



Smith-Magenis Syndrome Australia

2026 Chair's Annual Report

Chair's Annual Report: 1st July 2025 - 30th June 2026

OUR MISSION: TO SUPPORT AND EMPOWER AUSTRALIAN FAMILIES LIVING WITH SMITH-MAGENIS SYNDROME THROUGH AWARENESS, COLLABORATION, AND EDUCATION.

OUR PURPOSE: ENABLING FAMILIES AND INDIVIDUALS, IMPACTED BY SMS, TO GAIN ACCESS TO THE SUPPORTS THEY NEED, AND FOSTERING UNDERSTANDING AND INCLUSION IN THE BROADER COMMUNITY.

This Annual Report reflects the activities of Smith-Magenis Syndrome Australia throughout the financial year from 1 July 2025 to 30 June 2026.

Throughout the year, the Board remained focused on SMS Australia's **core objectives** of increasing awareness and understanding of Smith-Magenis Syndrome (SMS), supporting research and education, strengthening connections between families, and helping individuals and families access the services and supports they need.

Our **key priorities** continued to centre on:

- Increasing awareness and understanding of Smith-Magenis Syndrome.
- Supporting and communicating relevant research, education and practical information.
- Welcoming newly diagnosed families and strengthening connections within our community.
- Helping families navigate disability, health, educational and government support systems, including the NDIS.
- Building partnerships that strengthen the voice of the SMS community.
- Planning for the biennial SMS Australia Camp / Summit.

At the close of the 2025-26 financial year, our known Australian SMS community comprised:

- 135 known Australians diagnosed with SMS, noting that Australia does not currently have a formal national SMS registry.
 - 54% female, 41% male and 5% gender unknown.
 - 10% aged under 8, 33% aged 8-17, 50% aged 18-39 and 6% aged 40+.
 - 3 ACT, 39 NSW, 27 QLD, 14 SA, 9 TAS, 23 VIC, 14 WA, 1 NFI and 5 whose location is unknown.
- Over 180 family contacts, including parents, carers, siblings and grandparents. This network includes our eight SMS Australia state representatives and four of our five Board members.

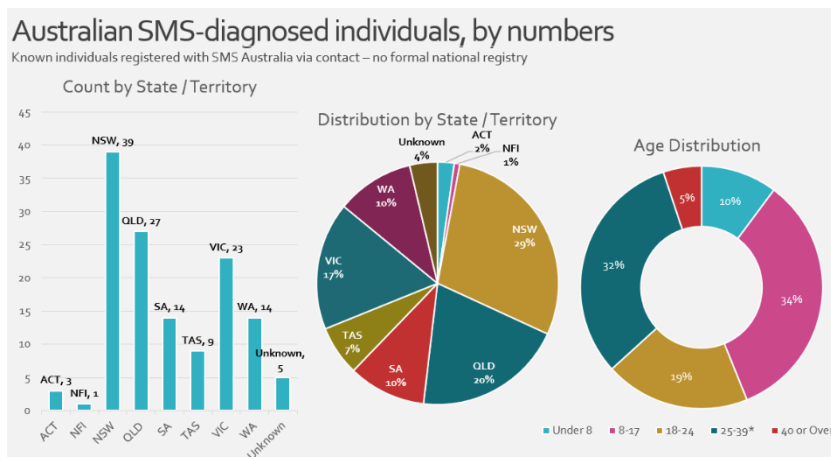
Ongoing growth year-on-year reinforces the importance of maintaining strong mechanisms for identifying, welcoming and connecting newly diagnosed families.





Smith-Magenis Syndrome Australia

2026 Chair's Annual Report



Changes to our Board

During the year, **Angela Matoka** retired from the SMS Australia Board after nine years of service as a **Director and Secretary**. Angela has made a significant contribution to SMS Australia over many years, providing both continuity and support through an important period in the organisation's development. On behalf of the Board and our broader community, I sincerely thank Angela for the time, commitment and energy she has contributed and wish her and her family all the very best.

