



SECTION 1: INTRODUCTION

Message from Swan Australia Committee and Executive Officer

Syndromes Without A Name (SWAN) Australia's Strategic Plan reflects an active consultation process with members and SWAN Australia's Committee of Management. It sets out our goals, aims, and values, outlining a clear vision for our continued growth and advancement over the next three years.

We are committed to making a difference to those families with children of undiagnosed or rare conditions. With genomic medicine advocacy it is more important than ever that SWAN supports its members with regards to diagnosis and rare diseases. However, we are also very aware that many of our members may not ever receive a diagnosis for their child's genetic conditions.

We advocate to ensure that our members have access to genome sequencing and receive the support services they require. This will assist all SWAN Australia children in reaching their full potential and lead to better treatment plans, therapy supports and better outcomes for them and their families.

It is estimated that 2400 children are born each year with an undiagnosed genetic condition. We aim to support more SWAN children over the next three years by increasing community awareness of not only SWAN but the fact that many children will remain undiagnosed in their life time.

The Strategic Plan considers these objectives, in particular the key considerations impacting undiagnosed families. The plan is outlines three sections:

- Section 1 is an overview of our organisation
- Section 2 describes our vision, mission, aims and goals
- Section 3 details our strategic priorities addressing our actions and outcomes

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Heather Renton

Executive Officer

SWAN Australia



Overview

SWAN Australia is the peak body for families who care for a child with an undiagnosed or rare genetic condition for which there is no other support group. We provide information and support as well as advocacy on an individual and systemic level to our members.

SWAN Australia was established in 2012 as a non-profit charity. We are incorporated as an Association under the Victorian Associations Incorporation Act (1981) and officially registered as a charity with Deductible Gift Recipient (DGR) status from the Australian Taxation Office.

We provide opportunities for our members to engage in peer-to-peer support, which limits the isolation, frustration and anxiety often felt by SWAN families. We work to ensure that no family has to parent an undiagnosed child without support. We liaise with politicians, educators and disability support agents to ensure the best outcomes for our children within the wider community.

Our membership is predominantly parents, carers and families who have a SWAN child. Membership is currently free for all SWAN families. SWAN presently receives no State or Federal Government funding. Our primary source of funding is through small grants and kind donations. SWAN Australia is governed by a Committee of Management.

This plan has been written with input from our members as to what they would like SWAN to provide in terms of support and information. The biggest challenges our members face include:

- Lack of support and isolation
- Limited knowledge of services
- Access to genetic testing
- Lack of awareness of undiagnosed and rare genetic conditions



We advocate for further funding into genetic research and genomic testing, so that more testing is available, turnaround time on testing is decreased and more accurate test results are achieved. We strive to obtain better resources and future pathways for our SWAN children.

We collaborate with a range of support organisations including; State and Federal Governments, Genetic Support Network Victoria, Genetic and Rare Disease Network WA, Australian Genetic Alliance, Rare Voices Australia, Victorian Council of Social Services, Australian Rare Chromosome Awareness, SWAN Groups around the world, Victorian Clinical Genetics Services, Garvan Institute in NSW and the Office of Population Health Genomics in WA, Melbourne Genomics Health Alliance and the Australian Genomics Health Alliance.

SECTION 2: PURPOSE AND PRINCIPALS

Our Vision

SWAN Australia's vision is to:

- Support and empower families as they care for their SWAN child
- Ensure that no SWAN families feel unsupported or isolated on their journey
- Have equitable access to a diagnosis and treatment plans
- See that SWAN families achieve better outcomes for their children so that they may reach their full potential

Our Mission Statement

Our mission is to provide support and information to families enabling them to navigate the health and disability sectors. We wish to provide opportunities for members to share information with each other and establish mutually supportive relationships. We advocate for better pathways for our families.



Our Aim

We offer the highest standard of peer support possible to our community so they can feel connected with one another for support and information sharing in relation to parenting a child with an undiagnosed or rare genetic condition.

Our aim is to ensure SWAN families know about SWAN as the peak body for undiagnosed and rare genetic conditions, so that we can continue to grow and support more SWAN families together.

Goals

1. Support

- To support the information needs of our members by providing current and relevant information related to caring for a child with an undiagnosed or rare genetic condition
- To support the psychosocial needs of our members by providing peer support or the opportunities to connect with others with a similar lived experience
- To support social inclusion for all SWAN families by building an active SWAN community which can offer peer support to one another

2. Empower

- Provide opportunities for families to connect with each other
- To empower SWAN families to navigate the health system and make informed choices at all life stages, drawing on their common experiences and accumulated knowledge

3. Advocate and Influence

- Achieve better pathways for our families to gain access to supports and resources.
- Encourage research into rare genetic conditions and support research translation to provide better treatment and outcomes to SWAN children
- Equitable access to genomic and genetic testing
- More accurate genetic tests with faster turnaround times
- SWAN families to feel empowered to advocate on behalf of their children
- Develop advocacy resources for SWAN families
- Establish clear aims and objectives when advocating on behalf of SWAN families



