**What questions should I ask my doctor?**

- Are you familiar with/knowledgeable about HHT?
- Have you treated patients with HHT? (If so, what were the results, referrals, complications, etc.?)
- How many of these procedures have you done?
- Can you give me another patient to talk to?
- Are you willing to consult with specialists in HHT?
- Would you be interested in reading the medical literature on HHT?
- Are you comfortable taking care of a patient with HHT?
- In an emergency, if you are not available will there be another doctor on call who is knowledgeable about HHT?
- What is this drug and what does it do?
- What are the side effects of this drug? If your doctor doesn’t know, talk to your pharmacist. Ask your pharmacist for a printout on the drug and on all the drugs you are taking to prevent interactions.
- Be clear about the dosage. If you are uncertain, ask your doctor about how to take the drug.

**How do I get my doctor to listen?**

- Choose a doctor who will listen.
- Prepare a list of written questions before the appointment.
- Bring someone else to take notes.
- If they are not all answered, schedule a telephone appointment to get them answered.
- It is very important that your primary care physician is an advocate for you, since the primary care MD is often the “gatekeeper” in insurance/HMO situations. If you don’t feel your primary care MD is listening and advocating for you, i.e., willing to write a letter on your behalf to the HMO/insurance plan for referral, etc., you should consider changing primary care doctors.

**How do I find out if I am getting the correct treatment?**

- Be your own advocate by learning as much about your disorder and its current treatments as you can.
- Only a doctor who has personally interviewed and examined you can make a correct diagnosis. If you are still not sure, get a second opinion.

**What should I do when nobody in the emergency room knows about HHT?**

- Always carry Quick Facts for Health Care Professionals and/or medical literature with you.
- Be firm about insisting that the medical caregivers look at the literature.
- Make sure your own physician is informed immediately about what has happened.
- Carry a medical alert card in your wallet saying you have a rare blood vessel disorder, HHT (Osler-Weber-Rendu), and referring the reader of the card to Quick Facts and/or medical literature you have with you, as well as the phone number of a family member who can provide further information for you.

**Does the physician treating the rare disorder have expertise in all the devices needed to treat the malformation, i.e., for PAVMs, Amplatzer plugs, and coils?**

Let’s take the example of the cardiac surgeon treating a common condition like heart valve replacement. In addition to doing 50 a year (the CABG standard), the surgeon should be familiar with tissue and mechanical valves. Depending on the patient's anatomy, age, life expectancy, etc., the surgeon should know all the common types of valves because he/she may encounter the anatomical situation requiring one type of valve over another one. Returning to HHT and the PAVM, the radiologist should be familiar with Amplatzer's and coils and other measures to close all of them successfully. We make decisions based on the anatomy primarily. This point is even more important for the patient with a CAVM(s). In this situation 3 inputs into the decision are needed since CAVMs can be treated 3 different ways, i.e., operation, embolization and stereotactic radiosurgery. This type of treatment requires 3 different physicians and each of the 3 must be expert in his/her field to discuss a possible treatment for the CAVM at a level of expertise that can be documented.