

# 2025 AS Congressional Advocacy Day

## Frequently Asked Questions (FAQs)

Thank you for taking part in 2025 Congressional Advocacy Day! For those of you who are first-time advocates and who are wondering “what have I gotten myself into,” this set of Frequently Asked Questions (FAQs) is designed to make any fears and hesitations disappear.

### Key Dates:

**Advocacy Training Day:** An in-person training session will occur  
**Tuesday, March 4th from 3pm through 8pm ET.**

**Hill Day:** In-person meetings with congressional offices will be scheduled for  
**Wednesday, March 5th between 9am and 5pm.**

### Preparing for DC

#### **Q: What should I wear?**

**A:** You can dress casual for the training. Please dress in business casual for your hill meetings. To show your spirit for the Angelman syndrome community, wear blue, and carry the AS branded bags provided. We highly recommend comfortable shoes as the day involves a lot of walking.

#### **Q: What should I bring?**

**A:** We will provide you with materials for your meetings. Plan to leave your luggage at the hotel during both the training on Tuesday and the hill day on Wednesday. If your flight is Wednesday evening, allow enough time to get back to the hotel to get your bag after your last meeting before you go to the airport. Snacks and dinner will be provided at training on Wednesday. On Thursday morning, breakfast will be provided and lunch can be found at cafeterias on the hill. Feel free to bring snacks and water with you. Bring this binder as well as your hill packets to distribute. And bring your pictures/stories!

#### **Q: What can I bring through House and Senate office building security?**

**A:** The rules are similar to airport security. You may bring a bag/backpack/purse, water and snacks, and electronics. You may not bring weapons of any kind. You and your belongings must go through a metal detector. We do not anticipate any meetings in the Capitol building itself, but if you do go into the Capitol, security is tighter and you may not bring food or drinks.

#### **Q: How are meetings with our Senate and House members scheduled?**

**A:** Meetings will be scheduled for you by FAST and ASF. We use a company called Soapbox Consulting who will handle all the scheduling. Meetings are scheduled ahead of time between you and the appropriate health policy staffers who work for your two Senators and one Representative. Your schedule will indicate if the Senator and/or House Member plans to attend the meeting or if it will be with staff. Please provide Soapbox with your home address when you register so they may correctly identify your representatives.

#### **Q: How many meetings will I have?**

**A:** Advocates are guaranteed 3 meetings. Depending on other constituents in attendance you may attend more meetings with the House of Representatives. Attendees are normally grouped with other Advocates from your state, so your schedule may include more meetings with house members.

**Q: How and when will I receive my schedule?**

**A:** Soapbox emailed each advocate his or her preliminary schedule on February 27th. That email contains a website (sboxmobile.com) for each attendee to plug-in a unique schedule code. Advocates will see their schedules in real-time, the roster for their meetings, the bios for their Members of Congress, feedback questions, the email addresses of others in their group, and documents describing the “asks” that will also be sent to the Hill. Schedules will be updated as meetings are scheduled and change, so please also double check your schedule the morning of **March 5th**. Please do not contact any legislative office directly regarding your appointments. We are coordinating a number of meetings and want to keep confusion to a minimum.

**Getting Around the Capitol**

**Q: Where are the meetings?**

**A:** Meetings will take place in the House and Senate office buildings. There are three of each, and they are located on either side of the Capitol. It is unlikely you will go into the Capitol building itself, but you will walk past it. Buildings might be referred to as HOB or SOB in addresses. Below are the building names:

Russell Senate Office Building (SR)	Cannon House Office Building (CHOB)
Dirksen Senate Office Building (SD)	Longworth Office Building (LHOB)
Hart Senate Office Building (SH)	Rayburn Office Building (RHOB)

The three Senate office buildings are connected via tunnels on most floors. You do not have to go outside or back through security to go between meetings in different offices on “the Senate side”. The same is true on the House side. For example if you have a meeting in Cannon and then in Longworth, you do not need to go outside. However, if you are going from the House to the Senate side or vice versa, you will need to go outside and traverse the Capitol.

There is some signage and you can always ask a passerby or Capitol Police. See maps at the end of this binder.

**Q: What should we / can we do in between meetings?**

**A:** If you have 30 minutes or less, you should head to your next meeting. Buildings can be tricky to navigate and it’s better to be early than late. There are public restrooms available and generally marked throughout all the buildings. If you have more than 30 minutes, you may want to grab a snack or lunch, wander the halls, or go outside. The Library of Congress and the Supreme Court are near the Capitol and all three are nice to look at from the outside.

**Q: Where is lunch?**

**A:** Each of the buildings has a cafeteria or a snack bar, generally on the ground or basement level. Longworth HOB has a Dunkin Donuts and a hot food cafeteria; Rayburn HOB also has a cafeteria. There are also vending machines. Cafeterias are also places to see and be seen - watch out for Members of Congress!