Following Angela's retirement, **Pauline Maniskas** stepped into the role of **Interim Secretary** while the Board commenced the process of recruiting a permanent replacement. We closed the financial year with this recruitment activity continuing.

As a volunteer-led organisation, the strength and sustainability of SMS Australia relies heavily on people willing to contribute their time, expertise and lived experience. Maintaining a capable and engaged Board remains an important priority as the organisation continues to grow.

Awareness

Awareness continues to be one of SMS Australia's central priorities, particularly given the rarity of Smith-Magenis Syndrome and the relatively low level of understanding of SMS outside our immediate community.

During **November 2025**, in recognition of **World Smith-Magenis Syndrome Awareness Day on 17 November**, we ran an SMS Facts social media campaign throughout the month. Rather than sharing facts about SMS in isolation, this year's campaign placed Australian individuals with SMS at the centre of the story. **Sixteen Australians with SMS were featured**, with their individual experiences helping to bring the information to life and provide the wider community with a more personal understanding of what living with SMS can look like. The campaign was accompanied by a Meta fundraising initiative, providing community members and supporters with the opportunity to both raise awareness and contribute financially to SMS Australia's activities.

In December, **Disability Sport & Recreation (DSR)** further broadened awareness through a campaign featuring **Amelie Lague**, a young Australian woman with SMS. The campaign highlighted the positive impact that



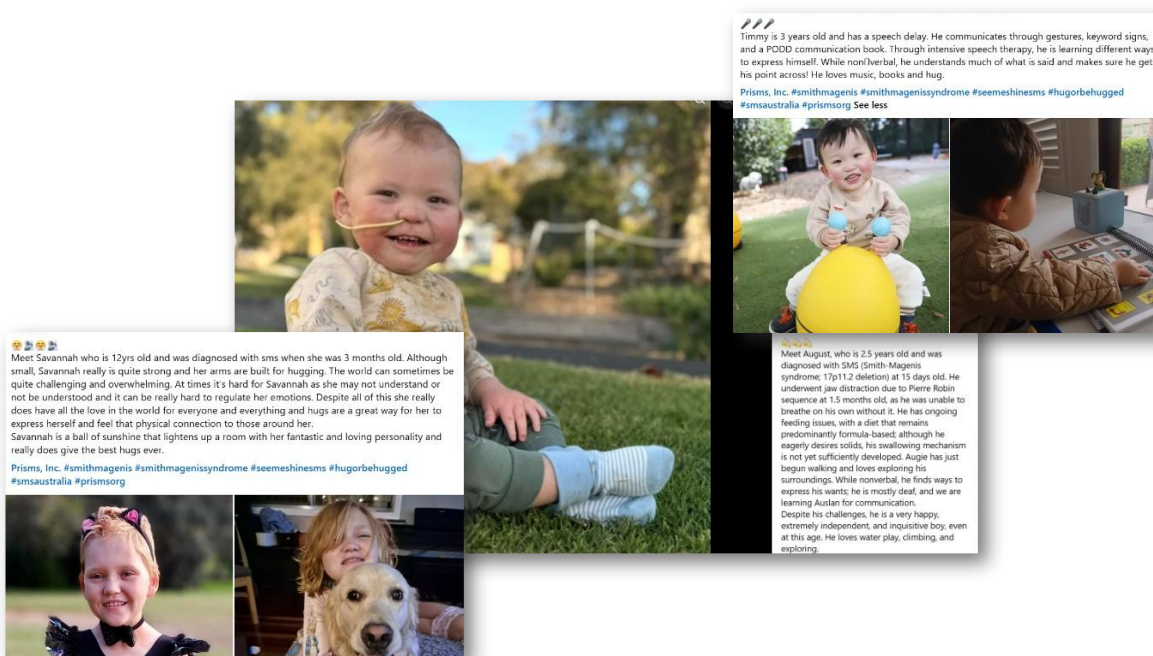


Smith-Magenis Syndrome Australia

2026 Chair's Annual Report

participation in inclusive sport and recreation has had on Amelie's life. This provided valuable exposure for SMS outside traditional rare disease networks and helped promote greater awareness within the sport, recreation and disability inclusion communities.

