

Survey 2016

Thank you for taking the time to complete this survey.

The aim of this survey is to get the opinions of as many people as possible who have had contact with Tuberos Sclerosis Australia (TSA). We will use this feedback to improve our services, communication and fundraising.

As with all personal information you share with TSA, 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.

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.tsa.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:

TSA Survey, 43 National Ave, Orange NSW 2800

before 25th November 2016.

Thank you for taking part.



Deb Crosby, TSA President

1. Please tell us whether you have a link to TSC

- I have TSC*
 - I am the partner or spouse of a person with TSC*
 - I am a parent of a child with TSC*
 - I am the parent of a teenager with TSC*
 - I am the parent of an adult with TSC*
 - I am the grandparent of a person with TSC*
 - I am a professional treating people with TSC*
 - I have a friend or relative with TSC*
 - Other - please specify:*
-

2. Please tell us your postcode:

3. 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> |

4. Please tell us how you heard about this survey.

- An email from TSA*
 - Reach Out (the TSA magazine)*
 - Facebook*
 - TSA website*
 - Through a health professional*
 - Twitter*
 - Instagram*
 - Other- please specify:*
-

5. Please tell us if you have contributed financially to TSA. You can choose more than one.

- I am a current TSA paid member*
- I was previously a paid member of TSA*
- I am a current TSA champion (monthly donor)*
- I have made one off donation(s) to TSA or a TSA campaign*
- I am a TSC Hero, and my friends have sponsored me by donating to TSA*
- I have held an event to raise money for TSA (e.g. morning tea, workplace or school event).*
- I have never made a financial contribution to TSA*

6. Please tell us how you first heard about TSA.

- I am a health care professional and was contacted by TSA*
- Someone I know has raised funds for TSA*
- A healthcare professional told me about TSA when we were given a diagnosis of TSC*
- I found TSA through an internet search*
- A friend/ relative told me about TSA*
- I found TSA on Facebook*
- Other*

7. Please tell us how long have you known about TSA

- 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*

8. We know it can be difficult to explain TSC to other people. How confident are you when explaining TSC to others?

Not confident at all *Not very confident* *Somewhat confident* *Quite Confident* *Very confident*

9. In your experience, how well known do you think Tuberos Sclerosis Australia is in the following?

| | <i>Unknown</i> | <i>Somewhat known</i> | <i>Very well known</i> | <i>I don't know</i> |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| <i>Among health professionals</i> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Within the community of people with TSC</i> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>In the general population</i> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

10. If you have experience of the following TSA activities in the past 12 months, how would you rate them?

| | Have you used this service in the last 12 months? | | How would you rate this activity, service or resource? | | | | | |
|---|---|--------------------------|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | <i>Yes</i> | <i>No</i> | <i>Poor</i> | <i>Fair</i> | <i>Good</i> | <i>Very Good</i> | <i>Excellent</i> | <i>Not Applicable</i> |
| A TSA fundraising event, such as Lizzie's Lunch | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| TSA's 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"/> |
| TSA facebook page | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| TSC Heroes facebook page | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| TSA on twitter | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| TSA on instagram | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Continued next page

| | Have you used this service in the last 12 months? | | How would you rate this activity, service or resource? | | | | | |
|--|---|--------------------------|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | Yes | No | Poor | Fair | Good | Very Good | Excellent | Not Applicable |
| TSC Information Service by phone or email | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Reach Out, TSA's magazine | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| TSA's website, including online information pages | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| The 'Discussions of TSC in Australia and New Zealand' 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"/> |
| Information sheet on the diagnosis, surveillance and management guidelines for TSC | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| The TAND checklist | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| TSC awareness cards | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Global awareness day picnic | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Surveillance and management guidelines for tuberous sclerosis

Tuberous sclerosis complex (TSC) is a genetic disease that may affect nearly every organ system. TSC affects people in many different ways and with different degrees of severity. Some symptoms of TSC can also progress at different rates in different individuals. The diversity and variation makes it challenging to determine what healthcare is needed to enhance the overall quality of life for people with TSC.

