

ADVICE FOR PEOPLE NEWLY DIAGNOSED WITH HHT



HHT is rare but not uncommon – it frequently goes undiagnosed and many physicians lack crucial information regarding treatment. The HHT Foundation will always be your best source of current information, and the “Learn About HHT” brochure and “HHT at a Glance” are essential guides to getting started.

FACTSHEET
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SOME IMPORTANT FACTS TO REMEMBER ABOUT HHT ARE:

The worst medical consequences of HHT are mostly preventable, once you know you have it.

Living with HHT can be stressful, at times, but most people can manage it.

Most people who take good care of their HHT can have pretty normal lives.



The Cornerstone of
the HHT Community

HHT Foundation International Inc.
P.O. Box 329 / Monkton / MD 21111



EDUCATING YOURSELF ABOUT HHT: 4 HELPFUL STEPS

Understand that your life will not be defined by this disease. HHT is highly treatable and managed by thousands of people all over the world. Each day and each diagnosis bring us closer to a cure.

STEP 1 - Learn About HHT

- HHT is rare but not uncommon – it frequently goes undiagnosed and many physicians lack crucial information regarding treatment. The HHT Foundation will always be your best source of current information, and the “Learn About HHT” brochure and “HHT at a Glance” are essential guides to getting started. This is an instance in which knowledge truly is power, and the best way to help yourself and your family is to stay informed.

<http://hht.org/about-hht>

STEP 2 - Contact an HHT Treatment Center

- HHT Treatment Centers and Centers of Excellence are staffed by multidisciplinary medical teams, which together are fully equipped to treat the multiple symptoms of HHT. Unlike local physicians who may have little or no knowledge of the disease, our HHT experts work cohesively to take an integrated approach to treatment.
- By visiting an HHT Center, you become a part of an international community dedicated to sharing knowledge and information in the effort to cure HHT.

http://hht.org/docs/HHT_Centers_Genetic_Labs_InsertB.pdf

STEP 3 - Continue Your HHT Education And Get Involved

- Utilize the numerous resources available to you through the Foundation website to learn more about HHT and become an advocate for the entire family.
- Attend an HHT Patient and Family Conference to make direct contact with physicians and experts and connect with HHT individuals from across the world. Foundation members receive a registration discount.

- Learn about other ways to get involved in the work of the Foundation – from volunteering to donating to fundraising, there are numerous ways to help, and every bit makes a difference.

<http://hht.org/get-involved>

STEP 4 - Join The Movement

2014 is the Year of Action for HHT. We are closer to a cure than ever before, and it has never been more important for all of us to stand together as we move to transform the future of HHT. The Foundation has developed four major initiatives on which to focus this year.

- Increasing Access to Expert Healthcare: We will increase the number of HHT Centers of Excellence throughout North America and establish a mentor program between existing centers and new proposed centers.
- Advancing Treatment: The HHT Foundation is committed to furthering relationships with Bio/Pharma Companies in an effort to accelerate drug discovery or repurpose existing drugs for use in HHT treatment.
- Building Outcomes Database: The Foundation has solely funded the development of the Outcomes Registry for HHT at Dartmouth’s Giesel School of Medicine. The purpose of the Registry is to conduct natural history studies to further research, and to follow HHT patients on a long-term basis.
- Increasing Awareness About HHT: This year, the HHT Foundation is committed to launching an original awareness campaign dedicated to increasing outreach and public knowledge of HHT as an unrecognized disease.



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