sciences University)

The goal of the panel discussion was to show that the same patient scenario may warrant a different medical treatment based upon the physician performing the exam and the equipment and other resources available at a particular HHT Center institution. It was made clear that, with nosebleeds, there is no one treatment method for a particular symptom. These otolaryngologists have discovered that, although there is a certain success rate for each type of procedure based upon a patients' symptoms, each person will react to a specific treatment differently. Because of this, it is important for each patient to understand how they are impacted by HHT and know the options that are available to them.

The Symposium on Nosebleed Management was a huge success. In fact, another HHT Center ENT has already requested that the same type of panel be presented at the American Academy of Otolaryngology meeting next year. It would be amazing if HHT is chosen to be a primary presentation topic at the largest meeting of ENT professionals in the United States.

This panel discussion was professionally recorded, along with the other general session lectures, and is available for purchase on the HHT Foundation website store.

Laser Treatments – Usually very effective for preventing bleeds, but not as good for stopping an ongoing bleed. Disadvantages include nasal perforation and triggering a bleed. Benefits are usually temporary but longer than with cautery. There are many different types of lasers including KTP, YAG, and pulsed-dye.

Sclerotherapy – Sclerotherapy uses a detergent like material mixed with air to produce foam that is injected directly into the telangiectasia. The lesion coagulates quickly and the average benefit lasts about 3 months.

Young's Procedure – The surgical procedure involves closure of the nasal cavity affected with atrophic rhinitis by creating mucocutaneous flaps. These flaps are sutured together in two layers: first the mucosal layer then the skin layer. The nasal cavity is kept closed for a period time ranging from nine months to forever.

Avastin (Bevacizumab) Injections – For those with an Epistaxis Severity Score greater than 5, Dr. Davidson would recommend Bevacizumab submucosal injection. Care is taken not to inject Avastin on or near the cartilaginous septum for septal perforation is the one real risk of this procedure. The benefit of laser with Avastin has lasted up to two years.



PRESIDENT'S MESSAGE

I would like to report on the very successful 16th HHT Patient Conference in Orlando, Florida. I say successful not just from my perspective but from the perspective of the many participants who during the conference came up to me to express their gratitude for the information communicated, the dedication of the doctors who give their time and for the exciting HHT research reports. From an attendance standpoint it was one of the Foundation's best conferences.

The presentations were well planned and thought provoking. I learned new facts about the clinical treatment of HHT and was fascinated by the scientific research that is ongoing in HHT, even though I have attended many previous conferences. The scientific presentations reaffirmed for me the Foundation's goal of a cure for HHT is possible.

During the course of the conference I had a chance to sit down with attendees from all over the United States. We discussed their life stories, how and why they decided to attend a conference and what goals they had for the conference. The primary goal I heard from my discussions was **knowledge**, a better understanding of what is HHT and how to deal with it. The second goal was to **meet people** who have HHT and understand how they cope and deal with relatives who are in denial. Thirdly, individuals wanted to know how they could **get involved**. The question I kept hearing was "How can I help?" The attendees were energized by what they learned and want to help the Foundation move forward and find a cure.

The two ways I recommended that attendees could help were **fundraising** and helping to **pass legislation** in Congress to get federal funding. In my last newsletter to you I explained the importance of fundraising. The HHT board felt that without significant effort by the HHT Board and HHT Foundation to fundraise the Foundation would never meet its goals. At the conference, representatives from the 'HopeCrew' who have done a significant amount of fundraising in Michigan attended the conference to talk about their success. There were multiple opportunities throughout the conference to discuss fundraising opportunities.

All during the conference, Roy Forey an HHT Board member, solicited help to identify those legislators in Congress who can help sponsor and pass the HHT legislation. Roy asked people to contact their legislators, send emails, make personal visits and participate in yearly visits to Washington to move our legislative agenda along.

I want to thank Marianne Clancy and her staff led by Nicole Schaefer for their outstanding work in the planning and execution of the conference. It is large undertaking that requires extensive planning, coordination, negotiation and lots of late nights. The conference went off without a hitch.

As I write this in my home, having power restored last night after six days without power, I am reflecting on the last eight days and the impact Superstorm Sandy has had on all my neighbors, friends and the northeast of the United States. Please keep those people who lost everything in your thoughts.

Dennis Routledge

HHT FOUNDATION INTERNATIONAL

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James Gossage, MD, Medical Director
Augusta, GA

Marie Faughnan, MD, Scientific Research Director
Toronto, Canada

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Call the HHT office at
800-448-6389

or e-mail us at hhtinfo@hht.org.

Tell us your talents and how you feel you can help
move the foundation forward.

HHT Foundation MISSION

The Mission of the HHT Foundation International is to find a cure for HHT while saving the lives and improving the well-being of individuals and families affected by HHT.

TO ACHIEVE THIS MISSION, THE HHT FOUNDATION WILL:

- ❖ **FUND RESEARCH** to find better treatments and a cure.
- ❖ **EDUCATE FAMILIES AND PHYSICIANS** about HHT so that awareness of crucial diagnosis and available treatments prevents needless disability and death.
- ❖ **PROVIDE LINKAGES BETWEEN PEOPLE AFFECTED BY HHT.**
- ❖ **COLLABORATE WITH MULTIDISCIPLINARY HHT TREATMENT CENTERS WORLDWIDE** while advocating for patient access to these Centers.
- ❖ **ADVOCATE FOR AND SUPPORT THOSE WITH HHT** while increasing public, private, and governmental awareness of the disorder.
- ❖ **ENGAGE THE SCIENTIFIC AND MEDICAL COMMUNITY** so that talented individuals dedicate efforts toward advances in HHT screening, diagnosis, treatment, and research.

The HHT Board of Directors and Foundation staff live by this mission on a daily basis. Every project must meet at least one of our mission's objectives. This mission acts as a beacon of light that we are always striving to reach.

HHT Foundation VALUES

Characteristics that direct all of our thoughts and actions as we strive toward a common goal.

- | | |
|---------------------------------------|---------------------------|
| ❖ COMPASSIONATE | ❖ RESPONSIVE |
| ❖ ETHICAL | ❖ RESULTS ORIENTED |
| ❖ PATIENT & FAMILY FOCUSED | ❖ COLLABORATIVE |

Strategic Initiatives CAMPAIGN

As a less well-known disease, we have always had to make our dollars stretch as far as possible. We are fortunate to have a remarkable scientific team guiding the Foundation. The Board of Directors have identified three crucial projects - HHT Outcomes Project, Innovative Research, and Patient Care Strategies - that will help advance our mission.

We can beat HHT much faster than ever imagined! A long time member and donor observed, "my eyes were opened to that stunning revelation when I attended my first HHT patient conference in October. I know that I am not alone to realize that we are at a critical moment, with several breakthrough opportunities within our reach."

Please remember to give to the HHT Foundation this year.

DIRECT CONNECTION

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The HHT Foundation International, Inc. was formed to aid and support families with the genetic disorder Hereditary Hemorrhagic Telangiectasia (Osler-Weber-Rendu Syndrome).

Please feel free to copy this newsletter and share with family, friends and physicians.

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Please note: Be careful dispensing or receiving medical information on Facebook or Twitter. The information contained on these sites should not replace necessary consultations with qualified health care professionals.

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FROM THE DESK OF THE EXECUTIVE DIRECTOR

Important Growth in Initiatives and Opportunities

Over the last year, several members of the Board of Directors drafted a Strategic Plan for the HHT Foundation. This plan resulted in a framework for expansion of the mission, resources, and a focused plan of execution.

Spurred on by the realization that HHT scientific breakthroughs are possible within the next few years and the impact of ushering in 21st Century new treatment advances through therapeutic and novel advances, the Board of Directors determined that certain investments will make these advances possible.

The HHT Foundation has hired Dr. Marie Faughnan as the Scientific Research Director. She will work closely with Medical Director, Dr. Jim Gossage and will specifically:

- Expand the medical and scientific HHT portfolio
- Extend partnerships with pharmaceutical companies and the NIH to lead to faster translation of discoveries into clinical use
- Expand HHT projects with Centers of Disease Control (CDC)
- Lead collaborations on developing new treatments and novel drug combinations for HHT

Through leading key collaborations with our clinical and scientific research partners, we are poised to realize our mission to find a cure for HHT in our lifetime.

We also recognize that in order to meet our goals that there is a need for increased focus on leadership in fundraising specifically on increasing grassroots awareness nationally through the HHT national constituency and Regional Networking Alliances.

We welcome Joe Wallen as Manager of Special Events. Joe has had much experience in organizing events and has worked with the HopeCrew in Michigan over the last several years. **We have designated May 2013 as National HHT Walk Month.** Joe will be organizing efforts in schools and communities across the North America to increase HHT awareness and funds for research. Joe's responsibilities will include:

- Organize, expand and standardize events nationally
- Obtain corporate sponsorship nationally
- Engage, local, national and social media for general HHT awareness.

The HHT Foundation has identified three major project areas as key priorities. Our goal is to raise \$2 Million in the next year in order to launch these crucial priorities: They include:

HHT Outcomes Project: This registry will link all North American HHT Centers so that information can be submitted to determine who will benefit from certain types of targeted therapies by understanding the risk factors. Through incorporation of clinical and treatment anonymous data, outcomes of treatments can be assessed and patterns requiring additional study will be discovered.

