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CureHHT.org

April 13, 2023

A Letter from Cure HHT Board Member, Jim Lapides

An HHT Patient Conference can change your life...

Dear HHT Patient,

I am writing to share an invaluable opportunity for all HHT patients - Cure HHT is hosting its first national patient conference since the Pandemic on June 3rd and 4th just outside Seattle, WA. I say “invaluable opportunity” because going to my first patient conference in 2012 saved my life.

I was in crisis; laser treatments no longer worked for me, and I could not control my bleeds. My wife and I went to the conference armed with notebooks and learned as much as we could at the sessions. We talked with as many doctors, fellow patients, Cure HHT staff, board members and center directors as we could to learn about potential solutions today and in the future. **I went home with a short- and long-term game plan – deciding on the best treatments and the right team to guide me.** It led to a new procedure that worked for me and then a second treatment that worked even better. And it led me to finding an HHT Center of Excellence “home base” as well as expert clinicians at other HHT Centers and beyond that have helped me avoid problems and treat new ones.

You might not think your situation is as dramatic, but the National HHT Patient and Physician Conference will open your eyes to possibilities. As you know, HHT is a very complex disease requiring a sophisticated team to properly manage and treat. Because of this, new patients are easily overwhelmed and confused when first diagnosed. Given the rapid proliferation of treatments today, even so-called “knowledgeable” patients often don’t know what to do.

The Patient Conference takes aim at this knowledge gap by **addressing the most important first step for each patient - to be knowledgeable and up to date about HHT.** Why are updates needed? Because virtually every aspect of care is changing, and old answers are often not the best answers. We have many resources available for HHT patients – our website, webinars, newsletters, social media, and our 30 HHT Centers of Excellence with dedicated HHT specialists. **But immersion in a Patient Conference is the most powerful and effective way to quickly get accurate, up-to-date knowledge about HHT.**

Equally important, a **Patient Conference explains why and how to assemble the right team to beat HHT**. The first step is to become affiliated with an HHT Center of Excellence (COE) and to take an HHT intake exam there. This establishes your current HHT situation, and determines a customized preventive testing program, and clinicians to see. The second step is to work with your HHT COE Director (who acts as your “HHT GP”) to manage your case over time and assemble your team at the HHT Center to choose the right treatments with you. As you get older, HHT symptoms often worsen and can cause additional problems. Your HHT Center Director looks at things that your regular GP or other specialists might not even know about – poor drug choices for HHT patients, etc.

Your team might also include specialists from other HHT COE’s or outside the HHT COE network. The National HHT Patient and Physician Conference is an excellent place to learn about other HHT COE’s and leading clinicians. If you move, have children in different cities, or vacation near another Center, it is useful to be familiar with all the Centers and areas of specialization.

Please carefully consider investing in your family’s future by going to the National HHT Patient and Physician Conference. I guarantee it will change your life! To learn more about the Conference and to register, go to <https://hhtconference.org>.

Sincerely,

A handwritten signature in cursive script that reads "Jim Lapides".

Jim Lapides
Board Member, Cure HHT

P.S. A note for those with HHT but no current or very mild symptoms - as awareness of HHT increases, we see many more cases of sudden onset, sometimes with serious consequences. A patient conference can help you be prepared.