

### 2015 MDF Annual Conference



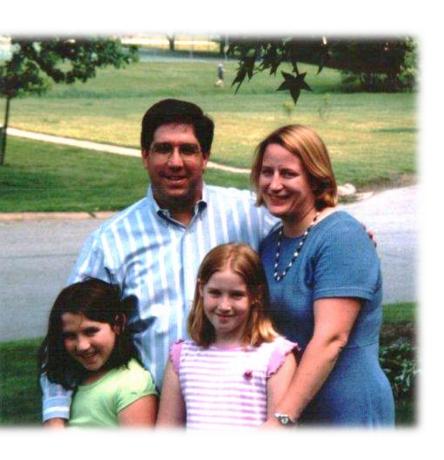
Sept. 18 - 19, 2015 Washington, DC

#### Community-Led Track

# Strategies for Motivating Your Juvenile-Onset Adult Children

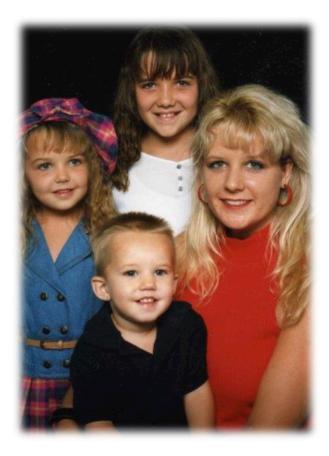
Suzette Ison
Denise Millett
Susan Trachtman

