

# Survey: Retinitis Pigmentosa (RP) Trial

\*\*\*Please fill out this form only if you are over 18 and have RP (or are filling out for a person with RP).\*\*\*

Thanks for taking a few minutes to answer the questions in this survey. We hope this information will help form the basis for clinical trials in the future. If you have any problems filling out this survey, please contact [cdorfman1234@gmail.com](mailto:cdorfman1234@gmail.com).

\* Required

1. What is your age? \*

*Mark only one oval.*

- ☐ 18 to 30
- ☐ 31 to 40
- ☐ 41 to 50
- ☐ 51 to 69
- ☐ 70 and over

2. With which gender do you identify? \*

*Mark only one oval.*

- ☐ Female
- ☐ Male
- ☐ Prefer not to say
- ☐ Other: \_\_\_\_\_

3. Approximately how long have you known that you have had Retinitis Pigmentosa (RP)? \*

*Mark only one oval.*

- ☐ Less than 10 years
- ☐ 10 to 20 years
- ☐ 21 to 30 years
- ☐ More than 30 years

4. Have you had genetic testing and do you know which gene, or genes, causes your RP? \*

*Mark only one oval.*

- ☐ Yes, I have had genetic testing and the genetic cause was found. *Skip to question 5*
- ☐ Yes, I have had genetic testing, but I did not receive the results. *Skip to question 6*
- ☐ Yes, I have had genetic testing but the genetic cause was not found.  
*Skip to question 6*
- ☐ No, I have not had testing. *Skip to question 6*

5. What gene is the cause of your RP?

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*Skip to question 6*

6. What is your level of visual acuity? \*

*Mark only one oval.*

- ☐ Between 20/20 and 20/40
- ☐ Between 20/50 and 20/80
- ☐ Worse than 20/80
- ☐ Don't know

7. Check all that apply: To get around I use... \*

*Check all that apply.*

- ☐ A sighted guide
- ☐ A cane
- ☐ A guide dog
- ☐ I do not require any additional assistance

Other: ☐ \_\_\_\_\_

8. Do you use email? \*

*Mark only one oval.*

- ☐ Yes
- ☐ No

9. Do you use a mobile phone? \*

*Mark only one oval.*

- ☐ Yes
- ☐ No Skip to question 11

## Untitled Section

10. Do you receive text messages with your mobile phone?

*Mark only one oval.*

- ☐ Yes
- ☐ No

Please answer the following questions that would be specific to a study being planned for an oral medication to slow or stop vision loss caused by RP. The study would take place over a 4 year period and would require taking medication two times per day over the length of the study. In addition, participants would be asked to record their usage and any missed dosing, as well as periodic visits with a participating physician.

11. Assuming you met eligibility requirements, how enthusiastic would you be about participating in such a study? \*

*Mark only one oval.*

- ☐ Very enthusiastic      *Skip to question 12*
- ☐ Somewhat enthusiastic      *Skip to question 12*
- ☐ Potentially interested      *Skip to question 12*
- ☐ Not interested

If you entered in the study mentioned in the previous section, how willing would you be to participate in the following:

12. A clinical visit with a doctor every 4 to 5 months for 45 months. \*

*Mark only one oval.*

- ☐ Very willing
- ☐ Somewhat willing
- ☐ Not willing

13. Telemedicine contact with a doctor between clinical visits. \*

*Mark only one oval.*

- ☐ Very willing
- ☐ Somewhat willing
- ☐ Not willing

14. Would you like to receive text message reminders twice per day that alert you when it is time to take the medication required by the aforementioned study? \*

*Mark only one oval.*

- ☐ Yes
- ☐ No
- ☐ I don't know
- ☐ I don't receive text messages

15. If there was a system that would allow you to report missing dosages or problems related to medication prompted by a text message, how often would you be willing to receive these text message prompts? \*

*Mark only one oval.*

- ☐ Daily
- ☐ Weekly
- ☐ Every 2 weeks
- ☐ Monthly
- ☐ I would not want to receive text messages
- ☐ I don't know how I would feel about that
- ☐ I don't receive text messages

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