



## The Importance of Telling Your Story

Thousands of advocates for every cause imaginable come to DC every week to meet with their members of Congress and staff. This is our opportunity to introduce them to Fragile X. To add faces to Fragile X, so when they are asked about the issues, legislation, and funding we are advocating for, they think of you and the stories you told.

We want you to be:

- Honest
- Vulnerable
- Clear
- Concise
- Impactful

Your story is key. You are a trusted voice from home, and we want them to know what we want and need for a brighter future for Fragile X and others living with associated conditions and disorders. It helps connect your life with Fragile X to theoretical and legislative outcomes. Your story helps them remember your ask when decisions are made.

Take a deep breath! You don't have to know our Asks inside and out to be a great Advocate. Advocacy Day is about sharing your story and putting faces to Fragile X. Let us take care of the legislative details.

## Personal Story Telling Basics:

- Keep it simple and immediate.
- Focus on your situation **today**. We have a limited amount of time, so be clear on the 2023 Asks.
- Help the staffers understand how Fragile X impacts you and your family's lives – the challenges and the successes. What would make the difference for you and your family?
- Have your family leave-behind available to show while introducing yourself.



## Other tips:

- Tell the story just like you talk - in your own voice.
- Underline the takeaway: find the point you want to drive home and make it clear by restating within your story.
- How does one of the asks relate to your story?
- Don't assume the staffers know anything about Fragile X: Share your journey with Fragile X syndrome in a way that educates someone who has no knowledge of it. We can't assume that the staffers have met someone living with Fragile X.
- Offer the right level of detail: Too little and the story is not vivid; too much and it gets bogged down.

## Telling the story:

Here are some prompts to help you craft your introduction. Share what you are most comfortable sharing, your connection to Fragile X and the impact Fragile X has on you and your family or your profession.

## Introductions:

If you are in a group with other advocates, allow them time to introduce themselves. Try to keep the introductions brief (**30 seconds – 1 minute per advocate/family**). Use the format below to craft your introduction:

1. I/we am/are here, along with nearly 150 others from across the country for the National Fragile X Foundation's Annual Advocacy Day.
2. My name is, (name) and I am a (parent, caregiver, sibling, self-advocate, Fragile X premutation, professional)...
3. I/My family live(s) in (city). (*This is so they know you are a voting constituent*).
4. Share your personal story and reference your family photo sheet if you brought one.
5. Share how Fragile X impacts you and your family's lives – the challenges and the successes.
6. Introduce the next advocate.



## Example:

*Hello, I am here along with nearly 150 others from across the country for the National Fragile X Foundation's Annual Advocacy Day. My name is Taylor Smith, and I am a parent of a 6-year-old with Fragile X syndrome and I have the Fragile X premutation. My family and I live in Fargo, North Dakota with our 3 children. My partner and I also have a 4-year-old daughter and a 1-year-old son who are typically developing. Our son, Lucas, was diagnosed when he was 2.5 years old due to developmental delays. He is currently receiving special education services in our local public school system. He loves pizza and playing with our puppy, Pluto. Lucas has a significant speech delay and is working on identifying his letters at school, something his same age peers learned years ago. He can become overwhelmed at times which leads to behavioral meltdowns. This is a challenge when trying to do simple tasks or outings with our family, such as going to the park. I would like to introduce, Elizabeth, who will now share about her family.*

## Asks:

Now that everyone has introduced themselves, select someone in the group to initiate the 'Asks'. The questions may vary depending on if this is a new Member of Congress or if this is someone who you or other advocates have previously met with.

- 1. Are you familiar with Fragile X associated conditions and disorders?**
  - a. Utilize the description on the State Fact sheet to:
    - i. Succinctly describe the associated conditions and disorders.
    - ii. Discuss the estimated number of individuals in your state that may be impacted by Fragile X
- 2. A packet of information was emailed with additional information, including our Asks. We also have this folder with that information available here.**
  - a. Let the Leave-Behind do the work! The NFXF will provide you a leave-behind folder for each of your meetings. This is a folder full of information about our Asks and Fragile X. If the staffer asks you a detailed question about an Ask, reference the folder and/or point them in our direction.
  - b. You will be provided with a folder for each meeting at the end of the training on Monday, February 27<sup>th</sup>. You do not need to prepare or provide this information.

## Closing:

Close the meeting by asking the staffer and/or Member if they have any questions. Don't forget to ask for a group picture!!! Thank them for speaking to you and helping make a difference in the lives of those impacted by Fragile X.