2025 ANNUAL REPORT

LEUKODYSTROPHY .org.au AUSTRALIA

Vision & Mission
Leukodystrophy Australia is the national peak organisation representing people impacted by leukodystrophy. We collaborate with local, national and international stakeholders to advance the care of our members, improve quality of life and ultimately seek a cure for leukodystrophy.

Vision
Empower people affected by leukodystrophy, through knowledge and support, to lead their best lives.

Mission
We strive to support people throughout their leukodystrophy journey and beyond. We foster member connections, provide service linkages, financial support, education, advocacy and promote current trends in treatment and research.

Objectives

- Support, advise and assist individuals impacted by leukodystrophy throughout their life journey.
- Support parents, partners and other caregivers in their caring roles.
- Maximize the quality of life for those impacted by leukodystrophy.
- Provide advocacy for those impacted by leukodystrophy at a micro and macro level.
- Operate in an effective, efficient, transparent and accountable manner.

Values
Leukodystrophy Australia is committed to the following values:

Respect
We respect and recognise our members' abilities, qualities, achievements and lived experiences.

We strive to ensure equitable access for all people with a focus on priority populations (Aboriginal and Torres Strait Islander peoples, people living in regional, rural and remote areas, people from culturally and linguistically diverse backgrounds and people experiencing socio-economic disadvantage).

We demonstrate a commitment to providing respectful, safe and inclusive support for people of all abilities, gender identities and ages.

Self-determination
We support and advocate for the rights and choices of members in their health and wellbeing decisions.

We work collaboratively with health professionals and other service providers to assist members to reach their full potential.

We promote and contribute to multidisciplinary research that seeks to improve treatment, quality of life and find a cure for leukodystrophy.

Accountability
We have rigid and transparent practices and processes that value the contributions of people affected by leukodystrophy, members, volunteers, donors, and beneficiaries ensuring accountability, financial integrity and high-level service delivery.

Professionalism
Our employees, committee members and volunteers demonstrate professionalism in undertaking our organisational activities.

Our service delivery is guided by the principles of social justice, accountability, transparency, trust, equality and equity.

Evidence informed
We incorporate our members' experiences and feedback, current research and ongoing professional development to inform our program and support services planning and delivery.

Our History

The Australian Leukodystrophy Support Group Inc. (ALDS) was established on 17 August 1992 by Sr Julie Thomas CSB OAM, as a not for profit charitable organisation run by a dedicated team of volunteers. In 2015, we began trading as Leukodystrophy Australia. We continue to run under a volunteer Committee of Management and with the support of other valued volunteers. We exist to provide information, support and advocacy to individuals and families affected by leukodystrophy, to raise awareness of this group of conditions and to encourage leukodystrophy related research.

ABOUT US

People diagnosed with leukodystrophy, their families and carers, are on a life-long journey of largely the unknown. In the main, there is no treatment or cure, diagnosis can be problematic and protracted, misdiagnosis happens. Devastation for families is enduring, and life changing.

We support our members, nationally, rurally and regionally, throughout their leukodystrophy journey, from pre-diagnosis and beyond. We offer support by fostering member connections, providing service linkages, education, advocacy, crisis support, promoting current trends in treatments and research.

Our holistic approach aims to improve the well-being of the diagnosed person, their family and carers, by empowering their decision making in life and health, across multiple facets. Leukodystrophy Australia offers time, comfort and practical support to help reduce the often overwhelming sense of isolation and despair.

