



In just two years, you will find yourself speaking at a press conference with two U.S. Senators.

If someone had said that to me the first time I went to Washington, D.C. to talk to my senators and representative, I never would have believed it. I'm actually an introvert, and the thought of doing something like speaking at a press conference, where there are no do-overs, was daunting. But because of my son Evan, I moved past my hesitancy to do what I've now easily done hundreds of times—share our story.

From the time Evan was born, we were sharing stories of some sort. The first story was how the doctor thought she delivered the surprise post-birth diagnosis of Down syndrome in a textbook-perfect way. In reality, she missed the most important part, telling us where to go from there. She never said you'll need to connect with the county so you can set up Early Intervention. She forgot to say you'll want to visit the National Down Syndrome Congress website because they have some wonderful information that will answer so many of your questions—and they have a wonderful meeting each year. She didn't say you'll want to connect with your local, amazing Down syndrome group.

I grew comfortable telling our story and advocating for Evan within our community. Like any parent of a child with Down syndrome, we had become comfortable advocating for things like tests, additional services, being included in typical classrooms. But when my husband approached me about advocating in Washington, D.C., I was intimidated. Was I ready to speak to United States Senators and Representatives? I didn't think so, but as the time came for the visit, my husband reminded me that it's just sharing our story.

In our first meeting on the Hill, I was nervous, until it was time for me to share. It really was much the same as advocating for Evan anywhere else. It was about communicating what he needed, how that could be accomplished, and what the implications would be in the future. As I talked about Evan, I realized that politicians just wanted information about what's important to their constituents, and we were the constituents with that information. By the end of the day, I felt much more confident, and I really enjoyed the experience.

I was hooked. I wanted to connect and advocate again, and I did. In between Hill visits, I started answering all the calls to action with calls, letters, emails, tweets, and Facebook posts. I got to know legislators and their staff, and they knew me. There were times when we were asked to share our perspective on important issues. And two years after that first day on the Hill, I did a press conference with Senators Casey and Hassan—something that I had never imagined I would ever do.

As we continued in our advocacy journey, we met a lot of advocates and self-advocates along the way. We learned how others shared their story, and we refined the way we told ours, because it's not just important to tell your story, it's important to tell your story in a way that's relevant to your audience. In a way, we're constantly self-training, sharing, and shamelessly stealing (with permission) what others do well, all in the hopes of improving how we tell our story so it's effective. It was self-training because there were few training opportunities for would-be advocates and for those who wanted to improve their advocacy efforts.

Last year, the National Down Syndrome Congress hosted its inaugural Advocacy Training Day (now called “Advocacy Training Boot Camp”). The day featured sessions about basic government processes to refresh participants on the process of bills becoming law. Legislators shared how advocates could effectively engage with them. Self-advocates and advocates shared their approaches to discussions with legislators. I even had a chance to share how I advocate and how we started the Pennsylvania Down Syndrome Advocacy Coalition. There was a session on creating a biography to leave with legislators to help make your message even more memorable. The event also included a presentation on how to engage with NDSC’s and Global Down Syndrome Foundation’s advocacy efforts. The day wrapped up with presentations on how to use social media as a tool in your advocacy toolbox.

The Advocacy Training Day was more than the sum of the wonderful presenters on the stage. It was about all the participants in the room sharing their wisdom and experience. It was about asking questions and having panelists and the audience jump in to share answers, approaches, and information. It was about a filled-to-capacity room of nearly 200 people who were eager to learn, problem solve, and share their stories to make change. It was about protecting and expanding the rights of individuals with Down syndrome and other disabilities.



I left the inaugural Advocacy Training Day with new ideas that have shaped my advocacy efforts this last year. Whether you’re thinking about advocacy, are a new advocate, or are seasoned in advocacy, come to this year’s Advocacy Training Bootcamp, and you’ll leave with new tools to enhance your advocacy efforts and some new mentors and friends. I look forward to seeing/meeting you all there!

Plan now to come early for the National Down Syndrome Congress Advocacy Training Bootcamp. The Bootcamp will be on Thursday, June 27, 8 AM – 12 Noon. It is free to NDSC Convention registrants. Be sure and register when Convention registration begins on March 25th.

Questions? Email lauren@ndscenter.org or call 800.232.NDSC (6372).