



The Cornerstone of  
the HHT Community

The HHT Foundation is your #1 resource for the most up-to-date news and information in the treatment of HHT. As part of our commitment to keeping the HHT Community well informed, the HHT Foundation will continue to update its website on a regular basis with any new developments in the field of HHT.

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In addition, the HHT Foundation provides links to other well trusted resources on our website.

## HHT SPECIFIC PHYSICIAN RESOURCES

### Brain AVM Definition, Symptoms, Treatment

[http://brainavm.oci.utoronto.ca/malformations/brain\\_avm\\_index.htm](http://brainavm.oci.utoronto.ca/malformations/brain_avm_index.htm)

### Clinical Description via GeneReviews

<http://www.geneclinics.org/profiles/hht/details.html>

### Clinical Description via Genetics Home Reference

<http://ghr.nlm.nih.gov/condition=hereditaryhemorrhagictelangiectasia>

### HHT Clinical Guidelines – Journal of Medical Genetics

<http://jmg.bmj.com/content/early/2009/06/23/jmg.2009.069013.full.pdf+html>

**PubMed** – Comprises more than 19 million citations for bio-medical articles from MEDLINE and life science journals. Citations may include links to full-text articles from *PubMed Central* or publisher websites. <http://www.ncbi.nlm.nih.gov/pubmed/>

## PATIENT SUPPORT

**Caring Voice Coalition** – serves the comprehensive needs of individuals affected by serious and chronic disorder, through collaborative efforts and partnerships with organizations established to serve those patient populations. They have programs to help patients with insurance reimbursement, financial assistance, patient support services and public advocacy. <http://caringvoice.org/>

**Families USA** - Families USA is a national nonprofit, non-partisan organization dedicated to the achievement of high-quality, affordable health care for all Americans. <http://www.familiesusa.org>

**The NeedyMeds PH Resource Page** – a resource page tailored specifically to pulmonary hypertension patients. It includes an overview of PH, a comprehensive list of FDA-approved treatments and their respective Patient Assistance Programs, link to other patient advocacy organization that work with the PH community and link to important pages on PHA's website. <http://www.needymeds.org/>

**Patient Advocate Foundation** – A Foundation that seeks to empower patients to take control of their health care. Case managers work with patients to discover local, state, and federal programs that provide assistance for their individual needs. <http://www.patientadvocate.org/resources.php>

## GENERAL INSURANCE INFORMATION

**Consumer Health Insurance Guide (Kaiser Family Foundation)** – a guide to handling disputes with your employer or private health plan. Use this guide to understand your coverage and learn how to make an effective appeal. [www.kff.org/consumerguide/7350.cfm](http://www.kff.org/consumerguide/7350.cfm)

**Health Insurance In-Depth** – defines some basic health plan terminology, explains deductibles, co-insurance and co-payments and describes the legal protections associated with major medical insurance. [www.healthinsuranceindepth.com/](http://www.healthinsuranceindepth.com/)

**Health Insurance Info (The Georgetown University Health Policy Institute)** – provides a consumer guide for getting and keeping health insurance for each state and the district of Columbia – fifty-one in all. These Consumer Guides are available at this website and will be updated periodically as changes in federal and state policy warrant. [www.healthinsuranceinfo.net/](http://www.healthinsuranceinfo.net/)

**Q&A About Health Insurance (USHHS)** – helps you choose a plan that is right for you. Definitions of health insurance terms are also given in order to help you with your task. [www.ahrq.gov/consumer/insurance.qa/](http://www.ahrq.gov/consumer/insurance.qa/)

## GOVERNMENT RESOURCES

### Centers for Medicare and Medicaid Benefits

<http://www.cms.hhs.gov>

**Health Finder** – Your source for offering reliable health information from the Federal Government.

[www.healthfinder.gov](http://www.healthfinder.gov)

**Medicare Rights Center** - The Medicare Rights Center works to ensure access to affordable health care for older adults and people with disabilities through counseling, educational programs and public policy initiatives.

<http://www.medicarerights.org/>

**MedlinePlus** - Health information from the National Library of Medicine. MedlinePlus provides easy access to health topics, medical dictionaries, directories and publications.

[www.nlm.nih.gov/medlineplus/](http://www.nlm.nih.gov/medlineplus/)

**My Family Health Portrait** – Provided by the Surgeon General, “My Family Health Portrait” is an internet-based tool that makes it easy for you to record your family health history. The tool is easy to access on the web and simple to fill out. It assembles your information and makes a “pedigree” family tree that you can download. It is private—it does not keep your information. It gives you a health history that you can share with family members or send to your health care practitioner.

<https://familyhistory.hhs.gov/>

### Social Security Disabilities Guidelines -

The Social Security and Supplemental Security Income disability programs are the largest of several Federal programs that provide assistance to people with disabilities. While these two programs are different in many ways, both are administered by the Social Security Administration and only individuals who have a disability and meet medical criteria may qualify for benefits under either program.

<http://www.ssa.gov/disability/>

**The Centers for Medicare and Medicaid Services (CMS)** – administers the Medicare program, and works in partnership with the states to administer Medicaid, the State children’s Health Insurance Program (CHIP) and health insurance portability standards.

<http://www.cms.hhs.gov/>

**Medicare.gov** – the official U.S. government site for people with Medicare. Through this site you can find out more information about Medicare, what your plan covers, choosing Medicare plans and enrolling in Medicare.

<http://www.medicare.gov/>

**Medicare Rights Center** – a national, nonprofit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs and public policy initiatives.

<http://www.medicarerights.org/>

## INFORMATION ON ASSOCIATED MEDICAL CONDITIONS

**American Society of Hematology - Blood: The Vital Connection** is a consumer campaign designed to educate the public about the importance of healthy blood. Developed by the American Society of Hematology (ASH), the campaign aims to raise awareness about the most common blood diseases, such as anemia, bleeding and clotting disorders, and blood cancers.

[www.bloodthevitalconnection.org](http://www.bloodthevitalconnection.org)

**National Anemia Action Council** – A nonprofit organization dedicated to improving the lives of people with anemia. This site provides patients and medical professionals with specific information on iron deficiency anemia, which can develop from heavy bleeding in HHT patients.

<http://www.anemia.org>

**Pulmonary Hypertension Association** - A nonprofit association whose mission is to find ways to prevent and cure pulmonary hypertension, and to provide hope for the pulmonary hypertension community through support, education, advocacy and awareness.

<http://www.phassociation.org>

**Cancer.Net(JuvenilePolyposisSyndrome)-** Cancer.Net, formerly People Living With Cancer (PLWC), brings the expertise and resources of the American Society of Clinical Oncology (ASCO), the voice of the world’s cancer physicians, to people living with cancer and those who care for and care about them.

<http://www.cancer.net/patient/Cancer+Types/Juvenile+Polyposis+Snyndrome>