



HEADACHE *on the* HILL

FAQ Document

How much does it cost to attend HOH?

There will be a sliding scale registration fee for 2021, ranging from \$25-\$100, with a goal of \$50 per person. No advocate will be turned away due to financial limitations; we will provide a limited number of scholarships to ensure the right advocates can partake.

What do I get out of attending HOH?

It can be hard to quantify the experience that you will have as an AHDA advocate taking part in HOH. "Life Changing" has been used by many past attendees. For starters, you will receive the necessary training on how to advocate on Capitol Hill and how to effectively present your personal story. You will also receive the materials and training needed to successfully present the Ask.

Though it will be different with a virtual event this year, you will have a unique opportunity to connect with other advocates (patients, caregivers, researchers and providers) who have dealt with similar experiences as you. For many, this could be the first time they are working side by side with a provider on an advocacy project.

You will be a critical voice in representing the United States' migraine, cluster and headache community to the people who make policy decisions for our country. You will be educating Members of Congress about our disease and showing them why we need to be taken seriously.

How much of my time is needed to participate?

You will need to be available between 8:30AM - 6:00PM EST on Tuesday March 23rd. Your meetings will be at various times throughout that day.

Prior to the 23rd, you will need to make time to watch about 2-3 hours of pre-recorded training sessions. Additionally, there will be two live sessions (about 90 minutes total) that you will need to attend to learn about the Ask and the technology we will be using on the 23rd for our meetings. All advocates will be required to complete a quiz following the training so show a base level of comprehension.

Why do you need so much information from me on the application?

Much of the information we request is to help us determine which meetings you can be scheduled for. A person from VT can't request to meet with a senator from MA for example. That person would need to have a residence in MA in order to get the MA meeting. We ask you for your home, work and any additional addresses as this could result in many more meetings for you. For example, maybe you live in VT, work just over the border in MA and have a vacation home in ME. You would be eligible to meet with the Members of Congress from all 3 states. The more offices we can touch, the better.

We also ask you questions about your advocacy experience and your connection to our cause to help understand your motivation for attending and if you would make a good advocate.

Finally, starting in 2020, we are asking more demographic based questions. With a renewed focus on diversity and disparities in our community, these questions are being used to help us bring more focus to ensuring a diverse representation of advocates.

Does everyone who applies for HOH get accepted?

Unfortunately, not. We have a limited number of advocates that we can support for this event. There are some states, and more specifically districts within a state, where we get 8-10 applicants. It is not effective to have a meeting with this many advocates. In addition to identifying which representatives you would be able to meet with, we need to identify applicants who we believe will be reliable and can effectively share their story and our “ask” in our meetings and who will complete the post event follow up after leaving DC.

What is the dress code?

As an in-person event, we have always encouraged business professional attire. With the event being virtual in 2021, we still encourage professional attire for the top. Tee shirts (even if printed with a group logo or message) are not considered sufficiently professional for congressional meetings. Additionally, as purple is the color for migraine and cluster headache awareness, if you have something purple (e.g. a purple shirt or blouse) to wear that would be wonderful.

Do I need to be a person who really understands "politics"?

No. You need to be a person who is passionate about driving change for people with migraine and cluster headache disease.

How do I know if I would make a good advocate?

If you have been impacted by migraine or cluster headache disease and have a desire to drive change, you should consider becoming an AHDA advocate.

We need people who are able to communicate effectively and succinctly (2 mins max) what it means to live with migraine or cluster headache.

You also need to be a team player. While we need for you to convey to Members of Congress and their staff your own personal story about the impact of headache disorders, our specific requests (“Asks”) must be consistent and uniform across all of our meetings. This will not be an opportunity to make personal requests or raise other issues. We only make progress when we all pull together.

You should know in advance that the 2 days in DC can be very taxing, both physically and emotionally. The event is something that often leads to attacks for those who are living with migraine or cluster headache. You should consider how you would manage your symptoms to maximize your ability to be present for your scheduled meetings with your Members of Congress. You should realistically assess whether participating is right for you.

How many meetings does an advocate typically have on Tuesday?

Typically, unless you are from a larger delegation like NY, CA, or PA, the average number of meetings for most advocates will be at least 3 and as many as 6.

How long is each meeting?

We will schedule the meetings on your behalf with ~30 minutes allocated. The meetings with your Senator, Representative and/or their staffers are typically about 10-15 minutes long. You have just enough time to introduce yourselves and share 1 person’s story then present our “Ask”.

Timeliness is very important for this event. Out of respect, you must arrive at all appointments on time.

Where do the meetings take place?

New this year, your meetings will be happening through your computer with an application like Zoom or Go To Meeting. You will have a designated “room” for your team to practice in advance and to convene in on the 23rd. It will be important for you to have internet access and a camera connected to your computer or device.

Will I be going to the Hill meetings alone?

No, we always try to have at least 2 advocates in every meeting. That may mean that you are doing your meetings with another person from your state or sometimes we group people from different states together. We also do all we can to have one returning advocate in each group, though this is not always possible.

Will I get to meet my Members of Congress or will it be someone from their staff?

We always try to schedule you with the Member themselves, but depending on their schedule, they may not be available. Don't worry, if they aren't available, you will likely be meeting with their Health Legislative Assistant (HLA). The HLA's are typically young professionals but they are incredibly knowledgeable about the issues. They are very trusted advisors to the Members of Congress and can become your biggest champions.

Can I record our meeting and take screenshots?

Photos are wonderful. Of course you always want to ask permission first, but we encourage you to take screenshots with the offices that you meet on Tuesday. It's also recommended that you tweet or post those images on Facebook and IG and tag your Members of Congress.

Recording of the meetings is generally not allowed. If you have something that you want to record, you absolutely need to get permission from the individual office in advance.

What is an “Ask”?

An Ask is an actionable request made of your Member of Congress. Asks are usually binary (yes or no) and are concrete. They are proposing a solution to an identified problem. An example of an Ask would be to request that your Member send a letter to another Member of Congress or that they sign or co-sponsor a specific bill.

What will the Ask be for Headache on the Hill this year?

Our Asks are often decided very close to our event and that decision is heavily dependent on what is currently happening in Congress and where we feel we have the most likelihood of success. The Ask will be shared with you about 1 week before the event in our webinar training.

How soon will we know if we were successful with our Ask?

The Asks that we have are usually big items. It will not be something that we declare victorious within days or even weeks after HOH. Some of our Asks have been projects that have been ongoing for many years. This can feel unsatisfying to new advocates. It's important to remember that every meeting we have is progress and awareness building. Our progress at AHDA is often compared to glacial movement. It happens slowly over time, but eventually it's significant.