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For
Senate HELP Committee Hearing on
Stay-at-Work and Back-to-Work Strategies: Lessons from the Private Sector
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Good morning Chairman Harkin, Ranking Member Enzi, and other Members of the Health, Education, Labor, and Pensions Committee. I appreciate the opportunity to provide my personal perspective today on stay-at-work and back-to-work strategies.

My story begins in January 1993. I was 24 years old and in my last semester of law school. In addition, I was working part-time as a Staff Assistant for Senator James Jeffords. During a pick-up game of basketball, I took a hit to the side and suffered a bad bruise. I noticed that after a few days, the bruise was not healing and I went to a doctor. They ran some tests, and I went to my law school classes as normal. When I returned to my apartment that afternoon, there was a message telling me to come to the hospital right away. They needed to see me.

When I arrived at the hospital, they informed me that my platelet count, which normally should be 300,000 – 350,000, was only 3,000. This meant that my blood was having problems clotting. They ran another series of tests and ultimately diagnosed me with Idiopathic Thrombocytopenic Purpura (ITP). Basically, this means my spleen thought my platelets were bad, and removed them as fast as my bone marrow could produce them.

Treatment for ITP is done more on an outpatient basis, so the hospital released me and I resumed my law school classes and work in Senator Jeffords' office. I was informed of some warning signs that would indicate that I would need to come back immediately to the hospital, but honestly being 24 years old, didn't think much about that. Unfortunately, very shortly after my release I experienced the warning signs. I called my roommate and he rushed home to take me to the hospital. His key unlocking the door to our apartment is the last thing I remember for the next two weeks of my life.

Later I was told, that by the time we arrived at Georgetown Hospital, I was complaining of being blind and I was unable to walk or stand up without assistance. I was placed into an MRI, to get a picture of the inside of my head, and was pulled out half way through the process because of the severity of the cranial bleeding. Hospital personnel immediately rushed me to surgery where a craniotomy was performed to relieve the pressure on my brain and try to stop the bleeding. The neurosurgeon removed part of the right occipital lobe of my brain during this surgery. There was still a concern that the ITP and the resulting low platelet count was going to lead to more bleeds, so it was decided to do a splenectomy. The doctors hoped that removing my spleen would raise the level of platelets in my blood. The splenectomy worked. My platelet count ultimately stabilized at an acceptable level.

As I slowly became aware of my surroundings, the effects of the brain hemorrhage began to become apparent to me. First, I was paralyzed on the left side of my body. Second, my field of vision had been reduced and I was seeing nothing from my nose left as well as having trouble focusing to read. Third, it was difficult for me to sustain my focus for any length of time without becoming overly tired, and it was also difficult at times for me to articulate thoughts and ideas.

This was definitely a down time in my recovery as I was becoming exceedingly bored spending my days in bed, doing very little other than watching television and sleeping. This all changed the day the therapists at Georgetown came and began to start a course of therapy. Therapy gave me something to do, something to work on, and added interaction with people.

After three weeks at Georgetown University hospital, I was transferred to the National Rehabilitation Hospital (NRH) to begin more intensive in-patient therapy. While there I did physical, occupational, speech, and vocational therapies. I also had individual sessions with a neuropsychologist who helped explain what the effects of the brain hemorrhage were. I also had group sessions with others that had experienced a traumatic brain injury. I found these individual and group sessions extremely helpful in understanding what had happened to me, and in letting me know that others were struggling with the same issues I was struggling with every day.

During this time at NRH, Senator Jeffords came for a visit and we talked about work. While it was unclear if, or when, I would be able to return, he stated that they were looking into accommodations to help with my return. As I wasn’t yet walking at that point, one of the issues they looked into was spacing between the cubicles and making the office wheelchair accessible. Throughout my stay at NRH, Senator Jeffords’ office had discussions with my therapists about accommodations necessary for my desk space, and the best way to bring me back in terms of the length of the workday.

After a little more than two months at NRH, I left in different shape than I had entered. I was walking at that point; better able to articulate my thoughts and ideas; had a higher and longer level of attention; and could get my eyes to focus together which allowed me to read again. Some effects of the brain hemorrhage still existed, like the reduction of my field of vision, I would get tired and neglectful sooner than before, and I continued to have some difficulty with word retrieval at times. However, the therapists at NRH had taught me a lot of strategies and techniques to help me compensate.

I continued to do outpatient therapy at that point for a couple more months, but my focus shifted from ***if*** I would return to work and school, to ***how*** to best accomplish these goals. I had discussions of my situation with both Senator Jeffords’ office and the American University School of Law, and settled on a plan to restart work first with a smaller set of hours per week, but building them up to the amount I was previously working over the course of a couple weeks. As for school, I would restart in January 1994 and complete the last semester of law school over the course of the year.