Innovative HHT Research: Discovery of new therapeutics to regress and prevent the development of AVM's is the target of novel research approaches through collaborations with academic, government and pharmaceutical enterprises

Advancing Patient Care: It is time to set new standards for HHT care through updating the clinical guidelines. Over the last six years, a plethora of research has been published. Continued efforts will be made to increase the number of HHT Treatment Centers and to educate the medical community.

We need you to engage with the HHT Foundation to make these projects reality.



Marianne S. Clancy
Executive Director

A handwritten signature in blue ink that reads "Marianne S. Clancy". The signature is fluid and cursive, written on a white background.

DR. MARIE FAUGHNAN NAMED SCIENTIFIC RESEARCH DIRECTOR WITH THE HHT FOUNDATION INTERNATIONAL



This position was created to accelerate our efforts to develop novel partnerships, target therapeutic HHT drug development and lead collaborations to accomplish specific strategies.

Over the last 10 years, Dr. Faughnan has championed many HHT related efforts:

- ❖ Led the first ever HHT International Clinical Guidelines process resulting in screening and treatment recommendations and publication in the Journal of Medical Genetics
- ❖ Principal Investigator for the HHT project associated with Brain Vascular Malformation Consortia funded through NIH NINDS and Office of Rare Disease
- ❖ Led the HHT Foundation Research Program from 2004 to present
- ❖ HHT surveillance projects with the Centers of Disease Control (CDC) and serving as an HHT speaker at CDC Conferences

- ❖ Submitted North American HHT TRND application through the NIH North American National Center of Advancing Translational Sciences Program
- ❖ Expanded the number of HHT Centers of Excellence throughout North America and mentored physicians at the new centers.

Currently, Dr. Faughnan is leading efforts to develop the North American HHT Center Registry with the Foundation.

We are grateful for all of her leadership, dedication, commitment and contributions to our community for many years and are excited about the future novel partnerships and collaborations!

Dr. Marie Faughnan is an associate professor at the University of Toronto, clinician investigator and staff pulmonologist at St. Michael's Hospital. Dr. Faughnan is the Director of the Toronto HHT Centre as well as the Director of the Montreal HHT Centre. Her degrees include an MD from Université de Montréal and an MSc in Clinical Epidemiology from the University of Toronto.

Please join us in congratulating Dr. Faughnan on this well-deserved appointment!

HHT FOUNDATION WELCOMES JOE WALLEN AS MANAGER OF SPECIAL EVENTS



It is with great excitement that we welcome Joe Wallen who has accepted the position of Manager of Special Events! He will be working as an independent contractor supporting the fundraising and awareness efforts of the HHT Foundation.

As Manager of Special Events, Joe will organize, expand and standardize events on a national level, as well as seek corporate sponsorship for these events.

For the past few years, Joe has served as a member of the HopeCrew and donated his time and talent as a graphic artist and marketing consultant to the Our Hope Holds the

Cure grassroots fundraising campaign. He has owned and operated a small graphic design, event and marketing company since 2008. Joe welcomes the opportunity to share his knowledge of fundraising and special event planning on a national level.

Joe has already hit the ground running and is now planning the first ever "**National HHT Walk For a CURE**" scheduled for May 2013. His goal is to have at least 30 schools and communities participate in the first year.

To receive more information on the "National HHT Walk For a CURE" or any other fundraising and awareness event, please contact Joe Wallen at joe.wallen@hht.org.



NAMED 14TH U.S. HHT CENTER OF EXCELLENCE

We are excited to announce a new partnership with Froedtert & Medical College of Wisconsin as our 14th HHT Center of Excellence in the United States.

Dr. Robert Krippendorf, MD, assistant professor in the Department of Medicine, Division of Internal Medicine at Medical College of Wisconsin, is director of the new center. Other team leaders include, William Rilling, MD, interventional radiology and David Poetker, MD, otolaryngology.

Froedtert & Medical College of Wisconsin combine the strengths of Froedtert Hospital and the Medical College of Wisconsin (MCW) in an academic medical center that delivers advanced medical care. Froedtert & Medical College of Wisconsin are nationally recognized for exceptional physicians, research leadership, specialty expertise and state-of-the-science treatments and technology. Froedtert offers the only HHT program of its kind in Wisconsin, and one of few HHT programs in the Midwest.



David Poetker, MD; Robert Krippendorf, MD, MPH; William Rilling MD, FSIR

The program follows international, evidence-based guidelines for screening and managing the disease. While the program is adult-focused, they will test children for HHT.

The dedicated HHT team offers the full spectrum of coordinated care, from genetic counseling to diagnostic testing and treatment. Treatment options include performing vascular interventional and neurointerventional procedures. Through the Froedtert & Medical College of Wisconsin HHT program, patients have access to more than a dozen physicians specializing in HHT, many of whom are recognized as Best Doctors in America®.

Dr. Krippendorf, along with Froedtert & Medical College of Wisconsin have developed an HHT program designed to educate patients about their disease and to give

them the tools needed to cope with HHT when they return home. Support Groups are also available.

HHT SPECIALISTS Froedtert & Medical College of Wisconsin

Cardiac Surgery	Interventional
Cardiology	Neurology
Dermatology	Interventional
Genetic Counseling	Radiology
Genetic Medicine	Otolaryngology (ENT)
Hematology	Pulmonology
Hepatology	Thoracic Surgery
Internal Medicine	Vascular Surgery

FROEDTERT & MEDICAL COLLEGE OF WISCONSIN HHT CENTER

9200 W. Wisconsin Ave.
Milwaukee, WI 53226

www.froedtert.com/SpecialtyAreas/HHT

Dr. Robert Krippendorf
Director (Internal Medicine)

414-805-3666

Ask to speak with the HHT Intake Nurse

Milwaukee HHT Regional Network Alliance Support Group

Contact RNA coordinator: hhtRNA@froedterthealth.org

HHT Q & A CORNER

The HHT Foundation receives questions on a daily basis through our website. Below are the answers to some of the most commonly asked questions answered by Medical Director, *Dr. James Gossage*.

If I have had coil embolization of lung or brain AVMs, can my coils set off airport scanners?

It is uncommon but it can happen. The likelihood of detection depends on the coil material, its location, its quantity, and the sensitivity of the particular detector. In any event, if you do set off an alarm at airport security, they will take you aside and pat you down or wand you, and you can explain the implant at that time. TSA has a procedure on their website, http://www.tsa.gov/travelers/airtravel/specialneeds/editorial_1374.shtm#1

Can you have HHT in the eye?

Yes. According to three studies that examined a total of 141 patients, AVMs were seen on the conjunctiva in about 40% of patients. The most common manifestations were bloody tears and a hemorrhage on the surface of the eye. Both of these are relatively harmless and typically resolve on their own. Retinal AVMs were seen in only 2% of patients but can rarely cause serious problems. Because serious problems are uncommon, routine screening for ocular AVMs is not recommended.

Can a four year old boy have a stroke?

HHT can cause strokes by 2 mechanisms: 1) bleeding into the brain from a ruptured brain AVM and 2) blockage of a brain artery by a clot that passed through a pulmonary AVM. There have been a number of reports of ruptured brain AVMs, in children, and thus it is very important to screen all HHT children for brain AVMs before the age of one. Strokes from lung AVMs are much less common in children than in adults, but age-appropriate screening at an HHT Center is still recommended.

How many genes are there for HHT?

There are currently 3 genes that can be identified through genetic testing. Most patients with HHT have mutations in one of the two known disease-related genes: either endoglin (ENG, HHT1) or activin A receptor type II-like 1 (ALK1, ACVRL1, HHT2), both of which are involved in the TGF β pathway. Mutations in the SMAD4 gene can cause the development of a rare syndrome that combines the symptoms of juvenile polyposis and HHT. Recently, additional genes have been linked to chromosome 5 (HHT3) and chromosome 7 (HHT4), but their exact location and identity remains unknown, at this time.

HHT QUICK FACTS FOR HEALTH CARE PROFESSIONALS

This information can be photocopied and taken to your local physician, pediatrician and dentist. It also is available at www.hht.org.

- Hereditary Hemorrhagic Telangiectasia (also known as Osler-Weber-Rendu Syndrome) is a multi-system vascular dysplasia.
- It is uncommon, but not rare. Approximately 1.4 million people worldwide have HHT.
- Telangiectases and arteriovenous malformations (AVMs) are the characteristic lesions.
- HHT has extremely variable expression in terms of both location of lesions and severity.
- It is frequently misdiagnosed in affected individuals.
- Most commonly affected organs are the nose, lungs, GI tract, brain, liver and spine (in that order).
- HHT is an autosomal dominant genetic disorder.
- Denovo mutations are rare. A detailed family history shows almost all cases to be familial.
- HHT is heterogenic. Defects in at least 3 separate genes are known to cause HHT.
- 90-95% of individuals with HHT will develop epistaxis by adulthood, but severity varies from infrequent and minor to daily and severe.
- 90-95% develop at least a few telangiectasia on the face and/or hands by middle age.
- 20-25% develop significant gastric or intestinal bleeding, but rarely before 50 unless affected with juvenile polyposis in conjunction with HHT.
- 30-50% have pulmonary arteriovenous malformation (AVM).
- 10-15% have at least one cerebral AVM.
- Hepatic AVM are relatively common, approximately 5% are symptomatic.
- The severity of epistaxis or telangiectases of the skin does not correlate with the likelihood to have cerebral or pulmonary AVMs.
- Antibiotic Prophylaxis for dental and other "dirty" procedures, such as tattooing, are strongly recommended in all HHT patients with PAVMs.
- Untreated pulmonary AVMs are a common cause of ischemic stroke and brain abscess in HHT families.
- Untreated cerebral AVMs are a common cause of hemorrhagic stroke in HHT families.
- A .22 micron IV Filter is recommended for all HHT patients with known PAVMs, untreated PAVMs, or those not yet screened by an HHT Center of Excellence.



