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Direct Connection

For Family, Friends
and Supporters

June Declared National HHT Awareness Month

By Marianne S. Clancy, Executive Director

I am thrilled to report that the United States Senate has PASSED Senate Resolution 161 (formerly Senate Res. 141) declaring June 2009 as the First National HHT Awareness month! Senate Resolution 161 was introduced and co-sponsored by Senators Tim Johnson, South Dakota and Robert Bennett, Utah. On June 11, 2009 the House of Representatives Resolution 536 was introduced and co-sponsored by Representatives Richard Neal, Massachusetts and Joseph Wilson, South Carolina. Check your email for an announcement of the House Resolution. Recognition by both legislative bodies dramatically increases HHT awareness while recognizing the need to pursue research to find better treatments and an eventual cure for the disorder.

This accomplishment is a huge step forward for all families affected with HHT and results in the culmination of years of work that began in 2004 forging relationships with members of Congress.

NOW, everyone within the HHT community needs to ensure that their Congressmen/women agree to co-sponsor House Resolution 536 by contacting either Rep. Richard Neal's (D) Chief of Staff, Ann Jablon, at 202-225-5601 or Rep. Joe Wilson's (R) Legislative Director, Melissa Chandler, at 202-225-2542.

You will find specific information about what you need to do next, along with the online links within the legislative section of this newsletter.

It is very important that all family members and close friends of HHT families who live in South Dakota, Utah, Massachusetts and South Carolina phone and e-mail the offices of the

sponsors to thank them for their leadership on our long neglected disorder.

The HHT Foundation will continue to keep you apprised through e-mail alerts and future newsletters as we continue to pursue our strategy for federal funding for research, HHT Centers of Excellence, and outreach awareness/education programs. Your support of the Foundation through membership and donations to our Legislative Call to Action have made this resolution possible.

National HHT Awareness Month is a reality due to the hard work of those who have worked closely with the Foundation through the years. I wish to gratefully acknowledge:

- **Bob Berkman**, President, for his leadership and vision
- **Jane Silk**, Past-President, who joined me on this journey in 2004
- **Beth Plahn**, Past-President, who obtained sponsorship from Senator Johnson
- **Chuck Abbott**, Past-President, and his wife, Oranee, along with Co-Directors of the Utah HHT Center, Dr. Jim Carlisle and Jamie McDonald, M.S., CGC, who met with Senator Bennett through the years to forge a working relationship
- **Chuck Atkins**, Board Member and Advisor on Legislative Strategy
- **Mike Daly, Parks Moss and Bob Berkman**, Board Members, for facilitating sponsorship



with Congressmen Neal and Wilson, respectively

- **Sharon Williams**, HHT Foundation Legislative Advocacy and RNA Manager, who has been assisting with this effort
- Everyone who has journeyed to Washington DC, visited local district offices, made phone calls, sent e-mails and letters to bring HHT to the attention of the legislators.

Our work will continue and your involvement is needed more than ever!

We look forward to presenting our case to our Washington allies during Capitol Hill Day and celebrating National HHT Awareness Month.

President's Message

By Bob Berkman



What an important period of time we are entering. The content of this Newsletter will provide details on what has occurred over the last six months. The work that our staff, our Board, and our active members have done gives us a unique opportunity to move our Mission forward in a dramatic fashion.

We are positioned to make great strides. We are positioned, but we are not there yet. This coming year could provide the breakthroughs that we have sought for years. In order for this to happen, we need your active support in our legislative and fundraising initiatives.

Our families and loved ones have suffered enough! Now is the time to do what is needed to find relief from this debilitating illness. If you have been sitting on the sideline waiting to see what will happen, now is the time to get into the game. I'm reminded of a quote I think of often, "If not you, who? If not now, when?" *Please join the foundation in this fight, call the office or visit the website to see how you can help.*

Bob Berkman

HHT Foundation Corporate Sponsors

New to the HHT website is a Corporate Sponsor page. Though this area is still in development, we celebrate the two companies supporting the HHT Foundation at this level of sponsorship! Information about these sponsors and their products can be reached from the home page by

following the path: I want to learn about the Foundation then Corporate Sponsors or by entering the URL address into your browser, www.hht.org/hht-foundation/corporate-sponsors. We truly appreciate the support of these corporations.

Thank You to Our Contributing Sponsor



Sponsorship and/or advertising in the HHT Foundation Direct Connection newsletter does not constitute endorsement of any treatment or product by the HHT Foundation International.

Interested in becoming a sponsor?

Contact HHT for sponsorship opportunities and see how you can contribute today! 800-448-6389

HHT Foundation Wish List

- 2 new computers or the funds to purchase them (1) tower for the office (2) laptop for the office and offsite conferences / meetings
- Website services – (1) programming (2) website management
- Legal services – contract review prior to HHT functions
- Writer – newsletter, PR campaign

Thank You

to Foundation volunteer, Trish Linke, for providing the funding to purchase another new laptop computer!

www.hht.org



You can now use your credit card online to:

- donate to our annual appeal campaign or make general donations,
- become a member
- renew your membership
- give gift memberships
- register for conferences!

Direct Connection

Published by:

HHT Foundation International, Inc.

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WEBSITE: www.hht.org

E-MAIL: hhtinfo@hht.org

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.

HHT Mission & Value Statements

Over the last 17 years, The HHT Foundation International, Inc. has grown from its infancy — a small group of dedicated individuals organizing and planning around a kitchen table, to its young adolescent years, which we are currently in, just waiting to break free and truly spread our wings. Through these years of growth, the HHT Foundation has been able to clearly define its 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.

In November 2008, the Board of Directors adopted an HHT Value Statement. A value statement is different from a mission statement in that it identifies characteristics that we want to be identified with as a Foundation versus actions we want to achieve. It is the sincere desire of the Board that all HHT Centers, physicians, researchers, staff, and members will incorporate these values into everything they do to advance the HHT mission.

HHT VALUES – characteristics that direct all of our thoughts and actions as we strive toward a common goal.

- **Compassionate**
- **Ethical**
- **Patient & Family Focused**
- **Responsive**
- **Results Oriented**
- **Collaborative**

HHT FOUNDATION INTERNATIONAL

Marianne Clancy, Executive Director
Monkton, MD

James Gossage, MD, Medical Director
Augusta, GA

Michael Nolan, International Ambassador
Cork, Ireland

BOARD OF DIRECTORS

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Blufton, SC

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Dennis Sprecher, M.D.
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Terry Thompson, Jr.
Summit, NJ

INTERESTED IN SERVING ON OUR BOARD OF DIRECTORS?

Call the HHT office at
800-HHT-NETW
or e-mail us at **hhtinfo@hht.org**.

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

Welcome New Board Members



Angela Carlisle-Brown, a “working mom” trying to educate herself about HHT for the last nine years, which affects her husband and two children. Angela completed her undergraduate studies at California State University, Chico and received her Juris Doctorate from John F. Kennedy University School of Law. She has been working in large international law firms for the last 18 years. Angela is currently the Office Manager at Townsend and Townsend and Crew, LLP in Walnut Creek, California, however, Angela believes that “working with the HHT Foundation will certainly be the most important work I do in my lifetime.”

Over the years, Angela has been a staunch advocate and supporter of the HHT Foundation by providing education materials to various hospitals and educating medical personnel about the disease; educating 350 families about HHT at her son’s school and in doing so, identified another possible HHT patient; attending two Patient and Family Conferences; taking on the role of Regional Coordinator for Northern California; participating in Capitol Hill Day; and organizing grassroots fundraising.

Angela and her husband, Greg, live with their two children in Concord, California. Her goal is to find a cure and see a generation in her family without this disease. With her infectious enthusiasm and boundless energy, she “will do everything in her power to make this goal a reality”.



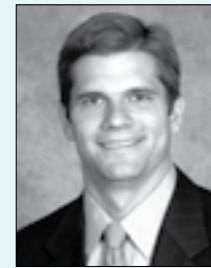
Dennis Routledge, Senior Vice President at Mutual of America which provides retirement products primarily for the non-profit industry. Dennis has over thirty years of experience in information technology and is currently responsible for supporting personal computers and servers for Mutual of America. He received a B.S. in Mathematics from Manhattan College in New York and an MBA in Finance from Adelphi University. Dennis is involved in philanthropic work through his church and has been a volunteer and strong advocate of the HHT Foundation for over a decade. He was a former member of the Board of Directors, serving as Treasurer for many years and providing instrumental guidance in the creation of the HHT website.

Dennis and his wife, Maureen, live in Garden City, New York. Maureen and their two grown daughters have HHT. Dennis’ entire family is very supportive of the HHT Foundation through their volunteerism at Patient and Family Conferences, United Way giving, and now fundraising efforts. Kerry Chu, Dennis’ youngest daughter, ran for the first time in the Country Music Marathon in honor of her mother and grandmother. The HHT Foundation is grateful for Dennis’ desire to continue serving on the Board of Directors in his new role of Vice President.



John Spencer, Jr., Retired Chief of the National Geodetic Information Center (NOAA). In this capacity, John coordinated the acquisition, maintenance, publication, and dissemination of geodetic data into the National Geodetic Data Bank and monitored the fiscal status of the Information Center. In his retirement over the last 21 years, John has served as an H&R Block Tax Preparer, Medical Advocate for an Afghan child to receive burn treatment at Shriners Hospital, and a math teacher. He received a B.S. in Biology and Mathematics from Virginia Tech University and an M.S. in Information Technology from George Washington University.

John and his wife, Pat, live in Spring Hill, Florida. Their level of commitment to the progress of the HHT Foundation was evident by their attendance at Capitol Hill Day. John wants to increase awareness of HHT at a national and local level, in addition to improving the HHT Foundation stewardship activities such as fundraising and membership.



Terry Thompson, Jr., Chief Operating Officer of Mercer, a Marsh & McLennan company. In this role, he is responsible for three lines of business, as well as Mercer’s overall corporate strategy, information technology, and properties and administration. Prior to Mercer, Terry has held positions of increasing responsibility at Mirant, Delta Airlines, the Boston Consulting Group, and Coopers and Lybrand. Terry holds an MBA from the Fuqua School of Business at Duke University and a BS in Accountancy from Villanova University.

Terry and his wife, Juli, live in Summit, New Jersey with their four daughters. Terry, his brother, his father, and three of his four daughters, all have HHT. Having been a direct beneficiary of the HHT Foundation’s progress to date, Terry is very enthusiastic to help continue the momentum and has a particular interest in advancing physician education, genetic testing awareness, and treatment options. Terry’s expertise will greatly benefit the Foundation and we are excited to have him join our team.

A Strong and Independent Foundation

The struggling economy has strained resources for all philanthropic organizations this year and the HHT Foundation International has had its challenges. It is during these difficult times that our constituency needs to ensure that the HHT Foundation remains independent and strong. Only a strong foundation can fulfill our mission and encourage the best from the HHT Centers of Excellence. Our role as an advocate is important for all of those affected by HHT, because the Foundation is not limited to helping just those who are proximate to a Center of Excellence.

As your advocate, the HHT Foundation secured the release of HHT patents that allowed a system wide means of performing genetic testing, thereby, eliminating the need for radiation screening for brain and lung avms for all HHT families. The Foundation's ability to avoid the biases held by individuals has resulted in fostering collaborative research and NIH quality research projects that will be utilized to advance exciting scientific breakthroughs for every HHT patient and their families.

Furthermore, the Foundation, through the Global Research Medical Advisory Board, has created an expanded international body of scientists and clinicians who are focusing their considerable skill sets on finding remedies and a cure for our constituency. This could not happen if the effort was being led by only one institution, regardless of its pedigree.

Since 2003, the HHT Foundation has been coordinating a massive effort to penetrate the legislative labyrinth that has ignored our constituency and prevented us from receiving an appropriate and proportionate share of our tax dollars to address this disorder, that, unlike many, can be resolved in an individual's lifetime. Failure to address this disorder is costing the U.S. health care system BILLIONS of dollars and causing our constituency untold amounts of suffering. We all have stories of unnecessary deaths and serious disability that have affected our individual families. **Only a strong and independent Foundation can gather these stories and represent us collectively.**

Finally, the Foundation is a wealth of information for those who do not know exactly what it is they have. Many have horrible stories of dealing with healthcare professionals who are ignorant about this disorder and have done great harm as a consequence. The Foundation has a centralized database of knowledgeable professionals and can refer patients to HHT Centers of Excellence. Many who contact us have information to give their health care professionals because the Foundation has made it available. These materials and the research underlying this information cost money to develop and make available to everyone, not just to those who have easy access to physicians who know how to treat them.

It is imperative that our constituency, and all HHT families, ensure that the Foundation remains independent and strong to fulfill our mission for their greater good. Through the collective power of collaborations led by the HHT Foundation, our membership will continue to benefit from the many scientific and therapeutic advances being achieved by institutions worldwide, not just locally. Only an independent organization, such as the Foundation, can lobby effectively for everyone with this disorder. **Far reaching success has occurred because collectively, through the combined power of the membership, the Foundation has been your advocate on every level.**

Sincerely,



Marianne S. Clancy
Executive Director



Diana R. Meiches
Board of Directors





Johns Hopkins Hospital Named 9th U.S. HHT Center of Excellence

Nicole Schaefer, Director of Operations

*“To wrest from nature the secrets which have perplexed philosophers in all ages; to track to their sources the causes of disease; to correlate the vast stores of knowledge so they may be quickly available for the prevention and cure of disease. These are our ambitions.”
— Sir William Osler*

The HHT Board of Directors has made increasing access to HHT professionals a priority. By increasing the number of HHT Centers of Excellence, diagnosis and treatment of HHT will be more affordable by decreasing travel costs and increasing the likelihood of insurance coverage. In 2008, the Foundation established a committee, led by Marianne Clancy, Executive Director, and Dr. James Gossage, Medical Director, to develop a process to evaluate the medical expertise and viability of an HHT Center. Although the HHT Foundation and the HHT Centers of Excellence are completely separate entities, we work in a collaborative effort to advance the diagnosis, treatment, and management of HHT.

