



Annual Angelman Syndrome Congressional Advocacy Day

Frequently Asked Questions

Who should attend?

Parents of individuals living with Angelman syndrome, as well as grandparents, aunts, uncles, siblings, and friends. Anyone can be a good advocate!

Should I bring my loved one with Angelman syndrome to DC?

This is completely up to you after reviewing the schedule of events and knowing your loved one best.

What should I expect now that I've registered? What do I need to do?

Please be sure to book your hotel:

- Note the deadline to book through the ASF/FAST hotel block.
- Adjust the dates as need for your stay.
- If you have other accommodations that work for you, please do take advantage of those.

Please be sure to book your travel:

- The closest airport to the hotel is Ronald Reagan Washington National Airport (DCA).
- You should arrive in DC in time for the training that starts on Tuesday at 3 pm ET. Once registration is complete, we will provide a detailed schedule. You can schedule your flight out on Wednesday to depart after 5 pm ET - if you need to schedule an earlier flight home, it's not a problem; please indicate that on your registration or email us those details.

How are Hill meetings scheduled?

You don't have to do a thing!

Meetings will be scheduled by FAST/ASF with the appropriate health policy staffers who work for your two Senators and one Representative for Wednesday. If schedules permit, your Senators and/or House Members may participate in your meeting or at least stop in for a minute or two to shake your hand.

Who will I be attending meetings with, and how will I know where to go?

Not to worry, we will provide you with all the information on the training day!

If you've never been to Washington before, don't be afraid, as you will be traveling in groups that will include experienced advocates and/or government relations advisors from FAST/ASF.

Each advocate will receive a personalized schedule with the times and locations of each meeting, as well as the staff members with whom you will be meeting. We will also provide you with maps and show you the lay of the land. All your meetings will take place in office buildings that are part of the Capitol complex. We will make sure you have clear instructions on getting to the hill.

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

Don't be upset if you only meet with staffers. Congressional staffers are generally young, but are tasked with many important responsibilities, one of which is meeting with constituents when the Member is unavailable. In many cases, the staffer will know a great deal about the general issues areas. In some other cases – particularly if you are meeting with a new staffer or a recently elected Member – they may rely on you for guidance. If this is the case, don't be angry that "they don't know anything" and instead use this with that office.

I've never been inside a Congressional Office. What should I expect? Congressional offices are, for the most part, small and quite cramped. This means many important meetings between staff and constituents often take place in a busy reception area, over a small table tucked into a corner, outside in the hallway, or even in a cafeteria. Both Members and staff are short on time, so rarely will a meeting last longer than 20 minutes. That's why you want to be succinct, to the point and make sure that people in your group are not overly repetitive.

What should I wear?

Dress is normally business casual on the Hill - blazer, slacks (no jeans), button-up shirts. We do encourage all advocates to wear something blue! But be sure to wear comfortable shoes and check the DC weather before you leave!

What should I/can I bring?

We will provide an informational template to distribute after the meeting. You're welcome to include an insert your child's photo to bring as a leave behind with your packet folder. It is important that legislators put a face to Angelman syndrome.

PLEASE NOTE: the following items are prohibited in Senate and House Office Buildings:

- Bags exceeding the size of 18" wide x 14" high x 8.5" deep. (Please note: a FAST/ASF-branded bag will be provided for your use.)
- Firearms to include replica guns and ammunition.
- Weapons (to include but not limited to): Black jack, sling shot, sand club, sandbag, knuckles, electric stun guns, knives (with blades longer than 3"), razors, box cutters, martial arts weapons or devices. Knives with blades 3" or less are permitted.
- Explosives and explosive devices to include, but not limited to, Molotov Cocktails, components of a destructive device, and fireworks.
- Pointed objects to include, but not limited to, knitting needles, letter openers, or other pointed objects deemed a possible threat. Pens and pencils are permitted.
- Sealed envelopes and packages.

What issues or policies will we be advocating for?

We will comprehensively cover this during the training on Tuesday equipping you with all the necessary information, tools, and knowledge to effectively convey your message to your representatives.