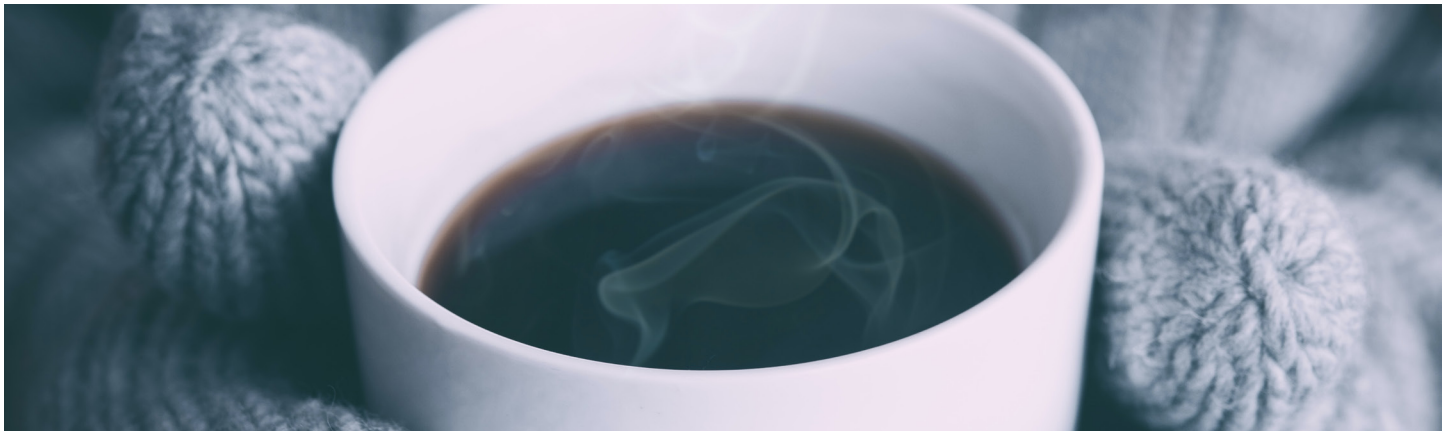
LEUKODYSTROPHY .org.au AUSTRALIA



newsletter / **winter 2025**

Message from the Team

Hi to all our members, families and supporters

Where has the time gone? It's already August and the year is flying by. We hope you have been keeping warm and as well as possible during these winter months. We look forward to welcoming some warmer weather across Australia soon.

Our Committee and Family Advocate Program have been keeping extremely busy this year, and we have a lot of information and upcoming events to let you know about in this issue.

Our Family Advocate Claire Kingsley certainly hit the ground running after commencing with us in October 2024. She has been progressively reaching out to individuals and families across Australia to introduce herself and check in on your support needs.

Claire organised and facilitated the very successful Queensland Family Lunch event in Brisbane in May 2025 which you can read about in this newsletter. Claire has arranged Family lunch events on the Central Coast NSW in September, and in Sydney in October this year.

Claire will attend The Charity Challenge Sydney Golf Day for Leukodystrophy Australia on Friday 10th October. She will also be travelling to Melbourne in December to attend The Charity Challenge Melbourne Golf Day. Claire will be reaching out to our members and families in Sydney, Melbourne and surrounding areas before the events to ask if anyone would like to meet with her while she is visiting from QLD.

Claire has also been engaging closely with medical specialists, leukodystrophy and genetic researchers, community and disability support organisations and international leukodystrophy organisations to provide education and raise awareness around leukodystrophy and the work of Leukodystrophy Australia.

Continued on page 2

Contents

Message from the Team	**1**
Leukodystrophy Australia – 33rd Anniversary	**2**
Family Advocate Program details	**2**
Upcoming Events	**3**
Recent Events	**5**
News	**8**
Research Update	**11**
Family Story	**12**
Your Voice Matters – Your membership counts	**12**

Message from the Team cont.

Our active consultative partnerships with Rare Voices Australia (RVA) and the Neurological Alliance Australia (NAA) have been progressing Leukodystrophy Australia's advocacy at a systemic and political level to ensure people affected by leukodystrophy are represented.

We are happy to let you know that our previous Family Advocate Jane O'Neill has recovered well from her illness which caused her to resign from her position in 2024. She has now returned to work alongside Claire on a part-time basis, currently 3 days per week.