Johns Hopkins Hospital is a world-renowned institution that has been coordinating care and treatment of HHT patients for decades. In fact, in the United States, it all started at Johns Hopkins with Dr. Osler in the late 1800's. Then in the late 1970's, Johns Hopkins began treating HHT Patients and the rest is history . . . Now, Dr. Christian Merlo and Dr. Sally Mitchell are Co-Directors of the new HHT Center and they have organized a team of over 30 pediatric and adult specialists who are knowledgeable in the care and treatment of HHT. We are really excited about this new collaboration!

The Benefits of Being Screened at an HHT Center of Excellence

At an HHT Center of Excellence, the specialists work with the disorder on a daily basis and they know what they are looking for. Similarly, they will evaluate your whole body not just a specific organ.

There are numerous benefits to being screened at an HHT Center but two of the most important include:

- **Genetics/Family History:** The Center Director (or Genetic Counselor) will help you trace HHT through the generations and other family members can be identified.
- **Guidance/Experienced Medical Resource for your local physician(s):** Once you've been seen at an HHT Center, your local physician can contact the HHT Center physician(s) about your specific condition, including but not limited to, treatment recommendations, second opinions, and clarification of diagnosis / management options. ■

Johns Hopkins HHT Center Physicians/Specialists

The staff of HHT specialists at Johns Hopkins Hospital HHT Treatment Center of Excellence are ready to serve you and your family. All members of this team are enthusiastic about their new role in the HHT community and they are thrilled to be in full collaboration with the HHT Foundation.



Dr. Christian Merlo:

Co-Director of HHT Center, Assistant Professor of Medicine in the Division of Pulmonary and Critical Care Medicine at Johns Hopkins Hospital. Dr. Merlo graduated cum laude from the College of the Holy Cross in 1992 and received his medical degree from Georgetown University School of Medicine in 1996. Dr. Merlo has worked very closely with Dr. Peter

Terry and Dr. Jeffrey Hoag in a clinical study to evaluate the impact of HHT on quality of life and the impact of epistaxis (nosebleeds) on those affect by HHT. He was instrumental in the development of the nosebleed severity index research study being funded by the HHT Foundation.



Dr. Sally Mitchell:

Co-Director of HHT Center, Professor of Radiology, Surgery, and Pediatrics at Johns Hopkins Hospital. Dr. Mitchell graduated summa cum laude from Ohio University in 1973 and received her medical degree from Ohio State University in 1976. In the early 1980's she joined the faculty at Johns Hopkins and was involved with Drs. Terry and White in the

development of HHT patient management and PAVM embolization. Dr. Mitchell's career spans 30 years of Interventional Radiology, with numerous publications, teaching awards, and experience in clinical, basic, and translational research.

JOHNS HOPKINS HHT CENTER

Radiology and Radiological Science
600 North Wolfe Street / Blalock 544
Baltimore, MD 21287-4010

Dr. Christian Merlo, Co-Director (Pulmonary Medicine)
Dr. Sally Mitchell, Co-Director (Interventional Radiology)

Contact: Courtney Myles-Ross, Phone Triage
410-550-LUNG (5864)
Email: cmyles1@jhmi.edu

HHT Specialists at Johns Hopkins Hospital

PEDIATRIC

Dermatology
Gastroenterology
Hepatology
Interventional Radiology
Neurology
Neurosurgery
Nutrition
Otolaryngology / ENT
Pulmonology

ADULTS

Cardiology / Pulmonary Hypertension / HF
Gastroenterology
GI Consult / Endoscopy
Genetics
Genetic Counselor
Hepatology / Liver Transplant
Interventional Radiology
Neuro-Interventional Radiology
Neuroradiology
Neurology
Neurosurgery
Otolaryngology
Physical Medicine & Rehabilitation

Breaking HHT Legislative News

Senate Resolution 161 (formerly Senate Res. 141) June Is Officially HHT Awareness Month

You may remember a Legislative letter that was sent to you a few months ago. In this letter, it was stated that Washington D.C had been ignoring HHT. **Well, Washington D.C. may have been ignoring HHT, but our HHT members did not ignore their HHT Foundation!** We were overwhelmed by your response. The Foundation received over 175 responses and donations keep coming in. **As a direct result of your support, we were able to obtain bipartisan sponsorship in the U.S. Senate and in the U.S. House of Representatives for an HHT Resolution that recognizes June as HHT Awareness Month!**

Sponsors in the Senate:

Senator Tim Johnson: Democrat, South Dakota

Senator Robert Bennett: Republican, Utah

Sponsors in the House of Representatives:

Representative Richard Neal: Democrat, Massachusetts

Representative Joe Wilson: Republican, South Carolina

I wish to acknowledge the fine efforts of our Board President, Bob Berkman; Board Member, Parks Moss; Alumni Board Member, Mike Daly; Past-President, Beth Plahn; and Utah Center Co-Directors, Jamie McDonald and Jim Carlisle, for their efforts in advocating for the HHT Foundation and getting this accomplished. In addition, we are eternally grateful to HHT Board Member and Treasurer, Chuck Atkins, for his steady leadership and strategic advisement throughout this process.

It's an exciting time for us as this resolution is a crucial first step and major accomplishment in our legislative strategy.

We need to take advantage of this opportunity, to get HHT the attention that you deserve! Susan B. Komen for the Cure, Autism Awareness Association, and the National Multiple Sclerosis Society are all examples of causes that started with a small and extremely dedicated membership who were able to make incredible gains for their cause by participating in their organizations.



HHT Tribute Cards

a meaningful way to show you care for any special occasion...

These cards were custom designed and donated by one of our valued HHT member families, **Michael and Daryl Anisfeld**. It was the Anisfeld's hope that these tribute cards would give people an opportunity to recognize special occasions of loved ones in a very meaningful way while at the same time increasing awareness about HHT and raising funds to further HHT research, educate families and physicians, and advocate for and support those with HHT.

The holidays and personal celebrations are a perfect time to reach out to your friends and family by sending them a tribute card that acknowledges that a contribution was made to the HHT Foundation in recognition of the occasion. These cards are specifically designed to be used for any occasion. No matter what the occasion, show you care by sending a HHT Tribute Card.

Please support the HHT Foundation by purchasing these tribute cards.

You can either order the card online at www.hht.org or mail a check to the HHT Foundation (P.O. Box 329, Monkton, Maryland 21111) specifying the number of packs of HHT Tribute Greeting Cards you want to purchase. If you have any questions please call our office at 800-448-6389.



ONE PACK OF 5 CARDS: \$25.00

Or

**TWO PACKS OR MORE:
Value Price Of \$20.00 Per Pack**

HHT Deserves and Needs Attention **and WE NEED YOU!**

There are many ways that you can do this. Every activity requires some of your time and effort but pick one or more that best meet your needs and abilities. It's time that we all step "outside of the box", leave our comfort zone, and fight for HHT.

- **Capitol Hill Day - June 15-16, 2009 in Washington, DC.** The purpose of Capitol Hill Day is to have our HHT members approach the federal government as a unified force by meeting with their respective Congressional Representative and/or their staffers. **Do not be concerned if you are not experienced in the political process.** We will be having a brief Advocacy Training Session in which you will be provided with information and materials. **Remember, your stories and experiences as a constituent can be the most powerful statement that we can make as an HHT community.** For more information and instructions, you can visit the HHT website at www.hht.org/hht-foundation/legislative-advocacy/ or call the HHT office at 1-800-448-6389.
- **Local District Offices** - For many, attending Capitol Hill Day may not be possible. However, you can still make a significant impact by visiting your local district office or making a phone call. It is so important that legislators hear from us and understand our needs!
- **Write a Letter to your Member of Congress** - Make sure your Congressperson hears from you! Consider writing an email or letter to your legislator telling them how HHT has affected you and your family. They are hearing from the Foundation already, *your individual voice is needed!* For help with this, you may visit the HHT website at www.hht.org/hht-foundation/legislative-advocacy/ for ideas, instructions, and sample letters.
- **Contact Local Media** - So many of you answered the Legislative Initiative request and sent heartfelt descriptions of the way in which HHT has affected you and your family. The HHT Foundation has been working towards getting HHT national and local media exposure to educate the general public (and medical professionals) about HHT. Yet, many newspapers and television stations want to hear from you! Contact your local newspaper, radio, and/or television station and let them know that June is HHT Awareness Month! For help with this, you may visit the HHT website at www.hht.org/hht-foundation/public-awareness-and-media/.
- **Educate Physicians** - HHT Awareness Month is an excellent opportunity to educate your local physicians and nurses! The HHT Foundation recognizes the immense need to educate the medical community about this disease. We hear your frustrations when a patient needs to educate their physician, even in emergency situations. There are tremendous resources, definitions, and medical publications on the Foundation's website: www.hht.org/medical-scientific that you can print and distribute to medical professionals in your community! This is a vital part of educating the medical community and we will not be successful without you!
- **Join an RNA Group** - The Foundation has formed "RNAs"- known as Regional Networking Alliances. These groups have been formed to provide support for those living with HHT, as well as to build a local structure for education and advocacy. There has been a lot of interest and participation lately and we hope that you will consider attending a local meeting. Please contact Sharon Williams for meeting information or visit the HHT website for a directory of existing RNA groups at www.hht.org/hht-foundation/regional-networking-alliance/
- **Plan a local fundraising event** - Scott Olitsky, Kerry Chu, Emma Purdy, and Lisa Bass are just a few examples of Foundation members who have made a difference by donating their time and efforts to raise funds and local awareness for HHT! Please refer to the Fundraising page on the website for ideas! www.hht.org/hht-foundation/hht-fundraising/
- **Write-On Letter Campaign** - Letter-writing campaigns are an easy and fun way to raise funds and awareness for HHT. To participate, all you have to do is write a letter and send it to your friends, family members, and business contacts requesting a donation during the month of June. You may visit the Fundraising page on the HHT website for more information www.hht.org/hht-foundation/hht-fundraising/ or call the HHT office at 800-448-6389.
- **Join the HHT Foundation!** If you are not already a member, this is the time to join! Exciting things are happening and we not only need financial support, we need **strength in numbers!** As a member, you will receive the latest information on HHT as well as advances that the Foundation is making on your behalf. More importantly, as our membership increases, so does outside recognition and awareness of the disease. You can join the Foundation on-line through the HHT website at www.hht.org/donate/membership/ or call our office at 800-448-6389.
- **Donate to the Foundation** - Making a donation to the Foundation will ensure that your needs are being addressed. Education, Advocacy, Research, and Outreach require a number of resources. Your support will enable the Foundation to continue the momentum in these areas on your behalf! You can donate on-line through the HHT website at www.hht.org/donate/ or call our office at 800-448-6389.
- **Purchase and Send HHT Tribute Cards** - this donation will help the Foundation while educating your friends and family about HHT. To learn more about HHT Tribute cards see our website at www.hht.org/donate/tribute-greeting-cards/
- **Visit our Website** - If you have not already done so, please go to www.hht.org and familiarize yourself with the wealth of information that can be found there. There is a discussion forum in which questions, comments, and concerns are all addressed! Consider sharing this information with friends and family members who may not be as informed as you would like them to be. We need to spread the word and we need your help to do so!
- **Conduct a family history and encourage relatives to get screened for HHT!** If you do nothing else, please talk to and educate your family members about the importance of getting screened for this disease- **you may save their lives and the lives of their children!**
- For those suffering from HHT and their families, we would like every month to be HHT Awareness Month! However, **we hope that you will make an extra effort during the month of June to take the extra step for HHT.** With your support, we will continue to inform the public, educated medical professionals, search for improved alternative treatments, and eventually find a cure!

THANK YOU TO OUR MEMBERS WHO MADE THIS
ACCOMPLISHMENT POSSIBLE . . .
Together, We Will Make A Difference!

HHT Capitol Hill Day • June 15th & 16th, 2009

By Sharon Williams, Legislative Advocacy and RNA Manager

The HHT's Capitol Hill Day will be held on **June 15th – 16th, 2009** in our nation's capitol. We want to personally invite you to join our Board of Directors, our Foundation Staff, and HHT Center Directors for this important event.

The purpose of Capitol Hill Day is to have our HHT members approach the federal government as a unified force by meeting with their respective Congressional Representatives and/or their staffers. In these brief meetings, individuals will share how HHT has impacted their life and that of their family and ask for their representative's support in gaining federal funding for this long neglected disorder.

Don't be concerned if you aren't experienced in the political process. You don't need to be. There will be Advocacy Training prior to your appointments and we will supply you with all of the information you need to have a successful appointment. *All you need to do is schedule your appointments.*

FIRST STEP:

Make a Reservation at the Hotel and RSVP to the HHT Foundation

Our home base for the HHT Capitol Hill Day will be the **Hyatt Regency Washington on Capitol Hill** this year. This beautiful hotel is centrally located just steps from the U.S. Congress. If you choose to stay at the Hyatt Regency Washington on Capitol Hill, we have negotiated special rates for June 15th.

SECOND STEP:

Prepare to contact your Members of Congress

As a participant of Capitol Hill Day, you will need to contact your **Congressional Representatives now to schedule an appointment for June 16th.** The objective of an appointment with your House Representative and Senators is to obtain recognition and funding for HHT by having them co-sponsor the HHT Resolution.

Typically, these appointments only last about 15 minutes. To be safe, I would allow about an hour between appointments, especially if your next appointment is in a different building. The offices are all within a short walking distance from each other but you do have to allow time to get through security when entering buildings. Most of the buildings have coffee shops in them if you have extra time.