SAVE THE DATE

10th HHT Scientific Conference
June 12-15, 2013
Cork, Ireland

Dear Colleagues,

On behalf of the organizing committee of the 10th International HHT Scientific Conference, we are writing to ask you to "save the date" for this important meeting to be held on June 12-15, 2013 in Cork, Ireland.

This meeting will be supported by the HHT Centre in Ireland based at Mercy University Hospital, The Grace Nolan Foundation, The Lord Mayor of Cork, The Irish government Department of Health & Children, and the HHT Foundation International.

Cork City is a regional capital, at the centre of an area of outstanding natural beauty and Ireland's premier tourism region. Since the city was founded by St. Finbarr over 1,000 years ago, it has grown from a trading merchant port to a cosmopolitan vibrant 21st century city. The city, situated on the banks of the Lee River, is home to 123,000 people. It is located on the southwest coast of Ireland and is the 2nd largest city in the Republic of Ireland. In 2010, Cork's international appeal was recognized by Lonely Planet, a leading travel guidebook, as one of the top ten cities in the world to visit. We hope you will agree.

The dates, June 12-15, 2013, have been selected in order to not overlap with any major scientific meetings or religious/national celebrations. The website, www.hht2013.com, provides information regarding conference registration, lodging, abstract submissions, and other activities.

We hope you will take advantage of the combination of scholarly collaboration and beautiful location that this conference offers.

Ceád míle fáilte chuig Corcaigh is Éireann - A hundred thousand welcomes from Cork and Ireland!

Sincerely,

Dr. Carmelo Bernabeu
HHT Foundation International
Chair, Global Research &
Medical Advisory Board

Dr. Adrian Brady
Director
Irish National HHT Centre,
Mercy University Hospital

Mike Nolan
HHT Foundation International, Board Director
The Grace Nolan Foundation, President

THE HHT FOUNDATION INTERNATIONAL WEBSITE, WWW.HHT.ORG, HAS VALUABLE RESOURCES AND REFERENCE MATERIALS OR PATIENTS AND HEALTH CARE PROVIDERS:

HHT Treatment Centers

HHT Genetic Laboratories

Clinical Guidelines

International Patient Support Groups

Legislative Advocacy Updates and Documents

Education and Awareness Videos

Medical Articles

Clinical Trials

AND MUCH MORE...

ROBERT I. WHITE YOUNG CLINICIAN AWARD RECIPIENTS



Dr. Justin McWilliams



Dr. Takeo Nishida

Congratulations to Dr. Justin McWilliams and Dr. Takeo Nishida who have recently been awarded the Robert I. White Young Clinician Award for 2011 and 2012. Dr. McWilliams was nominated by Dr. Gary Duckwiler. Dr. McWilliams is an excellent clinician who has set up an impressive HHT Center at the University of California Los Angeles within the past two years; he is an advocate for patient care, has expanded the awareness of HHT and his Center is currently participating in two international studies to expand knowledge about HHT related clinical care.

Carmelo Bernabeu, Ph.D

Chair, HHT Global Research and Medical Advisory Board

Takeo Nishida, Ph.D, the 2011 award recipient, is supported by Dr. Robert I. White, Dr. Marie Faughnan and Dr. Karel terBrugge. Dr. Nishida recently published the largest HHT brain AVM series to date, with detailed correlations with genotype; he is actively committed to establishing a comprehensive HHT Center of Excellence in Japan, increasing awareness regarding HHT in Asia and continuing to pursue research into HHT brain AVMs.

Both candidates have an excellent curriculum vitae and embody Dr. White's qualities as compassionate and dedicated clinicians, devoted to improving HHT care. All of these merits were unanimously recognized by their nominators and by three independent ad hoc reviewers. In addition to the honor, both Dr. McWilliams and Dr. Nishida have been awarded \$2500 and free registration to the next International Scientific HHT Conference to be held in Cork, Ireland in June 2013 by the HHT Foundation International, Inc.

On behalf of the HHT Foundation's Global Research and Medical Advisory Board, I wish to congratulate Dr. McWilliams and Dr. Nishida upon receipt of the Robert I. White Young Clinician of the Year Awards. These congratulations are to be extended to their teams in Los Angeles (USA) and Akita (Japan) and we hope they will continue achieving so much for the HHT patients worldwide.

EUROPEAN RESPIRATORY SOCIETY AWARD FOR RARE PULMONARY DISEASE 2012

Dr. Claire Shovlin, Director of the HHT Center in England, won the 2012 European Respiratory Society Achievement Award for Rare Pulmonary Disease, for her twenty years of work on pulmonary AVMs and HHT. She delivered the prize lecture in Vienna, Austria in September 2012. Dr. Shovlin runs the Pulmonary Endothelial Research Group and is the co-coordinator for the respiratory module of the Imperial College MBBS Graduate Entry Program, and as part of her clinical portfolio, runs a national clinic for people with Hereditary Hemorrhagic Telangiectasia (HHT) and pulmonary arteriovenous malformations.

The HHT Foundation is grateful for all of Dr. Shovlin's clinical research related to HHT. Her discoveries associated with the correlation of low iron and blood clots, the impact of HHT on



pregnancy, the management of other medical conditions on HHT patients, along with her dedication to the clinical care of HHT patients in England, make Dr. Shovlin an invaluable asset to the HHT medical and scientific community.

EDUCATE. EMPOWER. ENGAGE. ENLIGHTEN. ENTERTAIN.

By Nicole Schaefer,
Director of Operations, HHT Foundation International, Inc.

Although the HHT Foundation hosts a regional conference every year and a national conference every two years, no two events are the same. The 16th National Patient and Family Conference was by far the most entertaining and informative, not to mention unique, conference in the Foundation's 25 year history.



EDUCATE. [ej-oo-keyt] *to provide schooling, train or inform – to educate oneself about HHT* HHT is an 'equal opportunity' disease - it shows no preference to race, gender, age, religion, or ethnicity – everyone is affected equally. HHT is also autosomal dominant which means it does not skip a generation and, as a blood vessel disorder, it can impact all organs and tissues in the body. Whether you are an adult, child or healthcare provider, knowing the basics about HHT is critical for living life to its' fullest.



This year's conference not only discussed the signs, symptoms, and treatments recommended for HHT patients but it provided a forum for learning about other aspects of the disease. For instance, Dr. Claire Shovlin (Director, Hammersmith Hospital, Imperial College HHT Center, London) revealed to the audience that her research has correlated low iron levels with blood clots and Deep Vein Thrombosis (DVT) while Dr. Raj Kasthuri (Director, University of North Carolina HHT Center, USA) taught us that there are a variety of ways to regulate iron deficient anemia. In addition, Ronalee Robert and Daniel Cortes (Registered Dietician and Clinical Pharmacist, St. Michael Hospital, University of Toronto HHT Center, Canada) shared nutritional information about foods that can influence the effectiveness of a variety of medications. In conclusion, Dr. Christian Merlo (Co-Director, Johns Hopkins HHT Center, USA) summarized everything we learned by illustrating how a doctor triages an HHT patient, whereas Dr. Sara Palmer (Clinical Psychologist, Johns Hopkins, USA) acknowledged the psychological impact that HHT can have on an individual.

Dr. Palmer also confirmed that our feelings of anger, sadness, and fear are "normal" but she emphasized that an HHT patient must overcome these feelings in order to LIVE a full, productive, rewarding life.

EMPOWER. [em-pou-er] *to give power or authority; to enable or permit – information empowered him to live full life* The saying, "knowledge is power" is particularly true for HHT patients and their families. Once educated about the medical, nutritional, and psychological impact of the disease, patients and healthcare professionals alike yield great power over the treatment and management of this disease.

It is believed that HHT affects 1 in 5,000 people (1.4 million worldwide). The troubling statistic is that an estimated 90% of those people don't even know that they have the disease. They are walking time bombs! Thankfully, education, resources, medical care and new scientific discoveries are available and provide hope for all families afflicted with HHT. For those who have been diagnosed, it is important to learn as much about HHT as possible because you have to take control of your medical care and treatment. There is hope in this disease - for improved quality of life, for innovative treatments, and for a cure. Educated patients and healthcare providers have the power to make this happen.



