



Strategic Plan : 2009 - 2011

24 October 2008

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Executive Summary: Plan on a page

This strategic plan is intended to guide the Australasian Tuberous Sclerosis Society (ATSS) for 2009 through 2011. The key contributors to this plan were:

- committee members
- medical advisors
- attendees at the 2008 Seminar Day

This document provides the detail of the plan along with information about how the plan was developed.

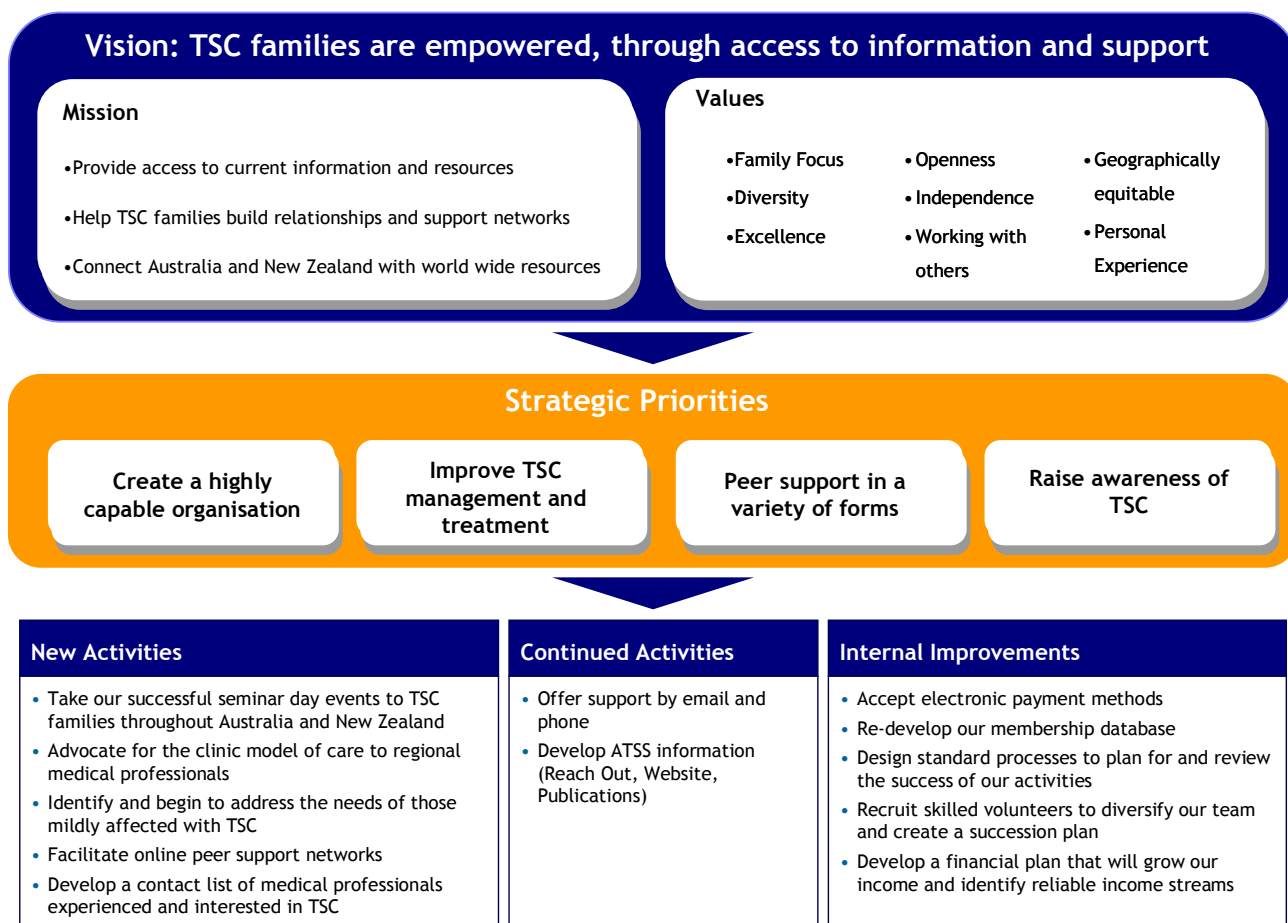


Figure 1: Plan on a page

Introduction

Why Strategic Planning?