A multidisciplinary professional team around the world with expertise managing TSC have developed guidelines for the surveillance and management of TSC. These have been published in a series of peer-reviewed papers. This publication summarises these consensus guidelines to help people with TSC, their families and health professionals.

WHAT IS TSC?

Tuberous sclerosis complex (TSC) is a genetic disease that affects many organs and causes neurological symptoms in the brain, skin, heart, liver, eyes, ears, nose, mouth and teeth. TSC is a rare genetic disease that causes tuberous sclerosis complex (TSC) to be a genetic disease that affects many organs and causes neurological symptoms in the brain, skin, heart, liver, eyes, ears, nose, mouth and teeth. TSC is a rare genetic disease that causes tuberous sclerosis complex (TSC) to be a genetic disease that affects many organs and causes neurological symptoms in the brain, skin, heart, liver, eyes, ears, nose, mouth and teeth.

Recommendations for Newly Diagnosed Individuals

- Review the newly diagnosed individual's medical history, including family history, and discuss the implications of the diagnosis.
- Undergo an exam by an ophthalmologist to check for retinal hamartomas or other ocular lesions.
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- Undergo an exam by an ophthalmologist to check for retinal hamartomas or other ocular lesions.

THE TAND CHECKLIST
Lifetime version (TAND-L)

Tuberous Sclerosis Complex (TSC) is associated with a range of neuropsychiatric disorders which we refer to as TAND (TSC-Associated Neuropsychiatric Disorders). All people with TSC are at risk of having some of these difficulties. Some people with TSC have very few, while others will have many of them. Each person with TSC will therefore have their own TAND profile, and this profile may change over time. This checklist was developed to help clinical teams, individuals with TSC and their families to cover for TAND at every clinic visit and to prioritise what to do next.

Instructions for use

The TAND Checklist was designed to be completed by a clinician with relevant knowledge and experience in TSC, in partnership with individuals with TSC or their parents/careers. The Checklist should take about 10 minutes to complete. Where individuals answer 'YES' to an item, the clinician should explore the difficulty in sufficient detail to help guide decisions about further evaluation or treatment. All items should be completed.

About the interview

Name of TSC Subject: _____ DOB: [] [] [] [] [] [] Age: [] [] [] [] [] []
 Name of Interviewer: _____ Date of Interview: [] [] [] [] [] []
 Name of Interviewee: _____ Self / Parent / Caret / Other (tick)

Let's begin

As you will know, the majority of people with TSC have some difficulty in learning, behaviour, mental health, specific aspects of their development and so on. We are going to use this checklist to help us check for these kinds of difficulties. I am going to ask you a number of questions. Some may be directly relevant; some might not be relevant at all. Just answer as best as you can. At the end I will check to see if there are any additional difficulties we didn't talk about. For individuals with TSC who complete this about themselves, please start with question 3.

01 Let's begin by talking about [subject's] development to get a sense of where they are at. How old was [subject] when he/she:

- First smiled? Age: [] Not yet: []
- Sat without support? Age: [] Not yet: []
- Walked without holding on? Age: [] Not yet: []
- Used single words other than "mama" or "dada"? Age: [] Not yet: []
- Used two words/short phrases? Age: [] Not yet: []
- Was toilet trained during the day? Age: [] Not yet: []
- Was toilet trained at night? Age: [] Not yet: []

I am _____ and I have a rare genetic disease called tuberous sclerosis complex (TSC) which causes tumours to grow in vital organs. TSC affects people in many different ways and with different degrees of severity. People with TSC may experience seizures, autism, challenging behaviours and learning difficulties. I ask that you take this opportunity to learn more about TSC at www.tsa.org.au

Tuberous Sclerosis Australia

www.tsa.org.au
 1300 723 425
 We think all families with TSC should have someone to turn to. Help us make this a reality.