Our first formal Peer Support Leaders' Program training has just finalised. Congratulations to LA's Peer Support Leaders Judith, Ryan and Carissa. Thank you for your time, your wonderful participation in the training and the commitment you've shown to supporting others affected by leukodystrophy. We look forward to welcoming more of you who wish to offer Peer Support into this training program. We will keep you informed of future training periods as they are arranged. In the meantime, should you like to find out more information about the program, please contact Claire.

We are very fortunate that our Family Advocate Program is moving from strength to strength thanks to generous donations from The Co-Group Limited and our other financial donors. We are so grateful for your support, and we know that Sr Julie would be extremely proud that her legacy of Leukodystrophy Australia is helping so many people affected by leukodystrophy.

2025 is the 33rd year since our organisation was established by Sr Julie and we would like to take some time to remember her achievements in this anniversary month of August.

Sending our very best wishes to you all.

The Team, Leukodystrophy Australia

Leukodystrophy Australia celebrates our 33rd year Anniversary

On the 17th of August 1992, Sr Julie Thomas launched Leukodystrophy Australia, previously called the Australian Leukodystrophy Support Group. This year marks the 33rd year anniversary of Leukodystrophy Australia. We recognise this special day and Sr Julie's vision and years of dedication in supporting hundreds of people affected by leukodystrophy and their families. We know she enriched the lives of so many and that she is remembered fondly by all who knew her.

We wish to thank the many volunteers, supporters, donors and employees who have worked tirelessly over the years to grow our organisation to become the national peak body for leukodystrophy, and care and support for individuals and families living with leukodystrophy in Australia. We are so proud and honored to continue Sr Julie's legacy.

Family Advocate Program Contact Details:

Family Advocate – Claire Kingsley

Claire is your main Family Advocate Program contact.

She works full-time, Mondays to Fridays, and can be contacted on:
0418 790 059
or email:
advocate@leuko.org.au

Family Advocate – Jane O'Neill

Jane works part-time, Tuesdays to Thursdays, and can be contacted on:
0418 755 994
or email:
jane.oneill@leuko.org.au

Upcoming Events

Please contact Claire for more information or to register your interest in relation to these events.
Further information about these events is contained in the following pages.

Sunday 21 September	**NSW Family Lunch Event – for those living in Newcastle/Central Coast areas and/or visiting the area** The Doylo, 80 Pacific Hwy, Doyalson NSW
Friday 10 October	**The Charity Challenge Sydney Golf Day for Leukodystrophy Australia and lunch event** Long Reef Golf Club, Anzac Avenue, Collaroy NSW
Saturday 18 October	**Leukodystrophy Australia Annual General Meeting**
Sunday 26 October	**NSW Family Lunch Event – for those living in Sydney areas and/or visiting the area** Castle Hill RSL, 77 Castle Street, Castle Hill
Wednesday 3 December	**The Charity Challenge Melbourne Golf Day for Leukodystrophy Australia and lunch event** Woodlands Golf Club, 109 White St, Mordialloc VIC

Leukodystrophy Australia AGM Saturday 18th October @ 2pm (AEDT)

The Leukodystrophy Australia Annual General Meeting (AGM) will take place on Saturday 18th October from 2-3pm (AEDT) via Zoom.

Please join us using the link below:

https://us06web.zoom.us/j/86487826472?pwd=b3kkWN5pibgqTgZkTHJ9nZx373Nua6.1

The Formalities

The formal business will include, as required by our Model Rules: the confirmation of the Minutes of the 2024 AGM; presentation of the Annual Report and Financial Statements; the election of the Committee of Management for 2025/26; and the confirmation of annual subscriptions.

The election of the new Committee involves the election of a President, a Vice President, a Secretary, a Treasurer and several ordinary Committee Members. We are calling for your support and involvement in the management of Leukodystrophy Australia, its support of members, families and LA's sustainability.

Eligible Members

Only eligible members of Leukodystrophy Australia may vote at the AGM.

To be an eligible member, persons must have completed and submitted a **"Membership & Supporters Application/Renewal"** form **https://www.leuko.org.au/support-us/membership/** during the 2025 financial year and up to a week prior to the AGM date. If an eligible member cannot attend the AGM personally, he or she may vote using the proxy form. A proxy must be received by post/email at least 24 hours before the AGM or may be given to the President of the AGM before the meeting.

