They Don't Know What I Know

Our son was 22-years old. His National Guard unit had been activated and scheduled for deployment to Iraq for Operation Desert Storm. Our son received what is now known as the signature wound of this war, a traumatic brain injury (TBI). He had injury to the frontal lobe, the temporal lobe, the parietal lobe and the occipital lobe. Multiple areas were affected, including attention, memory, organization, judgment, perception, communication, and social skills, as well as a multitude of physical impairments. From the moment our son opened his eyes it was evident his life changed. He had no memory, he wasn't able to breath, talk, eat, walk, or control his body temperature. We learned his brain was damaged and he would have to re-learn EVERYTHING or it was a possibility he may never recover any more than what we saw. He may be in a permanent vegetative state. With time perhaps, there might be improvement, but we shouldn't expect "100%" recovery. We just earned entry into the TBI Club. Could we pay the dues? Could we survive the initiation? Could he?

You'll notice that the term "we" is used a lot! That's because this is a team effort. Recovery, rehabilitation, research isn't something one person can do. The tiniest steps were huge victories. The day his body had huge balls of sweat appear; we learned the part of the brain that controlled body temperature had begun to work. Almost a month after the injury, our son was unable to talk, walk, or write. He didn't know what to do with a deck of cards, that a fork was used for eating or what to do with a toothbrush. His brain was a jumbled mess. Yet he picked up a pencil, put it between his fingers and intently moved his hand on a piece of paper. We sat there in wonder, what was he going to say to us? When we looked at the paper all that was there was a very small scribble no bigger than the size of a dime of circles over and over and over. Nothing was legible, but HE PICKED UP A PENCIL. WOW Praise GOD!

It has been a long arduous process. Its baby steps all over again. "The family" was prepared for life with a disability. He needed shoes with Velcro because he didn't know how to tie; and sweatpants because he couldn't handle buttons. He had been an athlete. He played high school and college baseball. One day we handed him a baseball, he still was unable to speak. He put the ball in his hands, rolled it around like pitchers do, got a grip like he was going to throw a curve ball, and brought his right hand behind his ear and his arm forward. But that was it. We then spent hours day after day, he sitting in a chair, one of us sitting directly across from him. We would rock back and forth trying to get him to release the ball. Whenever he re-learned anything, from throwing that ball, to continence, to eating, it was a time-consuming process. The simplest of tasks could take days, weeks or months to accomplish.

We were schooled on daily living skills, given instructions to transform our home to accommodate a disabled individual. Unknown to us, our son's feeding tube had been "permanently" placed. Days turned into weeks, weeks turned into months, months finally turned into years. It was sometime during the first year when he muttered "***They don't know what I know***". Our son didn't know the woman that spent nearly 18 hours a day with him every day for 4 months was his Mom. He didn't know the house we brought him back to was his Home.

Nevertheless, miracles began to happen. One day he smiled and laughed at a joke. One day he picked up the telephone and dialed an old cell phone number we had. And one day during the first year of recovery he left the hospital. It was during the 2nd year of recovery, he learned to heat food in the microwave, he learned to make his bed, do his laundry and drive a car. He also learned to swear and get very frustrated; that is just part of the process. His work was therapy. He spent hours completing Speech Therapy, Recreation Therapy, Physical Therapy, Cognitive Therapy and counseling. It was during this period of time our son told us "he felt trapped in his body and couldn't get out". He said that in his mind he knew what he needed to do to accomplish what he wanted, but his brain wouldn't work with his body. It was during the 3rd year of recovery he learned to enjoy reading again. He was able to have hopes and dreams. It was during the 4th year of recovery that he was able to achieve one of those dreams, earning a Bachelor of Science degree in Human Services with a minor in Psychology. It was during the 5th year of recovery that he was able to be employed for the 1st time since the life-altering injury. It was during the 6th year of recovery he married a very special woman who accepts who he is and was able to give her a special gift, his tears of joy. It was during the 7th year of recovery he stated he still needs quiet time to regenerate, rejuvenate and refresh. Articulation is still difficult; showing signs of emotion is not easy, fatigue remains, and physical exertion takes effort.

These past years have been full of struggles but also laughter and a tremendous amount of joy. We are of the opinion that a person never overcomes a brain injury/disorder. They must discover Awareness and Acceptance. A person only develops strategies to overcome the obstacles; and in so doing, they can achieve beyond all reasonable expectations.

Our son once told us that what we (well-meaning people who have not sustained a TBI or similar brain disorder) don't understand is that the person who has sustained a brain injury is keenly aware of who they were and who they are. They are conscious when faced with prejudices. They are deeply perceptive to the differences in themselves. Our son believes that we all must, to the best of our ability, take accountability for ourselves and that we must take responsibility for our own actions. He does not use the TBI as an excuse. Rather, he uses it as motivation to work harder to accomplish goals. He has tried to turn his deficits into a surplus. His definition of "disabled" might be "ability to alter direction when faced with seemingly insurmountable obstacles; ability to learn how to develop strategies for deficits; ability to say I can rather than I can't". Our son's road to recovery was paved certainly by *hundreds* of caring and dedicated individuals; nevertheless it takes connections at the Local, State and the Federal level to be able to provide those individuals with the tools necessary to allow the brain injury community the ability to become productive members of this society. We ought not to prevent the brain injury community from contributing to our well being. Nor, should we prevent them from being an example to all of us. The professionals we have met and worked with over the years are immeasurable; sometimes they were right and sometimes they were not.

Indeed, our son will never return to the "100%" individual he was prior to his injury. The percentage of recovery is no longer important because he feels the individual he has become is equal to that "100%", if not better. And irrefutably, "***they did not know what he knew***".