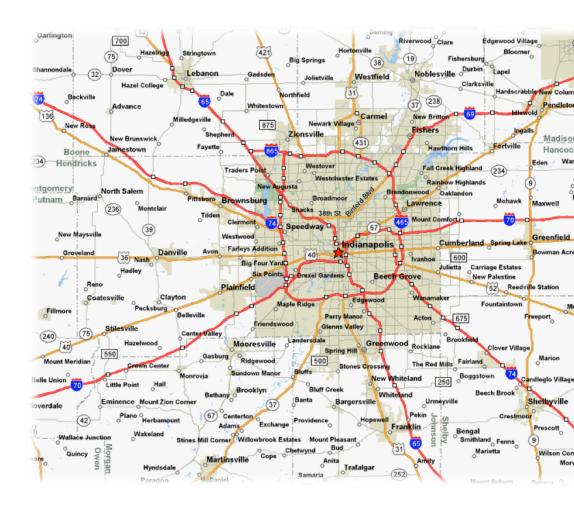
# san Trachtman





# Suzette Ison





# enise Millett





## Earliest Memories...





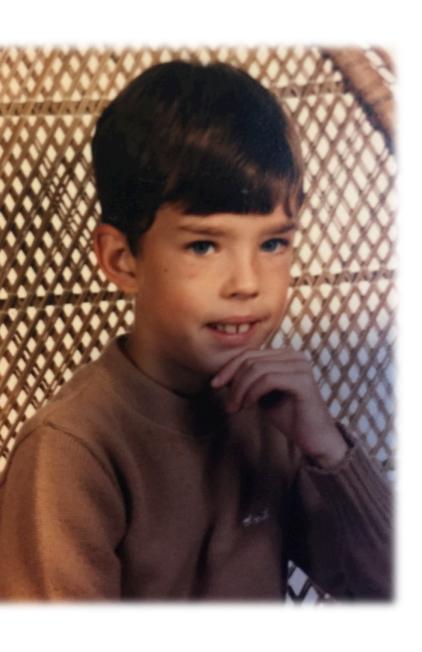








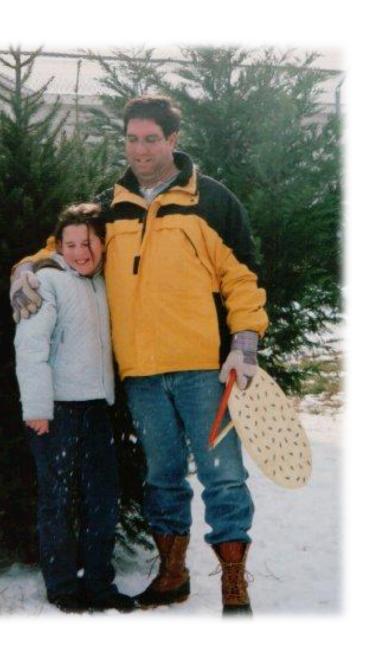


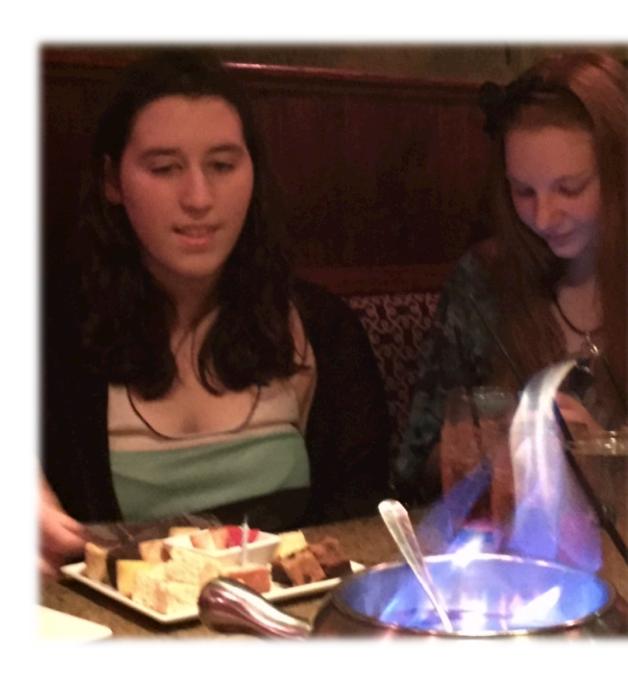




## What we've learned along the way...











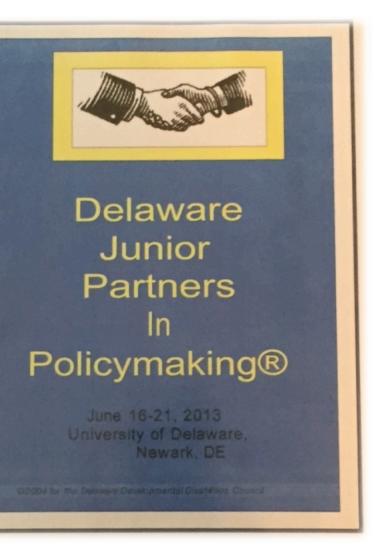












#### Delaware's Junior Partners in Policymaking 2013 Final Report



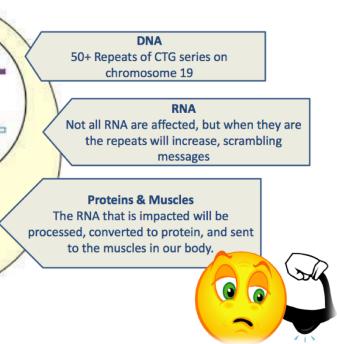
#### Dystrophy: A Scientific Explanation

cell

DNA

ssed RNA

rotein



My life with 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 5<sup>th</sup> 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.

#### 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.

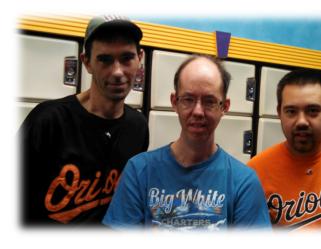
This was nothing new to me, but the doctor and my Mom were surprised. He knew right away that this was Myotonic Dystrophy.













#### Continue the Conversation

#### MDF Caregivers Group on Facebook

Face-to-Face MDF support groups throughout U.S., Ottawa, and Switzerland: <a href="http://myotonic.org/find-support">http://myotonic.org/find-support</a>