As ATSS grows, a plan will be a necessary tool to guide the organisation. It will:

- allow us to agree and communicate a common vision and goals
- ensure we focus limited resources (including money and time) into priority areas
- Develop a consensus and sense of ownership over the plan
- Provide a base to measure success against

Framework for Strategic Planning:

ATSS used a 4 step framework for strategic planning.

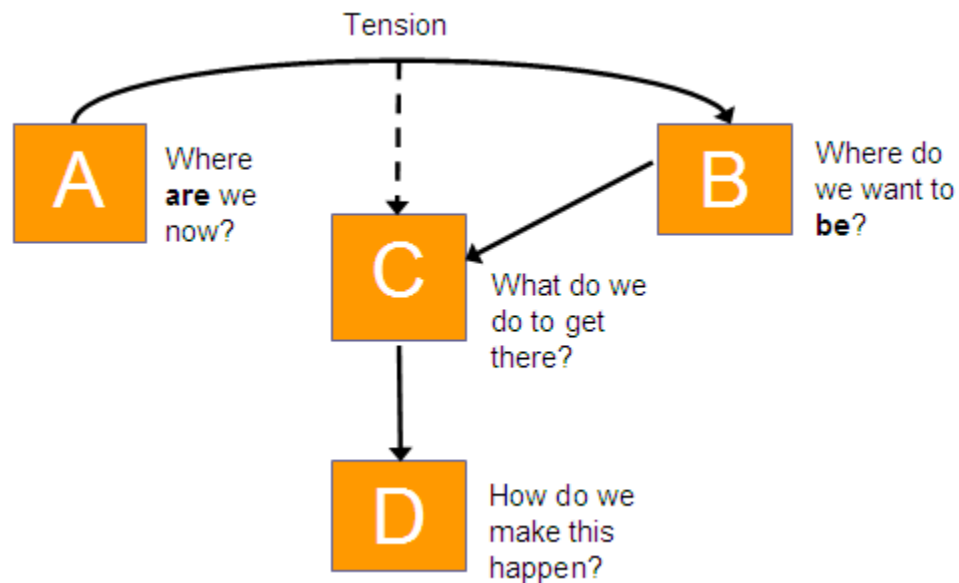


Figure 2: Framework for Strategic Planning

Step A: Where are we now?

The objective of Step A is to gain a shared understanding of the current situation ATSS is in. This will be used as a key input to formulating ATSS's plan for the next 3-5 years, many of which will be building upon strengths and opportunities and addressing weaknesses and threats.

This section presents a current state view, structured into a SWOT analysis i.e. Strengths, Weaknesses, Opportunities, Threats.

