Morning on the Hill Experiences

Devoted to real-life testimonies of coping with attention-deficit/hyperactivity disorder, Attention's newest department made its debut in December 2007. For this column, we asked conference attendees who participated in CHADD's Morning on the Hill on November 8, 2007, to share the stories of their experience with our readers.

From Tragedy to Purpose

NEVER IN MY WILDEST DREAMS did I consider I might have the privilege to speak to our Congressional leaders about issues that are so close to my heart. Even more wild, to find out that they truly cared and listened to my story was eye-opening on a whole different level. I tend to be a little cynical by nature; the old hippie from the sixties still comes out from time to time.

My story began 25 years ago with the suicide of my first husband, Cam, my high school sweetheart. It was the late 1970s and early 1980s. Cam was a professional man, a long distance runner, life of the party, and the kind of guy everyone always wanted to hang out with. I knew he would be a great father to the child we would someday have. He was also depressed, an alcoholic, and a drug addict. We tried to find treatment for him. The lack of mental health parity combined with the stigma about mental illness twenty-five years ago contributed to poor professional intervention. Cam received short-term solutions for a life-long problem. Suicide was his answer. Suicide was my new life. Cam and I did not have children; my parents do not have grandchildren nor will I. Cam was the last male in his family. His genetic lineage is dead. While driving to Cam's memorial service his best friend was killed by a drunk driver. I knew Cam's death had a purpose; it just took me twenty-five years to find it.

Every participant received a blue poncho emblazoned with the CHADD logo.

Fast forward twenty years. My cousin Debbie—stage four ovarian cancer—asked if I would help her out just a wee bit in her job. Just a wee bit. I'm retired by this time, living the good life….my dream of being an artist coming to reality. Debbie was the head therapist for a nonprofit youth organization, working with youth coming through the court system. Debbie's life purpose was taking care of the children in our world. She knew of my background working in mental health, thought I could help her a bit in her work…. Two years later, I was working full-time in Debbie's position, with a case load of 60 kiddos. I taught many drug and alcohol abuse awareness classes to this population. Here comes the AD/HD connection. All of these kids coming through the juvenile court system for various legal problems had AD/HD. And as I worked with their parents—voila, there was AD/HD, too. All of these people need long-term care, counseling, help. Not available in our mental health system. So…back to school for me…two years later my private practice as an AD/HD coach is born.

I still knew there were pieces of the puzzle waiting for me to put them together. I couldn't let Cam's life and death be meaningless. His story was too powerful and illustrative of the tragic results of poor diagnosis, treatment and lack of mental health parity.

As a coach and CHADD volunteer I learned the occasional sharing of my story powerfully illustrated the necessity for proper swift treatment of all mental health issues.

So in 2007, CHADD goes to the Hill to speak with Congress about the lived experience. I volunteer to be a captain. I speak to three young staffers from my state of Idaho. I tell them my story of loss, pain, hope, and my high expectations of them. Mental health parity is the same today as it was twenty-five years ago. How many tragedies, how many families liv-

PHOTOS BY LEE ANDERSON

Members of the Delaware delegation paused in front of the Capitol building in this photo that appeared in the *Conference Daily News*.

ing in pain with unanswered questions have resulted from the lack of proper care? How many families living without being completed? Now, it is their job as well as mine to begin the process of righting a tragic wrong. They listened to my story. They shared their own lived experiences of AD/HD. One was diagnosed as being AD/HD; two were married to spouses diagnosed with AD/HD. I heard the doors to my past closing in the Halls of Congress. I heard the doors open to new awareness and the new knowledge of much work to be done.

Gayla Wilson
CHADD volunteer group facilitator and AD/HD coach

With Delaware's Delegation

THE DELAWARE GROUP I went to the Hill with made it into the *Conference Daily News* issue for Friday, November 9. We are on the back page of the issue, in the lower left corner above the caption, *A CHADD delegation paused in front of the Capitol building.*

We had an appointment with and were fortunate to meet Patrick Johnson, an aide on health care to Senator Joe Biden. Mr. Johnson spent a good hour or more with our delegation. Our captain, Jean Buzzard, did a wonderful job presenting information on AD/HD and CHADD. Pat was very receptive to the information, asking each of us how AD/HD entered our lives and what impact it had on each of us, our children and other family members. He also commented on seeing quite a lot of people wearing blue on the Hill and was wondering who they were. He knows now.

We told Pat that we were proud to have Sen. Biden representing Delaware, the first state in the union, in Washington, DC, and his positive stance on mental health parity.

Next we were off to Senator Tom Carper's office to drop off information since we weren't scheduled to meet with anyone from his office. To our surprise one of Sen. Carper's aides met with us for several minutes and assured us that she would let the senator know of our visit and present the information to him. We also dropped off information to the office of Delaware's one and only state representative, Rep. Michael Castle.

All in all, it was a very successful day on the Hill for the Delaware CHADD delegation.

Patricia Wood
CHADD Parent to Parent Certified Trainer
Greater Newark Chapter of CHADD Professional Advisory Board member

Days on the Hill

LET ME START BY SAYING my day on the Hill felt a little more like *days* on the Hill. We had a terrific amount of planning and attention to detail before we actually went to our appointments. This was very

After the orientation by Rep. Patrick Kennedy, members of the Louisiana delegation discuss the day's agenda before heading off to visit the offices of their senators and representatives.

"As parents of children with AD/HD it is easier to accept the 'No.' But for the important times when we can change things for our children, we owe it to them to try. For as I learned on Capitol Hill, we cannot get a 'Yes' without challenging the 'No,'" wrote one participant.

advantageous to me since I thought I was already well prepared.