Our social media channels and website continue to play an important role in reaching families, professionals and members of the broader community seeking information about SMS.



Fundraising

With SMS Australia entering the year in a strong financial position following significant fundraising activity in previous years, and 2025-26 being a “non-camp” year, the Board deliberately placed less emphasis on major fundraising campaigns. Our focus was instead on maintaining a sustainable financial position while directing resources towards research, education, family support and preparations for the 2026 SMS Australia Camp / Summit.

Our November SMS Awareness campaign generated **\$2,770 through Meta fundraising**, demonstrating the continued generosity of our community and supporters. During December and January, SMS Australia partnered with the **Rotary Club of The Entrance, NSW**, through its Annual Community Raffle. This initiative raised **\$500** to support Australian families affected by SMS. We were also extremely grateful to receive a **\$2,000 donation from Terrigal Trotters**, generated through their Bay2Bay Running Festival. These funds will contribute directly towards supporting the 2026 SMS Australia Camp / Summit.

We sincerely thank everyone who donated, fundraised or supported SMS Australia during the year. Regardless of the amount, each contribution helps us continue providing information, advocacy, community connection and educational opportunities for Australian SMS families.





Smith-Magenis Syndrome Australia

2026 Chair's Annual Report

Research and Education

Research and education were particularly significant areas of activity during 2025-26, with SMS Australia continuing to support SMS-specific research while also expanding our engagement with the broader Australian rare disease community.

Rare Voices Australia Partnership and Partner Project Grant

During the year, **SMS Australia became a Rare Voices Australia (RVA) partner**, strengthening our connection with Australia's national peak body for people living with rare disease.

In October 2025, SMS Australia was successful in receiving an **RVA Partner Project Grant** through the **Rare Disease Disability Project**. Our funded project, **"Navigating Care for Children with Rare or Undiagnosed Disease Developmental Delay,"** recognises that many of the challenges experienced by SMS families are shared by families affected by other rare and undiagnosed conditions.

Developmental delay can be poorly understood across health, education and disability systems. Parents and carers are frequently required to become highly effective advocates for their children while simultaneously navigating complex health services, disability supports and the National Disability Insurance Scheme (NDIS). Through this project, SMS Australia is developing resources designed to strengthen the capacity of parents and carers of children with developmental delay associated with rare or undiagnosed disease.

The project has involved gathering lived experience through individual and group interviews and case studies, with the intention of translating these insights into practical, easy-to-use resources. These resources will assist families in advocating with health professionals and navigating NDIS applications, plans and reviews.

Importantly, the project has extended beyond the SMS community. The project steering group comprised **nine members – five connected with the SMS community and four from the broader rare disease community**. A total of **20 parents and carers participated in interviews**, again representing both SMS and other rare disease and developmental delay experiences. This broader participation has helped ensure the resulting resources address shared challenges across rare disease and developmental delay communities rather than being limited solely to SMS.

At the end of the financial year, development of the resources was progressing on schedule, with publication expected by **November 2026**, aligning with SMS Awareness Month and, ideally, the 2026 SMS Australia Camp / Summit.

We are deeply grateful to **Rare Voices Australia** and to the stakeholder reference group, including people with lived experience of rare disease disability, for supporting this important initiative.

Australian SMS Speech Research

The Australian SMS speech research collaboration developed during the previous financial year also progressed significantly. Working with **Dr Adam Vogel's team at the Translational Centre for Speech Disorders at the Murdoch Children's Research Institute (MCRI) and the University of Melbourne**, the study aims to advance





Smith-Magenis Syndrome Australia

2026 Chair's Annual Report

understanding of speech characteristics and speech biomarkers associated with Smith-Magenis Syndrome. Protocols and recruitment materials had been established during the previous year. Ethical approval was subsequently received from MCRI in July 2025, enabling the study to formally launch in **August 2025**.

