



**HHT Patient & Physician
National Conference
Bellevue, WA June 3-4, 2023**

PATIENT AGENDA

Schedule

All times reported in Pacific Daylight Time (PDT)

Friday, June 2 3:00pm – 5:00pm	Early Check-In Meet & Greet	<i>Cedar Ballroom Cascade Tower - Level 2</i>
Saturday, June 3 7:30am – 8:30am	Check-In Breakfast	<i>Evergreen Ballroom Foyer Evergreen Ballroom EF Olympic Tower - Level 1</i>
8:30am – 8:45am	Welcome A warm welcome from Cure HHT. Learn about our organization, current research, and our HHT community.	Marianne Clancy, MPA <i>Evergreen Ballroom AB</i>
8:45am – 9:00am	Patient Story	<i>Evergreen Ballroom AB</i>
9:00am – 9:45am	HHT Overview Introduction to HHT-specific terminology, the basic clinical features of HHT including the Curacao diagnostic criteria, and the differences between a telangiectasia and an AVM. This session	Mark Chesnutt, MD <i>Evergreen Ballroom AB</i>

will explain the general screening protocols at an HHT Center.

9:45am – 10:30am

HHT Screening and Guidelines

Steve Hetts, MD

Evergreen Ballroom AB

In this session, we will review standards of care, screening guidelines, and diagnostic tests and frequency of testing for HHT patients.

10:30am – 10:45am

Q&A Panel

Mark Chesnutt, MD

Steve Hetts, MD

Evergreen Ballroom AB B

HHT Overview
HHT Screening and Guidelines

10:45am – 11:00am

Break

Evergreen Ballroom Foyer

11:00am – 11:30am

Genetics: Unraveling your DNA

Katie Wusik, MS, CGC

Evergreen Ballroom AB

What is DNA? Learn about the inheritance pattern of HHT, the newly identified HHT genes, the role of genetics on family planning, new genetic testing programs and the impact of genetic testing on diagnosing family members.

11:30am – 12:15pm

Tangled Web of AVMs

Steve Hetts, MD

Claire Kaufman, MD

Evergreen Ballroom AB

Arteriovenous Malformations (AVMs) represent one of the most important manifestations of HHT. This session will discuss the symptoms and therapeutic approaches to AVMs in the brain and lungs.

12:15pm – 12:30pm

Q&A Panel

Katie Wusik Healy, MS, CGC

Steve Hetts, MD

Claire Kaufman, MD

Evergreen Ballroom AB

Genetics: Unraveling your DNA
Tangled Web of AVMs

12:30pm – 1:30pm	Lunch	<i>Evergreen Ballroom EF</i>
Concurrent Sessions 1:30pm – 3:00pm	<p>Session 1: (45 minutes) Q&A Breakout - Screening Guidelines & Tangled Web of AVMs</p> <p>(45 Minutes) HHT Center of Excellence Visit</p> <p>Session 2: Family Planning, Pregnancy, Pediatrics with Q&A</p>	<p>Mark Chesnutt, MD Claire Kaufman, MD <i>Evergreen Ballroom A</i></p> <p>Brittany Steed, MA <i>Evergreen Ballroom A</i></p> <p>Katie Wusik, MS, CGC Els de Gussem, MD Raj Kasthuri, MD, MBBS <i>Evergreen Ballroom B</i></p>
3:00pm – 3:30pm	Break / Group Photo	<i>Evergreen Ballroom Foyer</i>
3:30pm – 4:15pm	<p>GI Bleeding, Iron Deficiency, and Anemia</p> <p>Trying to figure out the cause of your anemia? Gastrointestinal (GI) bleeding tends to go untreated and is often misdiagnosed. Learn how to recognize the symptoms related to HHT in the stomach and intestines and the treatment options that are critical for the management of your health. This session will discuss the most effective ways to manage anemia in HHT patients.</p>	<p>Raj Kasthuri, MD, MBBS <i>Evergreen Ballroom AB</i></p>
4:15pm – 5:00pm	<p>The Heart of the Matter and Aging</p> <p>Discover how to care for your HHT in coordination with other medical conditions. This session will cover a variety of topics that are associated with aging including how liver AVMs can affect the heart, how HHT and Pulmonary Hypertension are connected and medications to avoid.</p>	<p>Kevin Whitehead, MD Edda Spiekerkoetter, MD <i>Evergreen Ballroom AB</i></p>

5:00pm – 5:30pm	Q&A Panel GI Bleeding, Anemia Iron Deficiency The Heart of the Matter and Aging	Raj Kasthuri, MD, MBBS Kevin Whitehead, MD Edda Spiekerkoetter, MD <i>Evergreen Ballroom AB</i>
5:30pm Onwards	Welcome Reception/Dinner	<i>Evergreen Ballroom EFGHI</i>

Sunday, June 4	Breakfast	<i>Evergreen Ballroom EF Olympic Tower – Level 1</i>
7:30am – 8:30am	Patient Story	<i>Evergreen Ballroom AB</i>
8:30am – 8:45am	Living with HHT	Katie Wusik, MS, CGC <i>Evergreen Ballroom AB</i>
	Explore the effects of HHT on your mental health and family relationships and learn coping skills that can help you live better with HHT. Get tips on how to educate your family about HHT and how to discuss HHT with potential partners.	
9:30am – 10:45am	Nosebleed Management Panel	Jeb Justice, MD Holly Boyer, MD Bryan McRae, MD <i>Evergreen Ballroom AB</i>
	-Medical Treatment -Surgical Treatment -Drug Therapy	
	Learn the medical terminology used by ENTs and the benefits of using the Epistaxis Severity Score (ESS) to evaluate nosebleeds and the effectiveness of treatments. Discover the more traditional interventions as well as the cutting-edge surgeries and drug treatment options now available to HHT patients.	
10:45am – 11:00am	Break	<i>Evergreen Ballroom Foyer</i>

Concurrent Sessions 11:00am – 11:45am	Session 1: Q&A Breakout - Nosebleeds, Bleeding, Iron/Anemia Session 2: Q&A Breakout - Living with HHT & Aging and HHT	Raj Kasthuri, MD, MBBS Jeb Justice, MD Holly Boyer, MD Bryan McRae, MD <i>Evergreen Ballroom AB</i> Katie Wusik, MS, CGC Kevin Whitehead, MD Edda Spiekerkoetter, MD <i>Evergreen Ballroom C</i>
11:45am – 12:15pm	Lunch	<i>Evergreen Ballroom EF</i>
12:15pm – 1:45pm	Advancing the Cure: An HHT Research Update It is important to know the basic science behind HHT to understand our current and future research initiatives. Dr. Hughes will define scientific terms, explain the relationship between basic, clinical, and translational research, and clarify Cure HHT's role in finding a cure for HHT. In addition, Cassi Friday will review the Cure HHT Research Network and the newly developed research roadmap while Dr. Chakinala will provide an update on current drug therapies, including studies with Pomalidomide and Pazopanib.	Cassi Friday, PhD Chris Hughes, PhD Murali Chakinala, MD <i>Evergreen Ballroom AB</i>
1:45pm-2:05pm	Research Presentations Two researchers will present their research topics to the patients and providers.	<i>Evergreen Ballroom AB</i>
2:05pm – 2:20pm	Closing Remarks and Awards	<i>Evergreen Ballroom AB</i>

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.