

Getting Community Involvement and Volunteers to Your ASF Walk Event

1. Make a list of all the community organizations you would like to have represented at your event. Here is a sample list:
 - a. Local Rotary Club
 - b. Local Kiwanis Club
 - c. Local Lions Club
 - d. Local Teen Group (high school Key Club)
 - e. Fire Department
 - f. Police Department
2. Go online and look up the contact person for each group and call or send them an email something like this:

Dear _____,

Would your (name of club) members benefit from learning about a Rare Disease called Angelman syndrome? A national event/fundraiser is coming to our community this May, and I thought this might be a great opportunity to educate your members about this rare disease and answer any questions they may have.

My name is _____ and I am the parent of (child name/age), who has Angelman syndrome. I am also the local coordinator for this National Walk event coming to (community name). Angelman syndrome (AS) is a rare neuro-genetic disorder that occurs in one in 15,000 live births or 500,000 people worldwide. Angelman syndrome shares symptoms and characteristics with other disorders including autism, cerebral palsy and Prader-Willi syndrome. Due to the common characteristics, misdiagnosis occurs often.

I would like to request just five minutes on the agenda of an upcoming meeting of your group. I will tell my family's story and give a short presentation of facts and then answer any questions from the group. Any time on your agenda would be greatly appreciated. I look forward to hearing back from you.

Sincerely,

(your name and contact info)

3. Once you are on their calendar, pull together the following to bring with you to the meeting:

- a. **One of your other leaders** (it is always good to present as a team and provide support to each other).
- b. Brochures on AS. Some were sent to you in fundraising packet. If you need more, contact Kitty.
- c. Flyer with information about your specific Walk.
- d. Sponsorship forms and Donation in Kind Forms.
- e. Promotional items (such as ASF Face masks). If you need some items, contact Kitty Murphy.
- f. PowerPoint presentation on Angelman Syndrome, and/or one of our AS videos to show to the group.
- g. Write up about 2 minutes of notes about your personal story, how AS affects your family and how the ASF is here to assist families as well as invest in research towards a cure.
- h. Something to show the video/PowerPoint presentation on. Check with the leader of the group to see if they have the equipment/audio to project your presentation on a screen. If not, find out if the group is small enough to view a laptop presentation.
- i. End your presentation by handing out a flyer about your Walk event and invite them to participate and or sponsor if they are able. Make sure to give a fundraising packet to the leader of the group containing a sponsorship letter, donation form, brochure, and walk flyer.

This process has proven to be very successful in recruiting community volunteers as well as donations toward your event. If you need anything at all or have questions about making this happen, please reach out to Kitty Murphy – kmurphy@angelman.org.