

8 items we learned from Jackie's PSP Journey



1. Get second (or third) opinions early, especially for unexplained symptoms.
2. Don't accept an unconfirmed or non-specific diagnosis. Push to get to a top neurologist preferably a Movement Disorder Specialist (MDS).

3. Make the significant care decisions early
 - a. Feeding tubes
 - b. Do Not Resuscitate (DNR) orders
 - c. Hospitalization or die at home
 - d. Brain donation

Use an Advanced Health Care Directive and Physician's Orders for Life-Sustaining Treatment (POLST)

4. Start exercise early and continue exercise as long and as much as possible



5. Make life as normal as possible.



6. Check out available clinical trials.

www.clinicaltrials.gov

The screenshot shows the ClinicalTrials.gov website interface. At the top, there is a navigation bar with the NIH logo and the text "U.S. National Library of Medicine". Below this is the "ClinicalTrials.gov" logo. The main navigation menu includes "Find Studies", "About Studies", "Submit Studies", "Resources", and "About Site". A blue banner at the top of the page states: "We updated the design of this site on September 25th. Learn more. We will be updating this site in phases. This allows us to move faster and to deliver better services. Show less".

The search results page shows a search for "Progressive Supranuclear Palsy" in the "United States". The search criteria are displayed as follows:

- Condition / Disease: Progressive Supranuclear Palsy
- Other Terms: (empty)
- Country: United States
- State: (empty)

The search results show 15 studies found for "Recruiting Studies | Progressive Supranuclear Palsy | United States". The search also found results for "Supranuclear palsy, progressive" and "Paralyses".

At the bottom of the page, there are buttons for "List", "By Topic", "On Map", and "Search Details". The footer includes a "Hide Filters" button, a "Download" button, and a "Subscribe to RSS" button.

7. As the caregiver or patient, be proactive,
- a. participate in support groups,
 - b. go to presentations on the disease and
 - c. research on-line.

Attitude

8. Keep a “Binder”

- a. Cross doctor communication
- b. Researchers

Summary

1. Second (or third) opinions early
2. Don't accept an unconfirmed or non-specific diagnosis
3. Make the significant care decisions early
4. Exercise as long and as much as possible
5. Make life as normal as possible
6. Investigate Clinical trials
7. Be proactive
8. Keep a "Binder"

