

# Tuberous Sclerosis Australia Strategic Plan

Last updated 27 November 2017

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

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### 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.



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## TSC is not just TSC



Epilepsy



Autism



Kidney tumours



Lung disease

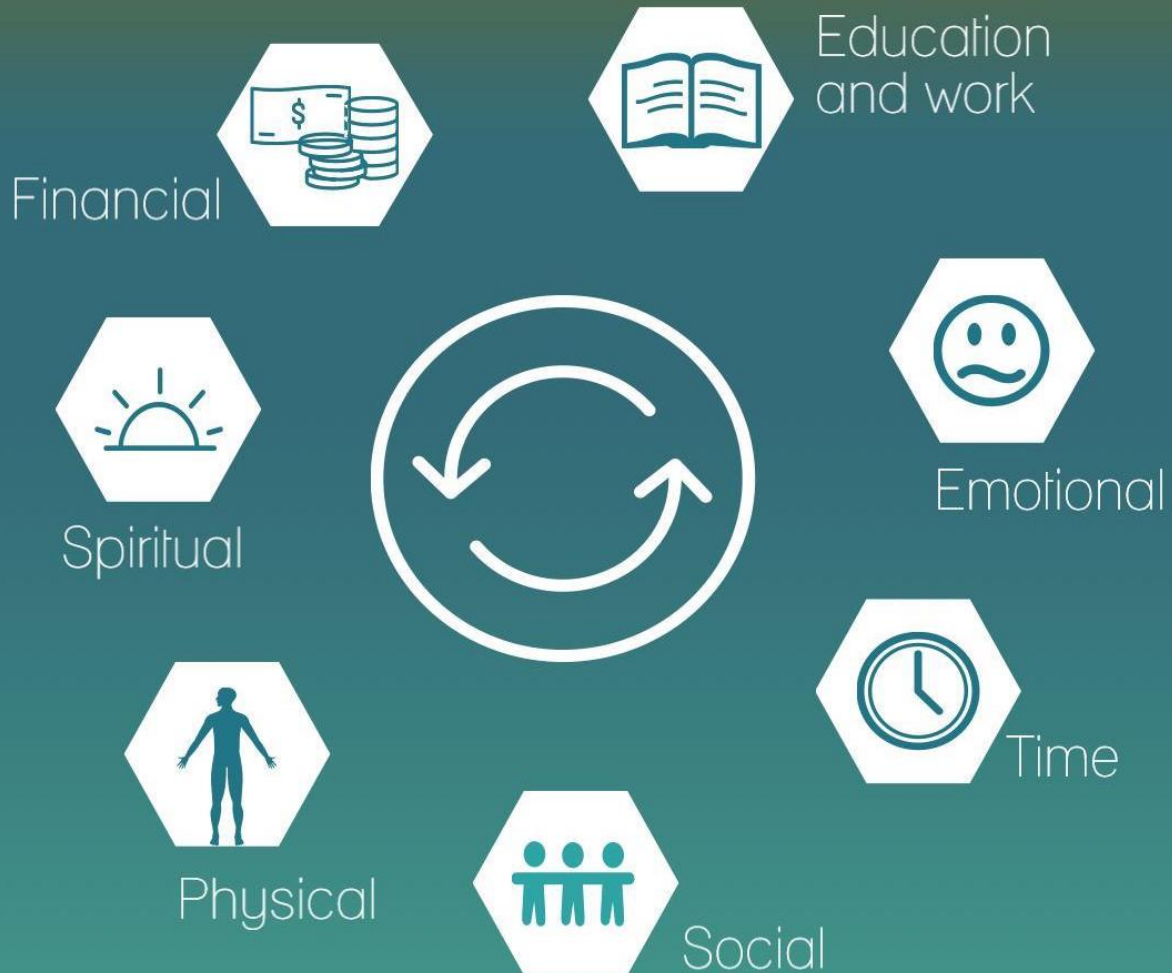


...and more

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"

## 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:

***Together we can a better life and a more hopeful future for every individual with TSC***

What we actually do (corresponds to our strategic objectives, but just the mission related ones):