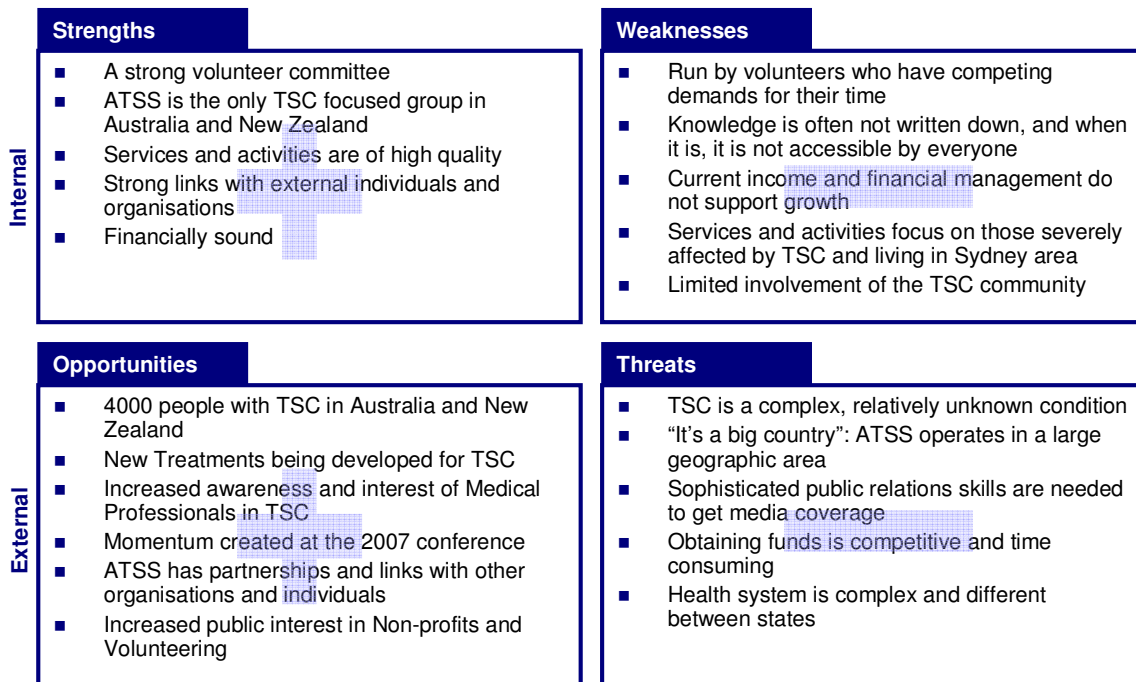


Figure 3: Summary of SWOT Analysis

Strengths: *Positive aspects of ATSS*

A strong volunteer committee

The ATSS committee is elected from ATSS members. All committee members have a personal connection with TSC:

- They have TSC or
- Someone in their family has TSC

This personal connection has resulted in a committee with a good understanding of the many aspects of TSC. They are also passionate about the work that ATSS does and willingly volunteer their time for little recognition or reward.

Many committee members have been in the same roles for a number of years, so responsibilities are well understood and members have built skills required for their roles. The committee also uses a variety of tools to work together, primarily email and teleconferencing.

ATSS is the only TSC focused group in Australia and New Zealand

ATSS is not competing with any other group in either Australia or New Zealand, so there are not wasted resources duplicating services.

ATSS also has a long history of being this key organisation as the society was founded 25 years ago.

Services and activities are of high quality

With limited resources, ATSS has been very successful in providing services to its members and in other activities supporting its mission.

Key services and activities:

- A professional quality DVD (*You are not Alone*) was produced in 2007
- A joint Medical and Family Conference (*From Pathways to Therapies*) was held in 2007
- Established genetic testing facilities in conjunction with SEALS
- Central contact points in the website and 1300 number
- The journal, Reach Out, connects isolated families

Strong links with external individuals and organisations

ATSS has developed links with both other organisations and key medical professionals, establishing a reputation as a professional and positive organisation.

Key links are:

- Drs David Mowat and John Lawson at the Sydney Children's Hospital and Randwick. These Drs are now ATSS Medical Advisors and have been instrumental in recent activities such as the DVD and 2007 conference
- Links with the peak international Tuberous Sclerosis organisations, namely TS Alliance in the United States and TSA in the United Kingdom. Through the more informal organisation Tuberous Sclerosis International (TSI), ATSS is also in contact with other national organisations. These links have been re-enforced at international medical meetings, although could be strengthened further.

Financially sound

ATSS has a sound financial position that supports current operations.

- Assets are approximately \$50,000
- Reliable income from regular donations covers operating costs such as insurance and administrative costs
- Most projects and activities break even or make a small profit or loss. This is primarily due to ATSS receiving project-specific grants

Weaknesses: Challenging aspects of ATSS

Run by volunteers who have competing demands for their time

ATSS has no paid employees, the committee members and regional coordinators are all volunteers. They are also dispersed throughout Australia. Relying on these volunteers to deliver the services and activities of ATSS has a number of limitations:

