



Caregiver Information Guide

At-a-Glance Schedule of the 2-Day Event

Advocate Training Day

- Arrive to the hotel for the 3pm-8pm training session for Advocates
 - This training is critical for caregivers so they understand the asks and have time to plan with their meeting partners.
 - Caregivers need to be focused to best absorb the information to feel prepared for meeting day.
- Dinner will be provided at the training.

Meeting Day on Capitol Hill

- Breakfast will be available at the hotel prior to departure to Capitol Hill
- Caregivers are responsible for transporting themselves to Capitol Hill and follow the schedule outlined for them.
 - Many advocates travel together in ubers and when walking around Capitol Hill.
 - Driving and parking on Capitol Hill is not recommended.
- Each advocate will receive a personalized meeting schedule where you will meet as a group or individually.
 - Meeting start times may be anywhere from 8am to 4:30pm.
 - Meetings will take place in an office or possibly a hallway and can last between 15-30 minutes.
 - There may be breaks between meetings or a day of change of schedule so flexibility is required.
- Meeting schedule may require significant walking between the House and Senate side of Capitol Hill which are approximately 0.6miles/ 15min walk apart.
- Once the last meeting has been completed, caregivers independently depart Capitol Hill - stopping at the hotel to retrieve their luggage, if applicable, before heading home.

Preparing for your visit with your loved one.

Preparing for the Trip

- Travel Arrangements:
 - Book accommodations through the hotel block provided by FAST and ASF. You can absolutely stay at another hotel/AirBnB that might fit your needs better. If you choose this option, we recommend staying close to hotel for training day and Capitol Hill for meeting day.
 - Plan for accessible transportation - the Metro, Uber and Lyft are recommended and can provide accessibility needs. Parking and driving to capitol hill is quite challenging.
 - Notify airlines or train services about specific needs, such as extra time for boarding or assistance. If flying, consider contacting TSA Cares for your inbound and outbound flight or order a [Hidden Disabilities](#) badge.
 - Closest airport option to the hotel and Capitol Hill is Ronald Reagan National Airport (~6 miles)
 - NOTE: Be sure to check the distance from the hotel to Capitol Hill. Please take this into consideration when packing. If your individual with AS has access to a stroller or wheelchair, we recommend bringing it.
- Packing Essentials:
 - Bring all necessary medications, equipment, and comfort items.
 - Please pack a bag of necessary items to help your loved one with AS during the training. But you do have the ability to go back to your room if you're staying in our hotel block.
 - Pack plenty of snacks, water bottles, favorite toys, and sensory tools to keep your loved one calm and comfortable during meetings.
 - Keep in mind the Capitol will not allow bags exceeding 18" wide x 14" high x 8.5" deep. (Please note: a FAST/ASF branded bag will be provided for your use.)
 - Make sure to bring any electronic devices, fidget toys, books, comfort items, toileting items, emergency meds.



- **Meals:**
 - On training day, dinner will be provided.
 - On meeting day morning, breakfast will be available
 - Hotels typically offer room service as well as a restaurant onsite.
 - Meeting day on Capitol Hill: lunch will be on your own at one of the cafeterias on campus.
 - If you are concerned about food options please consider packing a lunch for your individual with AS but the cafeterias do have a wide variety of options to accommodate all who visit Capitol Hill

Caregiver Support:

- **Pair Up:** Connect with another caregiver or AS staff member to form a buddy system. This can help with managing schedules, caregiving tasks, and providing emotional support. We will have many of our AS staff there that can at least be a call away to support if needed.
- **Small Groups:** Join a small group of caregivers to share responsibilities, like watching kids or navigating meetings together.
- **Prepare Ahead:** Meet virtually or in-person before Advocacy Day to coordinate schedules and share tips. Maybe those bringing their loved ones with AS can do a group call or be on a group text ahead of time

Managing the Day with your loved one:

- **Schedule Flexibility and Planning Ahead:**
 - While a schedule is created for each advocate, there may be last minute changes so advocates need to be flexible to maximize their time on the Hill.
 - Be prepared for long security lines at Capitol buildings and plan accordingly.
- **Comfort Breaks:**
 - Many Capitol buildings have family-friendly spaces or areas to decompress.
 - Once you get your schedule, review the building maps to identify quiet areas in advance for sensory breaks or downtime.
 - Keep a small kit on hand with sensory tools, snacks, and other items to help your loved one stay regulated.
- **Engaging During Meetings:**
 - Let your loved one's presence amplify your message. Legislators often connect deeply with seeing and meeting individuals with Angelman syndrome.
 - Encourage your loved one to participate if they are able, even if it's a simple gesture or communication through their device.