CARE-PSP: Understanding the Needs of People with PSP and Related Disorders

2017 CurePSP Midwest Family Conference

Who are we?

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What are we doing?

• Conducting a study to identify how people with PSP and related disorders use and seek healthcare
• What to expect:
  • Online survey
  • 1st survey takes 30-40 minutes
  • 2nd follow up survey after 1 year taking 20-30 minutes
• We hope to determine:
  • what kind of care is helpful
  • what needs may not be met
  • quality of life for patients and care partners over the course of one year

Why are we doing it?

• People living with PSP and related disorders and their care partners have different needs than those living with PD

Potential impact of our study:
• Guide future studies
• Use as a model of care to improve quality of life and care partner strain for individuals living with PSP and related disorders
• Improve future care
Who can participate?

- You can participate in the study if:
  - You have been diagnosed with Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA), Corticobasal Syndrome (CBS), or an atypical parkinsonism
  - You are 40 years of age or older
  - You voluntarily agree to participate
  - Care partners of people living with PSP and related disorders can participate too!

How to Participate

To participate you will need:
- Internet connection/ computer
- 30-40 minutes

For more information
- Share your email address with us today or
- Call Naomi Friede at 646-501-4871
Accessing the Survey:

1. Check your email for your personal link
2. Click on the link to visit the website and start the survey:

https://is.gd/pspsurvey
I agree to take part in this research study as described above.
I have read the information above and have decided to volunteer.
* must provide value

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Save & Return Later
What is your first language? English | Spanish

- Mandarin
- Cantonese
- Other

What is your highest level of education? Elementary or middle school (grades 1-8)

- High school graduate
- Some college or trade school (1.5 years, no degree)
- Bachelor's degree (BA, BS, etc.)
- Master's degree (MA, MS, MEd, etc.)
- Professional or doctorate (PhD, MD, DDS, etc.)

What is your marital status? Single

- Married, Partnered, or Living with Significant Other
- Separated
- Widowed

- We would like to know how good or bad your health is TODAY.

- This scale is numbered from 0 to 100.

- 100 means the best health you can imagine.

- 0 means the worst health you can imagine.

- Please click on the scale to indicate how your health is TODAY.

*Must provide value.

After the Survey

• One year after completing the first survey you will be contacted by e-mail to conduct a follow up survey

Questions?

Contact information:

• If you have any questions about the research, please contact Dr. Fleisher’s research team at (646) 501-4871
Thank you!