- Majority of these volunteers are juggling employment and commitments to families that are affected by TSC. The time that they have available for ATSS work fluctuates, making it difficult to deliver to fixed timeframes.
- The skills available to ATSS are limited to those the committee brings with them, often from their paid employment. Particular skills gaps in media and public relations have been identified.
- The volunteers have limited face-to-face contact outside of the quarterly committee meetings. Momentum builds around the committee meetings and significant events and is difficult to sustain outside of these times. Volunteers in other states often have face-to-face contact with each other every few years through attendance at ATSS conferences. Although teleconferencing has been used to involve remote committee members, it is of limited effectiveness.
- A limited number of committee members are actively involved with the day-to-day running of ATSS, while others contribute primarily to particular events or activities.
- Many operational processes are inefficient. For example, a cheque received for membership is handled by the assistant treasurer, treasurer and membership secretary before it is completely processed.
- No succession plans if a volunteer is no longer able to contribute their time. This is particularly of concern for the role of President, who is the primary driving force in ATSS.
- Committee members build up skills and ideas over the time that they are involved with ATSS and there is a risk that these skills and ideas will be lost if a volunteer leaves ATSS.

ATSS knowledge is often not written down, and when it is, it is not accessible by everyone

One of the primary functions of ATSS is providing information, however the information that ATSS has is not well managed:

- A lot of knowledge is not written down. For example, Sue Pinkerton (President) maintains links and contacts with several key people, knows the medical professionals that are experienced in TSC and how to deliver many ATSS events. If someone else in ATSS needs this information, Sue needs to be contacted.
- When information is written down, it is often not accessible to all volunteers. For example, Belinda Humphrey (Treasurer) maintains all accounting information and summary reports are presented at the committee meetings. However if more detail is required, Belinda would have to be involved in extracting this information from the financial records on her personal computer. Paper files are stored in various Committee members' homes.
- Information is disparate and disconnected. For example, the list of ATSS members is maintained in one database, and not connected with the lists of who attends ATSS events, uses the website or calls the 1300 number.

Current income and financial management do not support growth

ATSS is reliant on donations to cover operating costs. These donations are primarily through membership fees and small gifts (under \$500) from a portion of ATSS members and friends.

A number of key weaknesses in finance have been identified:

- To grow ATSS, a larger, more reliable income stream would be required. Some key costs in space and employees would be incurred if ATSS is to grow beyond its current structure and activities.
- Grants for projects are received at the initiative of a small number of committee members on an ad-hoc basis
- Donations are limited as ATSS only accepts payments via cheque. This not only limits donations, but creates additional work in receiving, banking and receipting donations.
- There are currently no financial plans or budgets in place to ensure that income needs are met. Financial management is primarily through cash basis accounting, making it difficult to forecast and plan.

Services and Activities focus on those severely affected by TSC and living in Sydney area

The majority of services and activities are focused on the Sydney area. This is a result of the majority of committee members being based in Sydney.



Links with external organisations and individuals, particularly medical professionals, are also centered on Sydney.

Services are also focused on those more severely affected with TSC.

ATSS has been making an effort to shift this focus. This includes obtaining grants to bring those interstate to conferences, supporting regional coordinators to organise events in their areas and including topics in conferences that are relevant to adults mildly affected with TSC.

Limited involvement of the TSC community

The incidence of TSC in the population is estimated to be 1 in 6000. This extrapolates to approximately 4000 people in Australia and New Zealand with TSC. ATSS is in regular contact with approximately 200 members, and this involvement is primarily one-way from ATSS e.g. Receiving Reach out, attending events. There is limited feedback and new ideas from the TSC community to ATSS. Most TSC families do not bother joining ATSS.

This lack of involvement means that it is hard for ATSS to determine how well they are meeting the needs of TSC families. Reach Out is only published twice a year and could also be improved through more contributions from the TSC community.

Opportunities: *Positive Elements Outside of ATSS*

4000 people with TSC in Australia and New Zealand

Tuberous Sclerosis is not a rare condition. There are a significant number of people in Australasia with TSC that can benefit from ATSS's services.

New Treatments being developed for TSC

Recent scientific achievements have begun to manifest themselves in new treatments for TSC. The key example of this is Sirolimus (Rapamycin). These new treatments offer an opportunity for ATSS be involved in access to these medications for people in Australia and New Zealand with TSC.

Increased awareness and interest of Medical Professionals in TSC

Medical professionals are taking an increased interest in TSC. This may be due to better diagnosis leading to professionals encountering more people with TSC or research advancements generating interest.

