

Witness Testimony for United States Senate Special Committee on Aging

ABLE Account Hearing

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Submitted by Carrie L. Bach

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My name is Carrie Bach, and I am living with Quadriplegia as a result of a Spinal Cord Injury (SCI) from an accident that occurred on November 3, 2019. I was 41 years old. This accident happened in my own living room when I slipped, broke my neck at the C5-C6 level, and my life changed forever in the blink of an eye.

Prior to my fall, I worked as a professional in an office just like all of you, but I also had a second career and identity as a professional performer. I am a classically trained ballerina; however, I realized early on that I was not physically built for a career in ballet. I am 5'2", and I had a compact, muscular build, not exactly what ballet companies hire. I took my training and focused it on swing dancing, partnered acrobatics, aerial performance, and stilt walking. This allowed me the opportunity to travel and perform around the United States and 33 countries. I also spent time as a competitive bodybuilder.

My husband is a professional performer, too, with talents that far exceed my own. We had both decided that we were going to retire as performers that year – in fact, I finished my final gig three weeks before I fell. However, those are all stories for another day. I am here to talk about November 3, 2019 – the day both of our lives changed in an instant.

We all know that accidents happen every day, and it could be any one of us. I even worked for an organization, Voices for Independence (VFI), that assists people with disabilities, but I still never thought it would be me. We plan and save money for vacations, buying a new car; we plan for our kids college educations and our retirement, but no one ever makes plans to have a disability. We just don't - even though we know it could happen to us or one of our loved ones at any moment. That is exactly what happened to my husband and me.

When I had my accident, we were both gainfully employed and had retirement accounts set up. I have a state pension in which I am vested, my husband has a 401(k) plan, and we both have IRAs. Our income and assets put us above the limit to qualify for most programs assisting people with disabilities. When I was in rehabilitation for my injury at UPMC Mercy Hospital, I remember being told that people with SCIs *rarely* return to work, and if they do, it usually takes 2-3 years. I returned to work 3 weeks after I left rehab.

I was also told by the social workers, whose job is to prepare people for a safe discharge, that my options were for my husband to quit his job to care for me at home or go to a nursing facility. Luckily, I knew from my years of working with the legislature and VFI that I had other options, and I discharged to my own home...well, a hotel to start while our home modifications were being completed, but then my own home.

Because of our financial situation and not qualifying for most programs, we immediately amassed a bill over \$70,000 to get our home ready for me. This included new flooring that could withstand the wear and tear of my wheelchair, a ramp, accessible bathroom, and a van. We had to wait to install a door opener at a cost of over \$6000. That's right, I could not safely exit my home if I was by myself if a fire broke out. We finally were able to make that investment this past year. That \$76,000 investment does not include the daily medical supplies that are not covered by insurance.

Speaking of insurance, my company's plan included 20 physical therapy sessions per year. I ran through those 20 sessions in two and a half months. That is certainly not enough therapy for a SCI; I was doing 6 hours each day at UPMC Mercy. What do you do the rest of the year to continue progressing when it takes three people to help you get in your braces to do therapy? I pay out-of-pocket because while I have finally, after almost 3 years, accepted that this is my "today," I simply CANNOT bring myself to accept that this is my "tomorrow."

The past two years, my company offered a health insurance option for a High Deductible Health Plan with a healthcare savings account (HAS) account. We changed insurance companies this year, and there is no longer the option for an HSA. Like most people, I read through the policy, but I do not yet fully understand how much my medical expenses will cost me this year between different deductibles, copays, co-insurance, or items that are not covered at all. I also no longer have the benefit of a plan that offers me a program with tax benefits for saving money for my medical expenses. I do not have the option of an ABLE Savings Account with similar tax benefits since I acquired my injury and disability after the age of 26. I would absolutely open an ABLE account for my medical expenses right now if the law allowed for it.

I was lucky in that I did not sustain a traumatic brain injury when I hit my head. My brain still works even if my body does not work. I chose to continue working because I can. I find my work fulfilling and necessary for so many reasons, personal and professional. My husband and I chose to not spend down our resources so the government would be responsible for paying for my care. When I say that, I am not being critical of those who may not have the option to work and do need government programs. What I am saying is that it would be nice to have the opportunity to open an ABLE account where we would have the same tax benefits. Therefore, I urge Congress to pass the ABLE Age Adjustment Act that would change the age requirement to 46 instead of 26 years old for onset of a disability.

Thank you for the opportunity to submit my testimony for this hearing on behalf of myself and others with situations similar to mine. I hope that you will remember and consider my story if this legislation comes before you for a vote. And so, I leave you with this last question...have you made plans for having a disability? Today, this is my story, but tomorrow it could just as easily be yours.

If you have any questions or would like additional information, I will make my self available to you and your colleagues. I can be reached by phone at 814.806.5449 or by email at cbach@vficil.org.