

TSC Family Survey 2014

Australia



Australasian
Tuberosclerosis
Society

Thank you for taking the time to complete this survey.

The reason for this survey is to learn more about you and your experience of living with TSC. We're also asking about your opinions on current ATSS activities and what ATSS should be doing in the future to better meet your needs.

As with all personal information you share with ATSS, your responses will be kept private and confidential. We will write a report showing the results of the survey and make this available on our website. No personal information will appear in the report. Everyone's responses will be pooled together. Your comments may be used in the report but you will not be quoted in a way that might reveal your identity to others.

This paper survey is for people living in Australia. If you are in New Zealand, there is an alternative version. Please go to www.atss.org.au/survey to download this version.

Wait! Do you have access to a computer and the internet?

Doing the survey online reduces our costs and errors because we do not have to type your responses.

To encourage you to complete the survey online, we will be conducting a prize draw. **Two prizes of a double movie ticket to the cinema of the recipient's choice will be given away.**

We will randomly draw this from the names of people completing the online survey only.

Please go to www.atss.org.au/survey to complete the survey online.

Of course, we understand if you do not have access to a computer and welcome your completed paper surveys. Please post your responses to us at:

TSC Family Survey, 10/47 Alt St, Ashfield, NSW, 2131

before 30 June 2014.

Thank you for taking part.

A handwritten signature in black ink, appearing to read 'Deb Crosby'.

Deb Crosby, ATSS President

1. Please tell us whether you are answering this survey as a person with TSC or as the carer of a person with TSC.

Note: Carer may include parents, grandparents, siblings, neighbours, and professional carers.

- I will be answering the questions as a person with TSC.*
- I will be answering the questions as a carer of a person with TSC.*

2. Please tell us where you live.

- Australian Capital Territory*
- New South Wales*
- Northern Territory*
- Queensland*
- South Australia*
- Tasmania*
- Victoria*
- Western Australia*
- I am an Australian living overseas*

3. Which best describes where you live?

- The metropolitan area of a state capital city*
- A metropolitan area that is not near a state capital city*
- A rural centre*
- Other rural or remote area*

4. Please tell us what age group you are in.

- | | |
|---|--|
| <input type="checkbox"/> <i>15 or under</i> | <input type="checkbox"/> <i>16 - 24</i> |
| <input type="checkbox"/> <i>25 - 34</i> | <input type="checkbox"/> <i>35 - 44</i> |
| <input type="checkbox"/> <i>45 - 54</i> | <input type="checkbox"/> <i>55 - 64</i> |
| <input type="checkbox"/> <i>65 - 74</i> | <input type="checkbox"/> <i>75 or over</i> |

5. If you are filling out this survey on behalf of someone you care for, please tell us how old they are.

- | | |
|---|--|
| <input type="checkbox"/> <i>15 or under</i> | <input type="checkbox"/> <i>16 - 24</i> |
| <input type="checkbox"/> <i>25 - 34</i> | <input type="checkbox"/> <i>35 - 44</i> |
| <input type="checkbox"/> <i>45 - 54</i> | <input type="checkbox"/> <i>55 - 64</i> |
| <input type="checkbox"/> <i>65 - 74</i> | <input type="checkbox"/> <i>75 or over</i> |

6. In which country were you born?

- Australia*
 - New Zealand*
 - Other - please specify:*
-

7. Do you speak a language other than English at home?

If more than one language, indicate the one that is spoken most often.

- No, English only*
 - Yes, other. Please specify*
-

8. How well do you speak English?

- Very well*
- Well*
- Not well*
- Not at all*

9. Are you of Aboriginal or Torres Strait Islander origin?

Please tick all that apply

- No*
- Yes, Aboriginal*
- Yes, Torres Strait Islander*

10. Please tell us what your connection to TSC is.

Please tick all that apply.

