



Questionnaire for members of, and those affiliated with, RAWA

Retina Australia WA (RAWA) is a not-for profit charity that raises funds for research into finding a cure for Inherited Retinal Eye Diseases, and facilitates support for those who are affected.

Over the last few years, we have increasingly struggled to connect with those affected by Inherited Retinal Diseases, (IRDs) and to raise money for research for a cure, and so we are trying to find out in more detail what it is that is needed, so that we can be as effective and as focused as possible in what we do.

We would greatly appreciate you giving 10 minutes of your time to fill in the questionnaire below. The de-identified results will be available on the website once the information has been collated. All information is treated as strictly confidential.

Questionnaire can be completed online by clicking 'Submit Now' in the top right corner of the page when complete or print the questionnaire, completed it manually and post to RAWA - PO Box 183, Osborne Park, 6917

Score each question from 1-5 according to how much it interests you. Tick the most appropriate response. e.g. 1 = not at all, ranging to 5 = extremely.

1. How important do you see the separate roles of RAWA?

- | | | | | | |
|---|---|---|---|---|---|
| a. Fundraising for research | 1 | 2 | 3 | 4 | 5 |
| b. Facilitating support to those affected with IRDs? | 1 | 2 | 3 | 4 | 5 |
| c. Being a source of accurate information about IRDs? | 1 | 2 | 3 | 4 | 5 |

2. How interested are you in knowing about upcoming treatments for IRDs?

- | | | | | | |
|--|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 |
|--|---|---|---|---|---|

3. How would you most prefer to keep up to date?

- | | | | | | |
|--|---|---|---|---|---|
| By intermittently looking at the RAWA website? | 1 | 2 | 3 | 4 | 5 |
| By receiving the RAWA "Insight" newsletter? | 1 | 2 | 3 | 4 | 5 |
| By attending a 2yrly RAWA State Congress with recognised, expert speakers? | 1 | 2 | 3 | 4 | 5 |
| By attending RAWA social meet-ups? | 1 | 2 | 3 | 4 | 5 |
| By doing your own private internet and other searching? | 1 | 2 | 3 | 4 | 5 |

4. How interested are you in donating your time to help RAWA?

- | | | | | | |
|--|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 |
|--|---|---|---|---|---|

5. If interested, how would you like to do this?

- | | | | | | |
|---|---|---|---|---|---|
| By volunteering with events | 1 | 2 | 3 | 4 | 5 |
| By volunteering in the office? | 1 | 2 | 3 | 4 | 5 |
| By helping promote and attending events? | 1 | 2 | 3 | 4 | 5 |
| By being available to talk to those affected as required? | 1 | 2 | 3 | 4 | 5 |
| By nominating to join the RAWA committee? | 1 | 2 | 3 | 4 | 5 |



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6. **How interested are you in helping to raise money for research into IRDs?** 1 2 3 4 5
7. **How would you like to do this?**
- By donating money to RAWA? 1 2 3 4 5
 - By holding your own fundraising event? 1 2 3 4 5
 - By assisting our office to organise an event? 1 2 3 4 5
 - By volunteering at an event or in our office? 1 2 3 4 5
 - By sponsoring part or all of an event? 1 2 3 4 5
 - By arranging corporate matched giving at your place of work? 1 2 3 4 5
 - Leave a legacy by putting a bequest to RAWA in your will? 1 2 3 4 5
- For those affected:**
8. **How important is it to you to share your hopes and fears with others who are affected by IRDs?** 1 2 3 4 5
9. **How do you/would you like to do this?**
- a. Via telephone 1 2 3 4 5
 - b. Via a closed Facebook group? 1 2 3 4 5
 - c. Via RAWA social meet-ups? 1 2 3 4 5
 - d. Via personal e-mail messages? 1 2 3 4 5
 - e. Via other private means? 1 2 3 4 5
 - f. Via contacts provided by RAWA? 1 2 3 4 5
10. **How useful have RAWA been to you personally:**
- a. By connecting you with others with IRDs? 1 2 3 4 5
 - b. By keeping you up to date with upcoming treatments? 1 2 3 4 5
 - c. By giving you accurate disease information? 1 2 3 4 5
 - d. By other means? Provide example _____ 1 2 3 4 5
11. If you are not interested in helping to raise money or volunteer your time to RAWA, can you please tell us why? (Put down as many reasons as you wish)



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12. What would need to change to enable you to attend events, raise money or volunteer your time more often for RAWA? (Put down as many reasons as you wish)

13. Do you have any other comments, compliments, or complaints that you would like to feed back about what we do at RAWA?

Additional Information (optional)

Are you male or female? M F

Which age group are you?

Are you personally affected by an IRD, if not applicable go to Question 10

	Yes	No	N/A
i) Which one?			
ii) How long ago were you diagnosed?			
iii) What age were you when diagnosed?			

	Yes	No	N/A
Do you know someone who is affected by an IRD?			
iv) What is their relationship to you?			
v) Which IRD do they have?			

Please contact Renae in the RAWA office by email on info@rawa.com.au or by telephone on 9388 1488, if you have any questions about this questionnaire or about the organisation.