- Ensure Australians with TSC have access to the best possible healthcare
- Provide up to date and accurate information to all Australians with TSC
- Support individuals and families affected by so no one has to face the challenges of TSC alone
- Champion an active research program in Australia that works towards a cure for TSC

## 2. Our values

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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

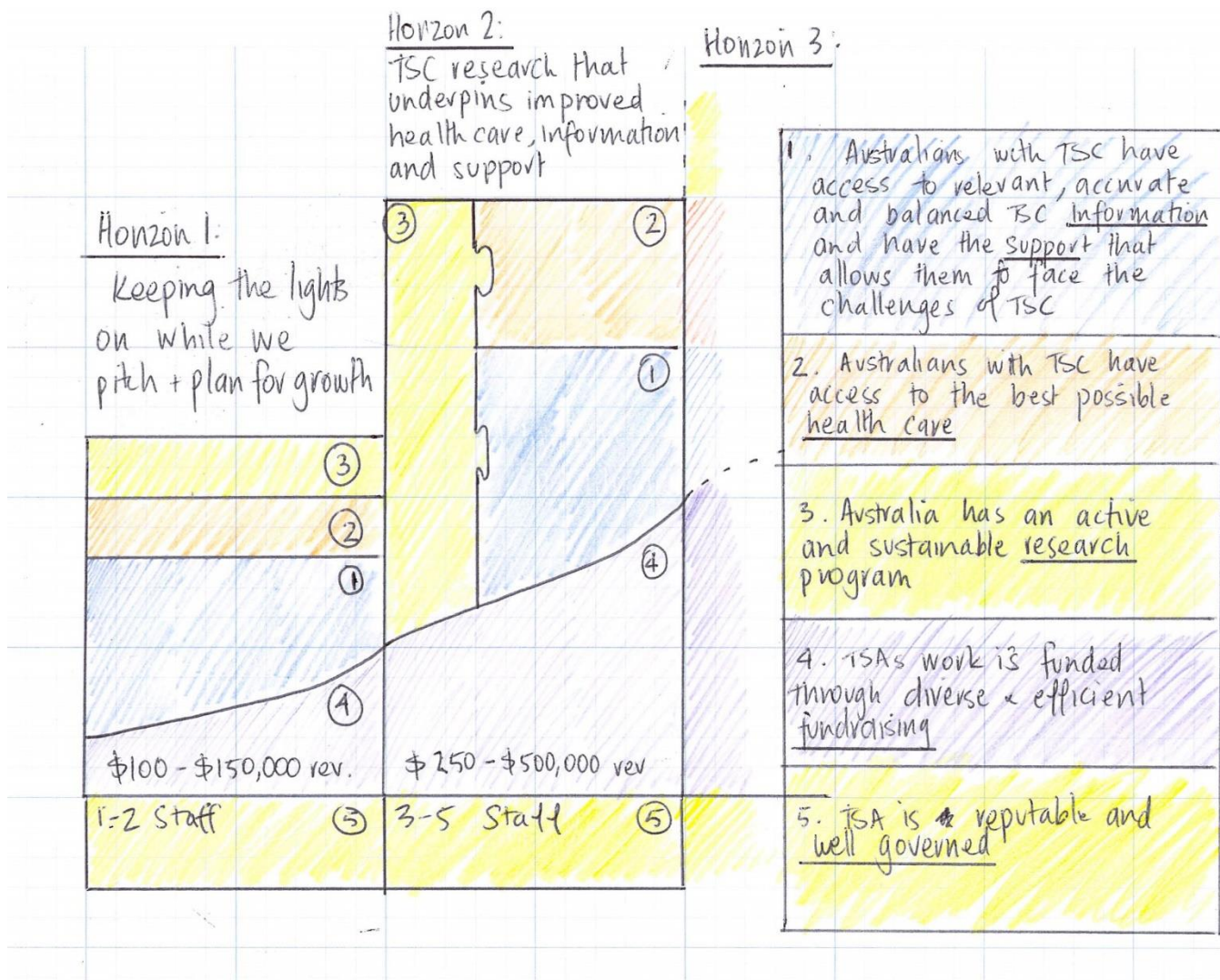
### 3. Our growth strategy

When considering our assets, revenue and team size, TSA is small. TSA is too small to confidently achieve its vision. Our growth strategy aims to increase funding and team size in order to deliver more projects that work together to achieve our vision.