4. Educate

- Encourage a better understanding by health professionals and health educators of SWAN families and their support and information needs
- Support SWAN families as they transition into the NDIS

5. Community Awareness and Membership

- Engage with the broad public community to raise awareness of the large number of children living with an undiagnosed or a rare genetic condition

6. Sustainability

- Ensure the sustainability of SWAN as an organisation by developing effective marketing and fundraising strategies to attract competitive income and resources
- Utilise the contribution of volunteers and engage with the health and disability sectors that assist SWAN families to create a supportive and active community



SECTION 3: STRATEGIC PRIORITIES

Support

Actions	Outcomes
Social activities - family days and parent social activities	Increased peer support amongst our members
Workshops for parents	Families provided with information relevant to caring for a SWAN child e.g. genomics, advocacy, NDIS
New members welcomed to SWAN	For members to feel engaged with the SWAN community for mutual benefit and inclusive support
Utilise social media to support and inform families	For SWAN community to follow us on social media and use it as support platform
Develop and implement an evaluation feedback tool to enable members to let us know how we can support them better	Gaps in services and support identified to highlight areas of service we can improve on
Continue to build on relationships with likeminded organisations for support and collaboration	Shared resources and a stronger voice to encourage support, and advocacy success A better use of resources and work place proficiencies
Develop reference groups around disability & education and Genomics and Health	Offer further support to SWAN families by having experts in the group to provide information when required
Apply for grants where appropriate to enable SWAN to deliver support and services to our members	More programs offered to members and opportunities for families to connect, so that support within SWAN can continue to grow



Empower

Actions	Outcomes
Connect families via events and social media	To limit isolation amongst members and provide opportunities for them to share information
Empower parents to seek out support to navigate the health and disability sector	For families to access relevant services which best support their child

Advocate and Influence

Actions	Outcomes
Provide information to service providers around supports and issues relating to SWAN families	For SWAN families to receive better supports around caring for their child
Seek out research projects and inform members of opportunities to participate	For SWAN families to engage in research in the hope of medical advances
Fair, affordable access to genetic and genomic testing	For genetic and genomic testing to be fully funded by Medicare
Improve current genetic and genomic testing methods	To increase testing turnaround times and accuracy of results
Upskill SWAN families with regard to advocating for their SWAN child	Resources developed to empower SWAN families to self-advocate for their SWAN child
Develop policy documents, policy briefs and position statements on key issues important for SWAN families e.g. disability, health, support services and genetic and genomics	Establish clear position statements which will guide SWAN when responding to submissions and government policies
Respond efficiently to Government inquiries and submissions to represent the values and views of SWAN families	Better policies which will ensure the needs of our families are met with relation to health, disability and education



Educate

Actions	Outcomes
Provide and inform SWAN families about the range of support services that are available to them	For SWAN families to have access to a range of support services to ensure better outcomes for their SWAN child
<p>Create a SWAN brochure aimed at health professionals and educators to assist them with supporting SWAN families on an emotional level.</p> <p>Develop a workshop aimed at educators, the health profession and service providers to give them strategies for supporting SWAN families</p>	<p>For SWAN families to feel supported emotionally so they feel less stressed about parenting a SWAN child and have better mental health outcomes</p> <p>For educators to be able to understand the strain and issues that SWAN families face so they can support their child's learning</p> <p>For families to feel comfortable about seeking support from those who support their SWAN children</p>
Offer workshops on the NDIS and host Q & A sessions and virtual coffee sessions with regards to the NDIS	For SWAN families to understand the complexities of the NDIS so they feel empowered to advocate for functional and adequate NDIS plans for their SWAN child

Community Awareness and Membership

Actions	Outcomes
Increase membership amongst our SWAN community for both families and professionals	<p>Financial assistance through professional memberships.</p> <p>More SWAN families feeling supported</p>
Increase community Awareness of SWAN Australia through event like Undiagnosed Children's Awareness Day	Increased public profile within the wider community
Increase community awareness through professional bodies	Professionals to support SWAN as an organisation and assist with raising our public profile as the peak body for undiagnosed and rare genetic conditions



Sustainability

Aims & Activities	Outcomes
Support Master of Genetic Counselling students by offering them opportunities to join our Committee and undertake course placements	Relationships developed with the people who will in future be supporting SWAN families. Giving back to the community which supports our families
Utilise the use of volunteers where possible	More productivity and support gained to assist SWAN reach and support more families
Develop marketing and fundraising strategies to engage the broader community and seek partnerships with the public and private sectors through sponsorship and support. Diversify funding base by building new sources of revenue	Funding avenues to be diverse; partnerships, grants and philanthropy to make operating more feasible and sustainable

SWAN Australia welcomes feedback on our Strategic Plan or any other aspect of our work. Please address all correspondence to:

Heather Renton

Executive Officer

Syndromes Without A Name (SWAN) Australia

T: 0404 280 441

E: president@swanaus.org.au

A: PO Box 390, Fairfield, Victoria 3070