

# Strategic Plan

## 1. Our vision for the lives of people affected by tuberous sclerosis (TSC)

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### 1.1. The impact of a diagnosis of TSC

Tuberous Sclerosis Australia is influenced by a comprehensive understanding of the impacts of TSC. This is informed by:

- Our lived experiences as individuals with TSC, parents, siblings, grandparents and friends of people with TSC
- Our research talking to people with TSC and their family members
- The insights we gain through our work in family support, at events and with professionals
- Academic research into the impacts of chronic health conditions, disability and genetic disorders

This can be summarised by these statements:

1. Although the diagnosis of TSC is given to an individual, it ripples through the family, community and our whole society
2. TSC is not one diagnosis. TSC is the underlying cause of a set of diagnoses unique to an individual that can change over time. This includes epilepsy, neuropsychiatric disorders, brain tumours, kidney disease, lung disease, skin tumours and much more.
3. There is no crystal ball that can predict how any individual will be affected by TSC. This fear in itself can be crippling.
4. All dimensions of wellbeing can be affected by TSC. This includes: physical, emotional, spiritual, social, education and work; financial, and time available to enjoy life. We know that for many people, getting the medical aspects of TSC under control can greatly improve other aspects of wellbeing.



Although the diagnosis of TSC is given to an individual, it ripples through the family, community and our whole society

## TSC is not just TSC



Epilepsy



Autism



Kidney tumours



Lung disease



...and more

And then there's the fear.

There's no crystal ball that can predict how any individual will be affected by TSC. This fear in itself can be crippling.

# All dimensions of wellbeing can be affected by TSC



"If we can get the medical aspects under control, then the other parts of our lives are easier"

## 1.2. With an effective Tuberos Sclerosis Australia, what is life like for people with TSC?

### They are **connected**

- To health services that provide best practice care
- To community, disability and social services to improve their wellbeing
- To a community of others experiencing similar challenges
- To someone who can provide direct emotional support

### They are **informed**

- With accurate, balanced and up to date information about TSC
- With knowledge of best practice management of TSC
- Of opportunities to be involved in research
- by being able to ask questions directly to TSA

### They are **empowered**

- To pro-actively manage their health and well-being
- by knowing TSA 'has their back' and represents their interests
- By knowing that research is driving us to new treatments and closer to a cure for TSC
- By living in a society that understands TSC

Our vision statement:

***TSA works to connect, inform and empower people affected by tuberous sclerosis complex as we work towards a cure for TSC***

## 2. How does TSA work towards this vision?

### 2.1. Our strategic objectives

#### Objective 1: Improve health services for people with TSC

##### Strategies

- Encourage the provision of best practice care for people with TSC, particularly in multi-disciplinary teams and through following the guidelines for management of TSC
- Work towards equitable access to TSC medicines and other treatments
- Influence policy in key areas that affect people with TSC and their families
- Encourage the interest and expertise of health professionals in TSC through the TSC professionals network

##### Activities

*We will put these strategies into place by:*

- Formally recognise existing TSC multi-disciplinary teams/clinics
- Complete the TSCi MDT toolkit to learn from experiences in other countries
- Provide printed summary of management guidelines in Reach Out
- Be involved in updates to management guidelines
- Advocate for government funding of topical mTOR inhibitor medicine
- Work in partnership with peak bodies including Consumer's Health Forum and Rare Voices Australia to provide input from TSC affected people in key policy discussions
- Fill gaps in the TSC Professionals Network
- Award the Elizabeth Pinkerton Memorial Award to recognise health professionals

*New activities:*

- Advocate for listing of abdominal MRIs on the medicare benefits schedule
- Work with existing clinics to assist them to strengthen and improve their services
- Work with potential clinic directors to understand barriers to offering multi-disciplinary team care and how they can be overcome.
- Develop white paper, video or other communication to explain the importance of coordinated care
- Identify barriers to adoption of the guidelines and ways these barriers can be overcome
- Develop a GP information pack
- Start a regular email communication with members of the TSC Professionals Network
- Develop a plan for the TSC Professionals Network by consulting with its members

##### Outcomes

*We will know we have been successful because:*

- All people with TSC will be able to access multi-disciplinary team care if they want to
- There is high awareness of TSC management guidelines amongst people with TSC and their families
- There is high awareness of TSC diagnosis and management guidelines amongst health professionals
- There is high adherence to TSC diagnosis and management guidelines
- Medicines and other treatments for TSC are available in the public health system (e.g. pharmaceutical benefits schedule, medicare)
- Topical mTOR inhibitor medicine is accessible to all Australians without significant cost
- TSA makes submissions in key policy decision areas and this input is reflected in final policy positions and reports
- The TSC professionals directory includes each key specialist in each age range in each state
- The TSC professionals directory is valued by its members

## Objective 2: Encourage research into TSC

### Strategies

- Directly fund research, particularly in Australia
- Encourage funding for research from other sources
- Represent the voice of the patients and in research planning and design
- Assist with recruitment to research studies
- Promote research projects and outcomes

### Activities

*We will put these strategies into place by:*

- Influence global TSC research through TSC International activities
- Publish news articles about TSC research, particularly Australian research through our website, magazine, email newsletter and social media

*New:*

- Establishing an Australian TSC research fund, with related priorities and governance
- Identify research funding opportunities, including government and philanthropic funds and raise their awareness of TSC
- Raise awareness of research funding opportunities with TSC researchers in Australia
- Develop and strengthen relationships with Australian researchers to understand their work and provide input from the perspective of people affected by TSC.
- Facilitate communication between researchers in Australia
- Seek media opportunities for promoting TSC research

