



Philadelphia, Pennsylvania | April 5 - 7, 2024

COMBINED AGENDA

Schedule

All times reported in Eastern Time (ET)

Friday, April 5 5:00pm – 7:00pm	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
8:30am – 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 (9:00am-12:45pm)	Alloy Ballroom A/B

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. 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

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.

Alloy Ballroom A/B
**Panagis
Galiatsatos,
M.D., M.H.S**
*Johns Hopkins
University*

10:00am – 10:45am

Iron Matters: Understanding Anemia, Iron Deficiency

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.

Alloy Ballroom A/B
**Allyson Pishko, MD,
MCSE**
*University of
Pennsylvania*

10:45am – 11:00am

Break

Alloy Ballroom Foyer

11:00am – 12:00pm

Tangled Web of AVMs

Alloy Ballroom A/B
**Lauren Beslow, MD,
MSCE, FAHA**

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.

Children's Hospital of Philadelphia
Panagis Galiatsatos, M.D., M.H.S
Johns Hopkins University

12:00pm – 12:30pm

Q&A Panel

Iron Matters: Understanding Anemia, Iron Deficiency & GI Bleeding
Tangled Web of AVMs

Alloy Ballroom A/B
Lauren Beslow, MD, MSCE, FAHA
Children's Hospital of Philadelphia
Allyson Pishko, MD, MCSE
University of Pennsylvania

9:00am – 9:45am

PHYSICIAN TRACK (9:00am-12:45pm)

***Management of Chronic Blood Loss & Iron Replacement Therapy**

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.

Alloy Ballroom C
Allyson Pishko, MD, MCSE
University of Pennsylvania

9:45am – 10:30am

***HHT in Children**

Providers will learn the clinical and screening guidelines for children and the differences in HHT manifestations between adults and children.

Alloy Ballroom C
Lauren Beslow, MD, MSCE, FAHA
Children's Hospital of Philadelphia

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 Providers will learn how to understand and utilize the diagnostic criteria for HHT, screening for pulmonary AVMs, recognizing complications of untreated pulmonary AVMs, and understand treatment options for pulmonary AVMs.	Alloy Ballroom C Charles Murphy, MD Vladmir 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 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.	Alloy Ballroom C Theodore Drivas, MD, PhD <i>University of Pennsylvania</i>
12:30pm – 12:45pm	Q&A Panel	Alloy Ballroom C Theodore Drivas, MD, PhD <i>University of Pennsylvania</i>

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

**Session 2: Planning for your
Family: Family Planning, &
HHT Care for Kids**

1:30pm-2:00pm

Family Planning

Ready to start your family or know who is? In this session, we

Alloy Ballroom A/B

**Sophia Kemble, MSN,
RN**

*Johns Hopkins
University*

**Theodore Drivas, MD,
PhD**

*University of
Pennsylvania*

Alloy Ballroom C

**Katie Wusik-
Healy, MS, CGC**

*Cincinnati
Children's Hospital*

	<p>will go over pre-implantation genetic testing and family planning with HHT.</p> <p>2:00pm-2:45pm HHT Care for Kids 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 Q&A Panel</p>	<p>Lauren Beslow, MD, MCSE, FAHA <i>Children's Hospital of Philadelphia</i></p>
3:15pm – 3:30pm	Break	Alloy Ballroom Foyer
3:30pm – 4:30pm	<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 <i>University of North Carolina Chapel Hill</i></p>
4:30pm – 4:45pm	<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 <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

8:45am – 9:45am

**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
Panagis Galiatsatos, M.D., M.H.S
Johns Hopkins University
Arndt Siekman, PhD
University of Pennsylvania

9:45am – 10:45am

**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

10:45am – 11:15am

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 cutting-edge surgeries now available to HHT patients.

Alloy Ballroom A/B

Jeb Justice, MD
University of Florida

11:15am – 11:30am

Break

Alloy Ballroom Foyer

Concurrent Sessions**11:30am – 12:00pm****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***Nicholas Rowan, MD
Panagis****Galiatsatos,
M.D., M.H.S***Johns Hopkins
University***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*

12:00pm – 12:30pm**How to Advocate for
your Health**

Learn about Cure HHT resources, including how to partner with Cure HHT for awareness, legislative initiatives in your own state, educating your physicians, insurance ins and outs, and educational resources.

Alloy Ballroom A/B

Cure HHT Staff

12:30pm – 12:45pm**Q&A Session**

Alloy Ballroom A/B

Cure HHT Staff

12:45pm – 1:00pm**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**

Credit Provided By

Washington University School of Medicine in St. Louis, Continuing Medical Education

Disclosure Statement:

It is the policy of Washington University School of Medicine, Continuing Medical Education, to ensure balance, independence, objectivity, and scientific rigor in all its educational activities. All planners, faculty, and other persons who may influence content of this CE activity have disclosed all relevant financial relationships with ineligible companies (previously referred to as commercial entities), defined as any entities producing, marketing, re-selling, or distributing healthcare goods or services consumed by, or used on, patients. All relevant disclosures have been reported and mitigated and are indicated with their presentations.

-All members of the CME department have nothing to disclose.

-Speakers are also expected to openly disclose inclusion of discussion of any off-label, experimental, or investigational use of drugs or devices in their presentations.

-Presentations are expected to be based on evidence that is accepted within the profession of medicine as adequate justification for their indication in the care of patients. All scientific research should conform to the generally accepted standards of experimental design, data collection and analysis.

-These presentations are not an endorsement of any ineligible companies.

-These presentations are the views and experiences of the presenters. The presenters' views do not represent the policy or position of Washington University School of Medicine. Washington University School of Medicine, Continuing Medical Education, is the provider for CE credits.

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

ACCREDITATION



In support of improving patient care, this activity has been planned and implemented by Cure HHT and Washington University School of Medicine in St. Louis. Washington University School of Medicine in St. Louis is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME), the Accreditation Council for Pharmacy Education (ACPE), and the American Nurses Credentialing Center (ANCC), to provide continuing education for the healthcare team.

CREDIT Available for this Activity:

American Medical Association (AMA): Washington University School of Medicine in St. Louis designates this live activity for a maximum of 4.75 *AMA PRA Category 1 Credits™*. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

American Nurses Credentialing Center (ANCC): Washington University School of Medicine in St. Louis designates this live activity for a maximum of 4.75 ANCC contact hours.

Interprofessional Continuing Education (IPCE)

This activity was planned by and for the healthcare team, and learners will receive a maximum of 4.75 Interprofessional Continuing Education (IPCE) credit for learning and change.