How to obtain your Senators and House Representatives Contact Information: For your convenience, I have included a website that will



provide you with your respective Senators and House Representative websites and contact information for their DC offices. You can enter this URL address, <http://www.congress.org/congressorg/home>, in your browser. Open the page and enter your zip code on the upper panel on the left where it says 'My Elected Officials'.

Be Prepared before you pick up the phone:

- Review your members' website. You need to **familiarize yourself with the member prior to calling them** (ex: what committees are they on, what positions have they held, etc...)
- Review our HHT information and make sure it is clear what you are asking for. These individuals get thousands of calls. **Make sure you show them you respect their time by being prepared, staying on track, and keeping the message concise.**
- Make sure you tell them you are a constituent of their state/district when asking for the appointment. **As a constituent, you are important.**
- Use your own words and don't be afraid to **share your story.**



THIRD STEP:

Call for an Appointment with your Members of Congress

1. **Call the Washington D.C. office number.** You can ask to speak to your representative but don't be disappointed if you don't get put directly through to them at first.
2. **Be ready to ask to speak with the staffer that handles health related legislative issues.** The staffer may be a younger, less experienced individual. Don't be discouraged. They are the means of getting your message to the Member. **Meeting with them is important and a typical first step.**
3. **Talking Points**
On the call you want to point out the following information early in the conversation.
 - I am a constituent from (State or District)
 - I will be in D.C. for our HHT Capitol Hill Day on Tuesday, June 16th and I want to have a few moments of your time to share how HHT has affected myself and my family and ask for your support in our HHT Legislative Initiative. Below see some key impact statements for HHT you may bring up even though it may not be necessary.
 - HHT is a **long neglected national health problem.**
 - HHT is a **Common "rare" disorder** affects 1 in 5000 people worldwide and 70,000 Americans.
 - HHT is a **Multi-system blood vessel disorder** which produces blood vessel malformations in the brain and lung which can result in **stroke, hemorrhage, heart failure and death.**
 - **20% of those with HHT, regardless of age, suffer premature death and disability**
 - Due to widespread lack of knowledge of the disorder by medical professionals, **approximately 90% of people affected by HHT are not yet diagnosed and are at risk of death or disability due to sudden rupture of the blood vessels in major organs in the body.**
 - **HHT has been solely funded by its members, with no federal funding at all, while other less common disorders have received millions of dollars over the years.**
4. **Ask for an Appointment** - What time can we meet on Tuesday, June 16th?
5. **Get Contact Information** - Make sure you obtain and document the staffer's name, title and email address, and physical address for the meeting before you end the conversation.

FOURTH STEP:

Advocacy Training

We will have an **Advocacy Training Session on Monday, June 15th** in the evening from 6:00 p.m. to 9:00 p.m. to prepare you for your appointment on Tuesday. Our office is currently developing our HHT legislative language and funding request for the 2010 bill and it will be made available at the Advocacy Training session.

In this training, you will be given all of the information, instructions, and materials you will need in order to make your visit with your Congressional Representatives as productive as possible.

FIFTH STEP:

Reporting

It is critical to report the following information back to the HHT Office when you schedule your appointment. You can send this information to Sharon Williams by email at Sharon.williams@hht.org or call the foundation office at 800-448-6389.

- **Your name**
- **Individuals you contacted**
 - *Senator or Representative Name
 - *Staffer's Name
 - *Title
 - *Email Address
- **Time of the Appointment** (Please let me know if the Senator or Representative will be at the meeting)

Our goal is to obtain 100 appointments this Capitol Hill Day. I will report our collective progress as you send me your information.

Please feel free to contact me at any time with questions, if you need any information, or want to discuss strategy. I realize how complicated this process can be at times.

Good luck and I'm looking forward to hearing from you and meeting you in our Nation's Capitol on June 15th & 16th!

**WE NEED
CO-SPONSORS OF THE
HHT RESOLUTION!**

Please contact your Senator and House Representative and ask them to Co-Sponsor Senate Res. 161 and House Res. 536 TODAY!

What If I Can't Make It To Capitol Hill Day

June 15th & 16th 2009

For many, attending Capitol Hill Day may not be possible. However, you can still make a significant impact by visiting your local district office during a recess, making a phone call to that office, or writing a letter. It is so important that legislators hear from us and understand our needs!

LOCAL DISTRICT OFFICE VISITS

Your House Representative and Senators will be in their home office at specific times during the next several months. Now is the time to contact their local district office and request an appointment during one of these time periods.

2009 Senate Recess Schedule

(Senators return to home state)

June 29 – July 2

August 10 – September 4

2009 House District Work Periods

(House Representatives return to home state)

June 29 – July 2

August 3 – September 4

WRITE A LETTER TO YOUR MEMBER OF CONGRESS

Make sure your Congressperson hears from you! Consider writing an email or letter to your legislator telling them how HHT has affected you and your family. They are hearing from the Foundation already,

your individual voice is needed!

To obtain your Senators and House Representatives contact information, enter this URL address, www.congress.org/congressorg/ home, in your internet browser. Open the page and enter your zip code on the upper panel on the left where it says "My Elected Officials."

For ideas, instructions, and sample letters, visit the HHT website at www.hht.org/hht-foundation/legislative-advocacy/.

NOTIFY THE HHT FOUNDATION OF YOUR EFFORTS

As we begin to really push our legislators it is important that the foundation know which Members of Congress have been contacted. Please send the following information to Sharon Williams by email at Sharon.williams@hht.org or call the foundation office at 800-448-6389.

- Your name
- Individuals you contacted
- Senator or Representative Name
- Staffer's Name
- Title
- Email Address
- Time of the Appointment (Please let me know if the Senator or Representative will be at the meeting)

HHT at a Glance for Health Care Providers

This information can be photocopied and taken to your local physicians, pediatricians & dentists. It is also available at www.hht.org

- Hereditary Hemorrhagic Telangiectasia (AKA Osler-Weber-Rendu) is a multi-system vascular dysplasia.
- It is uncommon, but not rare. Approximately 1.2 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 of symptoms.
- It is frequently misdiagnosed in affected individuals.
- The most commonly affected organs are nose, lungs, GI tract, brain and liver—in that order.
- HHT is an autosomal dominant genetic disorder.
- Denovo mutations are rare. A detailed family history shows most cases to be familial.
- HHT is heterogeneous. Defects in two 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 skin of the face and/or hands by middle age, but they can be pin point in size.
- 20% develop significant gastric or intestinal bleeding, but not usually before the decade of the 50's.
- 30% have pulmonary arteriovenous malformations (AVMs).
- 10-15% have at least one cerebral AVM.
- An unknown percentage have hepatic AVM.
- The severity of epistaxis or telangiectases of the skin does not correlate with the likelihood to have internal (i.e. Cerebral or pulmonary) AVMs.
- Severity and symptomology varies tremendously, even between close relatives.
- 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.
- Treatments are available for all manifestations of HHT and have evolved significantly in the last decade.



HHT Clinical Guidelines

Published in the Journal of Medical Genetics



On May 30, 2008 the HHT Clinical Guideline Recommendations were officially accepted for publication in the Journal of Medical Genetics. The guidelines will be available online at www.hht.org. Please pass this information on to your family members and HHT physicians.

In November 2006, Dr. Marie Faughnan, Chair Emeritus of the Global Research and Medical Advisory Board (GRMAB) of the HHT Foundation and Director of the HHT Center in Toronto, Canada, led the creation of the first International Clinical Guidelines Conference for HHT — a key step in improving the standard of care for people with the disorder.

An international panel of medical experts, health-care workers and patients with HHT, assembled near Toronto to develop these comprehensive guidelines for the diagnosis and management of HHT. The end result was the generation of 34 clinical recommendations regarding the diagnosis of HHT and the diagnosis and treatment of nosebleeds, gastrointestinal bleeding, liver vascular malformations, lung and brain AVMs. “We were really pleased with the outcome, especially that we had more than 80% international agreement on 31 of the 34 recommendations” says Faughnan. “This is a huge step forward.”

The guidelines developed by the panel will improve the standard of care for HHT patients, creating a benchmark in care for health-care professionals. It will also inform more physicians about the disease with up-to-date information.

Save the Date

NAVBO (North American Vascular Biology Organization) WORKSHOP *Genetics and Genomics of Vascular Disease*

September 13-16, 2009
Hyannis, Massachusetts

This is a one of a kind workshop that will provide a forum for basic and clinical researchers using either genetic or genomic approaches to vascular disease to share their recent and novel science. Douglas Marchuk (Duke University) and Miikka Vakkula (de Duve Institute, UCL) are the co-organizers for the 2009 workshop. In addition to the organizers, two members of the program committee – Drs Bischoff and Oh – are members of various advisory boards for the HHT Foundation. These individuals are fully committed to ensuring that this NAVBO workshop is relevant to furthering our understanding of HHT pathogenesis.

To learn more about this workshop or register online, please visit the HHT website at www.hht.org or the NAVBO website at www.navbo.org/event/ggvd.

Yale HHT Center of Excellence *Patient Conference*

October 24, 2009
New Haven, Connecticut

The Yale HHT Center of Excellence will be hosting their own one-day patient conference. Particular features of this conference will be presentations on exercise and aging along with Dr. Doug Ross' experience with mild, moderate and severe epistaxis.

To learn more or register online, visit http://conferences.med.yale.edu/conferences/conference_schedule.asp or www.hhtavm.org. All questions should be directed to the Yale Center at 203-737-5395.



Health Care and HHT

Obtaining health coverage and getting the most out of it is no easy feat. Families USA (www.familiesusa.org) has many useful resources to help people find, keep, and get good value from their health plan.

Healthcare and insurance are an issue for many people in the United States but even more so for those affected by HHT. Most insurance issues have to do with going out-of-state for screening at an HHT Center of Excellence or needing to see a specialist outside of your insurance program. Last September, FamiliesUSA conducted several, well attended workshops on healthcare/insurance at our Patient and Family Conference in Chicago, IL. Those who attended these workshops found the information valuable. FamiliesUSA has summarized their presentation so that all HHT members can benefit from their knowledge.

Medicaid and the State Children's Health Insurance Program (SCHIP)

What is it? Medicaid is free or heavily subsidized health care coverage. It's primarily for low-income children, pregnant women, parents, and seniors and disabled people, but some states cover other populations as well. You must meet income and asset guidelines to qualify, which vary state-by-state.

Each state has its own children's health insurance program to cover kids in low- and moderate-income families. In some states, it is part of Medicaid and in other states, children's coverage is offered through a separate program (names vary from state to state). States charge sliding scale premiums to moderate-income families. One state covers kids in families that earn up to \$85,000 a year, and a handful of states allow all children to get coverage through the program by paying the full premium.

What do you get? Medicaid benefits are typically comprehensive, but it may be difficult to obtain coverage outside of the state. Children in Medicaid are eligible for a benefit called Early and Periodic Screening, Diagnosis and Treatment (EPSDT), which entitles kids to a broad range of services if they are needed to correct or ameliorate problems found during a screening exam. This has led some states to establish arrangements with health care providers in other states to get kids treatment when no appropriate services are available in their state.

What if you need help? If you run into difficulty obtaining services you need through your Medicaid coverage, call your local legal services agency. They can help you:

- Check "prior authorization" requirements;
- File a grievance with a Medicaid managed care plan;
- Ask for a fair hearing through the Medicaid agency; and
- Call the state Medicaid agency regarding out-of-state service coverage issues.

These websites contain valuable information regarding Medicaid and children's health insurance:

- www.statehealthfacts.org
- www.nasmd.org
- www.familiesusa.org/resources/resources-for-consumers/
- www.familyvoices.org
- www.insurekidsnow.gov/
- www.patientadvocate.org

Medicare

What is it? Medicare is the federal program that covers seniors age 65 and older and people who are permanently disabled. To qualify for Medicare based on disability, you must receive Social Security disability benefits for two full years. There is an exception to the two-year waiting period for people with End Stage Renal Disease and Lou Gehrig's Disease.

What do you get? Medicare beneficiaries have choices with their Medicare coverage: they may choose the traditional Medicare plan, or a Medicare Advantage HMO. Traditional Medicare will allow beneficiaries to see any doctor anywhere who accepts Medicare. Medicare Advantage HMO plans are more restrictive. It's important to weigh the costs and benefits with an expert when choosing between your Medicare coverage options.

What if you need help? Each state has a State Health Insurance Assistance Program (SHIP) with experts to advise you about your Medicare coverage options, and to help you appeal Medicare service denials or other Medicare problems. You can find your local Medicare counseling service at www.hapnetwork.org/ship-locator/.

To apply for disability benefits, you must contact the Social Security Administration at 800-772-1213, or www.ssa.gov.

Private Health Insurance

What is it? Private health insurance can be obtained through a job (your own or a family member's), or in the individual health insurance market. Most Americans have job-based health coverage, while only a small fraction have individual health insurance. In employer health plans, you cannot be turned down or charged more than another member based on your health status, and federal law limits how long insurance companies can exclude coverage for your pre-existing conditions.

In the individual health insurance market, all bets are off. In all but five states, most insurance companies can turn you down based on your health status, and in all but seven states, insurance companies can charge you a higher premium than another person based on your health

Trish Linke, Patient Education Liaison and Website Discussion Forum Moderator, states, "The saddest thing is the people whose insurance won't let them go to an HHT Center."



status. Insurance companies can exclude coverage for your pre-existing conditions for at least six months or as long as you have the policy.

What do you get? Coverage varies a great deal in the private health insurance market. Some job-based plans are not subject to state laws, including laws that mandate health plans cover specific health services (such as mental health care, cervical cancer screening or maternity care). But many firms are subject to state benefit mandates. Job-based coverage tends to offer more comprehensive benefits than individual health insurance. When choosing an individual health insurance plan, be sure to read all the fine print to understand what's covered at what cost-sharing. Ask your doctors which health plans they contract with so you don't have to switch health care providers.