### Outcomes

*We will know we have been successful because:*

- Australian TSC research fund will be established and used to fund TSC research
- Australian TSC researchers are accessing other sources of research funding
- The amount of TSC research done in Australia increases
- TSC research is designed to address the concerns of people affected by TSC and meets their needs as participants
- TSC affected people know about research projects they can participate in
- The achievements of TSC research are known about by people affected by TSC
- The achievements of TSC research are promoted in the general media

## Objective 3: Publish and promote TSC information

### Strategies

- Publish accurate, balanced and up to date information about TSC
- Hold TSC information events for people with TSC, their families and health professionals.
- Publish and promote information relevant for people living with TSC, their families and professionals
- Promote TSC information through various channels including: face-to-face, printed, website, social media, email

### Activities

*We will put these strategies into place by:*

- Publish Reach Out twice per year
- Update and expand on our TSC Information Pages
- Maintain the TSA Resource Directory, part of the TSA website
- Develop one new 'Just between us' article for each issue of Reach out
- Hold the 2015 Australian TSC Conference in November
- Maintain TSA website
- Maintain TSA facebook page

### New

- *Hold webinars on various TSC topics in 2016*
- *Hold regional conference series in 2016/17*
- *Hold grandparent information events*
- *Conduct an evaluation of our information services*

### Outcomes

*We will know we have been successful because:*

- People with TSC can access the information they need on the TSA website
- Attendees at information events tell us they have learnt new things that will influence their behaviour
- Our communications including websites, magazine, information pages are all visible on multiple platforms and are viewed as reliable and credible sources of TSC information

## Objective 4: Provide direct support and facilitate peer support for people affected by TSC

Strategies	Activities	Outcomes
<ul style="list-style-type: none"><li>• Provide the TSC Information service that can listen, answer questions and connect people to services that can help them.</li><li>• Connect people affected by TSC to professionals and services that can help them</li><li>• Provide opportunities for people with TSC to connect online and face to face</li><li>• Encourage fundraising activities that provide peer support opportunities</li></ul>	<p><i>We will put these strategies into place by:</i></p> <p>Existing</p> <ul style="list-style-type: none"><li>• Develop a standard process for the TSC Information service, including how the service is evaluated</li><li>• Maintain the TSC professionals network to connect people with TSC to professionals knowledgeable in TSC</li><li>• Manage the 'Discussions' facebook page along with TSCNZ</li><li>• Hold yearly social events in each area for global awareness day</li><li>• Hold the 2015 Australian TSC Conference in November</li><li>• Encourage TSC Dads and others to join the TSC Heroes fundraising team in various events around Australia</li></ul> <p>New</p> <ul style="list-style-type: none"><li>• <i>Improve availability of the TSC information service</i></li><li>• <i>Establish a TSC Connect program that trains and matches peer support volunteers</i></li><li>• <i>Support volunteer regional contacts to foster networks of families living with TSA around Australia</i></li><li>• <i>Hold regional conference series in 2016/17</i></li><li>• <i>Hold grandparent information events</i></li></ul>	<p><i>We will know we have been successful because:</i></p> <ul style="list-style-type: none"><li>• Our TSC Information service meets defined service levels</li><li>• We can connect people affected by TSC to health professionals in their area</li><li>• People affected by TSC are able to meet someone else in their local area</li><li>• People with TSC are able to connect online</li><li>• Regional contacts feel supported in their role</li><li>• TSC Heroes fundraising team grows and creates connections between people affected by TSC.</li></ul>



## Objective 5: Ensure sustainable funding for our work

### Strategies

- Increase our fundraising reach into the family and friends of those affected by TSC
- Secure project specific grant funding to expand our services

### Activities

*We will put these strategies into place by:*

- Growing the TSC Heroes fundraising team
- Hold Lizzie's Lunch each year
- Identifying specific projects for pharmaceutical company funding

*New*

- *Rolling out the network campaign to willing TSC affected families*
- *Supporting TSC affected families to host their own version of 'Lizzie's Lunch'*
- *Encouraging diverse forms of giving such as salary sacrifice, employer matching, bequests.*
- *Defining grant-ready projects and a plan for securing grant funding*
- *Build relationships with business and corporate partners*

### Outcomes

*We will know we have been successful because:*

- Fundraising income to increase by 30% each year
- Funding secured from multiple funding sources

## Objective 6: Grow TSA as a reputable, well-governed organisation

### Strategies

- Adopt governance practices that uphold responsibility, accountability, transparency and compliance.
- Develop and implement our people strategy

### Activities

*We will put these strategies into place by:*

- Develop new policies and a rolling review of existing policies
- Expand the TSA team for achieve our goals and improve succession planning
- Consult with our stakeholders through more regular conversations, surveys and consultations.

### Outcomes

*We will know we have been successful because:*

- TSA will meet all of its regulatory requirements
- TSA stakeholders, particularly members, will have input into TSA activities.
- Staff retention will be high and all staff will have training and development plans

## 2.2. Our values

This is in addition to the comprehensive understanding of the impacts of TSC as described earlier in this document.

**Diversity** – we recognise everyone’s unique experiences and contribution

**Excellence** – our services and activities are of high quality

**Equity** – we aim to provide services that are accessible by all people with TSC, wherever they live in Australia.

**Openness** – our decision making and communications are clear and transparent

**Independence** – we value our independence and are accountable to TSA members

**Partnership** – collaboration with other organisations and individuals is critical to achieve our vision