OUR PEOPLE (current as at 30 JUNE 2025)

Committee of Management

Name	Position	Date (financial year)
Earl Schonberger	• Committee • President	2000's – current 2022 – current
Dr Dominik Froehlich	• Committee • President • Vice President	2019 – current 2021 – 2022 2022 - current
Kate Fernie	• Treasurer & Committee	2020 – current
Anne Patricia	• Committee	2023 - current
Susan Stenning	• Secretary	2022 - current

Employees

Name	Position	Date
Claire Kingsley	• Family Advocate Social Worker	2025 – current (Full-time)
Jane O'Neill	• Family Advocate Social Worker	2023 – current (Casual)

Volunteers

Name	Position	Date
Julie Merrett	• Social Media Advisor and Facebook	2018 – current
Minzy Kang	• Social Media Advisor and Facebook	2024 – current
Dimitra Minuzzo	• Leukodystrophy Australia Newsletter	2020 – current

Advisors

Name	Position	Date
Dr Chloe Cunningham	• Medical & Research Advisor	2020 – current
Dr Dominik Froehlich	• Scientific Advisor	2019 – current

Supporters

FOUNDER & LIFE MEMBER		
Sister Julie Thomas CSB OAM (passed away 6/2/2023)		
AMBASSADORS		
John Olsen OAM Long Walks for Leukodystrophy	**Gary Dawson OAM** The Charity Challenge	**Matthew Laverty** The Charity Challenge
NETWORKS (including the following)		
Genomics Australia (Commonwealth Dept of Health, Disability and Ageing)	**Australian Leukodystrophy Clinical and Research Program/White Matter Disorders Clinic**	**European Leukodystrophy Association (ELA)**
Genetic Alliance Australia (GAA)	**Genetic Support Network Victoria (GSNV)**	**Mission Massimo Foundation**
Neurological Alliance Australia (NAA)	**Rare Voices Australia (RVA)**	**Safe in Sound** (Robbie Avenaim)
Syndromes Without A Name (SWAN) Australia	**United Leukodystrophy Foundation (ULF - USA)**	
BUSINESS SUPPORT		
Julie Merrett and Minzy Kang Reach Social Media	**Regan Leen** Katipo Web Solutions **Naboth Semwayo** Defo IT Solutions	**Nick Cardenas and Penny Evans of Chilli Bookkeeping** Accounting
Deborah Gallagher Auditor		

GRANTS, DONORS AND FUNDRAISING

Numerous generous individuals and corporates including The Co-Group Limited, The Charity Challenge, IA Foundation, 1788 Charity Foundation, FibreConX, Bianca, Chase Gallery

PRESIDENT'S REPORT – Earl Schonberger

Overview 2025

The 2025 financial year spanned July 2024 to June 2025 – The President's Report covers organisational highlights and updates during this period.

The organisation remained in a comfortable financial position.

A locum Family Advocate continued after Jane's inability to return to work (due to health issues) and a successful candidate (Claire Kingsley) for the full-time role was secured and commenced in October 2024.

The organisation had a number of important projects to undertake in the 2025 financial year – in no particular order:

- Recommencing full-time Family Advocacy and associated aspects of support (e.g. more reach-outs to our leukodystrophy community and recommence family gatherings) – more on these later in the report.
- Move the Leukodystrophy Australia database from a proprietary system to a more modern, streamlined, flexible and supportable backend (built on Microsoft Dynamics). A great deal of work went into the transitioning process from the old system and the Family Advocates continue to work through a process of archiving and updating of records.

  We wish to thank John Epta, Ewan Duckworth and the team at Tonic for building and supporting our original database, all at no cost to Leukodystrophy Australia. Tonic's support over the years has been of great importance to Leukodystrophy Australia.
- Implement and roll-out a Leukodystrophy Australia Peer Support program thanks to a Commbank grant – more on this later in the report.
- Update Leukodystrophy Australia governance/policies and procedures. It has been a number of years since our governance and related documentation was updated, so working with experienced consultants in this space (Kathryn Milne and Isabella Kargiotis from Rare Insight Advisory) has allowed a complete revamp. We are a significant way through the exercise, which continues towards completion in the 2026 financial year.

