

# Must start with Patients' experience of how symptoms affect daily life and QoL

## **Symptoms usually develop in adolescence:**

- Slurred speech, excess saliva, drooling
- Tremor hands and body even tongue,
- Body, arms, legs, hands, feet twitching, muscle spasms, head nodding
- Worsening hand writing
- Difficulty swallowing
- Struggle with balance, walking, falling
- Difficulty focusing, uncoordinated, memory loss, light headed, brain "wired", could not focus my eyes
- Tired, exhausted from simple tasks, excessive sleeping
- Anxiety, depression

## **Impact on individual (and family):**

- "could not read out loud in school because of my hands were shaking the paper I was holding"
- "I knew the answers, but I couldn't finish a 3-hour exam, I used to be an A-student"
- I had a crush on a girl in HS wanted to speak with her, I remember talking to this girl, and I started drooling. I was humiliated.
- Gym teacher "informed my mother I was uncoordinated in class"
- Growing up athletics was a huge part of my life, I loved sports
- Kids made fun of my slow motions and slurred speech
- My confidence faded as physical limitations progressed
- The looks I got from people were disheartening
- People regarded me as a weird person, made assumptions about my intelligence and capabilities. "I can still think, I am not stupid"