Please contact us for an Appointment of Proxy form and/or to RSVP for the AGM: info@leuko.org.au OR 1800 141 400

Have you considered being a committee member?

For more information: https://leuko.org.au/support-us/committee/

Please contact our office if you have an interest in supporting Leukodystrophy Australia as a Committee member or in offering a specialist expertise to the Committee on an ad-hoc basis. If you are interested in nominating, please fill out the form on our website **https://www.leuko.org.au/support-us/committee/**

Upcoming Family Events

Calling all NSW Central Coast/Newcastle families!

Do you live around the central coast/Newcastle NSW or are you travelling through? We'd LOVE for you to join us for a small, warm and welcoming Leukodystrophy Australia Family Lunch on Sunday, 21st September!

This will be a relaxed and friendly get-together — a chance to connect, share stories, and enjoy a lovely meal with others who understand the journey.

The Doylo, 80 Pacific Hwy, Doyalson
Sunday, 21st September – 12noon to 4pm

Contact Claire to RSVP or discuss the event on 0418 790 059 or email: advocate@leuko.org.au

Whether you're local or passing through, we'd be so happy to see you there.

Sydney Family Lunch Event Calling all families from Sydney and surrounds!

Do you live in Sydney or surrounding areas, or will be visiting Sydney in late October?

We'd LOVE for you to join us for a warm and relaxed Leukodystrophy Australia Family Lunch on Sunday, 26 October!

Castle Hill RSL, 77 Castle St, Castle Hill NSW
Sunday, 26 October – 12noon to 3.30pm

Contact Claire to RSVP or discuss the event on 0418 790 059 or email: advocate@leuko.org.au

The Charity Challenge Golf Days for Leukodystrophy Australia and Lunch events

Friday, 10th October 2025
The Charity Challenge Sydney Golf Day for Leukodystrophy Australia
Long Reef Golf Club (Anzac Ave, Collaroy)

Please email **info@leuko.org.au** should you wish to find out more information about the Golf Day

OR

Register online to participate: **https://tiny.cc/sydneygolf**

Lunch event: The Charity Challenge Sydney Golf Day event will be followed by a free Leukodystrophy Australia Lunch at the Long Reef Golf Club.

You don't need to have played in the Golf Day event to attend the lunch.

Contact Claire to register your interest in attending the lunch on email: **advocate@leuko.org.au** or **0418 790 059**

Wednesday, 3rd December 2025
The Charity Challenge Melbourne Golf Day for Leukodystrophy Australia
Woodlands Golf Club (109 White St, Mordialloc VIC)

Please email **info@leuko.org.au** should you wish to find out more information about the Golf Day

OR

Register online to participate: **https://tiny.cc/vicgolf**

Lunch event: The Charity Challenge Melbourne Golf Day event will be followed by a free Leukodystrophy Australia Lunch at the Woodlands Golf Club.

You don't need to have played in the Golf Day event to attend the lunch.

Contact Claire to register your interest in attending the lunch on email: **advocate@leuko.org.au** or **0418 790 059**

History Behind the Charity Challenge

The Charity Challenge has made a wonderful difference in a variety of people's lives. 2025 is the twentieth year since The Charity Challenge Golf Days were introduced to the Corporate Golf market by its founders Gary Dawson OAM and Matthew Laverty.

These days support a key group of smaller charities each year, that perhaps don't receive a high public profile or adulation and highlight the services and the roles they play in the community. Leukodystrophy Australia thanks Gary and Matthew for their dedication and support for Leukodystrophy Australia.

QLD Family Day Lunch

On Sunday 25th May Leukodystrophy Australia was proud to host a special 2-course Family Day Lunch in Brisbane for people in QLD who are affected by leukodystrophy. After needing to postpone the first scheduled date of the event at short notice 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.

Continued on page 6

QLD Family Day Lunch cont.

As a small charitable organisation, our capacity to bring people together is limited—but thanks to the generosity of grants, donations, and fundraisers, we're able to create these special days and moments that make a small difference in the lives of those with rare leukodystrophies.

Please contact Claire on 0418 790 059 to find out more about our upcoming NSW Family Day lunches and ensure your contact details are updated with us.

