

Advocacy Day: Giving Fragile X a Voice

by Kim Young

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Kim Young, Laureen Majeske, Senator Debbie Stabenow and Jeffrey and Arlene Cohen

For the past three years, I have been fortunate to be part of a movement in Washington, D.C., created by goals and passions at the National Fragile X Foundation (NFXF). At the 2004 International Conference, over 200 families lobbied on Capitol Hill seeking federal funding for Fragile X. Although the number of families attending each year has become smaller, the momentum created in Washington has grown larger. It's exciting to see what a group of people can accomplish together.

The Fragile X Association of Michigan has created an Advocacy Day stipend for those able to attend the annual event, in order to help defray some of the costs. It is a very empowering experience to visit with elected officials and then see results in the Federal Budget as a result of those meetings. In 2004 and 2005, the NFXF sought \$1 million in federal funding through the Center for Disease Control (CDC) and sought requests, through the National Institute of Health (NIH), which could amount to as much as \$25 million to help provide awareness and educational and medical supports. Of that \$2 million sought over the last two years, \$1.8 million has been awarded! That is a great success, one on which to build. Our own Senator Debbie Stabenow is the Democratic lead on the letter circulating the Senate for the 2007 Federal Budget. The letter is asking Congress to support all of the requests of the NFXF because of the importance of our cause. It has been wonderful to see an increase in interest and support in all of the Michigan elected officials' offices each year I return.

For those of you who participated in Advocacy Day 2004, please consider rejoining the cause and attending next year's efforts. If it's something you've never participated in before, it is an exciting and empowering process, which really does make a difference – a difference in the lives of everyone affected by Fragile X. ✕✕