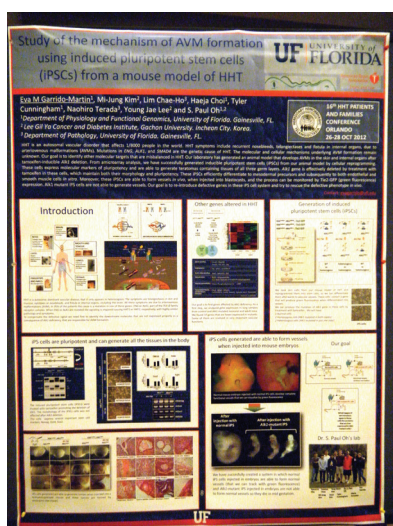
ENGAGE. [en-gey] *to occupy the attention or efforts of; to attract; to bind, as by pledge, promise, contract, or oath – He engaged himself in HHT education and research* For many people, attending an HHT conference can be a life-changing event. As a patient, the volume of information shared at a conference can be overwhelming and a little scary but having the knowledge, hearing about the scientific advances, and realizing that you aren't alone can be enough to conclude – "I need to DO something". The 'ah ha moment' for a physician or scientist may come when they make a discovery that they know will change someone's life. This leads them to attend a conference and meet other scientists and healthcare providers who are significantly impacting people's lives and the clincher happens when they hear about the unnecessary tragedies that occur because of ignorance, they meet HHT children and their families, and they realize that they can make a difference.



For the first time ever, three HHT research studies were onsite at the national conference engaging patients. Dr. Callyn Hall (Dermatologist, St. Louis Children's Hospital and Washington University HHT Center, USA), in her quest to learn more about skin manifestations in HHT, examined patients for skin

telangiectasias throughout the conference. Dr. Marie Faughnan (Director, St. Michael's Hospital, University of Toronto HHT Center, Canada) and Stacy Dornseif, (Research Coordinator, Washington University HHT Center, USA) enlisted eight patients for the Brain AVM Study while Dr. James Gossage (Director, Georgia Health Sciences University HHT Center, USA) recruited patients to participate in the multi-center clinical trial, the NOSE Study. We are anticipating that the results of these studies will have a tremendous impact on the treatment and management of HHT for people around the world. It's not too late to engage in this research.

Another first for the HHT national conference was the presentation of posters by scientists and clinicians engaged in HHT related research. Dr. Paul Oh (HHT Researcher, University of Florida) brought his team and three posters



describing the results of their ongoing research on the development and regression of malformed blood vessels in HHT mice. Dr. Reed Pyritz (Co-Director, University of Pennsylvania HHT Center, USA) summarized his research on the Cost Savings through Molecular Diagnosis of HHT (genetic testing) while Dr. Marie Faughnan presented preliminary findings from the NIH-funded Brain AVM

study. Several other presentations were made by North American HHT Centers, including UCLA, St. Michael's Hospital/University of Toronto and Washington University. The overall consensus was that we need to keep the research momentum going because a scientific breakthrough is within our reach and a cure for HHT is possible in our lifetime.

ENLIGHTEN. [en-lahyt-n] *to give intellectual or spiritual light; to instruct; to impart knowledge to – We need HHT patients, family members, friends and healthcare providers to enlighten their communities about this disease* With knowledge comes power and with power comes a responsibility to share what you have learned with others. In Orlando, we heard so many stories of how HHT patients are enlightening their community about HHT. The opportunities are endless.

Awareness can be as simple as wearing an HHT t-shirt or bracelet, leaving HHT literature in your doctor's office or sharing the video More Than a Nosebleed: HHT with your family and friends. Awareness can also come in the form of fundraising or contacting the press and media in your community. Joe Wallen, HHT Foundation Manager of Special Events shared with attendees our vision for a National HHT Awareness Walk in May 2013. We all interact with people who are unfamiliar about HHT - doctors, family members, teachers, colleagues, friends – on a daily



basis. The only way they will become enlightened about HHT is if YOU tell them.

The HopeCrew, volunteers who are organizing events in honor of the Nissan family, attended the HHT conference with the sole purpose of helping the Foundation, sharing their story, and encouraging others to do what they have done – raise awareness and money for HHT in their community. The Our Hope Holds the Cure events have helped several patients in Michigan identify the disease in their family, provided support to HHT families and friends who are uncertain about what HHT is, and educated a community of people who wouldn't know otherwise that HHT even exists. Whether you attended the conference or not, it may be time for you to share your story and enlighten others.

ENTERTAIN. [en-ter-teyn] *to have as a guest; show hospitality to; to hold the attention of pleasantly or agreeably; to amuse – We hope everyone was entertained at the HHT Conference* Orlando, Florida is never short on entertainment with Disney World, Universal Studios, and the multitude of other amusement parks in the



area. However, this year, the extracurricular activities associated with the HHT conference overshadowed the temptation of the local attractions.

The Hilton Orlando welcomed us by showing their hospitality through phenomenal facilities, amazing food, and managements' desire to make this an event that none of us will forget. The speakers entertained us with their informative talks. The 'Spooky Conference' was an unexpected Halloween treat that provided visual entertainment for us every day. On Saturday, the children in the Youth Program embarked a field trip to WonderWorks, a science center on steroids, and later enjoyed making s'mores over a bonfire by the hotel pool. A national conference just wouldn't be the same without the auctioneering antics of our very own Chuck Abbott (past board president and financial Founder of the HHT Foundation). And of course we can't forget Hurricane Sandy's impact on those of us travelling back to the mid-atlantic area.



Once again, the HHT Foundation is grateful for the speakers and researchers who donated their time to be part of this conference; for the patients and their families who made it a priority to attend this event; for the individuals who donated to the scholarship fund and the auction; and for the sponsors, exhibitors, advertisers, volunteers who support our mission. We hope to see many "old" friends and plenty of new faces in 2014.

CHILDREN LEARN ABOUT HHT AND HAVE FUN IN FLORIDA

By Cathleen Kinnear, Manager of Education and Awareness Programs, HHT Foundation International Inc.

Twenty-eight children from ten different states and Canada came to Florida for this year's HHT Youth Program. Many had never met another child with HHT and were glad to have the opportunity to speak freely about a disease that affects them.

"The goal of the Youth Program is to take the fear and uncertainty out of HHT", said Nicole Schaefer, Director of Operations for the HHT Foundation. "We do this by bringing in HHT specialists who work with children to speak to them at an age appropriate level."

Dr. Andy White, Co-Director and Pediatrician from St. Louis Children's Hospital / Washington University Pediatric HHT Center, explained to the children what HHT is and how it affects their bodies. They also learned the importance of genetic testing for children. Dr. Bob White and Dr. Jeffrey Pollak from the Yale HHT Center performed pulse oximetry tests on each of the children and explained the importance of exercise testing when looking for HHT problems in the lungs. Dr. White emphasized to the children that most sports, with the exception of scuba diving and football, are safe to do but you should always talk to your doctor first. Dr. Jay Piccirillo, an ENT from the Washington University HHT Center spoke to the children about nosebleeds and how to manage them.

The older children had the opportunity to meet separately and discuss how HHT changes with age and how to manage their HHT. They had in-depth discussions about handling the symptoms of HHT and also about how to talk to others about the disorder. Lori Spangenberg, a nurse with the Pediatric HHT Center in St. Louis, spoke to the group about the importance of



knowing as much as they can about HHT. She reminded them that many of them would be off to college soon and may need to speak to doctors on their own about the disease.

Lynne Sekarski, another nurse with the pediatric HHT Center in St. Louis, worked with the younger children and explained to them the basics of screening and treatment at an HHT Center and how HHT affects them. She used age appropriate materials, like pipe cleaners, to teach the younger children about coils and how they are used in the body.

Mixed in with all of this learning was plenty of fun. They played board games, video games, and took a thrilling ride down the Hilton Orlando's lazy river. On Saturday, all of the youth program participants took a field trip to WonderWorks, an inter-active amusement park, where they had the opportunity to experience a virtual earthquake and hurricane, as well as lay on a bed of nails. The children had another treat on Saturday evening – they enjoyed making s'mores by the hotel's firepit and watching a movie.

The end result of the three days together was a bonding between children who were brought together by a disorder that they all struggle with in one way or another. Many commented that would gladly return again.

"Knowledge is power and the ability to teach the young people in the youth program provides the knowledge that they will need to help educate and treat the future generations with HHT. It's amazing to hear a 5 year old talk about his/her "bubble echo" and how to control nosebleeds! I think the youth program serves a purpose and needs to continue at future conferences. These young folk could be our future medical providers that are now more well-versed in HHT than many other medical providers in the community today!"

Lori Spangenberg, RN

After the conference, I now understand all about HHT so that I know what to do when I have problems. It was really great, especially the activities and the field trip!"

Brandon W., Age 10

"The HHT Foundation has created a wonderful venue in the Youth Program, so that children can learn about HHT in a nonthreatening and fun environment. These children came to the program with varying levels of knowledge and I hope that we were able to meet all of their needs. Their willingness to participate in all the activities made this an exceptional experience for me. I was amazed by how much information these children had with relation to definition of HHT, screening tests and symptoms."

Lynne Sekarski, RN

THE HHT FOUNDATION RECOGNIZES MEMBERS MAKING A DIFFERENCE

This Year's Award Goes To... The national conference is the one time every two years that the HHT Foundation is able to recognize individuals who go "above and beyond". We are eternally grateful for everything that all of our members and their families do to advance our mission but want to give special recognition to this year's award winners.

COMPASSIONATE CHAMPION – L. Wayne "Doc" Hanks



Awarded to an individual who, while engaging in activities to further the cause of HHT, touches the heart of many and ultimately raises significant awareness of the disease as well as money to fund the Foundation's initiatives.

Doc Hanks is an active member of the HHT Foundation and serves as the Regional Network Alliance (RNA) Coordinator for his home state of Louisiana. His passion is conducting blood drives to raise awareness for HHT and replenish the blood supply that is used in part by HHT patients that suffer from nosebleeds and GI bleeding. Doc is also helping other HHT families across the nation to set up blood drives in their communities. He has been successful in getting wonderful media coverage for HHT, as well as legislative support for the HHT DATA Act.