- I have TSC*
- I am the parent of a child with TSC*
- I am the parent of a grown-up with TSC*
- I am the brother/sister of someone with TSC*
- My father has TSC*
- My mother has TSC*
- Other - please specify: _____*

11. Including yourself if you have TSC, please tell us how many people in your family have TSC.

Include brothers, sisters, parents, aunts, uncles, grandparents and cousins.

12. Please tell us which of the following affect you or the person you care for.

	Do these affect you (or the person you care for)?			How much of an impact does this have on your life?			
	<i>Yes</i>	<i>No</i>	<i>I don't know</i>	<i>None</i>	<i>Minimal Impact</i>	<i>Moderate Impact</i>	<i>Severe Impact</i>
Epilepsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Learning difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intellectual disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Autism	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ADHD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Challenging behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mental Health issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
SEGA brain tumour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skin problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kidney tumours or cysts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lung issues (e.g. LAM)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobility problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (e.g. eyes, liver)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13. Please tell us more about how TSC affects you and your family. You may like to tell us your biggest concern or the area you particularly need assistance with.

14. Please tell us if you, or the person you care for, has ever attended a TSC specialty clinic

- Yes* *No*

15. If yes, please tell us which clinic you, or the person you care for, has attended?

- Sydney Children's Hospital TSC Clinic*
 Mater Children's Hospital, Brisbane, TSC Clinic
 Prince of Wales Hospital TSC clinic for adults
 Other - please specify:
-

16. Please tell us if you, or the person you care for, regularly sees the same general practitioner (GP).

- Most of the time I visit the same general practitioner (GP)*
 Most of the time I visit the same clinic but I see a different general practitioner (GP) each time
 I do not regularly visit the same general practitioner (GP) or clinic

17. Please tell us if you were aware of the guidelines for the diagnosis, surveillance and treatment of Tuberous Sclerosis?

- Yes*
 No
 I am not sure

18. Please tell us which health professional manages Tuberous Sclerosis care for you or the person you care for? This may include managing referrals and scheduling regular scans.

- I do not have a health professional who manages my Tuberous Sclerosis care*
 General Practitioner (GP)
 Paediatrician
 Paediatric Neurologist
 Neurologist
 General physician
 Nephrologist
 Other - please specify
-

19. Please tell us when you found out about ATSS.

- I found out about ATSS at around the same time that I or the person I care for was diagnosed with TSC*
 I found out about ATSS some time after I or the person I care for was diagnosed with TSC
 I have always known about ATSS
 I don't know

20. Please tell us how long you have known about ATSS?

- For less than 6 months*
 Between 6 months and 2 years
 Between 2 years and 5 years
 Between 5 years and 10 years
 More than 10 years
 I don't know

21. We are currently reviewing our events. Please rank the following types of events.

	<i>Of most interest</i>	<i>Of interest</i>	<i>Of some interest</i>	<i>Of least interest</i>
Social (an opportunity to meet other members in a relaxed environment)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supportive (an occasion to meet other individuals/families and share experiences)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Informative (an opportunity to learn about the latest developments in research and support)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Practical (for example for advice on government benefits, services that may assist you live your life)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

22. Please tell us if you have ever been to an ATSS event.

- Yes, conference events only*
- Yes, social events only*
- Yes, both social and conference events*
- No, I have never been to an ATSS event*

If no, why? Select all that apply

- I could not get care for my family members*
 - The event did not interest me*
 - The dates did not suit*
 - The event was too far away from my home*
 - I was not emotionally ready to meet others affected by TSC*
 - Other - please tell us:*
-

23. Please tell us what duration of event would you prefer.

- Half day* *One day* *Weekend*

24. Please tell us how far you would travel for an event.

- Within my own city*
 - To the capital city of my state*
 - Anywhere, but only if travel costs were covered*
 - Anywhere, even if travel costs were not covered*
 - Other - please tell us*
-

25. We are considering holding webinars, a type of meeting you can attend on your computer over the internet. Would you attend a webinar on a topic related to TSC?