Another highlight for the organisation as in previous years were the two golf days (Sydney and Melbourne) run by our Ambassadors Gary Dawson OAM and Matthew Laverty as part of their Charity Challenge series. Also a unique keynote speaking opportunity at the annual Charity Challenge Ball (in November 2024) at the Hyatt Regency Hotel, Sydney.

We were recipients of significant donations from The Co-Group, Insurance Advisernet Foundation, The Charity Challenge, 1788 Charity Foundation, FibreConX, Chase Gallery and Bianca, as well as from several very generous individuals. There were fantastic fundraising efforts by families connected with us, including Travis Harris who created exposure through his meaningful iRacing initiative - Racing for James (his son). We are extremely grateful for everyone's work in support of Leukodystrophy Australia. These donations are extremely important for us as they are important in our striving to keep our running costs covered, including our most significant

costs, being wages and expenses for Family Advocacy and subsiding the donations of support that we provide to our community.

We are also thankful for our volunteers and pro-bono supporters, including Minzy from Reach Marketing group (with thanks to Julie Merrett), Dimitra, Cowell Clarke Lawyers (with thanks to Megan Jongbloed), Ability Connect (Support Co-ordination – with thanks to Elena Tselepi and Emanuel Gini), Dr Dominik Froehlich (Scientific Advisor) and Dr Chloe Cunningham (Medical and Research Advisor). Thank you also to the doctors/specialists and clinics (including the Australian Leukodystrophy Clinical and Research Program/White Matter Disorders Clinic) around Australia with whom we liaise on technical matters.

Speaking of volunteers, we could not do what we do without the tireless work and support of my fellow committee and team – Dominik Froehlich (Vice President), Kate Fernie (Treasurer), Anne Patricia and Susan Stenning (Secretary). Anne has advised that she will sadly not be in a position to stand for re-election on the 2026 committee at the upcoming AGM. We know she has a busy year coming up personally and we wish her all the best and thank her for her significant work with Leukodystrophy Australia, initially as Family Advocate and subsequently on the committee where she gave a great deal of her time and energy. We know Anne will remain as a member and will stay in contact with the organisation.

FAMILY GATHERINGS & EVENTS AND RELATED AWARENESS

Friday 27th September 2024 – Sydney Golf Day

The weather wasn't kind to us for the Leukodystrophy 2024 Sydney Charity Challenge Golf Day at Long Reef Golf Club – it was cold, wet and windy, yet there was no shortage of enthusiasm and smiles on the day. Avid golfers typically just get out there - rain, hail or shine - and this made for an enjoyable day despite the gloomy conditions. Gary Dawson OAM, Matthew Laverty and their team ran a great event as usual and the Attvest team came through to win on the day. Special thanks to the Tacca team (2 teams) for their ongoing sponsorship and support of this event, as well as the Fernie family teams, Steve Brady and Ardent, Mike & Mitch Blackers' Ausrisk Consulting teams along with the Charity Challenge corporate sponsors and of course, the Insurance Advisernet Foundation and Alma Insurance Solutions/Pelagic Risk Services for their significant donations.

Saturday 26th October 2024 – South Australia Family Day and Peer Support program launch

A good-sized group of our South Australian community attended our family event in Adelaide, which coincided with the launch of our inaugural Peer Support program.

Families enjoyed a delicious meal, while the kids were entertained with fairy face painting, balloon twisting, and even a petting zoo! Thank you to Judith for creating gorgeous succulent plant arrangements and delicious choc-coated oranges as thoughtful take-home gifts.

Thank you to Claire and Anne on planning, attending and running this special event. Special thanks to Commbank for funding this event and the development of the Peer Support program.

Saturday 16th November 2024 – Charity Challenge Ball – Hyatt Regency Hotel - Darling Harbour, Sydney

The Diletosso family (with a great deal of coordination) flew in from Melbourne and Enza was one of two keynote charity speakers at the event. She spoke with emotion and passion (in front of a crowd of 600 people) about her family journey with leukodystrophy and disability, as well as talking about the work of Leukodystrophy Australia.