TRISH LINKE AWARD – The HopeCrew



Awarded to an individual(s) who has led important initiatives or held a position in the organization, whose leadership has significantly moved the organization forward, made major contributions through fundraising, personal

donations, visible advocacy for HHT patients and families and encouraged awareness of HHT in the community.

The members of Michigan's HopeCrew are a dedicated group of volunteers, many of which do not have HHT, who work tirelessly to raise money and awareness in Southeast Michigan in hopes of finding a cure for a disease that affects their good friends, the Nissan family. The HopeCrew has set a goal to raise \$100,000 to fund research in 2013.

Accepting on behalf of the HopeCrew were: Jody Nissan, Clay Nissan, Angela Schram, Todd Schram, Joe Wallen, Shannon Loverich, Doug Cohen, Terri Mavity McLaren, Michael McLaren and Art Gutkowski.

LEGISLATIVE ADVOCACY AWARD – Roy Forey



Awarded to an individual whose leadership has helped advance federal recognition of HHT.

Roy Forey, an HHT Board of Director, serves as your ambassador for HHT in Washington, D.C. He cheerfully knocks on doors and follows up on your behalf and is an enthusiastic proponent of the political process. With Roy's perseverance, Congress is more aware of the HHT Diagnosis and Treatment Act (DATA).

ROBERT E. BERKMAN LEADERSHIP AWARD – Marie Faughnan, MD



Awarded to an individual who shows exemplary leadership qualities and is focused on achieving strong results. This individual is an effective communicator and visionary for the Foundation.

Dr. Marie Faughnan led the effort to establish the International Clinical Guidelines for HHT. She serves as a Principle Investigator for the Brain Vascular Malformation Consortia and is a key figure on many planning committees including the North American Database and the HHT TRND Program Application. She also serves as a Chair Emeritus of the Global Research Advisory Board for the HHT Foundation International.

LIFETIME SCIENTIFIC ACHIEVEMENT AWARD – Michelle LeTarte, Ph.D.



Awarded to a researcher who has committed their career to the study of HHT and has made great strides in scientific research.

Dr. Michelle Letarte, a Professor of Immunology at the University of Toronto and a Researcher at the Hospital for Sick Children, is best known among the HHT community for her discovery of endoglin, the gene that causes HHT1. Initially, Dr. Letarte spent several years establishing a genetic test for HHT while her more recent focus has been to understand the mechanisms which are defective. She has used mouse models to help her dissect the cells and molecules involved in HHT and to test potential treatments. Dr. Letarte has been a leading global researcher focusing on HHT.

RNA STAR AWARD – Keith Scouten



Awarded to the volunteer who has significantly raised awareness for HHT.

Keith Scouten, an HHT member from upstate New York, coordinated the first ever "Niagara Falls Lights Up for HHT Awareness" campaign in honor of HHT Awareness Month 2012. Keith took his campaign one step further and created a website, in which he embedded a link to a live webcam of the illumination so people all over the world could participate.

ACKNOWLEDGEMENTS

Thank You for your Contribution to the 2012 Patient & Family Conference

The HHT Foundation International would like to acknowledge the individuals, organizations, and corporations who contributed to the success of our 16th National HHT Patient and Family Conference.

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VOLUNTEERS

We have so many people to thank that have donated their time and talents throughout the year in preparing for this event. Thank you for making this conference a success!

Chuck Abbott, Auctioneer
Oranee Abbott
Amy Bertin
Angela Carlisle-Brown
Doug Cohen (Hope Crew)
Stacey Dornseif
Bonnie Gillis
Russell Haile
Marissa Maccia
Darlene Matonti
Terri McLaren (Hope Crew)
Chandra McMahon
Jack McMahon
John McMahon
Clay Nissan (Hope Crew)
Jody Nissan (Hope Crew)
Dennis Routledge
Maureen Routledge
Angela Schram (Hope Crew)
Todd Schram (Hope Crew)
Donna Stanford
Kim Sullivan
Shannon Loverich (Hope Crew)
Paul Nissan (Hope Crew)
Beth Plahn
Nichol Timothy

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St. Louis Children's Hospital and
Washington University School of Medicine
United Therapeutics

SCHOLARSHIP DONATIONS

We would like to thank the individuals who donated to the conference scholarship fund. Your support allowed 22 adults and 7 children to attend the 16th Patient and Family Conference.

Charles Atkins
Svetlana Vanjac, R.N.
Robert and Lee Berkman
Deborah Day
Michael Lewis
John and Chandra McMahon
John and Ruth McMahon
David and Charlotte Michael
Scott and Andrea Olitsky
John and Pat Spencer
David and Laura Rinn
Dennis and Maureen Routledge
Sheila Weiss

HHT FOUNDATION BOARD OF DIRECTORS

CONFERENCE SPEAKERS

We would like to thank the following individuals who donated their precious time as speakers to educate patients and families about the most current diagnostic, treatment, and management techniques for HHT.

Dr. Murali Chakinala	Dr. Jay Piccirillo
Dr. Mark Chesnutt	Dr. Jeffrey Pollak
Mr. Daniel Cortes, BSc. Pharm	Dr. Reed Pyeritz
Dr. Terence Davidson	Ms. Ronalee Robert, RD, CDE
Dr. Marie Faughnan	Dr. Douglas Ross
Dr. James Gossage	Dr. Nathan Sautter
Dr. Prakash Gyawali	Dr. Claire Shovlin
Ms. Katharine Henderson, MS, CGC	Ms. Lynne Sekarski, MSN, RN, CPN
Dr. Raj Kasthuri	Ms. Janie Sims, RN
Dr. Michelle Letarte	Ms. Lori Spangenberg, BSN, RN
Dr. Christian Merlo	Dr. Andrew White
Dr. Sara Palmer	Dr. Robert White

AUCTION DONATIONS

We would like to thank the Corporations, members, their families and friends who donated over 50 items, to support the mission of the HHT Foundation.

Chuck & Oranee Abbott
Michael & Daryl Anisfeld
Bob & Lee Berkman
Rena Bowser
Andrew & Marianne Clancy
Don & Deb Drysdale
Brian & Penny Fife
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Russell Haile
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University of Pennsylvania DNA Diagnostic Lab
Vitner's Collective
Vox International
Wheel of Fortune
5 Wacky Women

THE KEY TO UNLOCKING *THE CURE*

By Nicole Schaefer, Director of Operations, HHT Foundation International, Inc.

Does the word "Research" keep you from participating in the NOSE Study and the Brain AVM study? Do you want to help yourself and future generations overcome the complications of HHT? Do you want to get involved in the HHT Foundation but don't know how? If you answered yes to any of these questions then you need to consider participating in HHT Research!

Research is our best hope for understanding, treating and eventually curing HHT. The term "Research" can seem scary, intimidating or even time consuming but it is none of these things. People who take part in HHT research are contributing towards the care, treatment and wellbeing of countless numbers of people who are affected by this disease. There are many different reasons for wanting to be involved in research:

- To contribute towards the advancement of science
- To take an active role in your own healthcare
- To help combat feelings of helplessness
- To do something interesting
- To take an active role in society
- To access treatments which are not yet widely available
- To improve your own condition, wellbeing or quality of life

The HHT Foundation is currently recruiting patients to participate in two different types of research – a clinical trial and an information gathering study.

The **NOSE Study** (North American Study of Epistaxis) is a clinical trial designed to test the safety and effectiveness of current drug products (used in a nasal spray form) in treating HHT-related nosebleeds. Strict rules for clinical studies have been put in place by NIH and the U.S. Food and Drug Administration (FDA)

to ensure participant safety and the nasal sprays being tested in the NOSE Study have received FDA approval. **NEED: 93 more patients** (47 enrolled so far)

The NIH-funded **Brain AVM Study** is aimed at determining what genetic and clinical factors signal high risk hemorrhage from brain AVMs in HHT patients versus the general population. **This is a data gathering study.** Participants do not need to travel; all medical records (i.e., medical history, imaging, and saliva collection) can be retrieved remotely. **NEED: 725 more patients** (150 enrolled so far)

Some things you need to know about participating in an HHT research study:

- It is voluntary
- It is confidential which means personal information is seen only by those authorized to have access. Results from a study will be presented only in terms of trends or overall findings and will not mention specific participants.
- The Principal Investigator (PI) leads the research study and is responsible for the overall conduct of the study as well as the safety of the participants.
- Participating in clinical research is not the same as seeing your doctor.

Please consider participating in one, or both, of these studies. Why wait when you can make a difference NOW! For more information about each study, visit <http://hht.org/medical-scientific/researchstudies/> or call the HHT Foundation at 800-448-6389.

RESearch is necessary to help us understand the mechanism of a disease, to develop new treatments, to resolve conflicting theories or to determine what works best in a particular situation. Carefully organized and controlled research enables scientists to test and compare different theories and approaches, explore different methods and learn from other people's experience. It also enables them to rule out, or at least consider, external factors which might influence their results.

RESearch is also necessary to advance treatments from the laboratory to the practicing medical community. The findings from a research study can be recorded numerically and then statistically analyzed in order to determine whether the findings are significant.