- Yes* *No* *Not sure*

26. If you have experience of using any of the following ATSS services in the past 12 months, how would you rate them?

If you would like to expand upon your answer to this question, please do so on the next page.

	Have you used this service in the last 12 months?		How would you rate this service?					
	<i>Yes</i>	<i>No</i>	<i>Excellent</i>	<i>Very Good</i>	<i>Good</i>	<i>Fair</i>	<i>Poor</i>	<i>Not Applicable</i>
Reach Out	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ATSS Website	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ATSS Facebook Discussion Group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ATSS Email Newsletter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support and information by phone contact	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support and information by email contact	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

27. Please tell us how important it is to *you and your family* that the ATSS undertakes the following activities.

Please rank the activities by placing a number next to each one. Use a number 1 for the activity you think is the most important for ATSS to undertake, a number 2 for the second most important and so on. Use a number 12 for the activity you think is the least important for ATSS to undertake.

___ *Provide information about TSC*

___ *Host conferences for medical professionals and researchers*

___ *Provide advice about living with TSC*

___ *Advocate for individuals and families*

___ *Provide emotional support to people living with TSC*

___ *Lobby and campaign to improve health care for people affected by TSC*

___ *Provide opportunities for people affected by TSC to meet*

___ *Lobby and campaign to improve social services and benefits for people affected by TSC*

___ *Help connect TSC families to medical professionals*

___ *Raise awareness of TSC*

___ *Educate professionals about TSC*

___ *Fund research*

If you would like to expand upon your answer to question 26 or 27, please do so here
For example, is there anything else you think ATSS should be doing?

28. Please tell us how you satisfied you are with the services provided by ATSS.

- | | |
|--|---|
| <input type="checkbox"/> <i>Extremely satisfied</i> | <input type="checkbox"/> <i>Mostly satisfied</i> |
| <input type="checkbox"/> <i>Neither satisfied nor dissatisfied</i> | <input type="checkbox"/> <i>Mostly dissatisfied</i> |
| <input type="checkbox"/> <i>Completely dissatisfied</i> | |

Please tell us if you have any other views or ideas about ATSS that you would like to share.

29. The remaining questions are designed to help us better support those who either already raise money on behalf of ATSS or who would like to. You do not need to answer these questions if they are not relevant to you at this particular time.

- I will complete the questions about fundraising*
- I will not complete the questions about fundraising. I will skip to question 34*

30. Please indicate if you would be happy to help in any of the following ways (please tick all that apply).

If ATSS is to continue growing to provide the services you need, it is vital that we grow our income and develop a sustainable and diverse fundraising programme. Your support in helping us do this is key.

- Volunteering to support fundraising organised by others*
 - Organise your own fundraising event*
 - Setting up a local fundraising group*
 - Source raffle/ auction prizes*
 - Recommending ATSS as a charity of the year partner to your employer or child's school*
 - Write a testimonial about your experiences with TSC and ATSS*
 - Provide photos of yourself or your children for use in ATSS campaigns*
 - Ask your friends and family to support ATSS using a personalised letter*
 - Talk to your family and friends about including ATSS in their will*
 - Other(s) - please specify:*
-

31. Please tell us how you would like to be thanked for your fundraising efforts. Please check all that apply, as we do like to say thank you.

- Send me a thank you email*
- Send me a thank you letter in the post*
- A short article in Reach Out, the ATSS magazine*
- I do not need to be thanked for fundraising*

32. Please tell us if we have your permission to contact you about participating in fundraising.

If you select Yes, please provide your contact details below

- Yes* *No*

34. To thank you for completing this survey online, we will be randomly selecting two survey entries to receive a double pass to the cinema of their choice.

Would you like to enter this prize draw?

If you select Yes, please provide your contact details below

- Yes* *No*

35. Your contact details (optional):

Name:

Contact details: (e.g. phone, post, email)

Thank you for completing the survey.