



April 29 – May 7, 2022

PATIENT AGENDA

Schedule

All times reported in Eastern Daylight Time (EDT)

Friday, April 29

5:00pm – 5:45pm

Meet and Greet *(Patient & Provider)*

Let's connect! Grab a drink (if you so choose) and enjoy meeting and engaging with members of the HHT community.

Saturday, April 30

12:00pm – 1:30pm

HHT Through the Ages

It's important to know how to best manage HHT throughout various life stages. Hear about standard of care and diagnostic tests, common symptoms at different developmental cycles, managing psycho-social characteristics of HHT, when to seek emergency help, and what, if anything, you should do differently in an emergency situation.

3:00pm – 4:30pm

Together we can DEFEAT HHT!

Through early **D**agnosis, patient and provider **E**ducation, **F**unding research, **E**nhancing access to care, increasing **A**wareness, and developing novel **T**reatments, we can DEFEAT HHT! Learn how connecting to an HHT Center of Excellence can change your life and engaging with Cure HHT can change the trajectory of this disease for future generations.

Sunday, May 1

3:00pm – 3:45pm

Meet and Greet *(Patient/Caretaker)*

Share stories and build connections with members of the HHT community.

Monday, May 2

5:30pm – 7:00pm

Advocating for Yourself and Your Family

HHT patients often must be their own advocate in educating primary care physicians and other specialists. In this session, we'll talk about resources to help the education process, challenges associated with selecting your care team, care coordination with a Center of Excellence, navigating insurance in the US and travelling internationally to the US for care.

Tuesday, May 3

No patient session offerings.

Wednesday, May 4

6:30pm – 8:00pm

Your Questions Answered

Have a question? Our panel of HHT experts have the answers. We'll cover a broad range of commonly asked questions – including the importance of genetic testing for diagnosing family members; drug therapies; skin and nosebleed management – home remedies, surgical and therapeutic options; are children with HHT screened / treated differently than adults; symptoms and treatment for pulmonary hypertension & HHT; bleeding issues specific to women and much more.

May 5 – May 6

No patient session offerings.

Saturday, May 7

10:00am – 11:30am

Managing Patient Bleeding *(Patient & Provider)*

In this session, we'll discuss how to manage bleeds from the nose, skin, GI tract – in addition we'll review anemia and iron deficiency, an overview of the guidelines, types of iron to be used in infusions, frequency of blood tests, and drug therapy options.

1:30pm – 3:00pm

The Future is Now

There's reason to be optimistic about the future of HHT care and treatment. Join a discussion to learn more about clinical trials, emerging treatments and therapeutics, the Cure HHT Research Network and the newly formed research roadmap, and more.

Can't make a session? Please note that all sessions will be recorded and distributed to those who register for a specific session.

Although the information contained in the HHT Academy sessions have been developed by specialists knowledgeable in the management of care and treatment of HHT patients, Cure HHT makes no guarantee as to, and assumes no responsibility for, the correctness or completeness of such information. You must consult with your personal physician or contact an HHT Center of Excellence for any HHT-related medical concerns.

Disclaimer: HHT Academy is a Cure HHT educational program associated with patient and physician conferences. The HHT Academy is not an accredited institution and does not issue certifications or degree certificates. Cure HHT does not issue educational credits of any kind, including continuing education credits.