With quantitative studies, the results can usually be generalized to the wider population. Clinical trials are particularly important for new drug therapies, similar to those being tested in the NOSE Study, because the FDA requires proof that the drug in question is safe and effective for its' intended use before they give it their seal of approval.

In HHT, animal models have been key in learning the basic science of the disease but **now it is necessary to compare the effects of the disease on the human population.** The HHT Foundation intends to find a cure for HHT but this can only be accomplished with your continued financial support and your willingness to participate in as many research studies as you qualify for.



THE IMPORTANCE OF KEEPING A MEDICAL HISTORY

By Linda Parsons

On Sunday, January 8th 2012, my 60 year-old husband, Bob, sat down at his computer and wrote out a chronological history of his life with HHT—a combination of pulmonary and stroke issues that plagued him since his thirties. He was scheduled for a doctor's visit later that week, and he was very proactive before every appointment. He always went armed with notes and a comprehensive list of all medications, vitamins, herbal supplements and questions for his physician. I'm using his written account from that very day to relay his story to you.

To start this story, I must take you back to 1985 when a good friend of Bob's opened up his medical practice. Looking for someone to break in his new X-ray machine, Bob agreed to have a chest X-ray. To our surprise, he discovered a large mass in Bob's lung. Bob decided to seek another opinion. A pulmonary physician performed a needle biopsy on the large mass. The doctor declared it benign, but admitted he was puzzled by the strange mass. Bob had a strong feeling that it had something to do with HHT. His father had been diagnosed with HHT in his sixties after years of nosebleeds. Aside from causing the occasional nosebleed, we really didn't know much about the condition. Bob had nosebleeds all his life, so he figured he had HHT also. Once we knew the mass wasn't cancerous, and since the doctors did not indicate an immediate need to have it removed, Bob and I put his strange mass in the back of our minds and continued with our busy lives raising two young daughters.

Now, jump forward 16 years. One February morning in 2001, Bob (a former smoker) was having his first cigarette of the day. Suddenly, he started having weakness and coordination problems on the left side of his body. After being rushed to the hospital, doctors diagnosed Bob with a "vascular migraine". The experience frightened Bob and he ended up needing physical therapy to regain left side functions. The doctor also discovered Bob was

extremely anemic, so he started taking iron supplements as part of his daily regimen.

Then, one November morning in 2005, Bob collapsed while shaving. After a trip to the emergency room he was told that he probably experienced a TIA or small stroke. Bob had low blood oxygen levels, but his physicians assumed that smoking was probably the cause for that low number. Doctors kept him overnight for monitoring.

Finally, the hospital released Bob with a prescription for a blood thinner. Bob reminded the doctor that he had HHT and could not even take a baby aspirin. The doctor stared at Bob and asked, "Well, do you want to have a stroke?" Bob was terrified of that possibility, so we apprehensively returned home with the prescription filled. A couple of days crawled by with Bob having strange tingling and weakness again in his right hand. An emergency room doctor checked him out and said to come back if something more drastic happened. Bob felt a sigh of relief that there didn't seem to be anything wrong, at least from the ER's point of view. He was beginning to feel he was becoming paranoid and anxious. The doctors didn't seem alarmed...so maybe he was overreacting?

That day, Bob and I decided to take a walk to get his mind off his health issues. Sitting down on the fireplace hearth resting from our walk, he pulled out his cell to call and check on his father. I heard him suddenly yell, "It's happening again!" His phone dropped, and he lost consciousness as he fell backwards. I heard a strange gurgling sound and large amounts of blood spewed from his mouth. This time he was airlifted to Methodist Hospital in San Antonio, 60 miles from our home. An alert ER doctor took note of his low oxygen level and ordered a CT scan of his lung. He then discovered an AVM. The good news was....he told us it was fixable! A mystery lasting more than twenty years was finally solved. This was that same strange mass that was discovered on that X-ray back in 1985. It took two operations to coil several large AVMs, but it was such a relief to know what was wrong with him.

At that point, Bob started being more health conscience. He stopped smoking and educated every new doctor about HHT. Bob and I flew to the HHT Center in Salt Lake City for a thorough screening. He did the genetic testing and had several CT scans and MRI's. He commented to me that it was extremely comforting to be around a hospital staff that was knowledgeable about HHT. It was at this time that Bob became involved with the HHT Foundation and acted as a regional support person to help those who had questions about HHT. At that time, the Dallas HHT center was only a dream. Bob continued being proactive about his health. He encouraged our daughters to pursue genetic testing. We suspected our youngest, Kelly, of having HHT because she had nosebleeds and her dentist detected telangiectases on her gums and lips. Shortly after Bob discovered his AVM, Kelly experienced tingling in her arm after her daily run. She noticed she was feeling out-of-breath and so she was also screened via CT scan. The results showed two small AVMs in her lung. The AVMs were coiled and Kelly is still an active runner today.

The day after Christmas 2011, Bob was helping a friend put together a new electric heater. He experienced a strange tingling once again, but quietly sat on the floor and waited a few seconds for this feeling to slip away. He continued to finish working on his project, but he made a doctor's appointment the next day. He also wrote a question about the episode and posted it on the HHT Forum. He wanted to get to the bottom of what was causing this reoccurring ailment. Unfortunately, the next available date for a doctor's visit was Wednesday, January 11th.

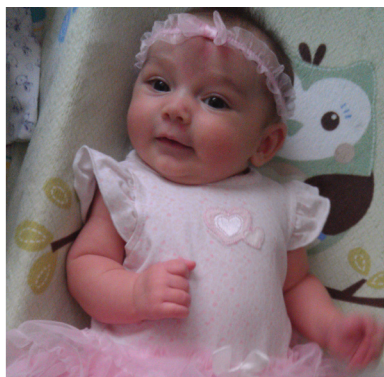
On Monday, January 9th, just one day after making that chronological history of his life with HHT, Bob awoke on a chilly day in Texas and began preparing for a business trip to Houston. He planned to return for his doctor's appointment that Wednesday. I received a phone call around 2:30 p.m. telling me that Bob had collapsed in his customer's office. The woman on the phone assured

One thing I think Bob's story highlights is that you, the patient, must be proactive about your own health. Ask questions if you don't understand something about your treatment. Educate yourself, and don't be shaken if your doctor has a blank look when you mention HHT.

me that someone was giving him CPR and the ambulance was en route. I told the woman that my husband had a condition called HHT and should NOT have aspirin. At first, I felt like this was probably another episode like the one a few weeks ago after Christmas. I remained calm and quickly called his doctor and had his records faxed to the ER that he was headed to in Houston. One of our dear friends lives close to that particular hospital, so I called her and asked her to be by Bob's side since I couldn't be there. After two nurses answered my frantic phone calls and laid the phone down to check on Bob, I finally heard a familiar voice of my friend on the other line. She said, "Linda, it's bad!" That is when I realized this wasn't going to have a good outcome. My husband and best friend of nearly forty years had suddenly passed away. The people on the scene told

me Bob didn't give any indication that he was feeling sick, he had been joking and talking with his customer just seconds before he collapsed on the ground. They believed he passed quickly...even though the paramedics tried for nearly an hour to resuscitate him. I didn't receive Bob's autopsy report until April. The cause of death listed was hypertensive cardiac disease. The damage done to Bob's heart in those early years from both untreated high blood pressure and his large AVM's probably contributed to his heart failure.

Fortunately, this story has a silver lining. On July 5th, 2012, our family was given a precious gift from God. Our first grandchild, Elle, was born. Bob knew that he had a grandchild on the way in those months before he passed away. My daughter, Kelly, knowing she had HHT worked closely with John Hopkins HHT Center of Excellence throughout her pregnancy. She and her husband live in Virginia, and she insisted that her doctors have a conference call to make sure everyone was on the same page and knew of the risks of HHT and a cesarean delivery. Kelly delivered a healthy girl, and her doctors performed a brain doppler sonogram to check for brain AVM's.



Through Elle's birth, we feel like Bob's legacy is living on. While he was not there to witness the birth in person, *Elle's precious smile, which is remarkably similar to Bob's, reminds us that we can find joy in the midst of a tragic loss. It also reminds us of the importance of continuing to fight for advancement in treatment and knowledge of HHT.*

Bob and I grew up in an era of watching TV shows where the doctors were bigger than life. Marcus Welby, Ben Casey, Dr. Kildare...

even those guys from the Mash unit. One thing I think Bob's story highlights is that you, the patient, must be proactive about your own health. Ask questions if you don't understand something about your treatment. Educate yourself, and don't be shaken if your doctor has a blank look when you mention HHT. When I had my teeth examined just recently, the dental hygienist told me how grateful she was that Bob had educated her about HHT. She visited the HHT website and passed information to her colleagues. Be a squeaky wheel and make sure you are heard.

At the conclusion of one of Bob's earlier writings, he noted two goals. *One* was to work towards getting a center established in Texas. I'm excited that Bob saw that dream fulfilled. But there was something else. *Two* Bob had a wish that someday there would be a network of physicians who understood and took an active role in treating HHT patients. *What if...every man, woman, child, and those others who love someone with HHT armed themselves with information explaining this disease?* It could be as simple as carrying a brochure about HHT (even printed from the website) into your doctor's or dentist's offices. Knowledge is a powerful tool that could prevent years of needless misdiagnosed cases of HHT.

Please join me in making Bob's wish a reality. My family and I appreciate your help with this ripple effect. Most of all, it helps to know that even though Bob is not with us physically, his spirit of service will continue to live on in the future.

