



Scientific Registry

"Patient Driven Research For a Cure"

Frequently Asked Questions

- 1) If I decide to participate in the US HAEA Scientific Registry, what kind of commitment is required?** In order to advance important research on HAE, the Registry will ask HAE patients to provide a blood sample (2 small vials), a cheek swab and a series of questionnaires submitted online over the span of five years. Following the lives of HAE patients over a length of time sufficient to monitor how new medications, lack of medication, or changes in medication affect health will help nail down the best treatment paradigms for HAE.
- 2) How do I sign up for the Scientific Registry?**
Please go to the US HAEA webpage at www.haea.org and click on the Scientific Registry icon. You will be directed to an online registration form. Just fill in the requested information and click SEND!
- 3) What will happen after I submit my Registration form?**
The US HAEA Scientific Registry Administrator will send you a letter to let you know your Registration has been received and that you are enrolled in the Registry. If you are neither a person with HAE nor a blood relative of a person with HAE, your letter will inform you that you do **not** meet the requirements for participation in this study.
- 4) I am ready to submit clinical samples to the Registry. How do I get my blood taken?**
Once your Consent form is received by the US HAEA Scientific Registry, you will receive a sample kit mailed directly to you from GeneLogic, the biobank facility that partners with the HAEA. Very specific instructions are included in this kit, but if you still have questions about the blood draw or the swab donation, you can simply dial 866-798-5598 and ask for the Scientific Registry Administrator.

- 5) **How much will it cost?** Your physician or lab may be willing to perform the blood draw for free if you inform them it is for research purposes. If not, the fee should be minimal. Many labs will perform this draw for under \$40. You may want to contact your physician for his/her best suggestion on where to go to have your blood drawn. **If you have questions or you are having difficulty with this process, you can dial 866-798-5598 and ask for the Scientific Registry Administrator.**
- 6) **Can children participate?** Yes, if they have HAE or have a blood relative with HAE. Children under 18 will need to fill out an additional consent form.
- 7) **I do NOT have HAE, but I am a blood relative of someone who does. Do I need to send in a blood sample and swab?** Yes, your samples will be important in understanding the pathophysiology of the disease.
- 8) **I do NOT have HAE, but I am a blood relative of someone who does. Do I need to send in all of the forms you collect?** You will be asked to complete a General Medical History - it is important to understanding how HAE works in families. You will **NOT** be asked to provide a Past History, nor the Quarterly Reports or Attack Event Reports. Only registry participants with HAE will be required to submit those additional forms.
- 9) **What is my incentive to participate in the US HAEA Scientific Registry? What will I get from it?**

If you are a participant with HAE, you will receive small awards and prizes as you complete the questionnaire section of the Registry over a five year period. And, along with your fellow participants who do not have HAE (but are blood relatives of someone who does), you will have the satisfaction of knowing you have helped to bring forward new medications, treatment strategies, and an advanced clinical understanding of HAE.
- 10) **How long until there will be a cure?** We don't know, but every patient who participates in the Scientific Registry brings us closer! A cure is our long-term research goal.
- 11) **I'm a member of the HAE Association, does this mean I am automatically in the registry?** No, the Scientific Registry is a unique endeavor of the US HAEA. A separate registration is required. If you do not already belong to the HAE Association, we encourage you to sign up as a member of the HAEA first (see the icon on our website homepage) and then click next on our Scientific Registry icon (also on the homepage) to register to help find a cure !

