LEUKODYSTROPHY .org.au AUSTRALIA

Newsletter | **Autumn | Winter 2024**

From the Team

To our wonderful Leukodystrophy Australia (LA) Community, we trust everyone is going well through this winter period.

Jane O'Neill – Farewell and Best Wishes

Our wonderful Family Advocate Jane O'Neill wished for me to inform our families, donors, stakeholders and others that due to a long-term illness she will not be continuing in her role as LA's Family Advocate. Jane officially resigned on the 7th June 2024.

Jane is going to spend time recuperating, enjoying her family and friends and taking some well-deserved walks along the beach.

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The LA Community will miss Jane dearly. I have heard many times that Jane was a great listener, compassionate, caring and very supportive.

Jane expressed to me that she thoroughly enjoyed supporting and assisting our LD families and that she was touched by each and every individual's and family's stories.

Jane had a wonderful time at some of LA's family events and she felt privileged to meet and have a rich conversation with Sister Julie and be part of LA's 30-year event.

The LA Committee wish Jane all the best in her personal life.

Get well soon Jane and know you will always be part of our LA Community.

See below section and introduction to Social Worker - Tracey Bachli, who has stepped into the Family Advocate role.

Love,

Anne Patricia and the LA Committee.

New Family Advocate/Social Worker – Tracey Bachli

LA has recently employed a part-time Social Worker – Tracey Bachli - to step into the Family Advocate role. Tracey is working two days per week with us. We are lucky to have someone as experienced and empathetic as Tracey and look forward to working with her.
Welcome Tracey!

I am a qualified Social Worker with over ten years' clinical experience at the Women's and Children's Hospital, Adelaide. I have worked extensively with children, young people, caregivers, and families who are living with chronic and life limiting medical conditions. In 2023 I relocated from Adelaide to Newcastle so I could more spend time getting to know my new grandson. My two elderly dogs have made the journey with me, and we are excited to see what the future holds.

I have been working part time as Senior Critical Care Social Worker in the hospital setting and work two days per week with Leukodystrophy Australia (Thursdays and Fridays).

I am grateful to have been offered the opportunity to work with Leukodystrophy Australia. I look forward to being a support and advocate to you and your family. Please do not hesitate to contact me to introduce yourself.

Hours of operation: 2 days per week Thursdays and Fridays (hours can be flexible to provide support to individuals and families in different time zones across Australia).

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

Upcoming Events

Fri 28th/ Sat 29th June (11.30pm to 7am (AEST time)	**United Leukodystrophy Foundation (USA) Family Conference (online viewing available) https://ulf.org/news/conference**
Fri 27th September 7am to 3pm	**Charity Challenge Leukodystrophy Sydney Golf Day – Long Reef Golf Club (please contact us for details)**
Sat 19th October 2pm to 4pm	**Leukodystrophy Australia AGM (online) – Zoom link to be provided closer to the event**
Wed 4th December 7am to 3pm	**Charity Challenge Leukodystrophy Melbourne Golf Day – Woodlands Golf Club (please contact us for details)**

Thank you to our important donors to Leukodystrophy Australia

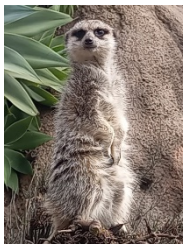
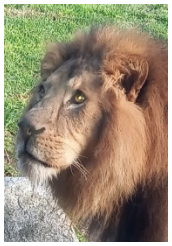
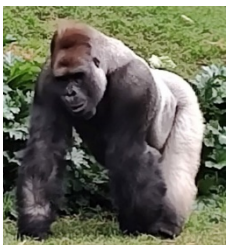
Donations are critical in allowing us to support our members/families in many ways such as respite funding, urgent bills, special travel, approved critical care equipment.

We would like to thank all of those who donate to Leukodystrophy Australia – you make a difference!

We would also like to acknowledge The Co-Group Limited and its board, who have generously funded much of the Family Advocacy that we are able to provide our members/families.

Meet our Families:

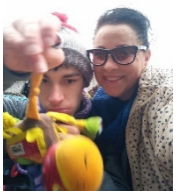
The Dilettoso family's day out at Melbourne Zoo

The Melbourne Zoo was wonderful, it has an easy-to-follow path system, with access for people using wheelchairs and strollers. We all had a wonderful family day. The weather was chilly, but luckily it was not raining.

All of us drove to the zoo in our new van, which was great because there was plenty of parking.

Alessio, Savio, Danilo and parents, Enza and Salvatore enjoyed the day.



The Wheeling Wanderers

Aaron, his carer Jodi and her son Connor left Gidgegannup in WA at the end of April. They hooked up the caravan after months of planning and off they went around Australia. They call themselves The Wheeling Wanderers and as you can see, they are having a ball.

Aaron always wanted to go deep sea fishing and here we see him with a huge fish which he caught at Exmouth.

No, they did not BBQ the fish on the boat, luckily for the fish it was thrown back into the sea to live another day!

Next, they are off to Broome and LA can't wait to see some photos of Cable beach and what that gorgeous part of Australia.

We are all looking forward to seeing and reading about The Wheeling Wanderer's continual travels around our gorgeous Australian coastline.

Look out for updates on the LA Facebook page in the weeks to come.

In the meantime, mum Mandy and Aaron's twin brother Ryan will wait patiently at home for him to return. Though, I have a feeling Ryan currently likes having their man cave to himself for a while.

Angus, the labrador is staying with Mandy and Ryan - he will no doubt be spoilt!

This is your space

Do you have a story to tell, or a contribution to make, to Leukodystrophy Australia's Facebook page or Newsletter? Please make contact with Anne to discuss. It is really important that we represent and share the range of experiences and requirements of our members. We would love to hear from you.