NEW ENGLAND WEDDING PLANNER CREATES UNIQUE OPPORTUNITY FOR HHT AWARENESS

By Allyson Clancy, Boston University Student, daughter of Marianne Clancy, and HHT Foundation Representative

Ever thought that you could find a connection between the HHT Foundation and weddings? Terri Altergott certainly has, and as the founder of the wedding planning company, *Something Borrowed, Something New Events*, she began to incorporate raising awareness about the genetic disorder through a new fundraising scheme: charitable giving. The idea is designed to allow either guests or the newlyweds to give a donation to a charity or organization in lieu of gifts. Terri, who has become one of the top wedding consultants in the New England area, found this concept to be an innovative way to give back to a community or cause while celebrating one of the happiest moments of a person's life. A showcase to support a charitable themed wedding event was hosted by New England Wedding Professionals on October 4, 2012 in Woburn, MA where Terri added elements of the HHT Foundation to her display table. Pamphlets and an engraved champagne bottle with the HHT Logo fit in perfectly with the soft blue and gold theme, and received many compliments on the presentation.

The Altergotts were first exposed to HHT just four years ago when their son, Ben, was diagnosed with the disorder after years of blood transfusions, nosebleeds and low blood count levels. After receiving the news that their son had HHT, the family still felt in the dark about the disorder. Terri took the initiative to research HHT, and found herself on the Foundation's Facebook page. As she recounts, "[HHT] gave me the educational resources to fully understand this disease and it put me in a better position to advocate for my son." Today her son Ben has regular visits with the HHT specialists at Massachusetts General Hospital in Boston, MA where his lung AVMs are monitored. Terri feels very lucky that her son was diagnosed and treated early,



Terri Altergott and Allyson Clancy

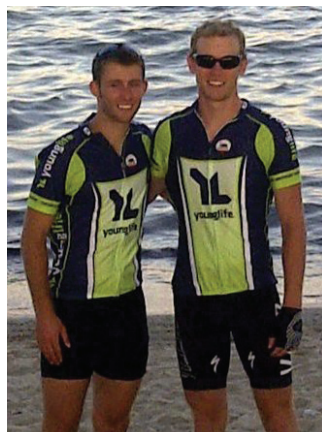
before things got worse. More importantly, she is educating those around her about the importance of checking family history and getting tested to see if individual family members have HHT.

Terri Altergott is a former teacher and financial analyst who started the *Something Borrowed Something New* consulting company in 2007. She specializes in planning weddings both in the United States as

well as in key destination locations such as the Caribbean Islands or in the breathtaking Italian countryside. She has been awarded the Best Wedding Planner in Boston and one of the Top 100 worldwide by the Wedding Industry Experts. She is extremely thankful for the assistance from the HHT community, and the continued dedication by the HHT Foundation to provide their members with the most up to date information regarding patient care and support. To contact Terri for a wedding consultation, please visit www.SomethingBorrowedSomethingNew.com. This novel yet simple idea to raise awareness for HHT is just one example of how those affected can make a difference and get the HHT Foundation closer to finding a cure!

LAKE TO LAKE BIKE TOUR

By Anthony Anzell



This past August my friend Jordan Campbell and I completed a bike ride from Lake Michigan (Holland) to Lake Erie (Monroe) in one day to raise money for our respective charities. The ride was 188 miles long and took us approximately 14 hours to complete. We departed from Holland, MI at 5:00 am and thanks to all the generous supporters we had during the

ride we were able to take pit stops every 30 miles to refuel and rehydrate. By the time we reached our destination at Monroe, MI it was 8:00pm.

Thanks to everyone who made donations. I was able to raise \$1,175.00 for the HHT Foundation. It was one of the best feelings in the world to be able to give back to a community that has already done so much for me. I was very blessed to not only have the opportunity to raise money for the Foundation, but to be an example that no matter what you are going through in life, anything is achievable.

Thank you everyone who supported us in our hopes to bike for a cause.

HOPEFEST 2012

By Cathleen Kinnear
Manager of Education and Awareness Programs,
HHT Foundation International



The HopeCrew from Southeast Michigan held the 3rd Annual HopeFest on Saturday, September 15, 2012 at Heritage Park in Canton, Michigan.

Over 300 people, many from different states, enjoyed a picture perfect day that included carnival rides, face painting, bounce houses, live entertainment and a petting zoo. Jody Nissan, the event organizer, continues to be touched by the HopeCrew, a group of friends and family who give unselfishly of their time to help raise money and awareness for HHT, a disease that affects her husband and two of her three children.



Terry Mavity-McLaren, a member of the HopeCrew, had five family members attend from two different states, three of which have HHT. Her brother, Rick Mavity came from Nashville, TN with his niece, Marisa to be part of this amazing event.



Jennifer Urbanek (pictured left with Amy Van Brussel)

are both members of the HopeCrew. Jennifer was so inspired from this year's event, she wrote this note to other members of the HopeCrew when she returned from this year's event.

The HHT Foundation would like to thank the Nissan Family and all of the members of the HopeCrew for all they have done, and continue to do, in their quest to help us find a cure. For more information on the Our Hope Holds The cure grassroots campaign, please visit www.ourhopeholdsthecure.org.

Dear Hopecrew,

Last year, we came to Hopefest to meet other families affected with HHT and to show our daughter, Skye, that she wasn't the only child in this world that had this terrible disease. We hoped that she could make some friends and contact them every once in a while. What we saw and got out of that day last year was nothing short of life-changing.

I've always wanted to do "my part" for HHT, but never really knew how. I would sign up for all the studies; send my blood, my MRI, test results, or whatever the next study needed in the hope that they would one day find a cure. That day last year at HOPEFEST I understood that I needed to do more; that WE needed to do more.

We joined the HOPECREW and for the last year we have been working with you all at the different fundraisers spreading the word about HHT and raising funds for research. We'll continue to do what we can until they find a cure.

It's been over a year now that we've known all of you and we are still just amazed at all the effort that you all put in; this past weekend being a shining example. HOPEFEST 2012 was just incredible.

Skye actually told me one day that she was glad to have HHT. Shocked to hear those words, I asked her why she said that. She answered, "Look at all the wonderful friends that we've made. Without HHT we never would have met them." I would have to agree with her, though I hate this disease and it scares me every time she has to have a test done; it brought us to the HOPECREW and all of you wonderful people.

We cannot thank you all enough for the love and caring that you show each and every day.

Thank you so much...

With LOVE and HOPE,

Skye, Jenn, and Bear
the Urbaneks

FUNDRAISING UPDATE

TOUGH MUDDER FOR HHT

By Terry Thompson, Jr., Vice President HHT Foundation Board of Directors

On October 20, 2012, six members of the "Nosebleed Section" team braved the 12-mile long course at the Tough Mudder in Englishtown, NJ to raise funds for HHT. Inspired by the Thompson family, with three daughters out of four having HHT, the group navigated 23 military-style obstacles alongside 15,000 other participants. It was not easy going, with electric shocks, ice baths, and underground tunnels providing plenty of challenges. There were many bumps and bruises along the way, but in the end five of the six members finished (one was lost to an eye injury in a mud pit!) and raised their full goal of \$10,000 for HHT. Thanks to the team for their effort, the many well-wishers, and the generous donors who helped advance the cause of HHT!



Eric Yeaney, Stephan Nowakowski, Greg Marion, Khaled Hamdy, Kyrsten Musich, and Terry Thompson

HOPECREW KIDS MAKING A DIFFERENCE

When HopeCrew member Alex Lividini heard her friend, Sydney Nissan, had to get surgery for her debilitating nosebleeds she was sad and felt like she needed to do something. She decided to get sponsors and run a 13-mile race in honor of Sydney and the HHT Foundation. She later presented her friend with a check for \$446.56 to give to the HHT Foundation. Alex is hopeful that they will one day find a cure for HHT so kids like Sydney do not have to suffer with this disease.

This is the definition of a true friend. The HHT Foundation wishes to Alex for all of her efforts to raise awareness for HHT.



SAVE THE DATE >> WILLPOWER 5K - APRIL 6, 2013



Nashville's newest 5K run is inspired by 13-year-old Nashville resident, Will NeSmith. In June 2012, then 12-year-old Will suffered a spontaneous brain hemorrhage -- an extremely rare event in children.

Surgeons saved Will's life, but his brain suffered serious trauma during the event. He endured 59 days in the hospital struggling to regain consciousness, his ability to move his body

and speak again. Since then, Will's inspiring journey has impacted thousands.

The WillPower 5K was founded by Will's supporters to help raise awareness for Will's rehabilitation and the genetic condition, Hereditary Hemorrhagic Telangiectasia (HHT), that lead to his brain injury.

You are invited to join Will on Saturday, April 6, 2013 at 7:30 am for the Will Power 5K!

