



HEADACHE *on the* HILL

FAQ Document

What is the schedule for HOH?

We provide an in-person training and briefing about the Ask that you will be presenting on Monday. This training typically lasts for a few hours. During this time, you will receive your final schedule for Tuesday and meet the team that you will be traveling with on Tuesday.

Tuesday AM we meet in the hotel lobby usually around 7:15-7:30AM and head over to the Capitol together. We capture a big group photo and then everyone heads off to their first meetings. We meet back up for lunch in the afternoon for a panel discussion with the Headache and Migraine Policy Forum. Following lunch, you head back out for your afternoon appointments. After your last meeting, you ensure your post appointment surveys are completed and return to the hotel. Depending on flight availability most advocates go home Tuesday evening.

How much does it cost to attend HOH?

Advocates are responsible for their own transportation to/from DC and living expenses while traveling. AHDA will cover at least 1 night of hotel for each advocate and lunch both Monday and Tuesday. Depending on your location, AHDA may be able to cover a second hotel night for you.

What does AHDA pay for?

AHDA will pay for 1 night of hotel stay for every advocate (Patients and Providers). If you choose to share a room with another advocate (over the age of 18) and need to stay for 2 nights, AHDA will cover the cost of both nights.

AHDA will cover a 2nd night of hotel stay for a limited number of Patient Advocates. Approval for coverage of the 2nd night will be made in conjunction with our supporting organizations and will be based on need.

AHDA will only cover the hotel night(s) for rooms booked through our application & reservation process with the Westin Crystal City hotel. Any arrangements made at outside hotels, or made outside of our reservation process, or after our reservation cutoff date, will be at the advocates own expense.

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.

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?

For the training on Monday, attire is casual to business casual. Attire for Tuesday is Business Professional. Tee shirts (even if printed with a group logo or message) or jeans are not considered sufficiently professional for congressional meetings. Definitely wear comfortable shoes – there will be a lot of walking to and from your appointments throughout the day. 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.

How much walking is involved/can I wear comfortable shoes?

There is a LOT of walking involved in the Hill day on Tuesday. We encourage you to go for function over fashion with your footwear, but not sneakers or sports shoes. Brand new shoes or high heels are not recommended. All of the buildings have hard marble floors. You will also be going back and forth between the House and Senate buildings (up to .7 miles each way) multiple times during the day.

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 5.

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?

Your meetings are scheduled to take place in the House and Senate office buildings. Each Member of Congress has an office that you would report to for your appointment. Depending on who else is there and who you are meeting with, you could be having a sit-down meeting at a large conference table or on a couch or you might be crammed into a storage room with a small fold out table. Some meetings even take place standing up out in the hallway.

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 bring a camera/can I take pictures/video?

Photos are wonderful. Of course you always want to ask permission first, but we encourage you to take photos 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.

Video 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 am I allowed to bring through security in the House and Senate buildings?

Each time you enter one of the House or Senate office buildings, you will need to go through security, similar to what you would experience at an airport. While we recommend that you travel with brief case, messenger bag or something else to protect your presentation folders, you will need to limit the contents of those bags.

Here is the list of prohibited items:

- Aerosol containers
- Non-aerosol spray (Prescriptions for medical needs are permitted.)
- Any pointed object, e.g. knitting needles and letter openers (Pens and pencils are permitted.)
- Any bag larger than 18" wide x 14" high x 8.5" deep
- Electric stun guns, martial arts weapons or devices
- Guns, replica guns, ammunition, and fireworks
- Knives of any size
- Mace and pepper spray
- Razors and box cutters

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.