



Philadelphia, Pennsylvania | April 5 - 7, 2024

COMBINED AGENDA

Schedule

All times reported in Eastern Time (ET)

Friday, April 5 5:00pm – 6:30pm	Early Check-In Meet & Greet Enjoy light refreshments and meet up with fellow HHT patients & families.	Alloy Ballroom Foyer
Saturday, April 6 7:30am – 8:30am	Check-In Breakfast	Alloy Ballroom Foyer
8:15am – 8:30am	For First Time Attendees: About Cure HHT	Alloy Ballroom A/B Cure HHT Staff
8:30am – 8:45am	Welcome A warm welcome from Cure HHT. Learn about our organization, current research, and our HHT community.	Alloy Ballroom A/B Marianne Clancy, MPA <i>Cure HHT</i>
8:45am – 9:00am	Patient Story	Alloy Ballroom A/B

9:00am – 9:30am

PATIENT TRACK

Alloy Ballroom A/B

(9:00am-12:45pm)

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 arteriovenous malformation (AVM). Also, learn about which body systems HHT affects, how it affects you, and what your doctor should know. **This session is perfect for those who are attending their first conference!**

Charles Murphy, MD
*New York-Presbyterian
Hospital/Columbia
University Irving
Medical Center*

9:30am – 10:00am

HHT Screening and Guidelines

Alloy Ballroom A/B

In this session, we will review standards of care, adult screening guidelines from the **updated international guidelines**, diagnostic tests and frequency of testing for HHT patients. Pediatric screening guidelines will be explained in an afternoon breakout session.

**Panagis
Galiatsatos,
M.D., M.H.S**
*Johns Hopkins
University*

10:00am – 10:45am

**Iron Matters:
Understanding Anemia,
Iron Deficiency**

Alloy Ballroom A/B

Anemia & iron deficiency are the most common manifestations for HHT patients secondarily to nosebleeds. This session will discuss the most effective ways to manage anemia in HHT patients and the other potential causes for anemia and iron deficiency.

**Allyson Pishko, MD,
MCSE**
*University of
Pennsylvania*

10:45am – 11:00am	Break	Alloy Ballroom Foyer
11:00am – 12:00pm	<p>Tangled Web of AVMs</p> <p>Arteriovenous Malformations (AVMs) represent one of the most important manifestations of HHT. This session will discuss the symptoms and most current therapeutic approaches to AVMs in the brain and lungs.</p>	<p>Alloy Ballroom A/B</p> <p>Lauren Beslow, MD, MSCE, FAHA <i>Children's Hospital of Philadelphia</i></p> <p>Panagis Galiatsatos, M.D., M.H.S <i>Johns Hopkins University</i></p>
12:00pm – 12:30pm	<p>Q&A Panel</p> <p>Iron Matters: Understanding Anemia, Iron Deficiency & GI Bleeding</p> <p>Tangled Web of AVMs</p>	<p>Alloy Ballroom A/B</p> <p>Lauren Beslow, MD, MSCE, FAHA <i>Children's Hospital of Philadelphia</i></p> <p>Allyson Pishko, MD, MCSE <i>University of Pennsylvania</i></p>
9:00am – 9:45am	<p>PHYSICIAN TRACK (9:00am-12:45pm)</p> <p>*Management of Chronic Blood Loss & Iron Replacement Therapy</p> <p>Providers will learn about screening for iron deficiency anemia, formulating patient-specific iron replacement strategies, and strategies for managing chronic blood loss in patients with HHT.</p>	<p>Alloy Ballroom C</p> <p>Allyson Pishko, MD, MCSE <i>University of Pennsylvania</i></p>

9:45am – 10:30am	*HHT in Children	Alloy Ballroom C Lauren Beslow, MD, MSCE, FAHA <i>Children's Hospital of Philadelphia</i>
10:30am – 10:45am	Q&A Panel	Alloy Ballroom C Lauren Beslow, MD, MSCE, FAHA <i>Children's Hospital of Philadelphia</i>
10:45am – 11:00am	Break	
11:00am – 11:45am	*HHT: An Overview of Pulmonary AVMs	Alloy Ballroom C Charles Murphy, MD Vladimir Sheynzon, MD <i>New York-Presbyterian Hospital/Columbia University Irving Medical Center</i>
11:45am – 12:30pm	*Diagnosing HHT: Curaçao Clinical Criteria and Utilizing Genetic Testing	Alloy Ballroom C Theodore Drivas, MD, PhD <i>University of Pennsylvania</i>
	Providers will learn the clinical diagnostic criteria for HHT, understand the utility of genetic testing for HHT, and be able to identify patients and family members with/at risk for HHT and describe HHT resources available to them and their providers.	