What if you need help? If you are having trouble getting the services you need in a private plan, your options depend on what type of plan you have. Among employer-based health plans, there is an important distinction: some plans must follow state insurance regulations and some do not. To start, ask your human resources department if your plan is "self-insured" or not.

If your job-based coverage is a "self-insured" plan, federal regulations set a few requirements about its coverage and govern its appeals processes. Check your health plan handbook for more information, and the Families USA website: <http://familiesusa.org/issues/private-insurance/legal-rights/erisa-appeals.html>

If you have job-based coverage that is not "self-insured" or you have an individual health insurance plan, your plan must comply with state regulations. Each state has different laws mandating certain benefits. In addition, some states have laws that may help you get the care you need, such as:

- Laws that explicitly require health plans to refer outside of the plan's network when the plan does not have accessible and appropriate network providers available to meet an enrollee's medical needs.
- Laws requiring plans to allow enrollees with chronic, disabling or life-threatening conditions to use specialists as their primary care provider.
- Laws requiring managed care plans, when appropriate, to allow a primary care provider to authorize a referral to a specialist for more than one visit without having to obtain the plan's approval for subsequent visits.

To find out if your state has laws that may help you access services, call your state's department of insurance.

You must first appeal a denial to the health plan. If your appeal for authorization or payment for services is rejected by the health plan, you may be able to appeal to an objective third party in a process called external review. Almost all states have external review, but call the department of insurance to find out if your case is eligible for external review. Remember to:

- Abide by appeal deadlines.
- Obtain letters from health care providers supporting treatment and explaining medical necessity. In some cases, it may be a good idea to ask your primary care provider to speak with a health care provider at the HHT center you're trying to visit; it may help your primary care provider understand why you would benefit from the specialized care of the HHT center of excellence.

- Frame argument to address specific terms of denial.

If you need assistance with private market appeals, check for a local consumer assistance program on the Families USA website: <http://familiesusa.org/resources/program-locator/>. Your state's department of insurance may have a consumer assistance center.

COBRA, HIPAA, and High-Risk Pools

What is COBRA? COBRA is a federal law that allows you to keep your job-based coverage when you leave your job if you pay the full premium. You can keep COBRA for 18-36 months, depending on your circumstances.

What is HIPAA? HIPAA is a federal law that guarantees individuals who have exhausted their COBRA policy a state-designated individual plan without pre-existing condition exclusions. Often, the plan for HIPAA-eligible people is the state high-risk pool, but some states require other insurers to offer designated policies to individuals eligible for HIPAA.

What are High-Risk Pools? High-risk pools are nonprofit health insurance pools for individuals who have high-risk medical conditions or who were turned down for individual health insurance coverage. Premiums are typically much higher than standard private market premiums, although some states offer premium subsidies.

What do you get? With COBRA coverage, you get to keep the same private coverage you had in your job. HIPAA-eligible people generally get high-risk pool coverage. The high-risk pool typically offers a comprehensive benefits package. However, some high-risk pools exclude coverage for pre-existing conditions, charge high deductibles, and impose lifetime benefit caps.

What if I need help?

During life transitions that may force you to change your health plan, ask lots of questions. When you are leaving your job, moving or getting a divorce, talk to your human resources department about COBRA. If you have exhausted COBRA, contact your state's department of insurance to find out about your HIPAA options. Be careful not to disregard COBRA or HIPAA because of sticker shock. Although COBRA and HIPAA plans often appear very expensive, they may be the best option, especially if you have pre-existing conditions. If you do not take COBRA or HIPAA, individual market insurers may charge an arm and a leg for a policy that does not cover the services you need, or they may not offer you a plan at all.

To talk to someone about your options, including high-risk pool coverage, call your state's department of insurance, or check the Families USA website for a consumer assistance program: <http://familiesusa.org/resources/program-locator/>.



Dr. Thomas Kinney Named Director

University of California, San Diego, HHT Treatment Center of Excellence

In January, Dr. Thomas Kinney, Professor and Interventional Radiologist at the University of California, San Diego, became the Director of the UCSD HHT Center of Excellence. Dr. Kinney has been actively working with Dr. Frank Miller for the last eighteen months treating HHT patients. His commitment to the HHT community has already been demonstrated by his participation in the March 2008 CDC HHT meeting and his attendance at a regional networking alliance meeting that was held in southern California. The HHT Foundation is looking forward to working closely with Dr.



Kinney in the coming months and is excited about his new role at the UCSD HHT Center of Excellence.

In addition to a congratulatory greeting to Dr. Kinney, we would like to express our sincere appreciation and gratitude to Dr. Frank Miller, former Director of the UCSD HHT Center, for his 13 years of dedication to the HHT community. Dr. Miller was responsible for establishing the second HHT Center of Excellence in the United States in 1995 at the University of Utah and the fifth U.S. HHT



Center in 2002 at the University of California, San Diego. His commitment to HHT is exemplary and his concern for his patients and their families is well known. "Frank represents what is great about interventional radiology in that it has become a real patient care specialty," states Dr. Robert White, Director of the Yale HHT Center of Excellence.

In 2006, Dr. Miller received the HHT Foundation's first Legislative Advocacy Award for his tireless work on our behalf with Senator Robert Bennett of Utah. We look forward to Dr. Miller's continued involvement through participation in HHT clinics in San Diego as well as advancing HHT therapies through research. Thank you, Dr. Miller, for your numerous contributions to the HHT community!

National Institutes of Health Announces New Program to Develop Therapeutics for Rare and Neglected Disease

Excerpt from NIH News that can be viewed in its entirety at www.genome.gov/27531962

The National Institutes of Health (NIH), "The Nation's Medical Research Agency", includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical, and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases.

A **rare disease** is one that affects fewer than 200,000 Americans. NIH estimates that, in total, more than 6,800 rare diseases afflict more than 25 million Americans. However, effective pharmacologic treatments exist for only about 200 of these illnesses. Many **neglected diseases** also lack treatments. Unlike rare diseases, however, neglected diseases may be quite common, especially in developing countries where people cannot afford expensive treatments. Private companies seldom pursue new therapies for these types of illnesses because of high costs, failure rates, and the low likelihood of recovering investments or making a profit. **HHT is a common rare disease** because it affects 1 in 5,000 which is estimated to be 70,000 Americans, but it also lacks diagnosis and proper treatment in many cases.

NIH is launching the first integrated, drug development pipeline to produce new

treatments for rare and neglected diseases. The \$24 million program jumpstarts a trans-NIH initiative called the Therapeutics for Rare and Neglected Diseases program, or TRND.

The program is unusual because TRND creates a drug development pipeline within the NIH and is specifically intended to stimulate research collaborations with academic scientists working on rare illnesses. Typically, drug development begins when academic researchers studying the underlying cause of a disease discover a new molecular target or a chemical that may have a therapeutic effect. Too often, the process gets stuck at the point of discovery because few academic researchers can conduct all the types of studies needed to develop new drug. If a pharmaceutical company with the resources to further the research does get involved, substantial preclinical work begins with efforts to optimize the chemistry of the potential drug. This process can take 2 to 4 years of work, \$10 million on average, and experiences an 80 to 90 percent failure rate.

To increase the success rate of drug trials, TRND will work closely with disease-specific experts on selected projects, leveraging both the in-house scientific capabilities needed to carry out much of the preclinical development work. Its' strategies will be similar to approaches taken by pharmaceutical and biotechnology companies, but TRND will be

working on diseases mostly ignored by private companies.

The HHT Foundation, in coordination with Dr. James Gossage, Foundation Medical Director, is actively pursuing participation in this NIH program. We will keep our members and researchers posted on our progress.

Online information about this program and affiliated government agencies is available at:

FAQ Therapeutics for Rare or Neglected Diseases (TRND) Program
www.genome.gov/27531965

TRND FAQ on Neglected Diseases
www.genome.gov/27531964

TRND FAQ on Rare Diseases
www.genome.gov/27531963

Information on TRND
www.rarediseases.info.nih.gov/TRND

National Human Genome Research Institute
www.genome.gov

Office of Rare Diseases Research
<http://rarediseases.info.nih.gov>

National Institutes of Health (NIH)
www.nih.gov

YOU can help advance HHT Research

There are several HHT related research studies currently taking place. You or a family member may be interested in furthering the advancement of HHT research by participating in one of these clinical research studies. You can contact the primary researcher directly, call the HHT Foundation office at 800-448-6389, or visit the HHT website at www.hht.org.

HHT and INTERFERON STUDY

Karen Swanson, DO
 Director, HHT Center
 Mayo Clinic College of
 Medicine
 (507) 266-0416

Jim Gossage, MD
 Director, HHT Center
 Medical College of Georgia
 (706) 721-6791

This clinical research study is funded by the HHT Foundation International and the Food & Drug Administration (FDA) Office of Orphan Products Development. This study will determine whether Interferon reduces the affects of AVM in various organs. The Mayo HHT Center is actively recruiting/enrolling HHT patients who are between the ages of 18-70 and:

- Are transfusion dependent; *or*
- Have liver involvement with HHT and heart failure; *or*
- Have diffuse lung involvement with low oxygen levels.

HHT and JUVENILE POLYPOSIS

Doug Marchuk, PhD
 Scientist, Molecular Genetics
 Duke University, Durham, NC

Dr. Doug Marchuk has an ongoing laboratory research study comparing HHT and Juvenile Polyposis. If you are interested in taking part in this study or just want to learn more about it, please contact:

Tracey Leedom, MS, CGC
 Certified Genetic Counselor
 Duke University
 Email: tracey.leedom@duke.edu
 Phone: (919) 668-5335

THALIDOMIDE STUDY

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Thalidomide and gastrointestinal bleeding: A research study is recruiting HHT patients who have gastrointestinal bleeding and require blood transfusions. This study will determine whether thalidomide reduces the need for blood transfusions. This is a controlled study of oral Thalidomide in patients with gastrointestinal bleeding due to telangiectasias in the stomach and small intestines, many of whom will have HHT. The patients will be monitored by physical exam and blood tests. Patients will be on Thalidomide for 24 weeks (six months). We will continue to monitor patients for 24 weeks after they stop taking Thalidomide.

Eligible patients MUST:

- have received at least 4 units of blood transfusion in the past two years *and*
- be able to travel to one of the two study sites once a month for monitoring
 - (1) Medical College of Georgia or
 - (2) Northport VA in Long Island, NY
 (Sometimes the VA will make travel arrangements for patients to be sent to another VA for treatment)

For more information:

<http://clinicaltrials.gov/ct2/show/NCT00389935?term=HHT&rank=25>

VARIOUS CLINICAL TRIALS

You can check ongoing HHT clinical trials through the website www.clinicaltrials.gov. You must spell out Hereditary Hemorrhagic Telangiectasia in the search box. This website will not acknowledge the abbreviation HHT.

Volunteers

The HHT Foundation is able to accomplish major tasks (i.e., conferences, website, fundraising) with a small staff because of the invaluable number of volunteers who help us.

WE CURRENTLY HAVE A NEED FOR INDIVIDUALS WITH EXPERIENCE IN (1) SOFTWARE PROGRAMMING AND (2) MEDIA & PRESS.

If you have experience in either of these areas or have other skills you would like to share with the foundation, please contact Sharon Williams at 800-448-6389 or Sharon.williams@hht.org.

Hereditary hemorrhagic telangiectasia: transient ischemic attacks

Dulka Manawadu MB ChB, Dilini Vethanayagam MD, S. Nizam Ahmed MD

See related primer by Grand'Maison, page 833, and clinical images by Nanda and Bhatt, page 838, and by Irani and Kasmani, page 839

A 39-year-old right-handed man presented to his family physician with sudden-onset weakness in his right arm and leg that had lasted 10 minutes and resolved completely. In the year before presentation, he had an episode of weakness on the right side of his face and difficulty comprehending that had lasted for 5 minutes. The patient reported having an unexplained collapse 4 years before presentation that had not been investigated.

The patient did not smoke, and he did not use drugs or alcohol. He had no history of hypertension, diabetes, coronary artery disease or hyperlipidemia. There was no history of hemoptysis, dyspnea or fatigue. The patient reported having recurrent nosebleeds since early childhood, and his mother also had nosebleeds regularly and "low blood oxygen levels." His maternal grandmother had experienced numerous "mini-strokes."

On examination, the patient was not in distress. He had a

Key points

- Hereditary hemorrhagic telangiectasia may present with neurologic manifestations secondary to arteriovenous malformations in the lung, liver, brain or spinal cord.
- Neurologic manifestations may include headache, stroke, seizure, cerebral abscess, encephalopathy and spinal compression syndromes.
- Hereditary hemorrhagic telangiectasia should be considered in younger patients presenting with stroke or transient ischemic attack if the cause is unclear.
- In these patients, a thorough personal and family history of epistaxis and of respiratory and neurologic symptoms should be elicited.
- These patients should be closely examined for the presence of telangiectasias.