Here is a link to a video of Enza's powerful and heartfelt speech:
https://www.youtube.com/watch?v=ixWt3dTyq50

We appreciate the support of the Diletosso family – for those who have attended the Melbourne golf day, Enza and her family are always involved and supportive of this event.

Wednesday 4th December 2024 – Melbourne Golf Day

In contrast to the weather at the Sydney event, the conditions were perfect for the Leukodystrophy 2024 Melbourne Charity Challenge Golf Day at the highly rated Woodlands Golf Club. With thanks as always to Gary, Matthew and team who run an amazing day and bring a golfing tour together for this event. As is often the case, being a December event, there was a relaxed atmosphere as the golfers tend to get into the swing of the upcoming holiday feel. While we often have some of the Melbourne Storm NRL stars play at this event, unfortunately the day coincided with their training, but we hope to see them at the 2025 event. Congratulations to the Lancashire Underwriting Australia team on winning the day.

Sunday 25th May 2025 – Queensland Family Day lunch

On Sunday, 25th May 2025, Leukodystrophy Australia was proud to host a special 2-course Family Day Lunch in Brisbane for Queensland families affected by leukodystrophy. After postponing due to the cyclone, we were amazed to welcome over 50 people for a beautiful day of connection and community.

For individuals and families with complex health concerns, attending an event like this is rare and takes great effort and courage. Families and individuals found comfort in meeting others on similar journeys and had the chance to share their stories with those who truly understand. It was a rare and meaningful opportunity to feel seen, supported, and celebrated. Families had the opportunity to meet Claire (the Leukodystrophy Australia Family Advocate) face to face. Thank you to Claire for putting this fantastic event together.

FAMILY ADVOCACY

The twelve months to the end of June 2025 have been a busy and productive year for Leukodystrophy Australia. Following Jane's resignation in June 2024 due to ill health, a locum Family Advocate provided support until Claire was appointed full-time in late October 2024.

As indicated in the President's Report, we implemented a new database in late 2024 and look forward to it providing a strong platform for access to and the storage of our important records.

Since commencing, Claire connected with and provided direct support to more than 200 families, including over 25 newly connected families. With a background in health and disability social work and advocacy, and lived experience of complex health and disability, Claire brings both professional expertise and empathy to the role. She describes this work as an immense privilege, valuing the diversity of the role and the opportunity to advocate for the community.

Our Family Advocate program has provided individuals and families with the following types of support this year:

- direct emotional support, general and grief counselling
- practical and financial assistance
- advice and assistance to source and access medical practitioners, NDIS funding and support, allied health services, disability services, counselling and other professional services as required by individuals and families
- linkages to information and resources relevant to leukodystrophy and specific conditions through direct contact with individuals and families, Leukodystrophy Australia newsletters, Facebook posts, Leukodystrophy Australia website
- advocacy for individuals and families within the health and community service system including professional liaison on behalf of individuals
- systemic advocacy and collaboration through involvement with other advocacy organisations including the Neurological Alliance Australia, Rare Voices Australia, Genetic Support Network Victoria, Australian Patient Advocacy Alliance, pharmaceutical and medical research companies, and international leukodystrophy organisations including United Leukodystrophy Foundation, European Leukodystrophy Association and the Kennedy Krieger Institute
- knowledge about national and international medical, health and community services and research relevant to leukodystrophy conditions

- community education such as presenting information about leukodystrophy and Leukodystrophy Australia to medical, health and community service professionals
- linkages between individuals and family members living with leukodystrophy for peer support

Further to her direct support and advocacy work, Claire has been active in representing people living with leukodystrophy through her involvement with Rare Voices Australia. At the Rare Voices Australia Summit in November 2024, Claire built valuable connections with various organisations to help strengthen our advocacy efforts.

We are very grateful to Anne Patricia who provided invaluable continuity to the Family Advocate Program, stepping in as needed throughout the recruitment and onboarding process.