The day before our appointments we were led on a very speedy walking tour of the Hill. I didn't realize how not prepared I was for this. The next day I had added an ankle brace and made sure I was more rested.

Coming from California, I was at a slight time disadvantage for the entire trip. We were up and eating as well as listening to instructions by 8 a.m. Washington, DC, time—by my account it was 5, and I felt less than coherent, even medicated.

Well, after a nice welcome address by a Kennedy who was gracious enough to note that Republicans and Democrats were in the audience, we were educated on mental health parity. This was good because I wasn't well educated on the Democratic force behind the issue.

Being the only representative from my district gave me a one-on-one meeting in Mike Honda's office. He was not there, but many of his office people were, so I spoke to almost everyone. I felt so welcome and so pleased to find out that Mike is a full supporter of mental health issues. I was able to talk about being an ADD patient, a parent of an AD/HD daughter, and the plights of being divorced and returning to school for a second career after twenty years.

I was also pleased to talk about being a Parent to Parent trainer for CHADD, and how much I have learned and how much I have been able to teach to others. Education is the key to understanding and to solving the mysteries of ADD. It is also the reality that ADD does exist and that it is so misdiagnosed and underdiagnosed.

My visit to the Senate was rewarding as well. Diane Feinstein was not available, but her representative for health issues was there to listen to our stories and concerns. We had a good showing from California. Many people were more geared to speak about the lack of educational funding but our representative clearly wanted to stick to medical issues. I had a clear opportunity to speak of poor insurance coverage and rising costs of medications and treatment. It was a natural to represent the single divorced unemployed mom starting all over again.

I was invited to stay longer on the Hill to visit the Gallery, but I was really feeling tired from speaking and listening to our representatives' representatives. Would I change a thing about my preparation and visit? No. Will I do this again if the opportunity presents itself? Without hesitation! Go CHADD and go HILL!

Pamela Roza-Bohrk
California

Challenging the "No"

WHEN I APPROACHED the CHADD public policy desk to find out the details of my appointment, I was told that my doors were closed. My representative had not set up an appointment and there was no one to talk to. I had traveled from another state, leaving my husband and children behind, to come to Washington, DC. I came to become a Parent to Parent teacher, I came to attend the CHADD conference, I came to present critical issues to our elected officials. Coming to Washington, DC, was financially and emotionally expensive for me, and here I was, shut out of my representative's office.

On the morning of our Capitol Hill visit I watched my fellow attendees board their buses to their appointments. I felt saddened and angry that there was no one to hear my voice. I thought of my children who so badly needed their legal rights, and I decided to try. I went, uninvited, to Capitol Hill.

I knocked on the door of my representative and told the clerk that our issues are too important to ignore. I begged for someone, anyone, to hear our cause and I sat down to wait. Ten minutes later a legislative aide gave me a private appointment and listened. She was wonderfully caring, sympathetic and helpful, and she gave me the contact information of someone at my local city office who can hopefully help me as I try to get help for my children in school.

As parents of children with AD/HD it is easier to accept the "No." It is easier to not force a congressional appointment than to beg for someone to listen. It is easier to say "All kids are restless; there is nothing wrong with my child." It is easier to let our children spend time in the hallways than to fight the schools for their right to stay in class. It is easier to say "My child has a problem, but he'll grow out of it." It is easier to let our children space out in class than to fight the teacher for accommodations. It is easier to say "A behavior modification plan takes too much time, why should I try?" It is easier to drive our children to school when they miss the bus than to teach accountability and endure the fuss of deducting the taxi fare from the allowance. But as we all know, the journey of raising a child with AD/HD to be a responsible and successful adult is anything but easy.

As parents of children with AD/HD we are responsible for our children's success. They need us to work hard when things are not easy. They need us to speak where they have no voice. They need us to stand up to the "No" and demand a "Yes." We will not get it all of the time. We will not get it most of the time. But for the important times when we can change things for our children, we owe it to them to try. For as I learned on Capitol Hill, we cannot get a "Yes" without challenging the "No."

Name withheld upon request
Brooklyn, NY

Remember My Daughter When You Vote

I'M NOT EXPECTING THIS to make any edition of *Attention*, but I wanted to write anyway. I did not see anyone on the Hill except the staff of three senators. Yes, three. I am currently a resident of Oklahoma, but will be moving back to my native state of Kansas next summer. I decided that I needed to try to visit both states as time would allow. I was fortunate enough to be with physicians each time. Somehow, it seems as though having an MD behind your name does more than an MA. At any rate, in addition to the senators' packets and meetings, I also dropped off a packet to a congressman's office, as no appointment had been scheduled. With each packet, I left a copied picture of my child that said, "Please remember Molly when you vote." I also wrote a paragraph or two about how far my daughter has come since she has been diagnosed and treated for AD/HD. My daughter was genuinely pleased that I had done this for her. Isn't that what this is all about?

My being a facilitator and P2P teacher has all come about because of her and my desire to improve the lives of others as they learn about AD/HD. My "going to the Hill" may or may not have had a real impact on anyone's vote. But I know I tried, and my daughter does, too. That's worth a million—or two!

Jody Conyers
Oklahoma and Kansas

Go Team Go

I WOULD LOVE TO EXPRESS my sincere gratitude for the outstanding leadership and patience you bestowed upon us to make the Morning on the Hill a huge success for me personally, and undoubtedly [it] will benefit the lives of many in the future. CHADD is what I've always envisioned a real "FAMILY" would be. A team of passionate unique individuals with the common goal to love, support and respect each individual's strengths and weaknesses within that team.

Go TEAM Go!! You are all my Guardian Angels!!

Marisa Burton
Pennsylvania