The study is being led by **Lucas Raniolo**, PhD candidate at the University of Melbourne and Murdoch Children's Research Institute. During the year, **27 Australian families enrolled** in the research. In March 2026, recruitment expanded internationally. SMS Australia assisted with establishing connections with **PRISMS in the United States** and SMS affiliate organisations in the **United Kingdom, Germany, France and Mexico**, helping broaden the potential participant base and international relevance of the study. Supporting credible Australian research that can contribute to the global understanding of SMS remains an important priority for our organisation.

Educational Resources

Newly diagnosed families continued to receive a complimentary copy of **"On the Road to Success with SMS"**, which remains an important practical resource containing information, strategies and guidance for families navigating life with SMS. During the year the book was also made available for purchase through our online store, making it easier for extended family members, educators, support providers and other interested people to obtain a copy.

Community and Connections

Building connections between families remains fundamental to SMS Australia.

Our **private Facebook group for family members of people diagnosed with SMS in Australia and New Zealand** continues to be our primary national platform for informal peer connection. The group remains highly engaged and provides families with a trusted environment in which to ask questions, share experiences and celebrate achievements. Importantly, the community continues to demonstrate a strong culture of empathy, inclusion and practical support.

We also continued to maintain and promote our secure **SMS Australia Family Portal**, which provides families with access to information and our referral-based **specialist registry**.

Throughout the year, SMS Australia responded to requests from families seeking connections with others living nearby or looking for allied health and medical professionals with previous experience supporting people with SMS.

More than one-third of our parent and carer network have authorised SMS Australia to connect them with newly diagnosed or newly identified families. This willingness to support others remains one of the great strengths of our community. Our state representatives complement these connections by providing a local first point of contact and helping families establish links within their own state or region.





Smith-Magenis Syndrome Australia

2026 Chair's Annual Report

Helping Families Navigate Supports and Services

For most individuals diagnosed with Smith-Magenis Syndrome, eligibility for the **National Disability Insurance Scheme (NDIS)** itself is not generally the principal challenge. SMS is a lifelong and complex neurodevelopmental disorder with substantial functional impacts.

The greater challenge continues to be the significant variation families can encounter when seeking adequate funding for the supports required by an individual. SMS Australia continued to provide direct advocacy and practical assistance to families navigating the NDIS during the year. This has included coordinating **Letters of Support** that draw upon individual assessments and information from **Prof. Ann Smith**, helping families clearly demonstrate the relationship between SMS, functional impact and the supports being requested.

Our role is not to replace professional or formal advocacy services, but to help families better explain the SMS-specific context and connect them with relevant knowledge, evidence and resources.

As a member of the **Down Syndrome Australia Disability Representative Organisation Consortium**, SMS Australia also continued contributing to national consultation and advocacy activities in areas including:

- NDIS policy and reform,
- supported employment,
- child safety, and
- disability voting reform.

Participation in the consortium provides SMS Australia with an opportunity to ensure the experiences of people with SMS and their families are represented within broader national disability policy discussions.

Our website also remains an important point of entry for families, support providers, allied health practitioners, medical professionals, educators and others looking for information or seeking contact with SMS Australia.

2026 SMS Australia Camp / Summit

Although the 2026 SMS Australia Camp / Summit falls outside this reporting period, a substantial amount of planning commenced during 2025-26.

In February, SMS Australia and **Disability Sport & Recreation (DSR)** commenced discussions and early planning for the next biennial event. In April, we advised our community that the proposed dates would be **6-8 November 2026** and invited families to submit an Expression of Interest. This early indication of likely attendance has been important for planning the event and supporting funding applications.

Our preferred venue is **Urban Camp Melbourne in Parkville**, which represents a change from previous camp locations. Its central Melbourne location is expected to provide easier access to activities and significantly reduce travel times from Melbourne Airport and other metropolitan locations. The evolving format is intended to continue combining the elements families value most from previous events: opportunities for individuals





Smith-Magenis Syndrome Australia

2026 Chair's Annual Report

with SMS and their siblings to participate in inclusive activities, high-quality education for parents and carers, family connection, and direct access to experienced SMS professionals.