We were very pleased to have Jane return to work in a casual capacity alongside Claire from May 2025.

Following the Rare Voices Australia Summit, Claire championed the appointment of a Rare Voices Ambassador for leukodystrophy. We are delighted that in June 2025, Ryan Zilioli was successful and will serve in this role for a two-year term, giving our community a stronger national voice. Read Ryan's full story → https://rarevoices.org.au/personal-story/ryans-story-2/

Alongside the committee, Jane has played an active role in strengthening Leukodystrophy Australia's policies and procedures, including the Peer Support Leader program. She continues to represent the organisation and leukodystrophy community through the Neurological Alliance Australia (NAA). A major milestone this year was the launch of Australia's first National Action Plan for Neurological Conditions at Parliament House during the NAA Day of Action on 4 September. We were proud that the Blueprint featured a lived experience quote from one of our families, ensuring our community was represented at a national level. You can view the Blueprint here: https://bit.ly/3V7ZORn

Connection remains at the heart of our work. Throughout the year, Claire, Jane and Anne continued to bring families together at meaningful family event lunches in South Australia and Queensland, with upcoming events in NSW on 21st September on the Central Coast and 26th October in Sydney. Claire will be visiting Victoria to meet with our community in early December 2025 and to coincide with the week of the Charity Challenge Golf Day. Please reach out to Claire if you would like to catch up with her.

Leukodystrophy Australia also launched our formal Peer Support Leader Program in February 2025 which was funded through a CommBank Staff Foundation Community Grant. Peer support brings people together to share information, ideas, knowledge and lived experiences with one another for emotional, practical and social support. People come together at different stages of their journey with different needs and provide and receive help and understanding based on their shared or similar experiences.

The Peer Support Leader Program comprises six modules of training for people who are interested and can attend the training to become Peer Support Leaders. The first training program ran over a period of seven months from February to August 2025. Three people with personal experience of leukodystrophy were formally trained through the program to provide support to others who are experiencing the effects of leukodystrophy for themselves and/or their loved ones. We wish to again thank Judith, Carissa and Ryan for their strong commitment to completing this program and supporting others within our leukodystrophy community. Further training will be run during the first half of 2026. Please contact Claire or Jane to register your interest in becoming a Peer Support Leader.

The committee is impressed by the passion and professional expertise that Claire, Anne and Jane have brought to our service. Social work is an evidence-informed and strengths-based profession which acknowledges that individuals and families have their own strengths and resources, regarding them as experts in their own lives. Social work is a values-led profession, and our Family Advocates are guided by the Australian Association of Social Workers - Code of Ethics and Practice Standards. Claire, Anne and Jane have continued to provide an empathetic, caring and supportive service for our Leukodystrophy Australia community during this financial year.

We remain deeply grateful for the generous donations and grants that make our Family Advocate program and supportive activities possible. In the 2026 financial year, we will continue to grow this vital work, offering information, support, connection and advocacy for our community across Australia.

Family Advocate Highlights 2024-2025

- Directly supported over 200 families including over 25 newly connected families.
- Launched the Peer Support Leader Program; three leaders trained, with additional leaders to be trained in 2026.
- Coordinated and hosted Family Events in South Australia (Oct 2024) and Queensland (May 2025)
- Represented our leukodystrophy community at the Rare Voices Australia Summit and through advocacy involvement.
- Appointment of Ryan Zilioli to represent leukodystrophy as Ambassador for Rare Voices Australia
- Contributed to the Neurological Alliance Australia launch of the national blueprint for neurological diseases

WELCOME TO NEW MEMBERS

We have welcomed several new members this year and we thank you for your support. Leukodystrophy Australia is always here to meet your needs for assistance, support, information and linkage into local services. Our membership is not limited to people affected by leukodystrophy conditions and we welcome interested others, groups, supporters and businesses to join. Thank you to those who joined our membership in 2024/25 and to those who continue to renew their membership with us every year.