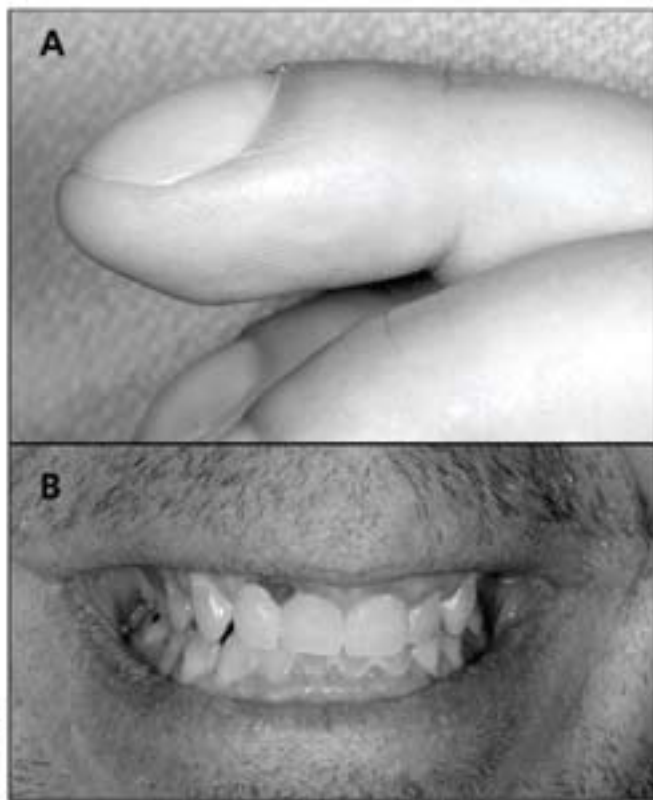


Figure 1: A 39-year-old man with clubbing of his fingers (A) and telangiectasia of the gums (B).

regular pulse rate, his blood pressure was 116/65 mm Hg, and his respiratory rate was 15 breaths per minute. He had finger and toe clubbing and several telangiectasias on his lips, tongue, gums and conjunctiva (Figure 1). The results of the rest of the clinical examination were normal.

Initial investigation showed that the patient had a normal hemoglobin level (151 [normal 120–160] g/L) and reduced oxygen saturation (90% [normal \geq 95%] on room air). The levels of his electrolytes, glucose, lipids and inflammatory markers were normal, as were the results of a hypercoagulable screen. Because we suspected pulmonary arteriovenous malformations, we measured the patient's arterial blood gases in the supine and standing positions. The patient had a supine pH of 7.4, a partial pressure oxygen of 60.2 (normal 80–100) mm Hg, a partial pressure carbon dioxide of 34.2 (normal 35–45) mm Hg and an oxygen saturation of 91%. When standing, his pH level was 7.4, his partial pressure oxygen was 56.8 mm Hg and his carbon dioxide level was 32 mm Hg with oxygen saturation of 89%. A shunt fraction of 21% was calculated by use of the 100% inspired oxygen breathing method (upper end of physiological shunt 5%–8%). Pulmonary arteriovenous malformations can lead to unexplained hypoxemia with further desaturation occurring when standing (orthodeoxia), as occurred in our patient. This finding is because of greater gravity-induced blood flow through basally situated pulmonary arteriovenous malformations which thereby increases the right-to-left shunt and hypoxemia.¹ The results of cardiography and chest radiography were normal.

From the Department of Medicine, University of Alberta, Edmonton, Alta.

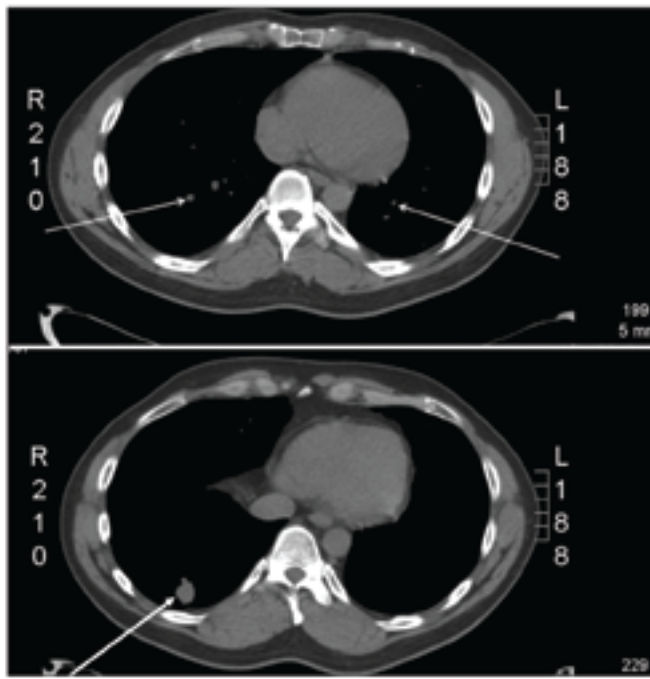


Figure 2: Computed tomogram of the patient's chest showing nodular soft-tissue densities (arrows), with the largest (lower panel) in the anterior basal region of the lower lobe with a feeding vessel of 8–10 mm in diameter.

Magnetic resonance imaging of the patient's brain showed an old cerebellar infarct on the right side, but there were no new infarcts, hemorrhages or malformations. The results of Doppler ultrasonography of his carotid arteries were normal. A transesophageal echocardiogram obtained with agitated saline showed microbubbles entering the left atrium from a direction suggestive of an extracardiac shunt.

A computed tomography chest scan without contrast showed multiple nodular soft-tissue densities scattered throughout both lungs, predominantly in the periphery. Many of the densities had a lobulated appearance (Figure 2). The largest was in the anterior basal region of the right lower lobe with a feeding vessel of 8–10 mm in diameter (Figure 2). This lesion, along with the 2 other large lesions in the right middle lobe and left upper lobe, represented the typical appearance of pulmonary arteriovenous malformations, each with a characteristic feeding artery and draining vein. At this point, a definitive diagnosis of hereditary hemorrhagic telangiectasia was made based on the presence of 3 of the 4 Curaçao criteria¹: history of epistaxis, presence of telangiectasias and presence of pulmonary arteriovenous malformations.

The largest pulmonary arteriovenous malformation in the right lower lobe was subsequently treated with coil embolization. The patient made a complete recovery and was discharged with a diagnosis of transient ischemic attack. He was followed-up in a hereditary hemorrhagic telangiectasia clinic. He had no recurrence of neurological symptoms over the following year and subsequently has had further therapeutic pulmonary embolizations with no complications. Genetic testing was not performed because the request for provincial funding was not approved.

Box 1: Neurological sequelae in hereditary hemorrhagic telangiectasia

Stroke

- Ischemic stroke or transient ischemic attack secondary to paradoxical embolus in the setting of pulmonary arteriovenous malformation. A vascular "steal" phenomenon is a much less likely cause.
- Hemorrhagic stroke secondary to cerebral arteriovenous malformation occurs in up to 10% of patients with hereditary hemorrhagic telangiectasia.
- Subarachnoid hemorrhage secondary to cerebral arteriovenous malformation or saccular aneurysm.

Seizure

- Probably caused by underlying cerebral arteriovenous malformation or a secondary complication of stroke or abscess.

Cerebral abscess

- Can be caused by paradoxical embolism of particulate septic material via a pulmonary arteriovenous malformation.

Headache (migraine)

- Caused by underlying cerebral arteriovenous malformation.

Motor, sensory, bladder or bowel symptoms, muscle wasting

- Caused by underlying spinal arteriovenous malformations.

Porto-systemic encephalopathy

- Caused by liver involvement and shunting through hepatic arteriovenous malformations.

Discussion

Our patient's diagnosis of hereditary hemorrhagic telangiectasia was made within a few days after presentation. However, he had previously been examined in hospital for neurological and gastrointestinal complaints, and hereditary hemorrhagic telangiectasia had not been recognized. Box 1 presents the neurologic sequelae of hereditary hemorrhagic telangiectasia. If the syndrome had been suspected earlier, appropriate intervention to treat his pulmonary arteriovenous malformations might have prevented his transient ischemic attack and, at the very least, allowed earlier testing and family screening.

We encourage physicians who encounter younger people with stroke or transient ischemic attack to ask questions about epistaxis and their family history of respiratory and neurological symptoms, and to closely examine the patient for telangiectasias as part of usual practice, especially when the cause is unclear.

This article has been peer reviewed.

Competing interests: None declared.

REFERENCE

1. Shovlin CL, Letarte M. Hereditary haemorrhagic telangiectasia and pulmonary arteriovenous malformations: issues in clinical management and review of pathogenic mechanisms. *Thorax* 1999;54:714-29.

HHT Treatment Centers Around the World

NORTH AMERICA

USA

Johns Hopkins Hospital
Baltimore, MD
410-550-LUNG (5864)
www.hopkinsmedicine.org

Mayo Clinic
Rochester, MN
507-266-0416
www.mayo.edu

Medical College of Georgia
Augusta, GA
706-721-6791
www.mcg.edu/som/medicine/
Pulmonary/PulmVasDis.htm

Oregon Health & Science University
Portland, OR
503-494-7660 or
888-222-6478 ext. 7660
www.ohsu.edu/hht

University of California Medical Center
San Diego, CA
888-770-0296
www.ucsd.edu

University of Pennsylvania
Philadelphia, PA
215-662-4740
www.uphs.upenn.edu/penngen

University of Utah
Salt Lake City, UT
Toll Free 866-292-4HHT (4448)
healthcare.utah.edu/hht/

Washington University School of Medicine
St. Louis, MO
(Adults) 877-888-5864 or
314-454-8717
(Pediatrics) 888-503-2237
hht.im.wustl.edu

Yale University School of Medicine
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203-737-5395
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Odense
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44.208.383.3269

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Hull
44 (0) 1482-674608
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Service De Genetique
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49-221-8907-12727

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49-6421-2866808

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www.renduoslerweber.nl

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Cork
353-21-2305040

ISRAEL

Schneider Children's Medical Center of Israel
Tel Aviv
972-3-9253654

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Ospedale Maggiore, Crema
0039.0373.280422 / 280726

University of Bari, Bari
39.080.5478708
www.hht-italia.com

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Akita
81-18-834-111 ext. 6531

NORWAY

Rikshospitalet University Hospital, Oslo
47-2307-5593

SPAIN

Hospital Sierrallana
Torrelavega (Cantabria)
34-942-84740 (8053)

HHT Patient Support Groups

US, INTL

HHT Foundation International
800-448-6389 (US)
410-357-9932 (Intl.)
www.hht.org

ENGLAND

www.telangiectasia.co.uk

FRANCE

www.amro-france.org

GERMANY

www.mobus-osler.de

IRELAND

www.gracenolan.com

ISRAEL

Meira Heiman at
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heimann@netvision.net.il

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www.informazioni@hht.it
www.hhtonlus.com

SPAIN & PORTUGAL

www.asociacionhht.org

DENMARK

www.osler.dk

SWEDEN

www.osler.se

North American Genetic Laboratories

Ambry Genetics

Aliso Viejo, CA
866-262-7943
www.ambrygen.com

ARUP Laboratories

Salt Lake City, UT
800-242-2787 ext. 3179
www.aruplab.com

HHT Solutions, Inc.

Toronto, Canada
416-603-5597
www.hhtsolutions.org

University of Pennsylvania

Philadelphia, PA
215-573-9161
www.med.upenn.edu/gdl//

Molecular Genetics Laboratory

The Hospital for Sick Children
Toronto, Canada
416-813-6590
www.sickkids.ca/molecular/

How Can You Help the HHT Foundation International?

15 EASY WAYS TO GIVE

BECOME A MEMBER!

1. **Renew** your HHT Foundation membership each year. You can automatically renew by credit card and avoid receiving renewal notices and mailing checks.
2. **Gift Memberships** are a wonderful way to support the Foundation while keeping family members or health care providers informed.

DONATE!

3. **General Donations**— Give whatever you can to support the Foundation's overall mission of education, advocacy, patient support, and research towards a cure.
4. **Annual Appeal**— Every December you will receive an Annual Appeal letter. Every gift counts! Does your company have a matching gift program? If so, you can double your contribution.
5. **Tributes**— Consider making a tax-deductible donation to the HHT Foundation in honor of your loved one's birthday or anniversary. And, as the holidays roll around, how about honoring your friends and family with a tribute gift. We will notify the honoree and let them know of your generous contribution.
6. **Memorials**— Consider a donation to HHT Foundation in lieu of flowers to remember a loved one.
7. **Name the HHT Foundation in Your Will**— Call the Foundation office for more information.

MAKE USE OF UNITED WAY, COMBINED FEDERAL CAMPAIGN, OR OTHER GIVING PROGRAMS!

8. If your workplace has a United Way campaign, think of the Foundation when you plan your giving. If you are in the U.S. military or a Federal employee, the CFC works just the same way. Use the Foundation's CFC number to designate the HHT Foundation as the beneficiary of your payroll deduction program. CFC Number: 10233

USE THESE WEBSITES

We have established several partnerships with websites / organizations that provide a portion of their profits or sales to the HHT Foundation. We all shop online or search the internet. Did you know you could earn money for the Foundation doing these activities? We're not asking you to buy or search for things you don't need, but if you are going to search or shop online, please try the sites listed below. If every member began to use one or more of these sites on a regular basis, the money raised would increase exponentially. Give it a try!

9. **www.goodsearch.com/**
www.goodshop.com— Set GoodSearch.com as your home page default. GoodSearch is a search engine powered by Yahoo that donates 50% of its revenues to the charities and schools designated by its users. Spread the word to your friends and family and ask them to put www.goodsearch.com as their internet home page default. The more people use GoodSearch, the more money will be directed toward HHT. you can now shop on www.goodshop.com at stores like Target, Best Buy, Walmart, LL Bean and many more. Your purchase will earn .5%-4% of the purchase price which will be donated to the charity of your choice (i.e., HHT Foundation).
10. **www.donationline.com/hht.htm**— This website will accept donations for automobiles, boats, trucks, RV's, motorcycles, jet skis, snowmobiles, planes, and real estate.

11. **www.iGive.com**— Shop 735 participating online stores with products for home or office (or gift cards) via this charitable website and a percentage of each purchase can be forwarded on to the Foundation. New iGive members earn extra money for their cause (HHT) just for joining.

12. **www.morethancards.com/give**— The holidays are quickly approaching and we all need cards. A percentage of the price of each card purchased is donated to the Foundation. Just click on the HHT logo under "Our Supported Foundations" and you're on your way.