ATSS has already been able to develop relationships with Drs David Mowat and John Lawson, who have been involved in production of the DVD *You are Not Alone* and organising the 2007 Conference *From Pathways to Therapy*. These doctors are also actively establishing themselves as TSC experts in Australia and attend international meetings to develop this knowledge and their networks.

Medical professionals and the public hospital system may also provide opportunities for ATSS to reach out to TSC families throughout Australia and New Zealand.

Momentum created at 2007 conference

The 2007 conference was attended by a large number of TSC families, relative to other events. This event facilitated lots of new connections between TSC families being made and new ideas and energy for ATSS. This energy can be used a springboard for new initiatives.

In addition, the event raised the profile of ATSS among medical professionals.

ATSS has partnerships and links with other organisations and individuals

The links that ATSS has developed with other organisations provide a number of opportunities:

- The SEALS laboratory for genetic testing for TSC has been established. ATSS's involvement with this project is an opportunity for further development: with SEALS, with the broader South East Area Health Service and with TSC families that use the laboratory service.
- Epilepsy Action and ASPECT provide specialist resources for aspects of TSC. ATSS has good relationships with these growing organisations and there are further opportunities for developing these.
- Larger, International TSC organisations have more resources than ATSS and can provide a lot of information and support to ATSS.

Increased public interest in Non-profits and Volunteering

There is increased public interest in non-profit organisations. This means that funding from private sector foundations is available. In addition, corporate volunteering is increasing, with a strong demand for opportunities for teams and individual from the private sector to contribute to non-profit work.



Threats: *Negative Elements Outside of ATSS*

TSC is a complex, relatively unknown condition

TSC is a difficult condition to explain and varies in how it affects each individual. This results in:

- TSC is a difficult condition to raise public awareness of.
- Medical professionals are, on the whole, not familiar with TSC. This provides ATSS with a steep learning curve to educate these professionals
- TSC is often grouped with 'rare' conditions and the true complexity of TSC is not understood

"It's a big country": ATSS operates in a large geographic area

Australasia is a large area with a dispersed population. This makes it difficult and more expensive to provide services to people.

One of the major challenges faced by TSC families is navigating the health system. The system also differs between states, so is difficult to understand. ATSS faces a challenging role in supporting families in these various systems. In addition, there is a difficult transition between pediatrics and adult systems.

Sophisticated public relations skills are needed to get media coverage

The media may have a large part to play in raising awareness of TSC with the general public. However, to effectively use the media to achieve ATSS goals and get the desired message out, public relations skills are required. ATSS does not currently have these skills.

Obtaining funds is competitive and time consuming

Although grants are available to provide funding, grant processes are becoming more and more time consuming. In addition, there is fierce competition for funding, so effort must be spent on finding appropriate grants and tailoring applications and projects to meet funding requirements.

Step B: Where do we want to be?

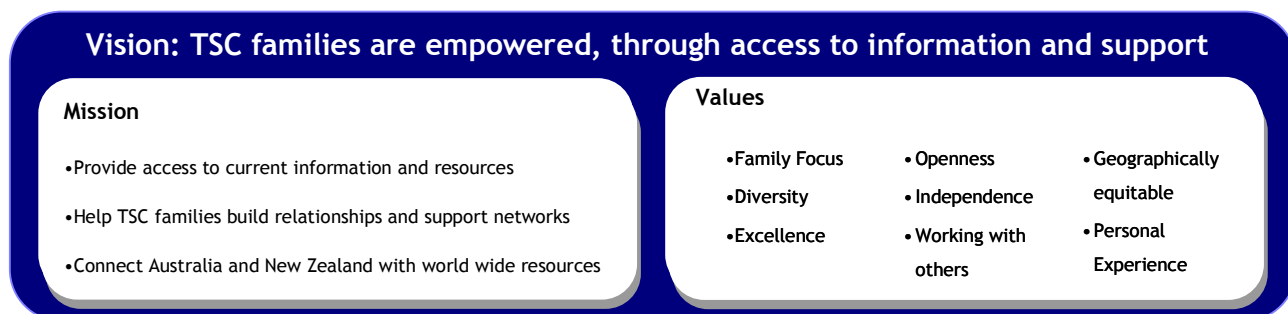


Figure 4: Summary of 'Where do we want to be?'