Peer Support Leader Volunteer Training Program

This year, Leukodystrophy Australia commenced a pilot volunteer Peer Support Leader training program which is evidence based and has been professionally developed through generous funding from the Commonwealth Bank.

The program is designed to connect individuals and families affected by leukodystrophy by offering support and shared experiences from others with lived experience who truly understand.

We wish to congratulate Carissa, Judith and Ryan, our Peer Support Leaders who completed the program in July 2025.

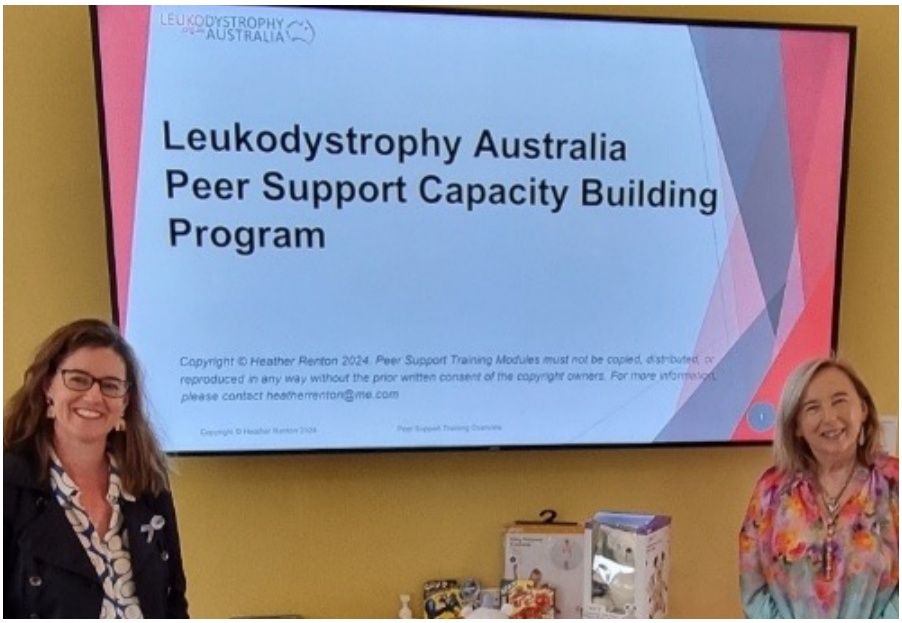
The program involves: attending pre-program interviews with our Family Advocate; undergoing safety screening checks including a National Police Check and Working with Children Check; attending 6 peer support training modules and additional educational training courses including Mental Health First Aid. This training is fully funded by Leukodystrophy Australia.

We intend to commence another Volunteer Peer Support Leader training course later this year or early 2026.

As a Volunteer Peer Support Leader, you will play a vital role in providing connection and support to others through your shared lived experience. You will receive comprehensive training and ongoing support from Leukodystrophy Australia to ensure you are well-prepared and supported in your role. This is a wonderful opportunity to make a profound impact on the lives of others, while growing personally and developing formal support skills and knowledge.

To find out more about becoming a Volunteer Peer Support Leader, please email Claire: **advocate@leuko.org.au**

If you are seeking peer support, please call Claire on **0418 790 059** to discuss your support needs.



Claire and Anne launching the volunteer Peer Support Training program in South Australia, with grant funds from the Commonwealth Bank in late 2024

Carissa and family

Judith

Ryan with Leukodystrophy Australia Family Advocate Claire

Introducing Rare Voices Australia Ambassador for Leukodystrophy Ryan Zilioli

We are incredibly excited to share that Leukodystrophy Australia member Ryan Zilioli has been appointed as the Rare Voices Australia (RVA) Ambassador for Leukodystrophy for the 2025–2027 term. **https://rarevoices.org.au/rare-voices-australia-ambassadors/**

Leukodystrophy is a group of rare, progressive neurological disorders that affect the white matter of the brain. While the challenges are immense, so too is the strength of those living with leukodystrophy— and their families, carers and advocates supporting them every day.

Ryan is committed to raising awareness, driving meaningful conversations, and advocating for improved support, diagnosis, and access to care for the leukodystrophy community across Australia.

This is more than a title, it is a responsibility Ryan will carry with purpose, passion, and hope. Thank you to Ryan and to Rare Voices Australia for this opportunity to amplify leukodystrophy, especially for those without a voice.

