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CAC Corner: Challenges and Blessings

Center for Persons With Disabilities

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CAC CORNER: CHALLENGES AND BLESSINGS

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Written by Mike Wyatt, a family representative on the CPD Consumer Advisory Council.

In 1983, our first child was born. His name is James Matthew Kalani Wyatt. Matt, as we called him, came to us as a great blessing. He was so darn cute. But after several weeks we noticed he was getting severely bruised. When I would pick him up by holding him under his arms he would later develop bruises where my fingers had gripped him. We mentioned this to our pediatrician and he sent us to the UC Davis Hospital in Sacramento. There we had him tested for several medical possibilities. It turned out he had a genetic bleeding disorder call Severe Factor VIII deficiency, commonly called Hemophilia A severe.

Well this diagnosis sent us on a great adventure into the realms of hemophilia. By the time Matt was about 18 months old we were versed and practiced on giving him his medications via IV. We had moved to McChord AFB in Tacoma WA. Being that Hemophilia is a bleeding disorder and the meds were made from plasma, we decided to enter Matt into a transfusion safety study. Mostly to track and find out if he had been exposed to Hepatitis. Well, one of the tests that was taken was called the Elisa Test for HTLVIII. Later to be called the AIDS test. Little did we think he would ever be exposed to HIV. On Halloween day, October, 1984 we found out he was indeed infected with the AIDS virus.

This was the beginning of a long scary journey into the world of AIDS. At that time we found little education was available and many doctors and nurses knew nothing about the disease and even less in children with Hemophilia. So we began a quest for knowledge that took us from Seattle to Honolulu to San Francisco and the National Institutes of Health in Washington DC. The Air Force transferred us to Hickam AFB in HI. There we found that Hawaii was so far ahead of the rest of the nation on being ready for the first known student in public schools (with AIDS). When Matt entered kindergarten it went very smoothly.

For me, it was a golden opportunity to not only learn more about AIDS, but to give back to the people knowledge and experiences to alleviate their fears and concerns about AIDS in their community. I spent 5 years working as a volunteer with the Dept. of Health, Dept. of Education, and the Hawaiian Red Cross. I was very honored to become the volunteer of the year for the Red Cross and to receive the Valley Forge Medal of Honor for doing AIDS education in the Hawaiian Islands.

Along about our third year in Hawaii, a co-worker on the Governor's subcommittee on AIDS, protocols asked my wife and I if we were interested in foster-caring a little girl who was HIV positive. This girl was not wanted by any family members, and they couldn’t find a couple who wanted to care for a baby. Well, we took her into our home as soon as we could. This turned out to be a great blessing for us, as well as for her. At 24 months of age, she seroconverted to HIV Negative!!

We finally adopted her after a long drawn out battle with the Hawaiian Department of Human Services. Unfortunately, she had also been exposed by her mother when she was still pregnant to meth, heroin, and alcohol. Today she has been diagnosed with Fetal Alcohol Syndrome. That’s #2 in our lineup of disabilities in our family.

After being transferred back to Washington State, our son, Matt, died in 1996 at age 13 years and a month. (Note: From the same lot numbers of factor 8 that Matt received and got infected with HIV from, 92 children have also died of AIDS.)

About two years after Matt died, we decided to move to Utah so I could attend USU. While in the process of packing and moving my wife starts labor pains. So we moved and she stayed with friends in Washington. Before I could go back and get her, she delivered our last child,
Paul. Paul was born with Trisomy 21 Downs syndrome. This brought the third disability into our home.

The Wyatt children

We have been blessed to have these children in our homes and our lives have been enriched by them. That's not to say it has been without challenges. Oh my, I cannot begin to tell that story. It would fill volumes.

But the most wonderful things have occurred. We learned to be our children's advocates. We have been helped and supported by many, many people--more than we could name. More than that, we have been very open and forthcoming about our children's disabilities and have reaped the benefits of that choice. We found people are more likely to trust you when you don't hide the facts, than if you do and get caught.

That brings us up to today. We try to share our story, not for pity or attention, but to help others to learn and grasp the blessings that have come from having children with special needs. That's why we try to give back to our community.

THANKS,

Mike Wyatt