

# **Patient with PSP**

Jeanette S. Brown, MD (retired)

# HISTORY- Pre-PSP

- At UCSF, since 1987
- Many papers, many NIH grants, spoke often at NIH, and international meetings
- Chair of multiple NIH Review Committees
- Director, UCSF Women's Health Clinical Research Center
- Director, Specialized Center of Research (SCOR)
- Director of Urogynecology
- UCSF Mentor of the year Award 2011

# Retirement

- Not what I expected...
- Shortly after diagnosis
- Professor in residence 7 at UCSF
- No multi-tasking
- Opt for Social Security benefits
- Move to SF a condo with an elevator, near family
- Grab bars
- Re-do bathroom to have a walk-in shower

# UCSF Memory & Aging

- 3 car accidents in 3 months
- Primary care Doc. concerned and sent me to Neurology
- Neurologist concerned and sent me to UCSF Memory & Aging Center
- Dr. Boxer made the diagnosis
- Difficult to hear... but he is a world expert
- Offered a phase 2 clinical trial

# Current Symptoms

- No driving since 3/ 2015
- Slow speech
- Inability to write
- Down to typing with one finger and lots of mistakes
- Balance wobbly and must be careful
- Tired and must nap every day
- Vision- now have prisms

# Feelings

- Sad
- Worried
- Fearful
- Anxious
- Powerless
- Disillusioned
- Indecisive
- incapable

# Travel

- Went to Machu Picchu with brother in January
- Just returned from Viking River Cruise Grand European tour with partner
- *Now* is the time- go with someone.
- Now always travel with assistance at the airport

Get assistance at the airport-if you need it!!!

# Lessons learned

Travel *now* or whatever you want you do!!

- Enjoy the moment; try not live your diagnosis
- Live one day at a time
- Get your finances in order
- Start PT & OT before you really need it
- Prepare your family and yourself
- For the inevitable decline



# Questions??

- Ask me now feel free to contact me:  
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We started a support group in SF- join us!

We are meeting once a month @Cafe Roma 526 Columbus in North Beach  
The 3<sup>rd</sup> Tuesday of the month @ 11:30