



Patient Conference

Sheraton Ann Arbor

3200 Boardwalk Street
Ann Arbor, MI 48108

October 20-21, 2018

Saturday, October 20

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| 8:00am – 9:00am | Registration / Book Signing |
| 9:00am – 9:15am | Welcome
A warm welcome from Cure HHT |
| 9:15am – 9:50am | HHT Overview and Screening Guidelines
Introduction to the basic clinical features of HHT including the Curacao diagnostic criteria. This session will explain the difference between an AVM and telangiectasia and how they affect your body in addition to the clinical features of HHT and general screening protocols at an HHT Center. |
| 9:50am – 10:25am | Genetics: Unraveling Your DNA
Learn about the inheritance pattern of HHT, identify your family gene mutation and discover the benefits and limitations of genetic testing for HHT. |
| 10:25am – 10:40am | BREAK |
| 10:40am – 11:15am | Tangled Web of HHT (AVMs)
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. |

11:15am – 11:50am	Caring for the Younger Generation
	Children are typically asymptomatic but this does not mean they didn't inherit the disease. Gain insight from a pediatric perspective about the different screening and treatment protocols for children, how to manage lung and brain AVMs and other special considerations regarding children such as anesthesia, radiation and exercise.
12:00pm – 1:15pm	LUNCH
1:20pm – 2:45pm	HHT Research Update
	It is important to know the basic science behind HHT in order to understand our current and future research initiatives. Dr. Hughes, Cure HHT GRMAB Chair, will define scientific terms, summarize Cure HHT's young research grants and clarify the scientific role in finding a cure for HHT. In addition, a leading researcher will provide an update on the Pazopanib Study while the developer of the HHT App walks you through this new patient tool.
2:45pm – 3:20pm	Living with HHT
	Explore the emotional and social aspects of living with HHT. Learn how to tell your family about HHT, deal with family denial and keep a good family history. This presentation will also include strategies to deal with HHT-related conversations on dating, marriage, parenting, genetic testing implications, and caregiving.
3:20pm – 3:35pm	BREAK
3:35pm – 4:10pm	Q&A Workshop (Choose 1 Session)
	<ol style="list-style-type: none"> 1. Genetics / Screening Guidelines 2. AVMs 3. HHT in Children
4:15pm – 4:50pm	Q&A Workshop (Choose 1 Session)
	<ol style="list-style-type: none"> 1. HHT Research / HHT App 2. AVMs 3. Parent Forum
5:00pm – 6:30pm	Welcome Reception

Sunday, October 21

9:00am – 9:35am	Nosebleed Management 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.
9:35am – 10:25am	GI Bleeding, Anemia and Iron Deficiency 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. Anemia is commonly experienced by those affected with HHT and it frequently results from bleeding of the nose and/or gastrointestinal tract. This session will discuss the most effective ways to manage anemia in HHT patients.
10:25am – 10:40am	BREAK
10:40am – 11:35am	Heart, Liver and Pulmonary Hypertension This session will cover various ways that the heart can be affected in HHT, including heart failure due to liver AVMs. In addition, learn how HHT and Pulmonary Hypertension are connected, specifically, how HHT can cause PH, how the combinations of these diseases affect a patient, and what treatment options are available.
11:35am – 12:00pm	HHT Patient Story
12:00pm – 12:30pm	Q&A Workshop (Choose 1 Session) <ol style="list-style-type: none">1. Living with HHT2. Nosebleed Management3. Heart, Liver and Pulmonary Hypertension
12:30pm – 1:00pm	Q&A Workshop (Choose 1 Session) <ol style="list-style-type: none">1. Ask the Doctor2. Nosebleed Management3. GI Bleeding, Anemia and Iron Deficiency
1:05pm – 1:15pm	Closing Remarks