



Syndromes Without A Name (SWAN) Australia

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INFORMATION FOR NEW MEMBERS

Welcome

Welcome to **SWAN Australia Inc.** SWAN is a not-for-profit Incorporated Association, registered under the Associations Incorporation Act 1981. It is a member based organisation.

Our aim is to offer support to parents, carers and friends of people whose child/children have an undiagnosed genetic disorder/syndrome or an extremely rare condition for which there is no support group. We want to ensure that nobody has to walk this journey alone and that information and professional services are accessible to everyone affected by a genetic condition.

We want to raise awareness of genetic conditions among the broader community. Services and support in our community are often allocated on the basis of a diagnosis. People without a diagnosis can miss out. We need to pressure the government and private sector for better services, resources and information for our families. Together we can unite to improve the lives of all those affected.

Our Purpose

- Offer emotional support for parents/carers who have a child/children without a diagnosis.
- Be able to listen to parent/carer stories and share the good and not so good parts of parenting/caring for a SWAN child.
- Provide information to parents/carers who have a child/children without a diagnosis.
- Advocate for more funding for genetic research so more testing is available, turnaround time on testing is decreased and more accurate results are obtained.
- Advocate for better resources and pathways for our child/children without a diagnosis.

Our Goals

Based on the needs identified by SWAN UK, SWAN Australia aims to:

- Develop a community of families with undiagnosed genetic conditions for mutual support and information sharing.
- Develop a network of health and social care professionals with expertise in undiagnosed conditions.
- Increase awareness and understanding of undiagnosed genetic conditions.

Members need to share our purpose and assist with us establishing our goals. We ask that all members abide by our constitution and regulations. Copies are available upon request via email: admin@swanaus.org.au.

Why Become a Member?

- You can help us make a difference to parents/carers of SWAN children.
- Eligibility to vote at our AGM and apply a position on our committee of management.
- We can unite to advocate for better outcomes for our SWAN children and their families.
- Receive via email our quarterly newsletter.
- Attend support group meetings, seminars and informal gatherings.

Who Can Join?

In line with our rules, anyone who is a carer/parent of a child without a diagnosis may become a member upon approval of our committee of management. Membership is also available to medical professionals and educators on a membership fee basis.

Membership Fees

Currently membership is free to all SWAN parents and carers.

Membership Process

Please complete the online membership form to apply for membership with SWAN Australia. You will be notified of your membership status within 4 weeks.

Please notify of us admin@swanaus.com.au if any of your membership details change or if you have any suggestions for improving the operations of SWAN Australia. We welcome feedback.

Disclaimer

SWAN Australia cannot be held responsible for any incorrect information given to members. All information is provided in good faith. It is not a substitute for independent professional advice.