Vision

TSC families are empowered, through access to information and support

Support means different things to different people. To ATSS, support includes medical, educational and emotional support.

Mission

ATSS's mission is to:

- Provide access to current information and resources
- Help TSC families build relationships and support networks
- Connect Australia and New Zealand with world wide resources

Values

Family Focus	We understand that TSC affects the whole family
Diversity	We respect diversity and recognize everyone's unique experience and contribution
Excellence	Our services and activities are of high quality
Openness	Our decision making and communications are clear and transparent
Independence	We will maintain our independence and be accountable to ATSS members

Working with others	TSC is a diverse condition. We will collaborate with other organisations and individuals to achieve our vision
Geographically equitable	We acknowledge that TSC affected families live throughout Australia and New Zealand, in urban and rural areas. We will attempt to make our services accessible to all
Personal Experience	We are personally connected through our experience of TSC



Step C: What do we do to get there?

Strategic Priorities

We have identified the following priority areas for the next 3-5 years.

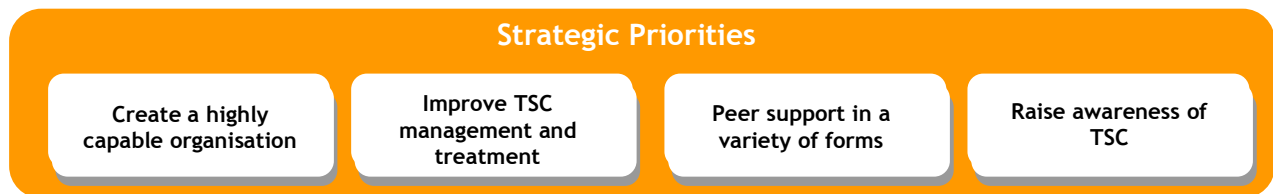


Figure 5: Strategic Priorities

Create a highly capable organisation

- Generate appropriate funding and put it to good use
- Share knowledge of how we work
- Get the right people involved to achieve our vision

Improve TSC Management and Treatment

- Advocate for high quality care and best available treatments for TSC affected people
- Empower TSC families to access the care they need
- Support research that leads to improved management and treatment of TSC

Peer Support in a variety of forms

- Provide opportunities for people affected by TSC to connect and support each other
- Ensure that these experiences are positive and are underpinned by up to date information
- Develop our network of regional contacts

Raise Awareness of TSC

- Improve awareness of TSC amongst the general public
- Provide accurate and current information about aspects of life with TSC

Step D: How do we make this happen?

We've identified the following initiatives as a focus for the next 3 years.

New Activities	Continued Activities	Internal Improvements
<ul style="list-style-type: none"> • Take our successful seminar day events to TSC families throughout Australia and New Zealand • Advocate for the clinic model of care to regional medical professionals • Identify and begin to address the needs of those mildly affected with TSC • Facilitate online peer support networks • Develop a contact list of medical professionals experienced and interested in TSC 	<ul style="list-style-type: none"> • Offer support by email and phone • Develop ATSS information (Reach Out, Website, Publications) 	<ul style="list-style-type: none"> • Accept electronic payment methods • Re-develop our membership database • Design standard processes to plan for and review the success of our activities • Recruit skilled volunteers to diversify our team and create a succession plan • Develop a financial plan that will grow our income and identify reliable income streams

Figure 6: Initiatives

New activities

- **Take our successful seminar day events to TSC families throughout Australia and New Zealand**

We've proven that our seminar days successfully bring together families and health professionals to discuss TSC and learn from each other. Holding events in major centres throughout Australia and New Zealand will build regional networks and go some way to addressing the weakness of ATSS's NSW focus.

ATSS will look for a funding grant for this project.