Clockwise from left: TSC awareness cards; information sheet on the diagnosis, surveillance and management guidelines for TSC; TAND checklist,

11. If someone you know was diagnosed with TSC, would you recommend TSA to them?

- Yes
 No
 Unsure

Tell us more:

12. When thinking about all your charity giving (not just to TSA), which of these applies to you?

- I make one-off donations
 I make regular donations through my credit card
 I make donations through payroll giving (make a donation from your pay every month)
 I have a gift planned in my will
 I donate to my friends participating in sporting and community events such as fun runs
 I fundraise by participating in sporting and community events such as fun runs
 I attend large charity events such as dinners and balls
 I attend smaller charity events such as morning teas
 I do not donate to any charities
 Other - please specify:
-

13. When you donate to TSA, or if you donated in the future, how would you prefer your gift to be used?

- Provide support for people living with TSC
 Fund research to find a cure
 Lobby and campaign to improve health care for people affected by TSC
 Raise awareness of TSC in the general public
 I have no preference and my gift can be used for the activity with the most need
 Other - please specify:
-

14. In July and August, we experimented with an online crowdfunding campaign. Did you see TSA's recent chuffed.org crowdfunding campaign?

- Yes No

If no, check it out at

<https://chuffed.org/project/tsc-2016>

15. What are some things you liked about this campaign?

16. What are some things you didn't like about this campaign?

TSA plans to develop a "soft landing" pack for families who receive a new diagnosis of TSC. This pack might include:

- Printed information on various aspects of TSC
- A soft toy mascot the child can take to hospital with them
- A children's book

17. Are you interested in helping us to fundraise for this project?

- Yes No

18. Are you interested to assist us with design and development of this pack?

- Yes No

19. And now for a bit of fun. We have been brain storming for a TSA soft toy mascot. Which do you like best?

- A TSC **tiger**: each one is unique with different stripes
- A TSC **leopard**: each one is unique with slightly different spots
- A TSC **lady bug**: each one unique with slightly different spots

20. For TSA to continue providing our services to the TSC community we need to grow our income. Which of the following ways to help interest you?

Become a TSC Hero and raise money for TSA

- Yes No

Hold a fundraising event with my friends and family

- Yes No

Join a TSA fundraising committee as a volunteer

- Yes No

Introduce TSA to a business I know that might support TSA

- Yes No

Recommend TSA to my workplace for payroll giving and/ or gift matching

- Yes No

Make a monthly donation to TSA as a TSC Champion

- Yes No

I have another idea of how I can help

- Yes No

Your contact details so we can follow up:

Name:

Phone number:

Preferred time for us to call:

Please fill in the remainder of the survey **ONLY** if you have TSC or care for someone with TSC

21. Please tell us which of the following affect you, the person you care for with TSC.

| | Do these affect you (or the person you know with TSC)? | | | If yes, how much of an impact does this have? | | | |
|--|--|--------------------------|--------------------------|---|--------------------------|--------------------------|--------------------------|
| | <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"/> |
| 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, including anxiety and depression | <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 signs of TSC, including facial angiofibromas | <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"/> |
| Eye tumours | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Liver tumours | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

22. 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.

If we can help you in managing life with TSC, please contact the TSC Information Service on 1300 733 435 or by emailing info@tsa.org.au.

In the next 12 months, TSA will be running a pilot project to deliver our educational events over the internet.

23. Please tell us if you have ever attended a face to face TSA educational event, such as a seminar day, conference or information day?

- Yes
- No

24. Have you previously participated in an online event such as a webinar e.g. related to your work?

- Yes
- No

25. Would you be interested in attending a webinar about an aspect of TSC?

- Yes
- No
- Unsure

26. If you were going to participate in an online event, what type of device would you use?

- A desktop or laptop computer
- A tablet such as an iPad
- A mobile phone such as an iPhone

27. Which of the following topics are of most interest to you? Please select up to three.

- Understanding the genetics of TSC
 - Learning about TSC research projects
 - mTOR inhibitor medicines (including everolimus, sirolimus, rapamycin, afinitor)
 - Guidelines for the surveillance and management of TSC
 - Managing anxiety in TSC
 - Treatment options for epilepsy in TSC
 - Strategies to manage challenging behaviour
 - Understanding and helping siblings of a person with TSC
 - Understanding the National Disability Insurance Scheme (NDIS)
 - Other - please specify:
-

28. Is there anything else you would like to share with the TSA team?

Thank you for completing the survey.