Tracey: 0418 790 059 Email: advocate@leuko.org.au

The Lion King 🦁 Simba Strava Art – in honour of Zack Lush

In March and April, in honour of **Zack Lush's** strengths and teachings of life, friends walked, ran, rolled (cruised) and rode the approximate **150km Strava route** over **Adelaide to draw baby Simba, The Lion King**.

At age 2, **Zack** was diagnosed with trichothiodystrophy - a rare type of childhood Leukodystrophy that affects multiple body systems and requires a high level of specialty care on a daily basis. Over his 7 years, Zack's engaging personality and ability to navigate through these difficulties saw him go beyond expectations, learn sign language, develop meaningful relationships, graduate from kindy, and attend primary school.

One of his favourite things was scaring people by going 'roar' and seeing how they reacted. From their reaction, he would crack up with big belly laughs which made everyone laugh and smile too. Zack even took his roar to school where he would roar to his classmates. His classmates unanimously chose him to play Simba in the class Lion King play, where he became aptly known as the King of Unley Primary School.

Through his resilience and courage Zack has shown that we are not defined by what happens to us, but by how we choose to respond. His roar is a legacy to all who had the privilege of knowing and loving him.

The Strava Art brought the community together to **raise awareness of Leukodystrophy Australia** and those living with a disability and raise funds for **Leukodystrophy Australia**.

For further information about Leukodystrophy Australia and to donate, please visit: https://www.leuko.org.au/support-us/donate

We ask that you note in the online donation form comments box: **Zack Strava Art**.

This will enable us to keep a track of donations made in honour of Zack.

Thank you to **Pete Stokes** who helped out with the Strava art route and coordinated everyone's efforts.

You are still able to donate to LA in Zack's memory at the above link.

Many thanks on behalf of Ann Marie, Brodie and Leukodystrophy Australia – over $8,000 has been raised in Zack's honour to Leukodystrophy Australia!

Leukodystrophy Australia Membership – how to join or renew your membership for the 2024/2025 financial year

Members are the essence of our organisation. Leukodystrophy Australia works with its members to achieve goals that benefit all people living with Leukodystrophy, with a specific focus on individuals and families living their best lives. Our members are vital to raising awareness of leukodystrophy, writing grant and policy submissions and keeping our organisation relevant.

Please initiate or renew your 2024-2025 membership today. Applications can be found on our website, https://www.leuko.org.au/support-us/membership/

Or contact us directly and we will forward on our Membership form to you.

We wish to thank all our members for their wonderful support this year.

Special Children's CHRISTMAS PARTIES

We are seeking expressions of interest for attendance at the 2024 Australia wide Christmas Parties for Special Children.

This is a completely free day, unique because it will be all inclusive just for children who have special needs.

Each location will hold a 2–3-hour stage show featuring many local and national celebrities who will keep the children entertained. There will be activities such as merry go-rounds, activities, face painting and much 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. Of course, no Christmas party is complete without Santa and after greeting the children from the stage he will go off to his toy room. There he will meet with all the children individually as they come to collect 2 or 3 brand new presents to take home and call their own.

To see what happens at the parties, please have a look at some of the videos on the Special Children's Christmas Parties website: https://www.sccpau.com.au/events.html

Eligibility

LA can apply for invites for children who have one or more of the following disabilities:

Vision Impairment - Hearing Impairment - Intellectual Disability - Physical Disability - Mental Health Conditions Seriously ill - Autism Levels 2 & 3

The age range eligibility does vary between locations, so please check your closest location below for details.

Children must be accompanied by parents or caregivers. There will be no child-minding facilities available

Unfortunately, the Special Children's Christmas Party is not able to extend invitations to siblings of children with special needs unless their circumstances also place them in the categories listed above.

If you are interested in requesting an invitation for your child, please contact Anne Patricia on:0418 755 994 **or email** advocate@leuko.org.au as soon as possible. These events are very popular, invitation numbers are limited.

I am currently working flexible hours and my time is limited, so please contact me ASAP so I can begin the invitation process.

All invitations will need to be applied through Leukodystrophy Australia and tickets go very quickly.

Remember the Girls - a website for X Linked Carriers

Taylor Kane is the founder and president of Remember the Girls, an international non-profit organization that unites, educates and empowers female carriers of x-linked genetic disorders—a group that is underrepresented and often overlooked by the medical profession **(rememberthegirls.org)**.

Snug Retreats

The SNUG project provides residential retreats for families caring for a child with a rare health condition. The whole family attends the retreat together and a program of activities is designed so that EVERY attendee can participate. All accommodation, meals and activities are provided. If you care for a child with a rare condition, or you work with a family who might be interested in these special retreats, please submit an expression of interest.

Future SNUG retreat schedule:

- 13 - 16 September 2024
- 11 - 14 October 2024
- 15 - 18 November 2024

SNUG / Family and Community Programs / Family Action Centre / Institutes and centres / Research / The University of Newcastle, Australia

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An exploratory music concert series for persons living with disability and their families/supporters.

Contact us for more information.

Research Update: Alexander Disease

- Blog post: https://www.rarediseasesnetwork.org/news/research-summaries/2024-05/rare-research-report-may-2024#GLIA
- Podcast episode: https://www.spreaker.com/episode/glia-ctn-exploring-potential-biomarkers-for-alexander-disease--60209692
- X (Twitter): https://x.com/rarediseasesnet/status/1801274722186903804
- Facebook: https://www.facebook.com/reel/980095440161858
- LinkedIn: https://www.linkedin.com/posts/rdcrn_leukodystrophy-biomarkers-alexanderdisease-activity-7207042488606326784-AWwP?utm_source=share&utm_medium=member_desktop

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Keep warm during winter