Registration for this event opens in January 2013. For more information, please visit the WillPower 5K Page on Facebook. <https://www.facebook.com/#!/WillPower5K/info>



FUNDRAISING UPDATE

WALKING FOR HHT – GOOD FOR YOUR HEALTH, GOOD FOR AWARENESS

Recently, Joe Wallen, our Manager of Special Events attended a meeting with his daughter, Cora, at her former elementary school after requesting that they host a walk for HHT. Joe and Cora went into the meeting prepared to secure one elementary school for a walk but, to their surprise, the principal suggested a DISTRICT WIDE WALK, totaling anywhere from 7 to 15 schools! Both



Joe and his daughter will be at the next principal's meeting in December to present the walk to all of the elementary, middle and high schools in their district. **Lesson Learned: Opportunity is out there, you just have to ask!**

Another member of the HHT Foundation recently lost his wife to HHT. In her memory, he has begun organizing a walk in a park in his hometown. Friends and family are helping coordinate the details of the event. Awareness is very important to this group – they want to make sure that their community recognizes HHT as a disease that needs to be recognized and taken seriously. Their walk will focus on education, fundraising, and remembrance. **Lesson Learned: A walk can be held anywhere and is a great way to pay tribute to a loved one with HHT.**

WE NEED YOU...

The HHT Foundation Board of Directors have priority projects that will significantly impact research, education and awareness but we need expertise, volunteers, and financial support to transition these projects from priorities to accomplishments.

Media and Public Relations Contacts – Do you or someone you know work in the media? How about someone in a PR department? Do you or someone you know work for a social media organization? We need people who know this industry and can help guide us through the process of getting our message to the masses.

Communications Consultant – We need someone to work in conjunction with the Board of Directors to develop and implement a full communications strategy. Our message needs to be coordinated through all of our programs, including media, website, branding, etc.

Board of Director Nominations – We have strong leadership and skill sets on our board of directors but we are always looking to add additional members. We have new positions opening July 1 but need to begin the application process now. This may be the most rewarding volunteer work you will ever do.

Please call the HHT Foundation (410-357-9932) if you, or someone you know, is interested in any one of these prospects. Your friends and family who don't have HHT may not know how to "help you" but these openings will give them the opportunity to make a difference in the HHT community.

National HHT Walk For A CURE

WALK

May 2013

Joe Wallen

Manager of Special Events

HHT Foundation International, Inc.

joe.wallen@hht.org

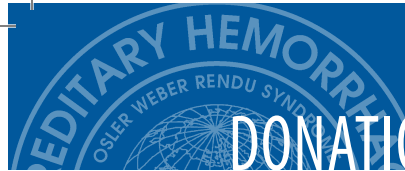
248.924.0797

Please join the **HHT Foundation** the fight against a disease that affects 1 in 5,000 people. You can organize your very own walk-a-thon to raise money toward funding research that will aid in finding a cure for HHT. The walks are not limited to school children. They can be done by anyone at their place of business, church or local park.

Please keep in mind, if you have another event in mind or would like to have a walk during a different month, we will accommodate your needs. If you need an idea for a fundraising event, please contact me via email or phone. Thank you!

- Walks may occur on any day during the month of May 2013. Pledge sheets must be turned in by April 26, 2013.
- Kids walk for a maximum of 30 minutes. Every walker gets an awareness bracelet!
- \$50 minimum pledge will get you a HHT Walk For A Cure T-shirt. \$75 pledge will get you a T-shirt, plus a movie day!
- The class that raises the most money also wins a PIZZA PARTY!
- And most importantly, the kids learn about helping others.

Teaching our children about **COMPASSION,**
HOPE and **HUMANITY,** as we work towards a **CURE.**



DONATIONS TO THE *Foundation*

Our sincere and heartfelt thanks go out to everyone who has contributed to the HHT Foundation whether through research fund, membership, general, or tribute donations. Below we list the donors who have contributed to the HHT Foundation through a memorial or tribute gift from July 1, 2012 to October 31, 2012.

TRIBUTE DONATIONS

DONATIONS THAT CELEBRATE *In Honor Of...*

Bob Berkman

Brent Berkman

Bob and Leora Berkman

Brenda Bouttell
Mr. and Mrs. Robert Brazener

James Caillouet

Ashleigh Garner

Anonymous

Evelyn Deane

Patricia Jedlicka

Natalie and Vincent Reis

Trish Linke

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Allan and Gwen Olitsky

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Mr. and Mrs. Keith Scouten

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Sublette Children & Grandchildren

Frank and Judy Sublette

Robert and Pat White, M.D.

Ms. Anne Legosa

MEMORIAL DONATIONS

IN LOVING *Memory of...*

William Adams

Margaret Adams Ibison
Alan Isspass
Carol J. Miller

Loren Anderson

Bill and Orda Podratz

Thomas Betz

Heather Coon
Charles and Nancy Karwelies
Steven and Georgette Pergola
Brian and Beth Routledge
Dennis and Maureen Routledge
Vincent and Lorraine Salamone
Marsha Spolansky

Evereste Black

Chris and Dena Engen
West Seattle Aux F.O.E. 2643

Dorothy Honchorek Cantrell

Bev Honchorek

Children Lost to HHT This Year

Allan and Gwen Olitsky

Ronald Corey

Barbara Corey

Donald Cruise

Bill and Orda Podratz

Adolf D-Amico

Arlene Lewis

Theresa Eichhorn

Kathy Davis
Karen Eichhorn
Karen Libor

Anthony David Garcia, Jr.

Mrs. Casey Matthews

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Mary Hollister Peterson

Beth and Jim Plahn

Patty Rosen

Jennifer Rosen

Ronald Sander

Bill and Orda Podratz

Evelyn White

Elisabeth Ruscitti

Dennis Wood

State Bank of Speer

The HHT Foundation wishes to thank the following people for their generous contributions that have made research advancements possible. They are responsible for raising over \$100,000 each for education and research either through personal donations, corporate giving and/or fundraising.

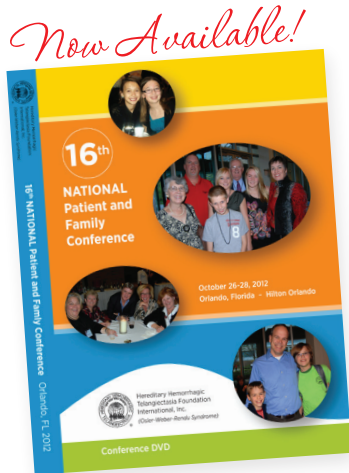
EDUCATION & RESEARCH FOUNDERS

*Charles and Oranee Abbott
Robert and Leora Berkman
Michael Nolan & the Grace Nolan Foundation
Dennis and Maureen Routledge
Clayton and Jody Nissan*

*Stephen and Jane Silk
Jennifer Blevins
Marc and Diana Meiches
Anonymous Donor Family
Anonymous Donor Family*

The 16th National Patient and Family Conference DVD

The HHT Foundation is thrilled to announce **The 16th National Patient & Family Conference DVD** is now available through our online store. This 3-Disc DVD Collection is filled with important information you will not want to miss. Learn the most current information on HHT research, diagnosis, management and treatment. Watch presentations on specific organ involvement and health concerns specific to HHT, including but not limited to:



- Brain and lung AVMs
- Cardiac Manifestations of HHT
- Symposium on Nosebleed Management
- A pediatrician's perspective on screening, treating, and managing HHT in children
- Nutrition
- Iron Deficient Anemia and the relationship of HHT and blood clots
- Emergency situations and medications to avoid

While we could not tape every workshop, all of the General Session lectures have been included in this DVD.. A 200+ page conference program book will accompany the 3-Disc DVD set which includes speaker profiles, a directory of North American HHT Treatment Centers, as well as the slide presentations from all lectures.

Special Discounts for HHT Members: HHT Members can purchase the DVD and Program Booklet at a special member price.

We hope that you will take advantage of this wonderful opportunity to educate yourself and others about HHT. If you have additional questions, feel free to contact the HHT Foundation at 800-448-6389.

ORDER ONLINE: www.hht.org/store

MAIL ORDER: Complete and return the order form below

The 16th National Patient and Family Conference DVD ORDER FORM

Conference DVD 3-Disc Set

(Includes Program Booklet)

HHT Member Price*

\$50.00

(Includes \$10.00 shipping & handling for U.S.)

Non-Member Price*

\$65.00

(Includes \$10.00 shipping & handling for U.S.)

*International Shipping Rates

Canada & Mexico - Add \$5.00

All other International Orders - Add \$10.00

ORDER INFORMATION:

_____ # Quantity @ \$50.00 (Member) \$ _____

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Domestic Shipping: \$ Included

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_____ Membership @ \$55.00 \$ _____

_____ Additional Donation \$ _____

Subtotal: \$ _____

Total: \$ _____

PURCHASER/ SHIPPING ADDRESS

Name: _____

Address: _____

City/State/Zip: _____

Phone: _____

Email: _____

For Office Use Only:

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PAYMENT OPTIONS: (CHECK ONE) *Make Checks Payable to the HHT Foundation*

() Check Enclosed

() Visa () Master Card () American Express () Discover

Card Number: _____

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Name as it appears on card: _____

RETURN ORDER FORM TO:

HHT Foundation International, Inc.
P.O. Box 329
Monkton, MD 21111 U.S.A.

OR EMAIL TO:

Cathleen.Kinnear@hht.org



HHT Foundation International, Inc.
P.O. Box 329
Monkton, MD 21111
U.S.A.

Double Your Donation... Double the Impact **STRATEGIC INITIATIVES CAMPAIGN**

Please consider donating to the HHT Foundation International

*Now through January 31st all donations will be
matched dollar for dollar up to the first \$100,000.*

Your support makes our Foundation stronger and allows for important
initiatives that benefit all families affected by HHT.

Look for your personal letter in the mail
or donate online at **www.hht.org**