**Congressional Meetings**

**Q: What do I say in my meeting?**

**A:** The training scheduled in person for **Tuesday, March 4** will cover everything you need to know about how to meet with a congressional office and what we are asking for this year.

**Q: How long do meetings last?**

**A:** Both Members and staff are short on time, so rarely will a meeting last longer than 15-30 minutes. That's why you want to be succinct, to the point, and make sure your messages are not overly repetitive. Schedules for Members and staff can be chaotic, especially during this time of year, so some meetings may start late. Your schedule should allow for some time for late meetings, but if you need to leave for another meeting, please inform the staffer. In a group, consider splitting up so that some attend the next meeting while others finish the delayed one.

Allow yourself about 10 minutes between meetings and more if going from House to Senate.

**Q: What if I only meet with staff and not my Member?**

**A:** Due to Member schedules, many meetings will likely be with the staffer. However, while congressional staff are generally young, they are tasked with many important responsibilities and are the direct line to inform the member on important topics. In many cases, the staffer will know a great deal about the issues. In other cases, they may rely on you for guidance. If this is the case, don't be alarmed that "they don't know anything" and instead use this opportunity to cultivate a deeper relationship with that office.

**Q: What if I'm asked a question that I don't know how to answer?**

**A:** Relax. Staff and Members know that you are parents, grandparents, aunts, uncles, siblings, patients and friends who are personally affected by AS. So, if a question comes your way that you don't know how to answer, simply say you don't know and that FAST/ASF will follow up to get them an answer as soon as possible. This is a great opportunity to follow up with the office later - just be sure to note the question and share in your meeting feedback.

**Q: What if the staffer seems unresponsive or hostile to our request?**

**A:** The chance of having a "hostile" meeting with a staff member working for your Member of Congress is unlikely. Staffers know that they are there to serve constituents and most take that job very seriously. If you have a meeting in which the staffer is unresponsive or non-committal, always thank them for their time and ask if there is anything they need from you and offer to follow up in a couple of weeks. Ultimately, NEVER GET DISCOURAGED as regular contact with the staff and Member by courteous and informed constituents has swayed staff and Members to take actions in support of individuals with Angelman syndrome.

**Q: What should I leave behind?**

**A:** You or another advocate from your state will have a leave behind packet for the staffer that includes all the materials. Don't forget to give any leave behinds that you personally created. It is important they put a face to AS.

**Q: Can we take pictures? Can we share on social media?**

**A:** YES! Photos are generally allowed inside and outside the buildings. Take pictures by your Member's door sign or outside in front of the Capitol. It's common to request group photos with Members or staff—don't hesitate to ask. For photos taken during the meeting, ask permission first. The best format for photos to post is vertical/portrait mode.

Video is a little more sensitive. You can take videos in the hallways, but we do not recommend recording your actual meeting. This will not allow the Member or staffer to focus on listening and responding to your requests.

If you do obtain a picture with your Member of Congress, you may post it to social media. For staffers, please ask permission before posting as they are not public figures.

1. Tag your fellow advocates and members of congress (with permission)
2. Post on your feed and on your story!
3. Use #AngelmanAdvocates

**Q: I know that my Member already voted against or opposes our legislative asks. What should I do?**

You catch more flies with honey than with vinegar. While a Member's opposition to our priorities may elicit a passionate response, please approach your member with respect and use the opportunity to educate them about the impact of their decision. On a vote on a large legislative vehicle that includes our priorities, the Member may have had to take a tough vote based on issues unrelated to us. Even in the case that the Member directly opposes one of our priorities, our job is to put a face and a story to the impact and to provide facts and information from our perspective to inform their stance.

**Q: I strongly support or oppose my local Member politically. What should I do?**

**A:** This is particularly important in today's politically polarized environment. As an AS Advocate, your mission is to secure federal support for Angelman syndrome research and care and influence relevant legislation. Avoid criticizing Members on unrelated issues or bringing up non-related matters during advocacy meetings. Please stick to the prescribed topics so we can maximize our impact with consistent messaging.

If a staffer recognizes you from other activities, you may acknowledge it but should not proactively discuss unrelated topics. Avoid discussing political fundraising with Members or staff, as it's prohibited in official offices. To support a campaign, contact their campaign office separately when you return home.

**Follow up**

**Q: What do I do after my last meeting?**

**A:** Take a sigh of relief - you did it! Head to the hotel to get your bag and head to the airport if you have a flight. Be sure to jot down notes about your meeting and upload any photos you took into the soapbox app to. Otherwise, you are free to go.

**Q: How do I follow up with offices after a meeting?**

**A:** FAST and ASF will send you follow up materials (essentially the information that is in the packet you are leaving behind). It is important to thank them after the meeting.