## 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 Tuberous 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 25<sup>th</sup> November 2016.

Thank you for taking part.

Shrly

Deb Crosby, TSA President



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 parent of an adult with TSC  I am the grandparent of a person with TSC	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
<ul> <li>☐ I am a professional treating people with TSC</li> <li>☐ I have a friend or relative with TSC</li> <li>☐ Other - please specify:</li> </ul>	<ul> <li>☐ I have held an event to raise money for TSA (e.g. morning tea, workplace or school event).</li> <li>☐ I have never made a financial contribution to TSA</li> </ul>
2. Please tell us your postcode:	6. Please tell us how you <u>first</u> heard about TSA.
3. Please tell us what age group you are in.   15 or under 25 - 34 35 - 44 35 - 54 55 - 64 65 - 74  75 or over	☐ 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
4. Please tell us how you heard about this survey.	7. Please tell us how long have you known about TSA
<ul> <li>□ An email from TSA</li> <li>□ Reach Out (the TSA magazine)</li> <li>□ Facebook</li> <li>□ TSA website</li> <li>□ Through a health professional</li> <li>□ Twitter</li> <li>□ Instagram</li> <li>□ Other- please specify:</li> </ul>	□ 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

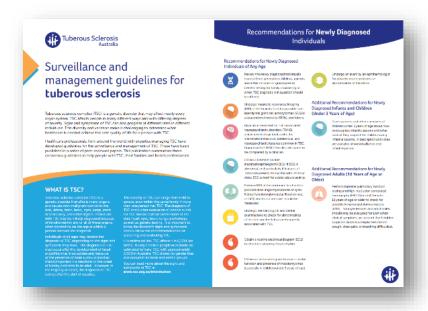


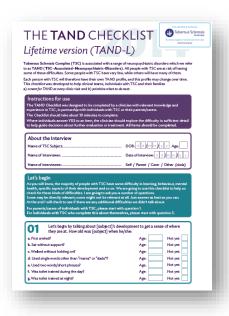
8. We know it can be difficult to explain TSC to other people. How confident are you when explaining TSC to others?									
Not confident at all	Not very con	fident	Somewhat confident		Quite Confident			Very confident	
9. In your experience, how well known do you think Tuberous Sclerosis Australia is in the following?									
				Somewh	pat	Very we	ell	I don't know	
		Unk	nown known		ı	known			
Among health professionals			]						
Within the community of po	eople with	ople with							
In the general population			<b>_</b>						
rate them?	Have yo this servi last 12 n	ce in the	Ноч	w would you	1 rate this :	activity, s	ervice (	or resource?	
	Yes	No	Poor	Fair	Good	Very Good	Excel	llent Not Applicable	
A TSA fundraising event, such as Lizzie's Lunch									
TSA's email newsletter									
TSA facebook page									
TSC Heroes facebook page									
TSA on twitter									
TSA on instagram									

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	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								
Reach Out, TSA's magazine								
TSA's website, including online information pages								
The 'Discussions of TSC in Australia and New Zealand' Facebook Discussion Group								
Information sheet on the diagnosis, surveillance and management guidelines for TSC								
The TAND checklist								
TSC awareness cards								
Global awareness day picnic								







