



My name is Jamie Plourde and I am 23 years old. I was diagnosed with Friedreich's Ataxia at the age of 8 and my life has never been the same. I live in New Hampshire with my parents, my brother, my fiance and my daughter. Prior to being diagnosed with FA, my family had no idea what the disease was or how it would affect my life.

I have had 14 years to begin to understand what FA is and what it means for my future; and I am still learning new things everyday. When I was a little girl, I did not expect this for myself. No one with FA does; no one thinks that when they're a normal, average, and active child that they will face medical problems and be in a wheelchair for the rest of their lives.

I have met some amazing friends through the Friedreich's Ataxia Research Alliance and I am thankful everyday of my life that FARA exists. FARA brings us all together to help us raise money and fight to find a cure. The friends that I have met and who are in the same boat as me, need a cure just as badly as I do. I have known people with FA who have died because of the disease. I do not want to be one of those numbers; I do not want me or any of my friends to act as a statistic for a disease without a cure.

I am not the type of person who will sit around and be bullied! Even if the bully, in my case, is my own body; I have refused to sit back and let that bully take my life from me. Ron Bartek, the President of FARA was quoted as saying "FARA is a business that is looking to go out of business!" It's people like him and comments like that, that make me realize I am not in this alone. I have no doubt that with all of these people working to stop my bully, we will find a cure!

Last fall, I was blessed with a beautiful baby girl. I never would have believed this was possible. For me, part of never giving up is to never stop learning about my health. Because of this persistence, my dream to be a mother has become a reality.