13. **www.justgive.org** or
www.americanexpress.com/give— You can easily donate to the Foundation via these websites. The American Express Program even lets you use your Rewards Points to give!

GET INVOLVED!

14. **Plan a Fundraising or Awareness Event**— You can plan an event any time of the year. Contact Sharon Williams at 800-448-6389 or by email at sharon.williams@hht.org.
15. **Volunteer Your Time**— The HHT Foundation is always looking for volunteers to help start a Regional Networking Alliance, help with events, serve on the Board of Directors, or assist with your specific skills. Your time is a valuable contribution to the Foundation!
16. **Tell Someone About HHT**— It's that simple! Share HHT Foundation materials, our number (800-448-6389), our website address (www.hht.org), our list of HHT Treatment Centers with family, friends, physicians, and dentists. Educate everyone you can!

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From the Membership Desk...



Let me take a moment to share the appreciation of Executive Director, Marianne Clancy, the Board of Directors, and all of us here in the HHT Foundation office for members that renew on a regular basis. Thank you!

MEMBERSHIP

Please renew your membership in a timely manner. It costs the Foundation—which is YOU— a tremendous amount of time and postage to send out multiple renewal reminders and email reminders. In an effort to streamline costs, we will assume that you do not wish to be a member if your membership expires. This means that you will no longer continue to receive the monthly electronic news bulletin, the tri-annual Direct Connection newsletter, or other benefits of memberships.

If you choose not to renew, you also choose to slow progress and advancements of the HHT Foundation. Crucial planning is based on projected donations. **We act and advocate on your behalf, and can't move forward without you.**

ARE YOU RECEIVING THE MOST VALUE FROM YOUR MEMBERSHIP?

- *Do we have your physical mailing address?
- *How about your current e-mail address?

If the answer is not yes to either question, please email maryleigh.krock@hht.org or call Mary Leigh Krock at 800-448-6389.

MATCHING GIFTS

Ask your company or favorite organization to SUPPORT YOU. Ask your company to match your gift—whether or not they have an existing program! In the last six months we have received matching gifts from 10 foundations/organizations. We would love to add your company to our list of donors!

Thank you to the following organizations for their support of the HHT Foundation through a matching gift program:

*Adobe Systems Incorporated
AXA Foundation
Chevron Humankind
GlaxoSmithKline Foundation
HSBC Philanthropic Programs
Johnson & Johnson Family of Companies
Moody's Foundation
Mutual of America
PepsiCo Foundation
Prudential Foundation*

CFC AND UNITED WAY

HHT Foundation CFC Code is 10233. The Combined Federal Campaign, CFC, is the world's largest and most successful annual workplace charity campaign, with more than 300 CFC campaigns throughout the country and internationally to help to raise money for thousands of charities every year. Pledges made by Federal civilian, postal and military donors during the campaign season (September 1st to December 15th) support eligible non-profit organizations, like HHT, that provide health and human service benefits throughout the world.

The HHT Foundation receives numerous pledges each year from the CFC, but in many cases, the CFC does not supply us with the donor's name. **If you donate to the HHT Foundation through a CFC or United Way campaign, please email maryleigh.krock@hht.org or call Mary Leigh Krock at 800-448-6389** so I can credit you with the donation and update your membership.

Renew Your Membership Today!

**Renew today
online at
www.hht.org**

The HHT Foundation International is the **ONLY** organization advocating for research, education and legislation.

While your moment of crisis may have passed, do you want to **STAY INFORMED** of the latest research, treatments, educational opportunities & regional support?

If you have HHT, if you care for someone with HHT, if you want a **CURE** for HHT, please renew your membership annually. We need your continued support today to improve your quality of life tomorrow! Please renew online at www.hht.org or mail the membership form in this newsletter.

Mary Leigh Krock • Membership Coordinator • 800-448-6389 • 410-357-9932 • maryleigh.krock@hht.org

Our Story

A Life Changing Event

By Ron Johnson, HHT Member and Alumni Board Member

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. If, based on an examination, the crusts have disappeared, a revision surgery can be performed and the nasal cavity is reopened. The theory behind Young's Procedure is that the closed nasal cavity has time to heal.

Although HHT can manifest in a variety of ways, 90% of patients experience nosebleeds (epistaxis) that can range from mild to severe. Epistaxis severity determines the appropriate treatment (i.e., ointments, nasal packs, surgery). According to the Utah HHT Center, the Young's Procedure is not indicated for HHT patients with mild to moderate nosebleeds, or even those with severe nosebleeds unless other less invasive treatment options have been tried and have not worked. But given current treatment options for nosebleeds in HHT patients, the Young's Procedure is an option for select HHT patients. Ron Johnson is eager to share his story (written in 2006) with others who are affected by this disorder.

I was a member of the Board of Directors for the HHT Foundation from 1990 to 1997 when I resigned to serve a mission for my church with my sweetheart. I got interested in this Foundation to see if something could be done to help me and my children and my grandchildren who have this disease. My mother lost her life because of this disease and her father lost his life because of it and I am sure others in the ancestry had problems with the disease before that.

I am very pleased with the volunteers of the HHT Foundation Board and the Medical Advisory Board, plus all of the HHT Treatment Centers around the world. What a blessing it is to have all of the research going on in our behalf.

On September 1, 2005, I went in for surgery at the University of Utah Hospital and had a Young's Procedure, closure of the nasal passage, done to stop my constant nosebleeds. It has been over a year now and it literally has changed my life for the better. Just ask my sweetheart, Merna. I am a new man. It is an absolute miracle. I have not had a nosebleed since and my HGB is up to 15.9 and HCT 49.2. It has been a real blessing. You can research this procedure online or ask your ENT at an HHT Center if the procedure is right for you or your family member(s).

I first found out about this procedure by reading in the 2004 spring issue of the HHT Foundation Newsletter, Direct Connection, where it had an overview of methods for the treatment of recurrent nosebleeds in HHT. One of the methods listed was 'Closure of the Nose" (Young's Procedure). I looked into it and found through my ENT,

Dr. Leland Johnson at the University of Utah HHT Center, that a doctor in England, Dr. Valerie Lund, had been very successful with this surgery. I contacted Dr. Lund and had my surgery scheduled in England for Spring 2005. In the meantime, Dr. Johnson had been in touch with her and had, in fact, performed one Young's Procedure in Utah. I was Dr. Johnson's second Young's Procedure patient.

It has been very interesting now that it has been over a year since I had this procedure done. At 71 years of age, I now have the energy to work on projects that I haven't been able to do for several years. Thanks to this procedure and Dr. Johnson, I am doing well and enjoying life with my sweetheart and family and working hard without any loss of blood through nosebleeds. I do not have problems breathing through my mouth only. I cannot smell, which was expected, but I can taste and I am back on schedule to live much longer now than I would have without this special event in my life. I am sure I would not have been around much longer the way I was going down hill prior to the surgery. My Mother died at the age of 71, because of HHT and her Father died at the age of 80 as of a result of HHT.

I would be happy to talk to anyone about my experience. My email address is ronmerna@hotmail.com.

Your Friend,

Ron Johnson

Ron Johnson

HHT Grassroot Fundraising Challenge

By Sharon Williams, Legislative Advocacy and RNA Manager

We all know that these are difficult times. The HHT Foundation's membership and general donations are significantly decreased from last year. That's why the grassroots fundraising events hosted by our members are more important than ever.

The accomplishments that the HHT Foundation has achieved this year would not have been possible without your support in fundraising and giving!

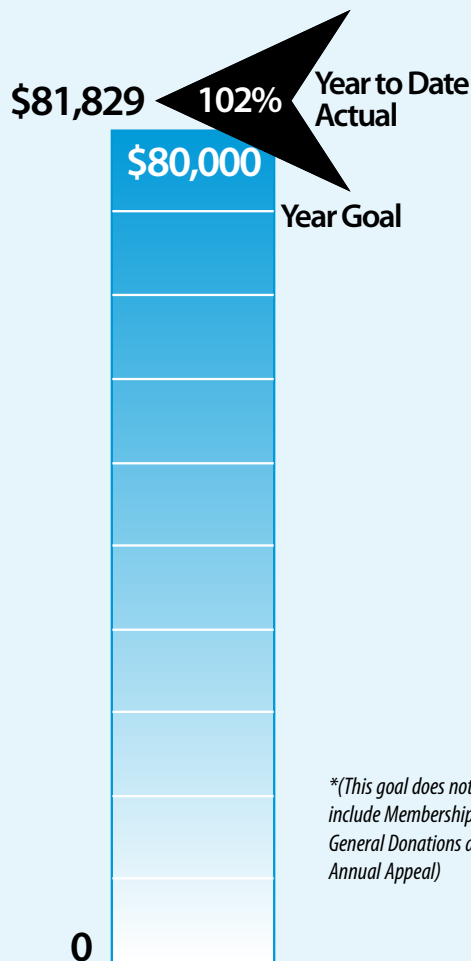
The simple fact is that we need everyone's help in raising funds in order to continue to be a responsive and results-oriented organization. The Foundation needs your help in funding to:

- continue and expand research
- develop improved treatments
- educate physicians and patients
- expand outreach efforts and availability of care
- ultimately find a cure

I want to thank all of the individuals that have supported the HHT Foundation in this fundraising challenge by organizing a fundraising event or by contributing to someone else's event.

If you are interested in learning more about fundraising for HHT, please visit the HHT website (www.hht.org) under HHT Foundation/Fundraising section. You can get numerous ideas there. You will see a listing of ongoing fundraising events, past events and lots of great ideas. Additionally, always feel free to call the HHT Foundation office at 800-448-6389.

Fiscal Year July 1, 2008 to June 30, 2009



**(This goal does not include Membership, General Donations and Annual Appeal)*

February 2009

Mt. Kilimanjaro Climb for Awareness

Scott Olitsky
Kansas

April 10, 2009

Purdy Family Bowling Fundraiser

Don, Diana, and Emma Purdy
Michigan

April 19, 2009

7th Annual Bass Open Golf Tournament

Sean and Lisa Bass
Maryland

April 20, 2009

Art Auction

St. Francis of Assisi School
California

April 25, 2009

Country Music Marathon

Kerry Chu
Tennessee

May 17, 2009

Bay to Breakers Marathon

Greg and Angela Brown
California

May 25, 2009

LA Marathon

Alex Lustig
California

We thank these valued members of the Foundation. They have taken us half-way up the thermometer in meeting our goal. If we are to reach our goal, we need more individuals, like yourself, to get involved with fundraising.

Upcoming Fundraising Events for FY 2009-2010

Grassroots Fundraising will continue to be a critical component of the HHT Foundation budget. The Board of Directors are meeting on June 14-15, 2009 to set our course for the next fiscal year that begins on July 1st. Although the grassroots financial goal for FY 2009-2010 is not yet set, we are grateful for those individuals who have already started planning events for the new year. It is because of these valued members that we are able to achieve so many of our education programs.

- **July 18, 2009, Trans Tahoe Relay**, Mike Lynch and his team of swimmers, Nevada to California
- **September 12, 2009, Ride for Life**, L. Wayne "Doc" Hanks, Louisiana
- **September 13, 2009, Ironman Triathlon**, Laurie Krause, Wisconsin
- **October 10, 2009, Baltimore Marathon**, HHT Foundation Office, Maryland
- **October 11, 2009, Long Beach Marathon**, California
- **Ongoing, Michael Timothy's Book Campaign**

Congratulations!

To Scott Olitsky for his Incredible Achievement in Making It to the Summit of One of the Tallest Mountains in the World – Mt. Kilimanjaro, Tanzania in Africa.



In Scott's own words on March 3, 2009:

"I just returned from Tanzania where my two friends, Mark Blocker and David Coats and I successfully reached the summit of Mt. Kilimanjaro. At 19340 feet, "Kili" is the "roof of Africa" and one of the seven summits...the highest peak in Africa."

"We spent 7 days getting to the summit to finally reach Uhuru peak at 19,340 feet. We had decided to climb Kili almost a year ago and had been running, biking and hiking in order to get ready for the climb."

"As an HHT patient, I was somewhat apprehensive about doing this. The high altitude and dry air was a major concern for me. I was worried that a significant amount of epistaxis could significantly hurt my chances of summiting and a year's worth of training would be ruined."

"In spite of aggressive lubrication, I did experience bleeding a few mornings. A company called Entegriion was nice enough to supply me with some of their product called Stasilon for my climb. I kept some with me in my pocket the entire trip. I found Stasilon stopped the bleeding very quickly."

Scott's goal for this climb was to raise funds and awareness for the HHT Foundation and he was extraordinary successful in both areas. On behalf of Scott Olitsky, the Olitsky family, and the HHT Foundation, we want to thank all the friends of the HHT Foundation that donated to this incredible venture. As a result of your kind and generous donations, Scott was able to exceed his goal of \$19,340 - one dollar for every foot of the climb.

The HHT Foundation wants to congratulate and send our very warm thank you to Scott for his "over the top" achievement. We have enjoyed following Scott's steps on this extraordinary journey!

The Purdy Family Bowling Fundraiser

Port Huron, Michigan • April 10, 2009



Over 100 letters for donations were mailed. Flyers were posted all around town. We created our own HHT shirt to giveaway at the event. We invited all of our family and friends. Then we waited for the day.

Our goal was to raise as much money as we had the year before with Emma's Lemonade Stand, which was \$1100. We arrived at the bowling alley at 6:00 and our family arrived with us to help setup. Doors opened at 7:00 and "WOW", here they came. We had over 100 people in attendance with 59 of them bowling! We even had the Nissan Family from Canton come to support our bowling

event. My gratitude to the Nissan's for giving Emma the opportunity to meet another child, who isn't a family member, dealing with HHT.

The night was a wonderful and very successful event. With the matching funds that we were able to receive from Thrivent Financial we raised \$6000!!! We just couldn't believe the support from all of our family, friends, and our local community.