So, in July of 1993, roughly six months after my hemorrhage, I started back to work in Senator Jeffords’ office. With the help of the therapists at NRH, my workspace was designed to best address my visual issues, and with the understanding of Senator Jeffords’ office I started with a few hours a day and then built back up to the amount I was working before the brain hemorrhage.

It was important for me to listen to my body and understand when I needed to take a break or I was going to become over tired. I could not spend hour after hour looking at a computer screen or reading every day. I also needed to plan my travel schedule much more as I was not able to drive. Finally, I needed to position myself properly in meetings to ensure that I was not missing anything, and that I was able to appropriately interact with everyone. By August, I was back to my previous workload, thanks to the work of my therapists, the support of my family and friends, and willingness of Senator Jeffords to provide accommodations.

As I mentioned earlier, I restarted my law school classes at American University in January of 1994 with the understanding that I would complete the last semester of work over the course of the year. I also received an accommodation for time and a half for any test I took in class. With these accommodations, I was able to complete law school and graduated in January 1995. I then took the bar exam in Maryland with the same time and a half accommodation in February and was beyond pleased to pass it on the first try.

Following the bar exam, I began to work for Senator Jeffords in a full-time capacity. I started as a Legislative Correspondent in 1995 and became his Legislative Counsel in 1996. Even though I was now putting in the long hours required of a Legislative Counsel, it was still important for me to continue to follow the strategies and techniques I had learned from the therapists at NRH. I still needed to listen to my body and take breaks from just sitting in front of the computer or reading all day and I needed to position myself well in meetings so I did not miss anything that was occurring.

During my time with Senator Jeffords as his Legislative Counsel, I handled a variety of issues, including: federal employees; banking, housing and insurance; labor law; judiciary related issues, including abortion and gun control, and campaign and election law, including the enactment in 2002 of the Snowe-Jeffords provisions on electioneering communications. I was also privileged to be Senator Jeffords Acting Legislative Director in 2006.

I stayed with Senator Jeffords up until his retirement from the Senate in January 2007, and then began the job hunt process for the first time since I had suffered my brain hemorrhage. This raised a completely new set of questions for me to consider, including how much I should disclose about my disability and past medical history. This was a struggle for me.

As my disability is not readily obvious to the casual observer, I did not always disclose my past medical history in an interview. A lot depended on my comfort level with the organization I was interviewing with and the questions that were asked. There were times that I was asked about the most difficult situation I had to overcome, and if I felt comfortable, I would discuss my recovery process from the brain hemorrhage. However, there were plenty of interviews where I never discussed this topic, and I have sometimes wondered if decisions about me were made on some manifestation of my disability, rather than my actual skills.

The tightrope I felt like I was walking along was the fact that the brain hemorrhage was a part of my life, an important component of who I am today, countered by concern of the stigma attached to medical issues and disability. In many ways, I wish I could have felt free to always discuss the topic, as it is such an important part of who I am, and I think it makes for a better interview and discussion of who I am and what I would bring to a job.

For example, my current employer, the National Disability Rights Network (NDRN), is the membership organization for agencies that provide legal advocacy for people with disabilities, and I had no qualms about disclosing my brain hemorrhage and its effects up front. I felt comfortable that I would be judged on my qualifications rather than my disability. Because of that, I freely discussed my past and challenges I faced, and issues I still faced from the brain hemorrhage, and I felt it was one of the best interviews in my search for a new job.

It has been my pleasure to work, the last five years, at NDRN and progress to my current position as Deputy Executive Director for Public Policy. Working at NDRN, and with the Protection and Advocacy agencies all around the country which we represent, has strengthened my belief that our country is better when we include people from all backgrounds, including those with disabilities. While employing a person with a disability may require accommodations, I believe the benefits far outweigh any costs.

January 2013, will be the twentieth anniversary of my brain hemorrhage. Testifying today has given me an opportunity to reflect on what worked to help me successfully return to work. First, a high level of family, friend, and coworker support was instrumental in my recovery. Knowing that I had a strong system of support allowed me to focus on my rehabilitation. Second, the ability to have over two months of good in-patient therapy was critically important. Being able to immerse myself in therapy pretty much every waking hour, 7 days a week allowed for a better recovery than would have been possible if I only did a little in-patient rehabilitation and then shifted to out-patient therapy. My strong relationship with Senator Jeffords and my desire to return to work, along with Senator Jeffords' willingness to work with my therapists to make the accommodations necessary for me to return to work (looking at office design, workspace layout, and work schedule) also made a big difference. Fortunately, I was lucky to have all of those things in place, but many people who experience an acquired disability are not this lucky.

Again, thank you for the opportunity to tell my story today, and I look forward to answering any questions you may have.