Ryan Zilioli was unknowingly born with an incurable rare neurodegenerative disease called X-linked Andrenoleukodystrophy, a disease that destroys the myelin sheath that protects the nerves throughout the body due to a mutation on the ABCD1 gene. The adult-onset subtype AMN causes significant chronic neuropathy, axonopathy, mobility limiting spastic paraparesis and Addisons Disease, a potentially fatal adrenal condition. A series of unfortunate medical events led to this devastating diagnosis on Ryan's 30th birthday. Since, Ryan has shown great resilience in adaptiong to life with this new set of challenges by living life with purpose and working in the disability sector with the Western Australian All Abilities Football Association. He also volunteers his time at Wheelchairs for Kids Australia as a peer supporter whilst contributing to many projects steering public policy around rare disease and advocacy.

Josh Yates – off to the World Transplant Games in Germany

We wish Josh Yates good luck and send him our best wishes with his sporting endeavours at the World Transplant Games in Dresden, Germany commencing on the 17th August 2025.

This will be the sixth time Josh has represented Australia in the World Transplant Games both in Australia and overseas. In 2019, Josh was the flag-bearer for Australia at the Games in Newcastle, England. At the World Games in Perth in 2023 he was chosen to give the Athletes oath. He has had a remarkable journey of perseverance and hard work. Josh was fortunate to receive a bone marrow transplant (BMT) 21 years ago and has used his second chance in life to demonstrate that despite health challenges and disability, great things can be achieved.

Josh will compete in the 5km run in the Great Garden of Dresden, the Petanque doubles, the 400m and 800m along with relays at the track and field stadium. Go for GOLD Josh!! You're a champion in our eyes.

Leukodystrophy Australia, through our contact with the European Leukodystrophies Association (ELA), was able to connect Josh with a family in Germany who also live with the challenges of leukodystrophy. They will be supporting and cheering Josh on at events. From our understanding Josh is the only one competing in the World Transplant Games who has had a BMT for leukodystrophy.

We look forward to sharing photos of Josh's time in Germany.

Josh sends his love to everyone associated with Leukodystrophy Australia.

Josh with his Gold medal at the 2024 World Transplant Games

Scott Takes Up Golf — And Redefines What's Possible

Scott showcasing the Paramotion

Scott Andrys lives with the condition Alexander Disease, a rare type of leukodystrophy. Due to declining mobility, he had not considered playing golf an option. This was until Scott recently discovered the Paramotion - an all-terrain wheelchair that raises the user into a standing position. With training from a golf coach, Scott is enjoying being out on the golf course and practicing his swing. It has given him new quality of life that he never thought was possible.

The Paramotion can access most areas of the golf course including driving ranges, greens and appropriately designed bunkers. The Paramotion can also be used where all-terrain and stand-up functionality are required, like fishing, archery, photography, shooting, or just hugging a loved one!

The Paramotion is available for hire from various golf courses around Australia. Empower Golf Hubs across Australia offer trial sessions through Come and Try Golf clinics.

The Paramotion was created and designed in Australia! Find out more: **https://empowergolf.com.au/equipment/**

Scott has fortunately been able to direct some of his NDIS funding towards golfing and community engagement.

This is more than a story about sport — it's a story about resilience, innovation, and inclusion.

Let's amplify Scott's story and raise awareness for the thousands of Australians living with leukodystrophy.

Contact Claire on **0418 790 059 for more information.**

The CHRISTMAS PARTY

Special Children's Christmas Parties

We're excited to announce the Special Children's Christmas Parties will be held again this year in various cities across Australia during November and December 2025.

A 2-3-hour stage show will keep your little ones entertained, along with rides, interactive displays, photo opportunities, and more! With all this fun to be had, they will need all the food, drinks, lollies and ice creams, which will be provided for free

And of course, no Christmas party is complete without a visit from Santa himself. Every child will receive a brand new present to take home and treasure.

The events are designed for children from birth to 12 years old who are living with disabilities or complex needs, including those currently receiving—or who may be eligible for—NDIS support. The aim is to provide these children with a day tailored to their unique needs, while also creating opportunities for parents and carers to build meaningful connections within the community.

Unfortunately, siblings who do not meet the above criteria are not able to attend these events.

