The Consumer Advocate's Voice

Rod Slaght: My Journey with Neurofibromatosis

My journey began at age five, actually long before, though few signs were visible, other than my left eye protruded slightly and what everyone thought were birth- marks, which actually are Café au lait spots or coffee and cream colored marks.

Growing up on a dairy farm in rural Wisconsin, our local doctor missed the diagnosis completely. At age three to four, I would walk fall down and not walk again for weeks. The family doctor sent me to a specialist in ophthalmology who the day I visited him could not find anything wrong, in fact his words still echo in my memory, to my parents he stated "I don't know what your son has, whatever it is, he's a kid and will grow out of it. Stop being over worried parents!!" As best we can guess is the day I visited the doctor was a good day for me vision wise. In the early to mid, 1960's there wasn't much information on neurofibromatosis (NF) out there.

A few months later, my parents and I were on a train to Denver, where we met my guardian angel. A nurse from Mayo Clinic who had the courage to talk with my parents, encouraging them to visit Mayo as soon as we returned from our trip to Denver, her Uncle was a surgeon at Mayo. After we got home, my parents talked it over for a few days. My dad's comments were "What do we have to lose? Maybe we will find an answer!"

Not long after my parents placed the phone call and scheduled a date for some appointments I found myself standing at a reception desk, third floor of the Mayo building. Fifteen feet from where my parents and I were standing, a group of doctors were talking, when one happened to pause, look at me, walk over and ask why we were there. After explaining why we are visiting, within what seemed less than thirty seconds he diagnosed me with von Recklinghausen disease or today known as NF 1.

The doctor went on to explain to my parents after the initial exam, that had we not come in when we did, within five years I would have been totally blind, as the neurofibroma would have crossed over to the optic nerve on my right side. Today, I am blind in my left eye, but have at last exam 20/20 vision in my right eye.

Several surgeries later: a few cosmetic procedures to remove the neruofibromas, which become bothersome and a whole more knowledge of neurofibromatosis. It all started with a train trip to Denver, and one courageous nurse from Mayo Clinic.

Learn more about NF at Children's Tumor Foundation at www.ctf.org . May is Neurofibromatosis awareness month.

I have lived in Golden, Colorado since 1987, I am unemployed, but volunteer my time on my HOA board of managers, this is my fifteenth year, non consecutive. I have held every office including the office of President for four years. I enjoy time with friends and family, traveling when I can. I have been involved with Mountain States since the early 1990's, as a consumer member serving on several committees, including former co-chair of the consumer advocacy committee. in 1987 I started the NF support group in Denver, serving on its board for thirteen years and as Public Relations Chairman.