Our Mission Is not Impossible:

- **Help** save lives
- **Hope** for a cure
- **To** raise awareness

Grass Roots Fundraising Really Works!

Concord, California • April 20, 2009



Sometimes it only takes a 6 year old boy with no front teeth and a very caring and motivated teacher to make a HUGE difference...

On April 20, 2009, in the little known city of Concord, California, an amazing event took place. The **kindergarten class of St. Francis of Assisi School** held an art auction featuring art created from purely recycled materials. The class worked for four weeks to create spectacular pieces of art! The children were glowing with pride at their accomplishment. The buyers were excited about being able to purchase one-of-a-kind artwork.

Why is this so important? The auction benefited the HHT Foundation and reassured six year old Anthony Brown, who has HHT, that his classmates, and especially his teacher, do care about finding a cure for his disease. **In one hour** the Foundation gained over \$600 dollars.

A very special thank you to Ms. Lisa Twomey for coming up with the idea for the auction and arranging the event. Ms. Twomey (who does not have HHT) will also be running in the upcoming Bay To Breakers fundraiser benefiting the HHT Foundation. To show your support for this event and the HHT racing team please donate at www.active.com/donate/BaytoBreakers



Bay to Breakers Marathon

San Francisco, California • May 17, 2009



Greg and Angela Brown and their two children

Greg has run the San Francisco ING Bay to Breakers Race many times in his life, but this year means the most to him. Greg is running, not to achieve a personal best time or prove that he can finish, but because he has HHT, his children have HHT, and his extended family have HHT. He is running to prove that with tenacity anything is possible, including finding a cure to this disease so that he can live to see a generation in his family without HHT.

Greg has had two brain surgeries, one abdominal surgery, liver failure, daily nose bleeds and IV iron (every other week for four years) because of HHT. Greg's grandmother and his 12 year old cousin died from the

disease. His sister had a stroke at 20 years old. Greg's children have lung and brain issues as well.

This is Greg's way of raising money for the HHT Foundation. The Foundation is dedicated to finding a cure to this disease. Please help Greg in his quest to heal many by donating to this very personal and important cause.

Greg routinely visualizes himself crossing the finish line in an effort to motivate himself to keep training. His wife and he visualize a world without HHT, a world where their children are healthy and happy. Please help him to realize this dream.

The HHT Foundation is committed to HHT education, research, and to finding a cure. You can get more information about the race and make an on-line tax deductible donation at: <http://www.active.com/donate/BaytoBreakers> or you can send a check to the HHT Foundation at the following address:

HHT Foundation International, Inc.
PO Box 329
Monkton, MD 21111

Please make your check payable to the HHT Foundation and indicate that your check is to support the Bay to Breakers Marathon for HHT.

"You can't tell by looking at us, but 3 out of 4 of our immediate family have a deadly disease. . . HHT, the Silent Killer."

Alex Lustig runs for HHT in the LA Marathon

Los Angeles, California • May 25, 2009



Alex has joined the Students Running the LA Marathon group and has been training since last fall to run the Los Angeles Marathon. He is 14 yrs old and will be running in the race on May 25, 2009. His race times have been impressive with one of his training runs, an 18 miler, clocking in at just over 11 minutes a mile. Alex's father, Rich Lustig, has HHT and he supports The HHT Foundation's efforts to find effective treatments and an eventual cure. Alex wants to use the race as a way to help raise funds for the HHT Foundation. In the coming year, Alex

and his sisters will be tested to see if they have HHT as well since it is a hereditary disease.

To make an on-line tax deductible donation you go to the following link www.active.com/donate/AlexLustigRaceforHHT or you can make a check payable to the HHT Foundation and send it to the HHT office at:

HHT Foundation
P.O. Box 329
Monkton, MD 21111

Your support is so appreciated by the Lustig family, the HHT Foundation, and all families that are affected by this disorder.

7th Annual Bass Open Golf Tournament

Westminster, Maryland • April 19, 2009



Written by Sean Bass, HHT Member

On April 19th, 118 fun-loving golfers, about a dozen tireless volunteers, and scores of generous donors participated in the 7th Annual Bass Open Golf Tournament to benefit the HHT Foundation.



This year's event took place at a new location: Wakefield Valley Golf and Conference Center in serene Westminster, Maryland.

Again, the tournament attracted participants with talent ranging from a past PGA teaching pro to 10 handicappers to first-time golfers just there for the fun and festivities. The atmosphere was relaxed but competitive as foursomes vied for prizes like Bass Open golf shirts, gift certificates to popular restaurants and retail stores, and much more. Raffles were also available for prizes ranging from sports memorabilia to vacation packages to free tickets to area attractions like the National Aquarium in Baltimore.

The tournament was started in 2003 after Lisa Bass, the tournament's founder and driving force, attended an HHT conference in her hometown of Baltimore. She was disappointed to learn how little fundraising the Foundation actually receives from its members. Lisa

does not have HHT but her husband and now 8 year old son both have HHT. She wanted to do something to raise money and awareness.



After a fantastic day of golfing and refreshments on the course, the attendees were ushered to the center's Ballroom for a wonderful dinner of prime rib and fried chicken. By the look of contentment and friendship in the room, this year's golf open was a rousing success.



Lisa and Sean continue to be impressed by the generosity of their friends and their community, in their endeavor to eradicate HHT and promote awareness of the disease. The tournament continues to make a generous financial donation to the HHT Foundation and the Bass' are already planning next year's event.

paid advertisement

Give Nature a Chance

**Stop Bleeds Without Clots
Regenerate Healthy Tissues**

Colostrum is Naturally Rich in Healing Agents

"Several colostrum components stimulate wound healing. Nucleotides, EgF, TgF, and IgF-1 stimulate skin growth and cellular growth and repair by direct action on DNA and RNA. These growth factors facilitate the healing of tissues damaged by ulcers, trauma, burns, surgery, or inflammatory disease. Colostrum's wound-healing properties specifically benefit the skin, muscle, cartilage, bone, and nerve cells." – Zoltan Rona, M.D., The American Journal of Natural Medicine, Mar. 1998

"I am delighted to say that at present I am only having about 3 or 4 nosebleeds a month, and they are of very short duration and stop quickly. When I think back to last year and how bad things had become at work and at home I am so happy to be virtually nosebleed free at the moment and believe me I am grateful for every "bleedfree" day. I take two lozenges a day; one first thing in the morning and the other one before dinner in the evening. I am also happy to say that I rarely need to use the liquid colostrum any more as my nosebleeds are so minimal these days!! I am so happy that I found your product and would definitely recommend that any fellow sufferers give it a try. There is nothing to lose!!" E.K.

All mammals first drink colostrum and then milk.



For Topical Use



For Internal Use

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800-308-4264



Kerry Chu's Race for HHT Awareness Country Music Marathon

Nashville, Tennessee • April, 25, 2009

On Saturday April 25th, Kerry Chu, ran her first marathon in the Country Music Marathon & ½ Marathon in Nashville, Tennessee for HHT.

"It was 90 degrees and barely any shade. I wanted to quit many times but pushed through and am very happy I did. I finished the race in 4 hours, 52 minutes and 26 seconds!" exclaims Kerry.

Kerry ran this race in honor of her mother, Maureen Routledge. Maureen and several other family members Maureen Routledge and Kerry Chu cheered Kerry on in the very hot weather.

The whole Routledge family has been so involved in helping families with HHT. Kerry's father, Dennis has been an extremely active Director of the HHT Foundation Board and Maureen continues to log countless volunteer hours as well.

Kerry's fundraising page received 90 donations. Kerry, her family, the HHT Foundation, and all those that are affected by HHT, want to thank you for your kind donations to Kerry's Race for HHT Awareness.



Maureen Routledge and Kerry Chu

Ride for Life to Raise Awareness of HHT

Lake Charles, Louisiana • September 12, 2009

L. Wayne "Doc" Hanks, an HHT member, in partnership with Lifeshare Blood Centers, is hosting a "Poker Run" and Replenishment Blood Drive to collect much needed blood and to raise funds and awareness for HHT.

The "Poker Run" is basically where motorcycle riders visit different businesses and cards are drawn to make the best poker hand. The biker community uses this type of event to benefit a charity as well as enjoy riding and socializing with many riders in their area. Doc is a member of the Patriot Guard Riders and many of its members will be participating in this event.

Doc states, "I am one of many people in the world suffering from HHT, along with several generations of my family. My grandmother, mother, aunt, brother, sister, son, along with cousins, nieces, and nephews have been affected by this disease. I have lost my grandmother, mother, and aunt to HHT, and as time goes on, it progresses in the others. The worst case I have seen, is with a cousin of mine. At one point he was losing so much blood, he was receiving 6-7 pints of blood a week."

Doc is hoping to continue to raise money and awareness as long as he is able. "I would appreciate your help in funding research to improve HHT patients' quality of life, now and for the generations to come. Hopefully one day through research, a cure will be developed, and HHT will be a thing of the past," exclaims Doc.

The HHT Foundation is committed to HHT education, research, and to finding a cure. You can make an on-line tax deductible donation



at www.active.com/donate/HHTRideforLife or send a check made payable to The HHT Foundation and mail to:

HHT Foundation
P.O. Box 329
Monkton, MD 21111

Please indicate that your check is to support Doc's Ride for Life. The Hanks family, the HHT Foundation, and all those that are affected by HHT appreciate your support.

Laurie Krause enters Wisconsin Ironman Triathlon for HHT

Madison, Wisconsin • September 13th, 2009



"When does somebody choose to take the opportunity to make a difference? Up to this point, I have been reluctant to pursue fundraising and awareness building activities related to my personal experiences with HHT," states Laurie Krause. "I am now facing my biggest athletic challenge so far in my attempt to finish the Wisconsin Ironman Triathlon and I am doing it for HHT."

The Wisconsin Ironman Triathlon includes a 2.4 mile swim, 112 mile bike ride, followed by a marathon, which is a 26.2 mile run. The event will take place on September 13th, 2009. Laurie comments, "I have been completely inspired by the HHT Foundation members who are doing so much to benefit others. It is time for me to put my apprehension and fears aside and look at this event as a perfect opportunity to raise awareness and maybe a little money for HHT!"

Laurie's personal history with HHT includes undergoing a craniotomy to remove two of her four Cerebral AVM's, one of which had ruptured, and an embolization of my largest Pulmonary AVM. Her grandmother, who is deceased, had daily nosebleeds and many other challenges with HHT. Laurie's mother, uncle, and her youngest daughter have HHT, each with their own unique presentation of symptoms.

Laurie states, "I feel so very fortunate to be able to pay tribute to those I love, as well as to all members of HHT families who continually deal with the difficulties associated with having this disorder. Please join me on this incredible journey, and together we can make a difference....one step at a time."

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You can make an on-line tax deductible donation at: www.active.com/donate/LaurieKrauseRace or you can make a check payable to the HHT Foundation and mail it to the HHT office at: HHT Foundation International, Inc., P.O. Box 329, Monkton, MD 21111. Please indicate that your check is to support the Laurie Krause Triathlon Race for HHT.

Want to organize a fundraising event but don't know how?

The HHT Fundraising Committee wants to help you. For ideas and "how to" templates of successful events, contact Sharon Williams at 800-448-6389 or email her at sharon.williams@hht.org.

News From Our Regional Networking Alliances

Northern and Central California RNA Meeting

Concord, California • April 4, 2009

HHT members and their families from the Northern and Central California Region participated in the first meeting of the year on April 4, 2009. Regional Coordinator, Angela Carlisle-Brown (alfaangle@aol.com), presented a PowerPoint presentation containing information about the HHT Foundation's achievements and goals, and fundraising and awareness efforts for the year.

After the presentation, there was a group discussion focusing on grassroots fundraising ideas and the importance of upcoming events, like the Bay to Breakers HHT Fundraiser being held on May 17, 2009. (To donate visit their webpage: www.active.com/donate/BaytoBreakers)

There was also discussion regarding the need for California residents to attend Capitol Hill Day on June 16th. We are happy to report that at least three members will be marching on Capitol Hill to represent California this year. (If you would like to join the California group please e-mail Angela at the e-mail address above.)

Other topics of discussion were the importance of learning the most up-to-date medical treatment options for nose bleeds, the necessity of having strong emotional support when faced with HHT related deaths, and challenging medical issues.



The group will be meeting again in early Fall 2009. If you would like to be notified of the upcoming meeting, please contact Angela Carlisle-Brown.

A very special thank you to **Adina Petty** and **Rick and Pat Escalambre** for supporting the meeting by providing catered items and IT equipment. The meeting was a great success largely due to their efforts. Another special thank you to those dedicated members who traveled to the meeting and helped make it a rousing success!!

New England Area RNA Meeting

Foxboro, Massachusetts • January 24, 2009

On Saturday, January 24, 2009, the Southern New England Regional Networking Alliance held their Kick Off Brunch in Foxboro, Massachusetts from 10:00 am until noon. The meeting was led by the group's Regional Coordinator and HHT member, Bob Resinger, who graciously provided a conference room as a meeting place for the group and a wonderful brunch that was enjoyed by all.

The meeting was well attended. Twenty two (22) individuals attended the meeting from the states of Connecticut, Massachusetts and Rhode Island. The attendees enjoyed being able to share their stories, experiences, and concerns with the group and getting to know each other a little better. Diana Meiches, an HHT Board member, was the guest speaker and reviewed the activities and accomplishments of the HHT Foundation as well as a review of the HHT Legislative Initiative.



Beyond the opportunity to get to know each other, the group consensus was to help make a difference for people with HHT. The attendees decided on two areas of focus: HHT Awareness and Fundraising. The group broke up into working committees with Dennis Ford and Mike Geake leading the HHT Awareness Team and Kathleen Tenney leading the Fundraising Team. The groups met again at the end of March and have scheduled future meetings in order to continue the momentum.