As per our constitution, there are three membership types – Ordinary, Honorary/Life Members, Institutional Members. Any changes to membership fees are determined by the committee in January (but these become applicable in the next financial year). We have previously determined that Ordinary and Institutional member fees are $25. Free membership is offered to members affected by a leukodystrophy (including immediate family members), Honorary and Life members.

CONDOLENCES

Leukodystrophy Australia extends our heartfelt warmth and compassion towards individuals and families who have become bereaved over the past 12 months.

Leukodystrophy Australia is always available to those who wish to reach out to us and we will assist and support you no matter what stage you are at on your leukodystrophy journey.

SECRETARIAL RESPONSIBILITIES

With its founding and registration originally in Victoria, Leukodystrophy Australia has fulfilled its statutory responsibilities under Victorian Legislation. This includes the lodging of statutory returns to Consumer Affairs Victoria (where required) and the Australian Charities & Not for Profits Commission in relation to our funding and financial activities.

Thank you to Susan Stenning for filling her obligations of Secretary. We greatly appreciate your efforts.

TREASURER'S REPORT

Our Treasurer completes the in-house accounting, while the Tax Office reporting of the BAS and Payroll is outsourced to Chilli Bookkeeping, where Nick Cardenas and Penny Evans provide their expertise. We engage Deborah Gallagher CA of Deborah Gallagher & Associates to conduct the annual audit. Our Financial Statements will additionally be available via the Australian Charities & Not for Profit Commission (ACNC) https://www.acnc.gov.au/ or by email request to: treasurer@leuko.org.au

We continue to be financially stable and confident as we move into the 2026 financial year. Our financial team will continue to work together to meet our Vision & Mission, supporting those living with Leukodystrophy to lead their best lives.

CONCLUSION AND FUTURE DIRECTION

On top of our South Australian and Queensland family events during the 2025 financial year, with two NSW family events upcoming in September and October 2025 and a Family Advocate visit to Melbourne in December 2025, we have been able to hit the ground running. With the recommencement of a full-time Family Advocate and with Jane also returning casual in May and moving to part-time in late 2025, we are well-placed to provide more touch points with our leukodystrophy community than we have ever before.

In 2026, we will continue to strengthen our governance.

Our Peer Support program is now in place – please reach out to our Family Advocates if you would like to find out more about this program, be it to potentially participate as a Peer Support Leader, or if you would like to be put in touch with a Peer Supporter.

As always, if you have particular skills (e.g. fundraising, marketing, governance, charitable committee experience) that might be of interest to our organisation, interesting contacts, or any other experience you feel might be of benefit to Leukodystrophy Australia, we would love to hear from you.

We continue to reach out to, consult and share information with other leukodystrophy networks, rare disease organisations and other stakeholders locally, nationally and globally. We look forward to continuing to raise awareness of leukodystrophy through our collaborative work with organisations such as: Genomics Australia (Commonwealth Govt), Genetic Alliance, Genetic and Rare Disease Network, Genetic Services Network, Global Leukodystrophy Initiative, the Australian Leukodystrophy Clinical and Research Program/White Matter Disorders Clinic, Neurological Alliance Australia, Rare Voices Australia, Mission Massimo Foundation, SWAN Australia, United Leukodystrophy Foundation (USA), Kennedy Krieger Institute (USA), and the European Leukodystrophy Association (EU).

We continue to be strongly committed to and driven by the needs of the individuals, families and members we support. We encourage those who feel they might (even if unsure) need support, to reach out to us through our Family Advocates – we are here for you.

We welcome all feedback about our organisational activities and Family Advocate Program via phone or the contact page of our website, https://www.leuko.org.au/contact-us/ to assist us to ensure our operations are relevant and helpful.

On behalf of the Committee, thank you to all members, volunteers, donors and supporters, we wish you all the best in the year ahead.

Leukodystrophy Australia
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