

My Perspective of Advocacy Day *By Heather Van Dam*

In life, we are given many opportunities. We don't always notice them because fear holds us back. I was recently given the opportunity to go to Washington, D.C. in March for my first National Fragile X Foundation Advocacy Day. Unlike many Fragile X carriers, I don't have a lot of anxiety. Mostly because I really love adventure! But this was totally different. I was going without my husband Derek who is always with me on my adventures. I was scared! I was also rooming with someone I had never met before and I was joining 200 other people and only knew a handful of them. All of my worry was overpowered by the chance to go and talk to Members of Congress. To say I was excited would be a major understatement. I was JACKED UP!! I had a million things I wanted to tell them about what needed to be done to help not just kids with Fragile X, but all kids. I wanted to point my finger and tell them what they needed to do to make the world a better place! My mind was a tornado of ideas. Upon my arrival at the hotel, I was greeted by many familiar faces I had never met in person but had only seen on Facebook. A few I had met at the 2014 NFXF conference in California. It was a little weird to meet strangers with whom I had an instant connection. They were all so welcoming and friendly. I was instantly reminded that I was a member of a special club. I arrived on Tuesday for training that afternoon. The training they provided gave me a feel for what was to come the next day. There

was a lot of talk about how we should tell our story and the kind of information that we should include. It was great to be given direction. I sat at a table with other Michigan advocates. I had met all of them before and it was so great to know they had done this before and would have my back if I froze. We went over the K.A.S.S. Act and the T.I.M.E. Act which we would be discussing the next day with Members of Congress. They also gave us leave-behind folders with all of the necessary information about the Acts, Fragile X syndrome and who they could contact at the NFXF if they had questions. When the training was over, I felt ready for the next day. On the day of our visit to Capitol Hill, we all boarded busses that would take us to the Hill. We stood on the steps of the Capitol building for a BIG group picture. We then went into the Capitol building where Congressman Gregg Harper gave us a tour of the House of Representatives and told us about his son who has Fragile X. After the tour, we split up into groups and went to our meetings with Members of Congress from our state. The day was like a marathon: rushing from a meeting in one building to a meeting in the next building. Each meeting left me feeling more prepared for the next. I just sat back at the first ones to see how it went and what I could add. I was so fortunate to spend the day with the Price Family. They have been to Advocacy Day every year for many years. They were pros. Dave Trott is the Representative from



Alli Cohen with Heather in D.C.

my district. Luckily, it was the last meeting of the day so I had a lot of time to go over what I wanted to say. When we arrived for the meeting, Representative Trott was on the House floor for a vote. We met with a member of his staff. She was so kind and really seemed to genuinely care and have concern for what we had to say. I felt like I was really being heard. When the meeting was over and we were leaving we ran into Representative Trott in the hallway. He was apologetic for having missed our meeting. We spoke with him in the hall for several minutes and told him our

**"Don't go through life,
grow through life."**

~ Eric Butterworth

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story and asked if he would support the Acts. He said he would have a look at the folders we left and see what he could do to help. Besides the birth of my children, I have never felt so powerful in all my life. It made me feel as if I could do anything. I

had the amazing opportunity to meet face to face with Members of Congress! How many people can say that?! I had the chance to be a lobbyist for a day. I told them what we wanted and how it would help all kids. Not just kids with special needs. I felt like a real life

super hero. The Members of Congress were all very kind and listened closely to everything we said. The more people who go, the more things will begin to change. If you have never done it... I say DO IT! Your words and actions have POWER!



Heather Van Dam

Pictured with Congressman Dave Trott of Michigan's 11th District. See Heather's story on page 2.