



*Michelle DeCiantis*

Ataxia came to me as a? More than 15 years ago and each year that passes more questions are added to my story. I have been diagnosed with SCA unknown type with an overlapping of upper motor neuron disease unknown I've seen doctors from UCLA to University of Michigan. I work hard to get involved in any clinical trials or research studies that I can in order to help them find out about these rare illnesses in order to help the next generation.

The thing that sticks out the most to me is that when I first went to the doctors heard the word ataxia, had never heard before I also was unaware that there were any kind of support groups or that there was a National Ataxia Foundation! Since finding those things out I have made many friends who are really like family whom I have built close relationships with over the years and stay close with and attending the annual convention with the newfound family members of mine, are what help me get through each day, to pick up my Facebook or the phone to talk to one of my sisters or brothers that I have adopted through this organization and who I share these diagnosis with has been part of my life line. Because no matter how much you educate someone or tell them about what you're going through.

No one really understands except someone who is experiencing that themselves or at least experiencing something close to what you have and it is because the NAF, allowing me to meet these wonderful people and to attend the conference every year with the help of travel grants and discounted hotel rates to meet with doctors and hear the specialist in the field talk about the progress that is being made with scientists research helps me fight harder and to keep going to help them find treatments and cures for these diseases.