If you are interested in securing a ticket for your child to attend a party closest to your area, please contact Claire ASAP as tickets are limited.

Email: **advocate@leuko.org.au** or **0418 790 059**

August is Grief Awareness Month

Grief affects us all – but support doesn't always follow.

Griefline invites you to take part in Let's Talk About Grief 2025 survey.

If you've experienced grief in the last 12 months, Griefline invites you to complete their survey which is open until 31 August / **griefline.org.au/2025-national-grief-survey**

Grief support is available through the Griefline Helpline

8 am – 8 pm AEDT/AEST, 7 days a week

Call **1300 845 745**

https://griefline.org.au/

Leukodystrophy Australia is also here to support you in your grief so please don't hesitate to reach out to Claire if you are needing support or would just like to talk about your loss and grief experience.

The 24th of July was International Selfcare Day

This day should be every day because you are number one!

Give yourself permission to slow, to think, to breathe, to look at the sky, the trees, the birds, the butterflies and recognise how beautiful and amazing and strong you are.

Saturday 28th June was International Neonatal Screening Day

In December last year, Australian Health Ministers approved male Adrenoleukodystrophy (x-ALD) newborn screening with the pending introduction to commence late 2026/2027.

Leukodystrophy Australia had the opportunity to connect clients to a research study regarding their lived experience and knowledge of ALD. The study outcomes were utilised to inform the Health Ministers' decision making around including females in ALD newborn screening. Reports regarding this comprehensive research have been sent to all Australian Health Ministers and a decision is pending.

Leukodystrophy Australia looks forward to participating in planning for the introduction of x-ALD newborn screening to promote the need for best-practice, holistic, trauma-informed and collaborative care being made available for families from the moment they receive diagnostic results of ALD for their newborn.

Clinical Trial Opportunity for Adult Males with Progressive cALD

Minoryx Therapeutics is conducting a **Phase 3 clinical trial – CALYX** – to evaluate the efficacy and safety of Leriglitazone in adult males with progressive cerebral adrenoleukodystrophy (cALD). Cerebral adrenoleukodystrophy (cALD) is a rare neurological disease that may develop in men with adrenomyeloneuropathy (AMN). Those with AMN are generally recommended to do yearly MRI screenings for cerebral ALD. If you have AMN or cALD, this clinical trial could be a good option.

This international study is open to eligible participants from around the world.

Key Inclusion Criteria:

- **Males aged 18 years or older**
- **Gadolinium-enhancing brain lesions**
- **Loes Score between 0.5 and 12**
- **Confirmed genetic diagnosis of X-ALD**

ALL COSTS related to testing and travel (for both the participant and one carer) are FULLY COVERED.

CALYX aims to enrol 40 adult males with progressive cALD, identified by the presence of gadolinium-enhancing brain lesions.

For more info:

CALYX

Interested?

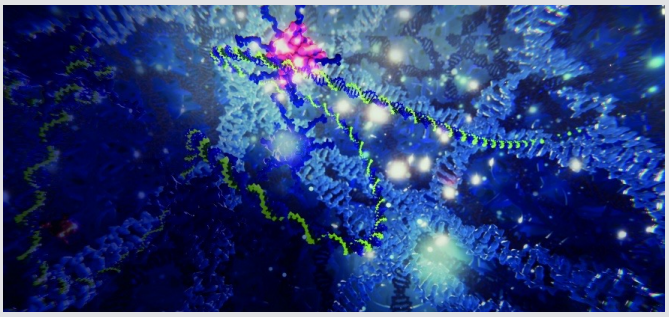
If you or a loved one may qualify for this trial, or wish to learn more, please contact:

Claire **0418 790 059**
advocate@leuko.org.au

Help us spread the word and advance research for rare neurodegenerative diseases.

