



# Holding Steady on Shaky Grounds

LESLIE WOLF

# How it Started

- ▶ **Shooting pain in left fore arm. Could not:**
  - ▶ Pull up pants
  - ▶ Close car door
  - ▶ Wash hair
  - ▶ Put on lotion with left hand.
  - ▶ Left arm was in constant pain.
  - ▶ Left thumb shakes
  - ▶ Left eye shakes
  - ▶ Left eye lid takes long to open
- ▶ **Loss of smell (have not had this for years).**
- ▶ **Saw numerous doctors ended up at Orthopedic surgeon.**
- ▶ **Had Rotator Cuff clean up (Not Needed in Hind Sight)**

# My Timeline

- ▶ **Jan. 2012**      **Loss of use of left side**
- ▶ **April 2012**    **Rotator Cuff Surgery**
- ▶ **Dec. 2012**    **First Brain MRI - Showing Brain Shrinkage**
- ▶ **Aug. 2013**    **At my worst - Starting seeing every doctor possible**
- ▶ **April 2014**    **First Diagnosis of CBD/CBDS - Dr. Michael Geschwind**
- ▶ **Nov. 2014**    **Phase 1 Trail - TPI-287-4RT to Treat CBS and PSP**
- ▶ **Oct. 2017**    **Living on Carbidopa & Levodopa with Entacapone**
- ▶ **Oct. 2017**    **5 years and Holding Steady!**

# The Chicken Dance

# ***Professional*** Clinical Trial Volunteer

- ▶ **Phase 1 Trail -Safety Study of TPI-287 to Treat CBS and PSP (TPI-287-4RT)**
- ▶ **4 Repeat Tauopathy Neuroimaging Initiative**
- ▶ **FTD/PPG, Dementia Genes, Images & Emotions**
- ▶ **Sleep Study (Twice)**
- ▶ **18F-AV-1451 Tau Imaging in subjects with PSP & CBD and Healthy Volunteer**
- ▶ **Amyloid PET Imaging in AD, FTD & PPA & Glucose FOG Scan**
- ▶ **TAU AV 1451 Scan**
- ▶ **Creation of Stem Cells from Patient w/ FTD**

# What is Working?

- ▶ **Possibly the Safety Study of TPI-287**
- ▶ **Meds every 3-4 hours**
- ▶ **Working out & Water Aerobics**
- ▶ **Having my own business & going in daily**
- ▶ **Very supportive husband**
- ▶ **Two kids still at home (Ages 16 & 23)**