



ADVOCACY ALERT

April 1, 2009

Hello Everyone -

It's "April Fool's" Day! Not that I'm a big observer of this day, but it has crossed my mind given that I hold a close association with this silly day because I was born at twelve minutes after midnight (making it safely to April 2nd) because my mother refused to have an "April Fool's Baby". Mother's have our best interest at heart, even before they meet us. I learned a great deal about mother's hearts this weekend. But, first things first.

I am writing this as I am waiting to depart from Dallas on my way home from Washington DC where I attended the Epilepsy Foundation's 2009 Public Policy Institute and Kid's Speak Up! Program. I attended the conference with Emily Barnes and her mother April Torres of Lafayette. Emily was selected as this year's Louisiana state delegate. She is a 14-year-old with juvenile absence epilepsy. She was diagnosed four years ago and with perseverance, patience and the right combination of medicines, has been seizure free for nine months.

The conference packed a week's worth of information into two solid days of meetings from 8 am until 8 pm. Sunday we heard from very informed, educated, experienced people on subjects of advocacy and research and from people actually drafting the health care reform bill. But, the highlight of my trip had to be when the youth delegation arrived. The Kids Speak Up! delegates met at an Opening Session on Sunday night where they were asked to talk about any experience they had encountered with "bullying" at their school due to their disorder. Many children told their personal experiences and then Joyce Bender, the guest speaker, gave a rousing rebuttal of empowerment and confidence to these young people. It was a stirring moment to see the children's faces when she called them tomorrow's leaders and today's conquerors. It was suggested to purchase the book, *Letters to a Bullied Girl*, by *Olivia Gardner* as a good source to read. Many schools have implemented a "No More Bullying" Program in their schools as "Bullicide" (a new term to describe children committing suicide due to extreme cases of this behavior) continues to increase.

Monday we heard from parents of children with epilepsy. Parent after parent told story after story inspiring us to dig in, stay the course and not let go of the fact that "we" are our best children's advocate. YOU are your best advocate. No one knows more about epilepsy than those people experiencing epilepsy.....those families living with epilepsy. Epilepsy is not a disorder of one..... epilepsy affects everyone IN the family and everyone involved WITH the family. Mothers and fathers, both, shared heart breaking and heart warming stories of strength and courage.

Then came Tuesday, Capitol Hill Day, the day to put our training into action! Excited and nervous, our little delegation of three set off to meet with four of our national congressmen (and women). The National Foundation had set appointments with both Louisiana Senator's Mary Landrieu and David Vitter and Representative's John Fleming, from my district and Charles Boustany, from

Emily's district. Our task at had, to put a personal face of epilepsy with our "asks". Unfortunately, we did not get to speak personally with any of the Congressmen (due to voting on the hill) but were able to speak with staff members serving in the Health Care division. Emily did a great job. She told her story about her condition and answered their questions directly and sincerely. April, too, did a wonderful job. She expressed how epilepsy affects everyone in the family and that epilepsy is a "disorder of anticipation". I left behind an information package with the federal agenda and our state agenda.

We felt the meetings were productive. Actually, I found the meetings to be fun. I don't know how much headway we made in acquiring \$10 million dollars for our "Training Nurses in School Program" or \$160 million dollars for research, but it felt good speaking for the parents that I had met and those I have not, speaking for people who endure on a daily basis a disorder that they never know when and if it will strike. With or without headway, we made contacts, we made friends and we learned a great deal. Tuesday we were lobbyist, maybe pretend lobbyist for a day or, perhaps, real lobbyist for life. I choose real lobbyist for life. You, too, can choose to be a real lobbyist for life.

**Lobby for Yourself * Lobby for your family **

** Lobby for whatever you believe in **

Until next month,

Sincerely,

Amy Nichols
Lobbying for you