- **Advocate for the clinic model of care to regional medical professionals**
ATSS believes that the clinic model offers an effective model of care for many TSC families. The clinic model will also build centres of expertise in TSC in the medical profession.
- **Identify and begin to address the needs of those mildly affected with TSC**
One of the key weaknesses identified was in ATSS's focus on severely affected cases of TSC. To redress this, ATSS will identify specific needs of families mildly affected with TSC.
- **Facilitate online peer support networks**
Historically, ATSS has facilitated support through face-to-face contact, such as at conferences and picnics. We've also offered support directly from the committee through email and phone calls. Recently, we've had requests for ways for TSC families to connect using the internet. ATSS will look at the options for doing this in a way that is both a positive experience and one that is supported by current information.

- **Develop a contact list of medical professionals experienced and interested in TSC**
This list would be used to refer ATSS members to a medical professional in their area. This list would be maintained by ATSS and would be created by information from ATSS members and from the TSC Clinic at Sydney Children’s Hospital through their special interest group.

Continued activities

- **Offer support by email and phone**
This has been ATSS’s traditional model, where a central phone number and address are available. This is often used for first contact or for specific questions and information requests. This support will continue.
- **Develop ATSS information (Reach Out, Website, Publications)**
To support our mission of “Provide access to current information and resources” - ATSS will continue to ensure up to date and relevant information is available in Australasia.

Reach Out

Reach Out is an important publication as for many members it is their only regular contact with ATSS. ATSS will continue to publish Reach Out and seek high quality information that is relevant to TSC families for each bi-annual edition.

Website

ATSS will continue to maintain our website, including personal stories, information about Tuberous Sclerosis and ATSS

Publications

We recognize an ongoing need for ATSS to produce or make available publications about Tuberous Sclerosis. This may be done through online or print copies and may be publications authored by ATSS or by other organisations. Particular areas of focus are:

- Gene testing
- Monitoring guidelines through life stages
- Transition from paediatrics to adult health system

Internal improvements

- **Accept electronic payment methods**

A decision was made in 2007 to use Paypal for payments by credit card. This is not yet available.

ATSS needs to allow credit card payments to make it easier for our members and supporters to register for events, pay their membership fees and make one-off and recurring donations.

- **Re-develop our membership database**

The information ATSS holds about our members and supporters is valuable. Work is required to ensure the information is up to date and accessible.

- **Design standard processes to plan for and review the success of our activities**

As ATSS grows, the way in which we work needs to be more organised and consistent. This Strategic plan is the first step. A standard set of processes and documents should be developed that will help committee members and other volunteers work effectively. This will be a way to address the weakness of *ATSS knowledge is often not written down, and when it is, it is not accessible by everyone.*

- **Recruit skilled volunteers to diversify our team and create a succession plan**

This initiative is to address the weakness of *ATSS is run by volunteers who have competing demands for their time.* Recruiting volunteers with specific skills will help ATSS to deliver on this plan. Understanding how key roles will be filled in the future will ensure that ATSS is not at risk by key people leaving.

- **Develop a financial plan that will grow our income and identify reliable income streams**

The new initiatives in this plan require funding beyond ATSS current income. A financial plan will help ATSS grow its income and manage money better.

Accountability

Each of the activities agreed as a part of this plan will be assigned to one of the ATSS committee members to deliver.

This means that the committee member will commit to ensuring the activity is completed within an agreed timeframe and will report to the committee at each committee meeting on progress.

This does not mean that the committee member must do all of the work for that activity.

Activity	Accountable
Take our successful seminar day events to TSC families throughout Australia and New Zealand	Sue Pinkerton
Advocate for the clinic model of care to regional medical professionals	Sue Pinkerton
Identify and begin to address the needs of those mildly affected with TSC	David Matheson
Facilitate online peer support networks	Clare Pinkerton
Develop a contact list of medical professionals experienced and interested in TSC	Committee Member: ?
Offer support by email and phone	Email: Kellie Buckley Phone: Leanne Park
Develop ATSS information (Reach Out, Website, Publications)	Reach Out: David Matheson Website: Clare Pinkerton Publications: Committee Member: ?
Accept electronic payment methods	Clare Pinkerton
Re-develop our membership database	Volunteer to be sought
Design standard processes to plan for and review the success of our activities	Committee Member: ?

Recruit skilled volunteers to diversify our team and create a succession plan	Committee Member: ?
Develop a financial plan that will grow our income and identify reliable income streams	Committee Member: ?