At the close of the financial year, DSR had indicated its ongoing support for the event, with a final Board decision regarding allocation of funding still pending. SMS Australia nevertheless continued preparing for the Summit and, in recognition of the importance of international expertise to our community, committed a significant proportion of retained earnings towards airfares for **Prof. Ann Smith, Dr Gail Reiner and Gail Kopp** to travel from the United States. Their attendance will support continued research engagement, family education and direct consultation opportunities during the November event.

We are also exploring the possibility of a **second, smaller interstate gathering during November**, potentially in Queensland or Western Australia, to create additional opportunities for families who may not be able to travel to Melbourne.

Acknowledgements

As Chair, I am extremely grateful to everyone who volunteers their time, skills and experience to support Smith-Magenis Syndrome Australia.

We remain a small organisation with a national reach, and everything we achieve is made possible through the commitment of volunteers, families, partners and supporters.

My sincere thanks to:

- | | | |
|--|--|------------------------------------|
| • Liz Tesone , Vice Chair | • Pauline Maniskas , | • Sabrina Roberts , QLD Rep |
| • Angela Matoka , Secretary
(retired Oct 2025) | Programs & Acting
Secretary | • Michelle Carr , SA Rep |
| • Dr Jenny Maturi , Research | • Amanda Starr , ACT Rep | • Vanessa Baxter , TAS Rep |
| • Layken Sargent ,
Community & Fundraising | • Mary Storch & Kate Fraser , | • Katrina Simpson , VIC Rep |
| | NSW Reps | • Sharon Henderson , WA Rep |

I would particularly like to acknowledge **Angela Matoka** for her nine years of service to SMS Australia as a Director and Secretary and thank **Pauline Maniskas** for stepping into the Acting Secretary role during this transition.

We again extend our sincere thanks to **Steven Tolhurst and Paul Woodford at W Morley & Co**, and **Robert Bell, Managing Director at PKF Sydney & Newcastle**, for generously donating their professional time and expertise to prepare our financial statements and undertake our annual audit at no cost to SMS Australia.

I also acknowledge our ongoing and valuable relationship with **PRISMS and its International Partnership Program**. This connection continues to provide Australian families with access to international SMS research, educational information, expertise and opportunities to connect with the broader global SMS community.

Our growing relationship with **Rare Voices Australia** has also been an important development this year. Becoming an RVA partner and receiving support through the Partner Project Grant has enabled SMS Australia to





Smith-Magenis Syndrome Australia

2026 Chair's Annual Report

contribute knowledge generated from our own community to work that has the potential to benefit families affected by rare and undiagnosed conditions more broadly.

Likewise, our ongoing collaboration with **Disability Sport & Recreation** continues to open new opportunities for inclusive participation and provides invaluable support as we prepare for the 2026 SMS Australia Camp / Summit.

Closing Remarks

The **2025-26 financial year** has been characterised by research, collaboration and preparation for the future.

We have seen our known SMS community continue to grow, strengthened our relationships within Australia's broader rare disease sector, progressed important Australian-led SMS research, supported families navigating complex disability systems and commenced preparations for our next national Camp / Summit.

Perhaps most importantly, the year has demonstrated the benefit of looking beyond SMS alone. Through our partnership with Rare Voices Australia and our disability advocacy work, the experiences of Australian SMS families are contributing to broader conversations about rare disease, developmental delay and disability support.

At the same time, we remain firmly focused on the individual families at the centre of our organisation - connecting newly diagnosed families with others who understand their experience, sharing trusted information, advocating where assistance is needed and creating opportunities for people with SMS to participate, connect and thrive.

With the 2026 SMS Australia Camp / Summit approaching and several significant research and educational initiatives due to reach important milestones, there is much to look forward to in the year ahead.

I am enormously grateful to our Board, state representatives, volunteers, professional partners, donors and, most importantly, the families who continue to support one another and make the SMS Australia community what it is.

I look forward to another year of progress, connection and opportunity for SMS Australia and our community

Cally Bauman

Executive Director and Chair

Smith-Magenis Syndrome Ltd.

07 October 2026

