



Our Michigan Advocates!

Thank you for taking the time to be our voice in Washington!

Advocacy Day 2010 - One Hundred for One Million *by Kim Young*

I have been very fortunate to have attended Advocacy Day every year since its conception in 2004. This year, twelve people from Michigan were there to represent us from three generations of our fragile X families. It is an empowering experience that allows you, armed with stories of your personal experiences living with fragile X, to make a difference. This year was no exception, but in many ways was better than any year before. I decided to take both of my children with me this year, Andrew, 14, and Ally, 12. No other field trip or history lesson can compare.

Like years past, we went requesting federal funding through the Centers for Disease Control (CDC) and the National Institutes of Health (NIH). But the past two years, we have also gone requesting legislation, the ABLE Act (Achieving a Better Life Experience Act) and the Harmful Restraint and Seclusion Act.

Both of my children attended all of the meetings and I even put Ally on the spot in a few of them to have her voice heard. The day that we were all on The Hill, over one hundred people from over 35 states, the

Harmful Restraint and Seclusion Act was passed by the House of Representatives. I have to say, after hearing stories from our "fragile X family", from all over the country and even from our own backyard, of physical and emotional abuse at the hands of some in education entrusted to care for our kids, the little hairs on the back of my neck stood up. History was made!

Please consider attending next year. You need not be an expert on government or the science of fragile X. You need only be an expert as a mom, dad, grandparent or sibling living with someone with fragile X.