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?	14. In July and August, we experimented with an online crowdfunding campaign. Did you seen TSA's recent chuffed.org crowdfunding campaign?				
☐ Yes ☐ No ☐ Unsure	□ Yes □ No				
Tell us more:	If no, check it out at <a href="https://chuffed.org/project/tsc-2016">https://chuffed.org/project/tsc-2016</a>				
12. When thinking about all your charity giving (not just to TSA), which of these applies to you?	15. What are some things you liked about this campaign?				
<ul> <li>□ I make one-off donations</li> <li>□ I make regular donations through my credit card</li> <li>□ I make donations through payroll giving (make a donation from your pay every month)</li> <li>□ I have a gift planned in my will</li> <li>□ I donate to my friends participating in sporting and community events such as fun runs</li> <li>□ I fundraise by participating in sporting and community events such as fun runs</li> <li>□ I attend large charity events such as dinners and</li> </ul>	16. What are some things you didn't like about this campaign?				
balls  I attend smaller charity events such as morning teas  I do not donate to any charities  Other - please specify:	TSA plans to develop a "soft landing" pack for families who receive a new diagnosis of TSC. This pack might include:				
13. When you donate to TSA, or if you donated in the future, how would you prefer your gift to be used?	<ul> <li>Printed information on various aspects of TSC</li> <li>A soft toy mascot the child can take to hospital with them</li> <li>A children's book</li> </ul>				
<ul><li>□ Provide support for people living with TSC</li><li>□ Fund research to find a cure</li></ul>	17. Are you interested in helping us to fundraise for this project?				
<ul> <li>□ Lobby and campaign to improve health care for people affected by TSC</li> <li>□ Raise awareness of TSC in the general public</li> </ul>	□ Yes □ No				
☐ I have no preference and my gift can be used for the activity with the most need ☐ Other - please specify:	18. Are you interested to assist us with design and development of this pack?				
	$\square$ Yes $\square$ No				



19. And now for a bit of brain storming for a T Which do you like bes	'SA soft toy mascot.	Your contact details so we can follow up: Name:
☐ A TSC tiger: each one stripes ☐ A TSC leopard: each different spots ☐ A TSC lady bug: each	one is unique with slightly	Phone number:
different spots	1 8 3	Preferred time for us to call:
20. For TSA to continue services to the TSC congrow our income. White ways to help interest y	ommunity we need to ich of the following	
Become a TSC Hero and rais		
Yes	•	
Hold a fundraising event with	my friends and family No	
Join a TSA fundraising comm	nittee as a volunteer l No	
Introduce TSA to a business	I know that might support	
$TSA$ $\square Yes$	l No	
Recommend TSA to my work and/or gift matching	kplace for payroll giving	
	l No	
Make a monthly donation to Champion	TSA as a TSC	
☐ Yes ☐	l No	
I have another idea of how I c	an help l No	



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?			
	Yes	No	I don't know	None	Minimal Impact	Moderate Impact	Severe Impact
Epilepsy							
Learning difficulties							
Intellectual disability							
Autism							
Challenging behaviour							
Mental health issues, including anxiety and							
depression SEGA brain tumour							
Skin signs of TSC, including facial angiofibromas							
Kidney tumours or cysts							
Lung issues (e.g. LAM)							
Eye tumours							
Liver tumours							
Other							

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	27. Which of the following topics are of most
a pilot project to deliver our educational	interest to you? Please select up to three.
events over the internet.	☐ Understanding the genetics of TSC
<ul> <li>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?</li> <li>□ Yes</li> <li>□ No</li> <li>24. Have you previously participated in an online event such as a webinar e.g. related</li> </ul>	<ul> <li>□ Learning about TSC research projects</li> <li>□ mTOR inhibitor medicines (including everolimus, sirolimus, rapamycin, afinitor)</li> <li>□ Guidelines for the surveillance and management of TSC</li> <li>□ Managing anxiety in TSC</li> <li>□ Treatment options for epilepsy in TSC</li> <li>□ Strategies to manage challenging behaviour</li> <li>□ Understanding and helping siblings of a person with TSC</li> </ul>
to your work?	☐ Understanding the National Disability Insurance
Yes	Scheme (NDIS)
$\square$ No	☐ Other - please specify:
25. Would you be interested in attending a webinar about an aspect of TSC?  ☐ Yes ☐ No ☐ Unsure	28. Is there anything else you would like to share with the TSA team?
26. If you were going to participate in an online event, what type of device would you use?  \[ \textstyle A \text{ desktop or laptop computer} \] \[ \textstyle A \text{ tablet such as an iPad} \] \[ \textstyle A \text{ mobile phone such as an iPhone} \]	

Thank you for completing the survey.

