Community-Led Track

Strategies for Motivating Your Juvenile-Onset Adult Children

Suzette Ison
Denise Millett
Susan Trachtman
Earliest Memories...
What we’ve learned along the way...
Dystrophy: A Scientific Explanation

DNA
50+ Repeats of CTG series on chromosome 19

RNA
Not all RNA are affected, but when they are the repeats will increase, scrambling messages

Proteins & Muscles
The RNA that is impacted will be processed, converted to protein, and sent to the muscles in our body.

My life with Myotonic Dystrophy

Two weeks before I started High School, we saw a new doctor. He asked me to squeeze his mallet but my hand got stuck.

This was nothing new to me, but the doctor and my Mom were surprised. He knew right away that this was Myotonic Dystrophy.

- When I was younger, I didn’t even know I had Muscular Dystrophy.
- I learned to read really early, but when I got into first grade I had a lot of problems with writing. None of us knew why, so the teachers told me to try harder.
- We kept trying, but my writing got worse and soon I hated to write. I also had troubles lining up my numbers in math.
- By 5th grade, we didn’t know what was going on but we knew I wasn’t doing well in school. I went to the Pilot School and they helped me a lot. I stopped hating school, but writing was still hard and I didn’t know why.
Continue the Conversation

MDF Caregivers Group on Facebook
Face-to-Face MDF support groups throughout U.S., Ottawa, and Switzerland: [http://myotonic.org/find-support](http://myotonic.org/find-support)