Horizon 1: 2017-2018

Horizon 2: 2019-2022

Horizon 3: 2023 and beyond



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

### Goal 1: Australians with TSC have access to relevant, accurate and balanced TSC information and have the support that allows them to face the challenges of TSC

#### 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
- Provide the TSC Information service that can listen, answer questions and connect people to health and other services that can help them.
- Provide opportunities for people with TSC to connect online and face to face
- Encourage fundraising activities that provide peer support opportunities

#### Activities

##### *Horizon 1: Provide basic information and someone to turn to*

- Maintain the TSC Information Service
- Publish Reach Out twice per year as a focus for sharing new TSC information, including one new 'Just between us' article for each issue of Reach out
- Keep our TSC Information Pages up to date
- Maintain TSA facebook page, website and email as communication channels
- Hold occasional face to face education events in various locations
- Hold occasional online webinars
- Maintain the TSC professionals network to connect people with TSC to professionals knowledgeable in TSC
- Manage the 'Discussions' facebook page along with TSCNZ
- Encourage people living with to join the TSC Heroes fundraising team in various events around Australia
- Support volunteer regional contacts to foster networks of families living with TSA around Australia, including social events such as annual picnics
- Publish TSC picture book for children, adapting the Mito book

##### *Horizon 2: Improved access to more tailored information and support services*

- Hold grandparent information events
- Complete an evaluation of our information services
- Develop a plan for local peer support that builds on current work done by regional contacts. For example, establish a TSC Connect program that trains and matches peer support volunteers.
- Develop peer support for specific sub-groups e.g. the TSC Man Cave for Dads of TSC children, more for teens and adults living with TSC
- Develop information packages suitable for specific audiences, e.g. parents of those newly diagnosed with TSC, grandparents, schools

#### 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
- Our TSC Information service meets defined service levels
- We can connect people affected by TSC to health professionals in their area
- People affected by TSC are able to meet someone else in their local area
- People with TSC are able to connect online
- Regional contacts feel supported in their role
- TSC Heroes fundraising team grows and creates connections between people affected by TSC.

- Consider TSA's role in the National Disability Insurance Scheme (NDIS)

*Horizon 3 might include:*

- Comprehensive education and support services for all people impacted by TSC throughout their lifetimes that is integrated with health, education and disability services.



## Goal 2: Australians with TSC have access to the best possible health care

### 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

*Horizon 1: Help people with TSC navigate health systems and ensure their needs are represented in decisions made by others*

- Through TSC International activities, be involved in updates to TSC management guidelines and learn from other TSC organisations around the world
- 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
- Award the Elizabeth Pinkerton Memorial Award to recognise health professionals
- Advocate for reimbursement of new medicines that are being considered by the PBAC
- Fill gaps in the TSC Professionals Network
- Develop a plan for the TSC Professionals Network by consulting with its members
- Start a regular email communication with members of the TSC Professionals Network

*Horizon 2: Move TSC health services in Australia towards world best practice*

#### **Establish and strengthen TSC Centres**

- Formally recognise existing TSC multi-disciplinary teams/clinics
- 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.
- Identify barriers to getting patients connected to TSC Expert Centres and how these can be overcome

#### **Develop a strong TSC Professionals Network**

### 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 among people with TSC and their families
- There is high awareness of TSC diagnosis and management guidelines among 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

- Implement the plan for the network as developed in consultation with the network members. This might include: specific network publications and project, involvement of other specialists. E.g. radiology.

