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Personal NF Story – Miranda Bealko

Our story starts with my mom. When my mom was a young girl, she struggled in school with no one really understanding why. A small bike accident at that age knocked her unconscious and resulted in a trip to the emergency room. Along with a small concussion, the doctors found that she had a heart murmur. After visits to the cardiologist they discovered that she had a coarctation of the aorta, and at 10 years old, she underwent open heart surgery.

In addition to the several medical complications she had already experienced, the doctors also noticed many café au lait spots. They were stumped. Unsure of what they were, they wrote it off as her skins' pigmentation. It wasn't until years later, when she was married and starting our family, that she began to meet doctors that started to open her eyes to the diagnosis of NF1.

Since it has a 50% chance of being passed on genetically, two of my mom's three children, including myself, were diagnosed with Neurofibromatosis Type 1 (NF1). Growing up, I also struggled through school like my mom. Thankfully we lived in an area where there is a clinic specifically dedicated to neurofibromatosis in Cleveland, OH so our symptoms were closely followed and monitored. In 2006, we moved to Albuquerque, NM and our optimism for treatment changed dramatically. When meeting with local neurologists to find continued care for our NF, most of them did not know what NF was. We were once even told "I think I read about that in my textbook one time, but that is all I've heard of this condition." With little knowledge from our new medical professionals, our NF care stopped all together. Due to the nature of NF, more symptoms and complications arise as you get older, and it was at this time when my neurofibromatosis started to affect me in ways of nerve and joint pain in my knee, wrists, and ankles, as well as a rapid resting heart rate.

In 2014, I was pregnant with my first child. I knew the 50/50 odds of it being passed on to my children. Because I had not continued receiving experienced NF care, I was not aware of the risk of many aliments for those with NF during pregnancy. My daughter was born term with in-uterine growth restriction (IUGR) and was as big as a baby born preterm. While we later learned that IUGR could be a complication from NF during pregnancy, she herself did not end up with the NF gene.

In 2017, I was pregnant with my second child. I encouraged my midwife to research NF. This time, with the proper care and knowledge, I gave birth three weeks early to my healthy baby

boy. At 2 months old he developed his first of many café-au lait spots – an identifying marker for NF1. Since I knew what it was, I started the long process of finding care for him.

There are not many specialists in New Mexico that have knowledge about neurofibromatosis. In order to see the ones that do, you can expect to wait almost a year to get in, and even then, they still do not have a full working knowledge of how this condition can manifest in many ways. After my son received his official diagnosis, we were sent to Nephrology, Orthopedics, and Ophthalmology. After his appointments, we were told he had high blood pressure and possible pseudarthrosis of the tibia which both can be very detrimental to NF patients. Because of the lack of support and knowledge in our state, we kept being told to come back in 6 months. Each appointment left us with more questions, no answers and a different doctor's appointment every month.

Because of contradicting information and the lack of NF knowledge in the state of New Mexico, I did some research and found there are other NF clinics dedicated to helping with this condition outside of New Mexico, similar to the one in Cleveland. The closest one to us specializing in pediatric NF care was in Denver, CO. I contacted them immediately for more information, and they were able to squeeze us in for an appointment. This was a huge blessing, as they are a very busy clinic and see many NF patients from out of state, including New Mexico.

Unfortunately, the only appointment they had available was February 11th, conflicting with the opportunity to join the NF Network in Washington DC. We were faced with a tough decision. We are advocating to help the many people in our state that suffer from this condition, and many more throughout the nation who need help. There are 2,500 NF patients in the databases at University of New Mexico Hospital alone, with many more that seek care out of state – us included. The choice, though difficult, was a no brainer – to go to the appointment in Denver to hopefully get answers for my son.

Since neurofibromatosis is progressive, we do not know how it will change or manifest in any of us. Unfortunately, my mom and myself will not be able to receive care for it unless we move out of state, and we will have to take my son to Denver once (or more) a year to continue his NF care. Our only request is to continue funding the Neurofibromatosis Research Program to help continue to improve the care for individuals like myself and to get closer to a future of one without neurofibromatosis.

Thank you for your time,

Miranda Bealko and family
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