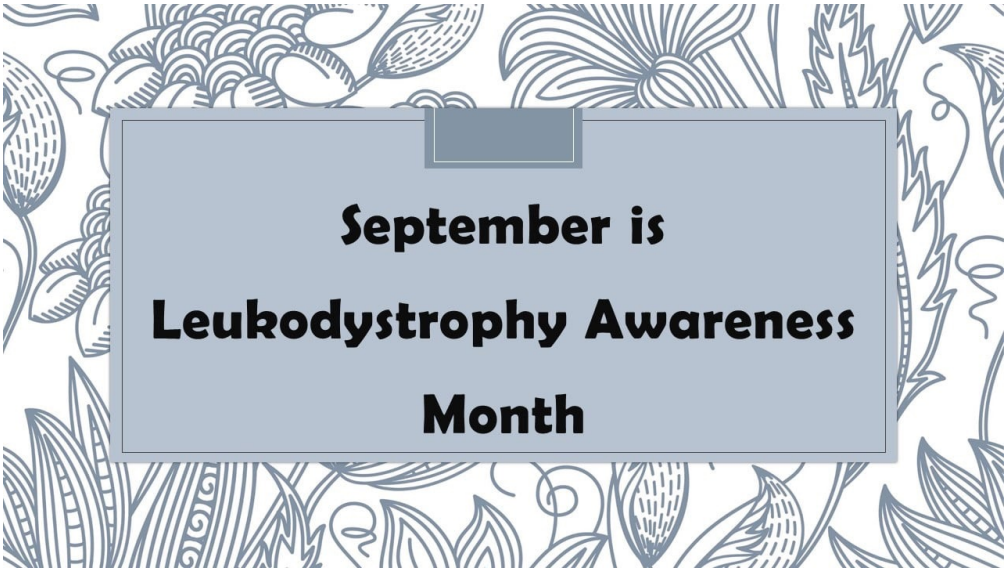
Together, we can make a difference.

The Garvan Institute of Medical Research has launched the Genomics of Rare Disease Registry



While progress is slow in rare diseases, it is happening, from improved genetic testing for diagnosis to developing treatments and support for people living with rare diseases. The registry is open to Australians with known or suspected rare genetic diseases as part of a national study focused on understanding their cause.

Genomics of Rare Disease Registry
Garvan Institute of Medical Research



Mateo's story

Shared with permission of Mateo's family

Mateo

Right now, there is no active research into Adrenoleukodystrophy (ALD) being conducted in Australia. That's why Mateo's courageous mum has launched a GoFundMe to raise funds for future research—because individuals and families can't wait.

No Adrenoleukodystrophy (ALD) Research in Australia? This Needs to Change.

Mateo recently underwent a bone marrow transplant (BMT) following an ALD diagnosis—the only current treatment option for a fortunate few in a small window of opportunity. Even with BMTs and future new-born screening, the journey is full of obstacles, complications, and disability.

ALD is a rare genetic disorder that attacks the white matter coating of the brain and spinal cord of children and adults. Early detection helps, but we urgently need Australian-based research to improve outcomes and offer real hope, improved treatments and cures.

We're calling on scientists, researchers, and universities across Australia— please step forward. Let's spread the word.

Donate if you can and help bring ALD research home.
https://gofund.me/4cbf8c4e

This is Your Space

Do you have a story to tell, or a contribution to make, to Leukodystrophy Australia's Facebook page or Newsletter?

We would love to hear from you!! It is really important that we represent and share the range of experiences and requirements of our members.

If you would like to contribute, please contact our Family Advocate Claire on: Phone: **0418 790 059** Email: **advocate@leuko.org.au**

Your Voice Matters: Your Membership Counts

The essence of our organisation is Members. By working with our members, **Leukodystrophy Australia** achieves goals that benefit all people living with Leukodystrophy. We do this through our focus on supporting individuals and families to live their best lives. For our awareness raising and our grant submissions to government and private benefactors, our 'Memberships' and our 'Members lived experience' is vital. It is imperative we continue to show strong Membership.

Please initiate or renew your 2025-2026 membership today. Applications can be easily processed on our website

https://www.leuko.org.au/support-us/membership/

It is important to note that membership is free if you or someone in your family has been diagnosed with a leukodystrophy.

Please help us update your details:

It has been a particularly busy year at **Leukodystrophy Australia** with the introduction of a new database to meet our current confidential record keeping and data collection needs. Rolling over to the new system has seen the usual teething problems but we are now mastering it.

We'd like to ensure that you are receiving all information from **Leukodystrophy Australia** that may be relevant to your situation and that we are able to stay in touch with you. To ensure that our new database is as up to date as possible, we would greatly appreciate it if you could call or email Claire to confirm or update your contact details (unless you have recently done this through contact with us).

Email: **advocate@leuko.org.au** or **0418 790 059**