12:30pm – 12:45pm

Q&A Panel

Alloy Ballroom C
**Theodore Drivas, MD,
PhD**
*University of
Pennsylvania*
Charles Murphy, MD
*New York-Presbyterian
Hospital/Columbia
University Irving
Medical Center*

12:30pm – 1:30pm

Lunch

Hotel Restaurant & Bar
Area

(Both tracks back
together)

Concurrent Sessions

1:30pm – 3:15pm

**Session 1: Take Charge
of Your Care**

1:30pm-2:00pm

**HHT Center of Excellence
Visit**

In this session, you'll learn what to expect when visiting a center of excellence as a new patient and as a returning patient. You'll also learn about the process of genetic testing and how to get your family tested.

2:00pm-2:45pm

Unraveling Genetics

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.

2:45pm-3:15pm

Q&A Panel

Alloy Ballroom A/B

**Sophia Kemble, MSN,
RN**

*Johns Hopkins
University*

**Theodore Drivas, MD,
PhD**

*University of
Pennsylvania*

	<p>Session 2: Planning for your Family: Family Planning, & HHT Care for Kids</p> <p>1:30pm-2:00pm</p> <p>Family Planning</p> <p>Ready to start your family or know who is? In this session, we will go over pre-implantation genetic testing and family planning with HHT.</p> <p>2:00pm-2:45pm</p> <p>HHT Care for Kids</p> <p>Learn about the international pediatric screening guidelines, how HHT manifests differently in children than adults, and how to explain HHT to your kids.</p> <p>2:45pm-3:15pm</p> <p>Q&A Panel</p>	<p>Alloy Ballroom C</p> <p>Katie Wusik-Healy, MS, CGC</p> <p><i>Cincinnati Children's Hospital</i></p> <p>Lauren Beslow, MD, MCSE, FAHA</p> <p><i>Children's Hospital of Philadelphia</i></p>
<p>3:15pm – 3:30pm</p>	<p>Break</p>	<p>Alloy Ballroom Foyer</p>
<p>3:30pm – 4:30pm</p>	<p>The Heart of the Matter and Aging</p> <p>Discover how to care for your HHT in coordination with Pulmonary Hypertension. 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>Alloy Ballroom A/B</p> <p>Raj Kasthuri, MD, MBBS</p> <p><i>University of North Carolina Chapel Hill</i></p>
<p>4:30pm – 4:45pm</p>	<p>Q&A Panel</p> <p>The Heart of the Matter and Aging</p>	<p>Alloy Ballroom A/B</p> <p>Raj Kasthuri, MD, MBBS</p> <p><i>University of North Carolina Chapel Hill</i></p>

5:00pm – 6:30pm

**Welcome Reception &
Group Photo**

Alloy Ballroom C

Sunday, April 7**7:30am – 8:30am**

Breakfast

Alloy Ballroom Foyer

8:30am – 8:45am**Patient Story**Alloy Ballroom A/B
**Maureen O'Donnell
Hardiman**

8:45am – 10:00am**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. Cassi Friday, PhD will present our research roadmap, Panagis Galiatsatos, MD, MHS, will present on HHT clinical trials, and Arndt Siekman, PhD, will present on the newest innovations in basic science.

Alloy Ballroom A/B

Cassi Friday, PhD
Cure HHT
**Raj Kasthuri, MD,
MBBS**
*University of
North Carolina
Chapel Hill*
**Arndt Siekman,
PhD**
*University of
Pennsylvania*

10:00am – 11:00am**Chronic Bleeding
Management: Nosebleeds &
GI Bleeding**

Do you have chronic bleeding for HHT? Learn about your medical and therapeutic treatment options for bleeding. 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.

Alloy Ballroom A/B

**Raj Kasthuri, MD,
MBBS**
*University of North
Carolina Chapel Hill*

11:15am – 11:30am**Nosebleed Interventions**

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

Alloy Ballroom A/B

Jeb Justice, MD
*University of
Florida*

cutting-edge surgeries now
available to HHT patients.

11:30am – 11:45am

Break

Alloy Ballroom Foyer

Concurrent Sessions

11:45am – 12:15pm

**Session 1: Q&A Breakout -
Chronic Bleeding
Management: Nosebleeds &
GI Bleeding**

Nosebleed Interventions

Alloy Ballroom A/B

**Raj Kasthuri, MD,
MBBS**

*University of North
Carolina Chapel Hill*

Jeb Justice, MD

*University of
Florida*

**Session 2: Q&A Breakout -
Advancing the Cure: An HHT
Research Update**

Alloy Ballroom C
Cassi Friday, PhD
Cure HHT

**Arndt Siekman,
PhD**

*University of
Pennsylvania*

12:15pm – 12:45pm

Closing Remarks

Alloy Ballroom A/B

**Marianne Clancy,
MPA**

Cure HHT

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.

****Indicates CME session***

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For reference: <https://accme.org/fag/what-accmes-definition-ineligible-company>



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