



## **Progressive Supranuclear Palsy (PSP) Study FAQ**

The Rainwater Foundation is working with Modus Outcomes, an independent consulting company, to learn more about the experience of people who have PSP. To support this study, we are recruiting 15 people diagnosed with PSP and their caregivers to participate in an interview. We have provided more information about the study below.

### **Q. What is the purpose of this study?**

- A. The purpose of this study is to learn more about the experience of people who have PSP and to publish the information so more people can understand what it is like to live with PSP.

### **Q. What will I need to do if I agree to participate?**

- A. If you agree to participate in this study, you and your caregiver will participate in a 1-hour interview (by phone or internet-based platform). The interview will consist of questions about your experience having PSP. We will also ask you to give us information about your general health and other information about you.

### **Q. How much time will this take?**

- A. We expect that your total participation will be about an hour and a half, including a screening call, completing paperwork, and participating in the interview.

### **Q. Where will the interview take place?**

- A. The interview will take place on an online platform called Microsoft Teams (similar to Zoom). A Modus Outcomes researcher will provide you with the information if you agree to participate.

### **Q. Will I be compensated for this research?**

- A. Yes, if you complete the interview, you will be paid \$200 in the form of a gift card (\$100 per patient and \$100 per caregiver).

### **Q. Will it cost me money to take part in this research?**

- A. Taking part in this research will not cost you any money.



## **(PSP) Study FAQ, continued**

**Q. What happens if I agree to be in this research, but I change my mind later?**

A. You can decide to stop your participation in this study at any time with no consequences.

**Q. Will being in this research benefit me?**

A. There are no benefits to you from your taking part in this research. We cannot promise any benefits to others from your taking part in this research. However, possible benefits to others include helping researchers to better understand PSP or develop new tests or medications to assist others in the future.

For more information, please contact Gerrit Vandenberg by phone at **(515) 231-3527** or email at [Gerrit.Vandenberg@modusoutcomes.com](mailto:Gerrit.Vandenberg@modusoutcomes.com).