

From Helplessness to Advocacy



The author and his son.

October 22, 2007 was the most helpless I've felt in my entire life. That was the day we got my son's diagnosis of fragile X syndrome. What in the world is that? Where do we go from here? What is his/our future going to be like? One question led to another—and there was no answer in sight.

The next few months were a whirlwind of

doctor appointments and more questions. Finally, my wife convinced me to go to our first support meeting with the Fragile X Association of Michigan. At the meeting, we met people who would start to help us understand what Fragile X really is, and that no, our world was not over.

And so began the transformation from helplessness to advocacy.

We attended our first NFXF International Fragile X Conference in St. Louis in 2008, and when we returned our life was forever changed. The knowledge and compassion we found there were unbelievable. During the conference and at some of our support group meetings, there was talk of Advocacy Day—a couple days in Washington D.C. meeting with our leaders in Congress to try and increase funding and awareness of Fragile X. Being a bit of a political junkie, this was right up my alley.

I had no idea how empowering these short two days

would be. First was just being able to meet with all the advocates from around the country, sharing stories, strategies, triumphs, and determination. Then meeting Congressman Gregg Harper (R-MS), whose son has FXS, was an amazingly uplifting experience. His story was like so many of our stories—and his passion for our cause was intoxicating. This was just day one.

Day two was an even more amazing experience. Congressman Harper met us on the Capitol steps and was gracious enough to take us on a tour of the House floor and some of the rooms in the Capitol. The pep talk given by Rep. Harper and Rep. Delahunt (D-MA) on the House floor got our blood flowing. There we were in the chamber where the president addresses Congress and leaders of the world speak and mingle; we were about to embark on a day filled with excitement.

Kim Young, Jeff and Arlene Cohen and I met with staff members of our state representatives and senators and even with some from other states, all of them trying to help increase funding, research, and awareness of Fragile X. On that day I wasn't helpless, I wasn't afraid of the future, and I knew where I was going. I was guided by my love for my son, by a passion for helping him, and by everyone in this country whose lives are affected by Fragile X. On that day I was an advocate—as I will be every day for the rest of my life—helpless no more. ☺

The author lives in Harper Woods, Michigan, with his wife Tina and 4-year-old son Hayden. He is on the Executive Board of the Fragile X Association of Michigan.



Nevada and Georgia advocates Herah Osborne, Kim Miller, Gail Heyman.



Michigan advocates Arlene Cohen, Jeffrey Cohen, Kim Young, and Mike Makris.



NFXF advocates gather on the East Steps of the Capitol.