

LIVING WITH HHT

IN COLLABORATION WITH
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Cure HHT prides itself on developing a strong sense of community among all affiliated parties. We believe that one of the most important aspects of managing HHT is providing mutual support, and that patients and families feel empowered not only by the help of others, but by their own ability to provide help in return.

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.



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



EDUCATING YOURSELF ABOUT HHT:

We understand that HHT can be frightening, isolating, and even frustrating, and it is important to remember that thousands of families all over the world manage HHT every day. Each diagnosis brings us one step closer to finding a cure. Cure HHT is committed to providing you with the best possible resources and information, and to answering all questions and alleviating any concerns you may have.

SIX SIMPLE STEPS: FOR LIVING WITH HHT

Perhaps most important to remember is that HHT does not have to define your life. It can be tempting to ignore an HHT diagnosis, particularly if you have very few symptoms of the disease, and while it may seem as though choosing not to acknowledge HHT means not having to deal with it, this solution is both temporary and dangerous.

VISIT AN HHT CENTER OF EXCELLENCE

- Our Foundation-approved centers all across the country are certified to provide HHT patients with the best possible treatment and care from dynamic teams of experts.

USE THE EPISTAXIS SEVERITY SCORE

- This service is available on the HHT Foundation website, to monitor nosebleeds and their response to treatment.

SCHEDULE REGULAR AVM SCREENINGS

- Watch for symptoms of iron deficiency and discuss treatment options with your HHT physician.

WATCH FOR SYMPTOMS

- Encourage other members of your family to receive screening for HHT.

BECOME AN AMBASSADOR

- Encourage other members of your family to receive screening for HHT.

GET INVOLVED!

- Follow the Cure HHT on Facebook and Twitter to receive updates on conferences, walks, webinars, and other local and regional events.



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