



FATHER OF TWO

Father of Two

Wilbur Hawke



"Like a starving man at an all-you-can-eat buffet, I began to access information and resources. I attended workshops and conferences. At these meetings I soon learned I was not the only person to have a child with a disability. I began to learn from these parents on how to advocate for my child effectively."

[DONATIONS](#)

[ESPAÑOL](#)

[SPONSORS](#)

[CONTACT US](#)

My introduction to the world of fatherhood came with the birth of a healthy male child we named Conan, before the movies made it a household name. I can still recall the doctors' remarks as my son emerged into the world. "From the size of those shoulders it looks to be a boy on this end," soon to be followed with "It looks like a boy on this end too!" The next five years progressed normally and without event, my wife and I learning how to be parents by trial and error. Then came the birth of child number two. Once again my wife blessed me with the gift of a strong healthy son. For the first six months, Cayman, which means island man, developed in advance of what all child publications said he should. Having acquired our 2.2 children and being married for ten years, it looked as if we were set to settle in and live the traditional family life.

We were not prepared for the course of events that soon followed. Cayman developed flu like symptoms which introduced us to the first of many new terms, such as meningitis, soon to be followed by hydrocephalus, shunt, ventricle, and a host of others. The ensuing struggle to save our son's life is even now, eleven years later, difficult to relive. The one thing that I can never forget about the month long hospital stay was my promise to God that if he would let my son live, I would take care of him, knowing that the effects of this disease were often devastating. As I held my son and watched him lose half of his body weight with little sign of improving, I never lost hope that things would work out. God answered my prayers and now I had to keep my end of the bargain.

The care that Cayman would require meant one of us would have to quit work and provide full time care. My wife's income was greater than mine so the choice was not a difficult one. This was a new experience for me, having been raised in a family where the father went to work and the mother stayed at home. I learned to change diapers, cook, clean, and do laundry. I will admit there were times my family all wore pink underwear until I learned to separate the laundry. Even now they refer to me as "Chef from a can," but we pulled together as a family and survived.

Our doctor said it would be impossible to determine the extent of damage done until Cayman was older, then referred us to an early intervention specialist in our county. The group's name was Step by Step; little did we know at the time just how appropriate the name was. We found ourselves at the beginning of a very long road to try and re-teach Cayman all of the things he had done so quickly before. The child who was cruising at six months had to learn to crawl again. Once again new terms -- occupational therapy, physical and speech therapy -- all became commonplace in our home. The early intervention was working and Cayman continued to make steady progress. When he turned three, testing finally revealed what would be the worst blow dealt to our child. Cayman had lost 80 percent of his hearing and another term, deafness, entered our vocabulary. Cayman was fitted with a new set of hearing aids and we continued to move forward. Through all of this I began to feel like the Stranger in a Strange Land. Sitting in the pediatrician's office or in the Pre-K therapies I was the only Dad to be seen.

At first I felt less than adequate when confronted with the task of dealing with professionals. I did not possess the day-to-day history of my child required to answer the questions posed by the doctors and therapists. I had a better understanding of why these professionals would always turn to my wife when seeking information about our son. I began to develop a

healthy respect for my wife's abilities to cope so nonchalantly with issues that to me created crisis situations. As time passed, I too began to acquire the skills needed to fulfill the tireless, endless, thankless task of primary caregiver for our two sons. With the acquisition of these skills came a self confidence in my abilities and an understanding of the role I had accepted. With the support of my very patient wife I continued to make steady progress, and the whining of our sons began to diminish.

The next step came when we were weaned from the warm fuzzy protective environment of pre-K and went off to public school. Having an older brother who had already been at the local elementary school, it was only logical to me that son number two should attend the same school. A special school in a neighboring county or even another state where we could see our child him once a month was suggested but quickly rejected. Once again I found myself submerged in an environment alien to most fathers, the responsibility of dealing with the school system.

Cayman went to a regular class, had friends, and all seemed fine. He was getting some extra help from a special education teacher and from speech therapy. We attend a meeting called an I.E.P. (Individualized Education Plan) once a year where we listened to a whole lot of people say things we really didn't understand, but we left secure in the knowledge so many people must know what was best for our child. By the end of second grade Cayman was beginning to develop a severe gap in reading and language skills compared to the other children. We attended another meeting where we were informed the best place for our son would be a program in a neighboring county just for deaf children. We were told the bus ride would only be two hours a day and Cayman would receive the services he so desperately needed. Still trusting in the opinion of so many, we consented.

The bus ride turned out to be two hours one way -- four hours a day. The pain we were experiencing when we placed our son on the bus each morning in the darkness with a pillow and a blanket, and then watching the neighborhood children arrive home from school each afternoon only to have to wait an additional two hours for our child to come home cannot be put into words. The professionals we so readily trusted didn't seem too willing to listen to our concerns.

A new chapter in my life began and once again I entered an arena dominated by mothers. I found myself lacking in the skills or having the information necessary to accomplish the task at hand. The difference this time was that my wife also lacked those skills. Our vocabulary expanded to include more new terms, a few still dear to me today -- Free Appropriate Public Education, Least Restrictive Environment, Individualized Education Plan, Section 504, and I.D.E.A. (Individuals with Disabilities Education Act).

Our first taste of discrimination was very unpleasant and a bitter pill to swallow. Our search for information began with my wife visiting the library and myself going to the yellow pages. We were given some direction by a very brave ESE teacher who mentioned "least restrictive environment" and something about section 504, but she could do no more for fear of losing her job. Our search led us to an organization called the Advocacy Center for Persons with Disabilities; they informed us of certain rights granted parents of children with disabilities not mentioned by the local school district. We were also informed of a group called Family Network on Disabilities of Florida which was something called a Parent Training and Information Center. Like a starving man at an all-you-can-eat buffet, I began to access information and resources. I attended workshops and conferences. At these meetings I soon learned I was not the only person to have a child with a disability. I began to learn from these parents on how to advocate for my child effectively. As before, I found myself in a room of a hundred women, with myself being the only male. I admired their tenacity and brilliance. The lessons I learned we applied to returning our child back to his neighborhood school. This involved teaming with other parents and attending school board meetings, filing complains with the Department of Education and eventually filing a complaint with the Office of Civil Rights, U.S. Department of Education.

That summer our son returned to his local elementary school; he was

provided the appropriate services to enable him to be taught alongside his non disabled peers. We noticed changes in Cayman. The stories he had written in the special school were about his brother, mother, and myself. He now wrote about his friends at school. He began to blossom and was invited to birthday parties and sleep overs. He was appointed the Collier County Dreamer and Doer, a Walt Disney program honoring individuals who have overcome adversity to become successful. He was awarded a medal by Miss America, who also happens to be deaf. Today Cayman continues his success as an honor roll student in regular education. His four hour bus ride is just a five minute bike ride down the street.

As for his father, I now work for the Family Network on Disabilities of Florida teaching others the lessons I learned from my son. I am happy to say that today I don't have to look very far in the crowd to find a Dad. The task of raising and advocating for a child with disabilities is enormous, too much for any one parent to go it alone. Mothers and fathers will find strength in working together for the well being of their entire family.

Wilbur Hawke
580 5th Avenue
Marco Island, FL 33937

Published in "Fathers Voices," Exceptional parent Magazine.



PRINT PAGE



SEND PAGE



FEEDBACK