Pennsylvania RNA Meeting

Philadelphia, Pennsylvania • April 19, 2009



Allan Olitsky

On Sunday, April 19, 2009, about 120 people gathered in an amphitheater at the University of Pennsylvania's School of Dental Medicine for the first Philadelphia Regional Networking Alliance meeting, hosted by Co-Coordinators, Dr. Allan and Gwen Olitsky. The impressive number of attendees is due, according to Gwen, to the support of the HHT Foundation, Joel and Abbe Rosner (Board Member and the Co-Coordinators of the NJ/NY RNA) and the HHT Center at the University of Pennsylvania's support in contacting their patient base.

"We expected to have a turnout like most RNA's for their first meeting, maybe 18 – 22 people. We had to change the room three times to accommodate everyone, and this really shows what a need there is for HHT families to network and get current information," said Gwen Olitsky. "We had people from PA, NJ, NY, DE, MD and DC. Almost all of them said, 'I never met anyone outside of my own family with HHT' and watching them network was one of the highlights of my day." Allan Olitsky went on to say, "My personal goals are to see a cure for my children and grandchildren and to promote awareness of HHT to dentists, especially all dental students, because the members of my own profession can be the first line of recognition when they see the telangiectases on the lips and tongue, then refer to HHT Centers."

Allan Olitsky welcomed everyone by giving a brief overview of his family's HHT history, including tracing HHT back to a great-grandfather in Russia. He talked about his interest in promoting awareness and research into treatment by describing the testing and treatment of his own children and grandchildren as well as the impact of HHT on his extended family. He reminded the audience, many of whom had asked "Was it your son who climbed Mt. Kilimanjaro a few months ago?", that "It is thanks to early detection, diagnosis and treatment that my son, Scott, was able to successfully complete his Climb for HHT Awareness in February." He stressed that "my wife and I agreed to volunteer to facilitate this meeting because we are so grateful for the progress the HHT Foundation supports, what it's done for our family, and because we want our grandchildren to have a better quality of life than my father and grandfather had."



Dr. Reed Pyeritz

Dr. Reed Pyeritz, the Director of the HHT Center at the University of Pennsylvania, gave an overview of the genetics of HHT, emphasizing the need to become involved with HHT Centers and their databases to enhance opportunities for research and treatment. He described the role of the HHT Center in educating physicians and other health care providers about HHT. Dr. Pyeritz noted that he presents an HHT case study to all incoming medical students and they remember years later that he introduced them to HHT as part of his lecture on Genetics.



Dr. Douglas Ross

Dr. Douglas Ross, known for his work with the Yale HHT team, currently Chief of Surgery at St. Vincent's Hospital in Bridgeport CT, described the various treatments for nosebleeds, offering pros and cons of each treatment and reiterated Dr. Pyeritz's call for participation in studies for HHT research projects. His descriptive slides helped attendees understand the mechanics of treatment of nosebleeds, including various surgical remedies. Dr. Ross emphasized the need for HHT patients to have their physicians coordinate with HHT specialists, due to special considerations and new therapies relevant to the disease.

Other presenters discussed the 'mechanics' of getting genetic testing, answering questions about privacy issues, insurance coverage, fees for testing and methods of coordinating services for people who travel long distances to HHT Centers.



Marianne Clancy

Marianne Clancy, the HHT Foundation's Executive Director, brought her slide presentation describing the work of the Foundation with samples of materials used to promote awareness of the impact of HHT in the world, the U.S. and in each state. Marianne urged everyone to participate in Capitol Hill Day in June, or at the very least, to contact and visit their Senators and Representatives in their local offices, armed with statistics about HHT and the need for federal funding.

In his summation at the end of the meeting, Allan thanked everyone for attending and said that Marianne would like us to consider an expanded Regional Conference next year with an assortment of workshops, presentations, panel discussions and networking opportunities. "We want to see a cure for our children and grandchildren, and by working together and showing our strength in numbers, we can make that happen!"

For more information about the Philadelphia area RNA, contact PhillyHHT@aol.com.

Michigan RNA Meeting

Grand Rapids, Michigan • March 28, 2009

Jill Wilterdink and Carole Gaertner, Co-Regional Coordinators of the Michigan Regional Networking Alliance, started the meeting by introducing themselves and sharing how HHT has affected their lives. They further shared how their experiences have created a desire to dedicate time and resources to helping the HHT Foundation and others with this disorder.

Jill commented about the meeting, "The meeting was well attended with 27 individuals representing all regions of the state with the majority from the SE region. Those in attendance either had HHT or had a loved one with HHT. Each person introduced themselves and all had a story to tell that ranged from concern about HHT and wanting to learn more to heart wrenching stories of the loss of loved ones. Common threads shared include family physicians being ill-advised on this disorder, misdiagnosis, mishandling of treatment, and the subsequent negative impact this can have on their lives. The majority had other family members similarly afflicted including children."

There were three specific areas the group focused on: Support and Education, Fundraising, and Outreach/Awareness. The purpose of the meeting was not to start working in these areas but to identify who would like to participate, in what capacity, and to start a dialogue.

The group did have a lot of lively discussion around fundraising opportunities and community involvement. The following fundraising ideas were discussed, with action items established, for the next meeting: Meijer Community Rewards, TV Raffle, \$1Shot, and HHT Walk. Additionally, the group was interested in legislative advocacy. Some of the meeting attendees were interested in attending the HHT Capitol Hill Day in Washington DC this June and are looking into chartering a bus.

Diana and Don Purdy attended the meeting and spoke of the **Bowling Fundraising Event they are holding on April 10th in Port Huron, MI.** For this event, they had HHT t-shirts and sweatshirts made up for sale. If you want to order one of these shirts, send an email to Diana Purdy at prudy5415@aol.com. **Costs are \$10 for a t-shirt, \$16 for a sweatshirt and \$20 for a hooded sweatshirt. Please indicate sizes when ordering.** The front has the HHT blue logo in the upper right hand side of shirt.

There was ample opportunity to get to know each other during the break and after the meeting. It was decided that the next meeting will be held in late September or early October timeframe.



Directory of Regional Networking Alliances

Living with a rare disorder can be isolating and frightening. Whether you are newly diagnosed with HHT or have been living with the disorder for years, you don't have to face this illness alone.

The HHT Foundation has an ever-growing network of support groups called Regional Networking Alliances (RNA) operating across the United States and Canada.

What is a Regional Networking Alliance (RNA)?

A Regional Networking Alliance is an informal group of empowered and caring volunteers that work closely with the HHT Foundation to facilitate local connections for individuals and families affected by HHT. An RNA can provide a forum for individuals

to share their concerns and experiences so they no longer have to feel isolated. In an RNA, you can move from despair to hope by discovering the tools you need to cope on a day to day basis as well as have the opportunity to get involved in issues that affect your life.

Join one of our existing Regional Networking Alliances:

We currently have RNAs in the following areas. Please feel free to contact the Regional Coordinators in your area to learn more about the group. If you are interested in starting an RNA in your area, please contact Sharon Williams at 800-448-6389 or sharon.williams@hht.org.

CALIFORNIA RNA — NORTH CENTRAL

Co-Regional Coordinator: **Angela Carlisle- Brown**
Concord, CA

Contact Information:

alfaangle@aol.com
(925) 998-0099

Co-Regional Coordinator: **Denise Hitzeman**

Scotts Valley, California

Contact Information:

hhtcoordinator@highono2.com
(408) 839-9503

CALIFORNIA RNA — SOUTHERN

Regional Coordinator: **Debra Drysdale**

Newport Beach, California

Contact Information:

debradrysdale@cox.net
(949) 854-0557

GEORGIA — NORTHERN GA AND WESTERN SC

Regional Coordinator: **Bette Holzberg, M.D.**
Evans, GA

Contact Information:

betteholz@yahoo.com
(706) 447-8501

ILLINOIS RNA — CHICAGO AREA

Co-Regional Coordinator: **Sandra Lurie**

Highland Park, Illinois

Contact Information:

Dziner115@sbcglobal.net
(847) 831-2291

Co-Regional Coordinator: **Reta Kunz-Jankowski**

Lake in the Hills, Illinois

Contact Information:

Retats@juno.com
(847) 659-1606

KANSAS RNA

Regional Coordinator: **Scott Olitsky**

Leawood, Kansas

Contact Information:

scottolitsky@aol.com
(913) 897-6688

MARYLAND RNA — MD, DE, DC AREA

Regional Coordinator: **Sara Palmer**

Baltimore, Maryland

Contact Information:

spalmer@jhmi.edu
(410) 653-2245

MICHIGAN RNA

Co-Regional Coordinator: **Carol Gaertner**

Saginaw, Michigan

Contact Information:

carolgaertner610@msn.com
(989) 752-3342

Co-Regional Coordinator: **Jill Wilterdink**

Wyoming, Michigan

Contact Information:

j.wilterdink@comcast.net
(616) 531-5671

NEW JERSEY

Regional Coordinator: **Joel & Abbe Rosner**

Teaneck, New Jersey

Contact Information:

joelrosner@yahoo.com
abberosner@yahoo.com
(201) 692-3696

OHIO RNA

Regional Coordinator: **Denise Sherman**

North Olmsted, Ohio

Contact Information:

dsherman09@gmail.com
(440) 779-1650

PENNSYLVANIA RNA (PHILADELPHIA AREA)

Co-Regional Coordinators: **Allan and Gwen Olitsky**

Landsdale, Pennsylvania

Contact Information:

ajolitsky@aol.com
GwenOMS@aol.com
(215) 368-8636

RHODE ISLAND RNA — (RI, CT, AND MA)

Regional Coordinator: **Bob Resinger**

West Warwick, Rhode Island

Contact Information:

Dbobbins@cox.net
(401) 615-5642

TENNESSEE RNA

Regional Coordinator: **Cassie Hamilton**

Nashville, Tennessee

Contact Information:

psychopharmrx@yahoo.com
(423) 710-3395

TEXAS RNA

Regional Coordinator: **Bob Parsons**

Kerrville, Texas

Contact Information:

rparsons@stx.rr.com
(830) 257-3406

WESTERN CANADA SUPPORT GROUP

Regional Coordinator: **Delaine Elle**

Edmonton, Alberta

Contact Information:

celle@telus.net
(780) 475-1717

Donations to the Foundation

Our sincere and heartfelt thanks go out to everyone who has contributed to the HHT Foundation whether through research endowment, membership, general, or tribute donations. Below we list the donors who have contributed to the HHT Foundation through a memorial or tribute gift since the publication of our last newsletter through May 28, 2009.

Tribute Donations

DONATIONS THAT CELEBRATE In Honor Of...

<i>Mr. and Mrs. Louis Acerra</i> Camille Toto	<i>Danielle Holsapple</i> Keith and Phyllis Bridson	<i>John and Ruth McMahon In honor of their 50th Wedding Anniversary</i> Carl and Craig Doerrmann Jeanne Funrue Nathanael Harrison Marian Harrison Griswold & Therese Hurlbert David and Carole Jochen Kevin Miller James Polski Robert and Alice Reinbold Mr. & Mrs. Harry Smith Maureen Weiss	<i>Bill, Terri, Blake, Caitlin Presson</i> Frank and Judy Sublette
<i>Sean and Lisa Bass</i> Tom and Susan Barnard Fraser	<i>Barbara Isenberg</i> Rita Jacobs	<i>Marc and Diana Meiches</i> Maurice and Rosalie Meiches Daniel & Mary Beth Meiches	<i>Bill Racz and descendants</i> John and Donna Halligan
<i>Robert Berkman</i> The Parducci Family Fdn.	<i>Cate Lacy</i> Linda McGennis	<i>Sandy Osser</i> Dr. Matthew Nagorsky	<i>Kayla Sublette & Frank Sublette, Jr.</i> Frank and Judy Sublette
<i>Carol Ann Bourgault</i> Deborah & Steven Knapp	<i>Noell and Ben Lacy</i> Linda McGennis	<i>Bill and Terri Presson</i> Frank and Judy Sublette	<i>Jane and Hani Talebi</i> Linda McGennis
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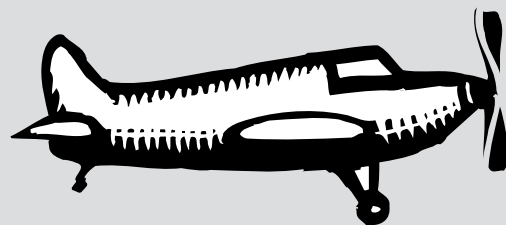
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HHT SENATE RESOLUTION PASSES!!

We are thrilled to announce that Senate Resolution 161 (formerly S. Res. 141) which was introduced on June 1st, has been passed by the United States Senate! *This resolution recognizes June as the first National HHT Awareness Month.*

HHT HOUSE RESOLUTION #536 • We Need Your Immediate Help!

On June 11, 2009, the House of Representatives introduced a bipartisan resolution recognizing June as the first National HHT Awareness Month that was co-sponsored by Rep. Richard Neal (D), Massachusetts and Rep. Joe Wilson (R), South Carolina.

CALL TO ACTION:

By June 30, 2009, we need hundreds of House Representatives to join Rep. Neal and Rep. Wilson in co-sponsoring the House Resolution #536.

1. Identify your House Representative and their contact information by accessing www.congress.org.
2. Call your House Representative's office and ask them to sponsor House Resolution #536 by contacting either:
Rep. Richard Neal's (D) Chief of Staff, Ann Jablon at 202-225-5601 OR
Rep. Joe Wilson's (R) Legislative Director, Melissa Chandler at 202-225-2542
3. Notify your family and friends and ask them to contact their House Representative as well. They do not have to have HHT to help!

**As a constituent, it is important that your House Representative hear from you!
Together, we will be heard and we will make a difference!**