**Implement the TSC management guidelines in Australia**

- Identify barriers to adoption of the guidelines and ways these barriers can be overcome. For example, this might involve advocating for listing of abdominal MRIs on the Medicare benefits schedule
- Advocate for government funding of topical mTOR inhibitor medicine to improve access
- Develop a GP information pack to equip GPs to play their role in care coordination and primary health care for people with TSC
- Education activities such as grand rounds to improve and update TSC knowledge amongst medical professionals

*Horizon 3 might include:*

- Work directly with health services to formalise a TSC model of care and secure policy commitment to providing this to all Australians with TSC
- TSA takes an active role in health service provision such as providing care coordination or counselling services
- Creation of TSC fellowships to ensure we have an ongoing stream of motivated and skilled TSC professionals

## Goal 3: Australia has an active and sustainable TSC research program

### Strategies

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

### Activities

#### *Horizon 1: Take advantage of available research opportunities*

- 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
- Develop and strengthen relationships with Australian researchers to understand their work and provide input from the perspective of people affected by TSC.

#### *Horizon 2: Create a TSC research agenda in Australia that underpins high quality health care, information and support for people with TSC*

- Conduct and/or fund research projects that improve the quality of TSA's Information and support and improving health care goals
- Establishing an Australian TSC research plan and funding program, with related strategy and governance
- Identify research funding opportunities, including government and philanthropic funds and raise their awareness of TSC
- Set specific goals to ensure Australia continues to participate in key international clinical trials and other research projects

#### *Horizon 3 might include:*

- Plans developed in horizon 2 are implemented, particularly big ideas and collaborations. For example, a comprehensive TSC registry as a piece of research infrastructure, formal ongoing collaborations with medical research organisations.

### Outcomes

*We will know we have been successful because:*

- There is funding available for Australian TSC research
- Australian TSC researchers are accessing other sources of research funding
- The amount of TSC research done in Australia increases
- Australians with TSC have access to new treatments through clinical trials
- 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

## Goal 4: TSA's work is funded through diverse and efficient fundraising

### Strategies

- Increase our fundraising reach into the family and friends of those affected by TSC
- Define and document projects in need of funding
- Launch new fundraising campaign or event
- Secure project specific funding to expand our services
- Improve donor care

### Activities

*Horizon 1: Streamline and strengthen existing activities; revenue \$100,000 - \$150,000pa*

- Growing the TSC Heroes fundraising team
- Holding Lizzie's Lunch each year
- Identifying specific projects for funding
- Reinvigorating the Imagine Postcard campaign
- Improving quality and timeliness of donor thank you communication
- Strengthen TSA's Membership Program
- Utilise social media to inspire community support and increase awareness
- Supporting TSC affected families to host their own fundraising events

*Horizon 2: Dreaming big, increase revenue to \$250,000pa*

- Encouraging diverse forms of giving such as regular giving, workplace giving, employer matching, and bequests.
- Defining grant-ready projects and a plan for securing grant funding
- Develop systems for recording projects in need of funding, approaches and funding secured
- Build relationships with business and corporate partners to create major sponsor partnerships for specific projects
- Launch new major fundraising event/campaign(s)

*Horizon 3: Support truly world-changing work; increase revenue to \$1 million pa*

### Outcomes

*We will know we have been successful because:*

- We meet our horizon 1 and 2 revenue goals
- Funding secured from multiple funding sources
- New fundraising sources secured
- Fundraising activities have expanded and diversified
- We consider the efficiency of our fundraising activities throughout our planning and decision making processes
- Donors, members and supporters feel engaged and appreciated

## Goal 5: TSA is strong, reputable and well-governed

### Strategies

- Maintain our governance practices that uphold responsibility, accountability, transparency and compliance.
- Proactively manage the growth of our staff and volunteer teams to ensure we have the right people to deliver our work
- Invest confidently in our growth while ensuring we remain a highly cost-effective organisation

### Activities

We will put these strategies into place by:

#### Horizon 1:

- Develop new policies and continue our rolling review of existing policies. Our 2017/18 priorities are our code of ethics, risk management, financial procedures
- Actively work on our succession planning and management of our key person dependencies
- Consult with our stakeholders through more regular conversations, surveys and consultations.
- Encourage our volunteers to take advantage of training opportunities

#### Horizon 2:

- Recruit new staff to drive our work in two main areas:
  - Information and support
  - Research and Improving health care
- Use the flexibility of contractors and suppliers to manage risk and access required specialist skills and experience.
- Consider the roles of sub-committees and advisory groups as we grow

### 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