LEUKODYSTROPHY .org.au AUSTRALIA

newsletter / **summer 2024**

From the Leukodystrophy Australia Team

Hi all and happy 2024 to you! We hope you had a peaceful and enjoyable festive season.

We know that many of you have been battling with extended periods of extreme temperatures and weather events over this summer and we hope these settle quickly moving into the Autumn season. Please don't hesitate to reach out to our Family Advocate Jane if you are experiencing a need for emergency support and assistance related to these events.

We had a very busy end to 2023 with our Annual General Meeting held on 14 October, our South Australian Family Gathering held on 29 October, our Geelong Family Gathering held on 9 December and our Melbourne Family Gathering held on 10 December.

Jane very much enjoyed meeting everyone who attended these events in person and seeing you catch up with old friends, making new friends, sharing your stories, and having fun together. We truly appreciate the effort you took to travel to these events and take time out of your busy schedules and routines. We'd like to share some lovely photos from these events below.

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Upcoming Events

Fri 1 Mar – Tues 30 Apr	**The Lion King, Simba Strava Art in honour of Zack Lush** Adelaide
Thurs 21 Mar	**Online Event: Child & Family Disability Alliance – NDIS Review Live Q&A** (Specifically for families with children and young people who have disabilities)
Fri 27 Sept	**Charity Challenge Leukodystrophy golf day at Long Reef Gold Club** Anzac Avenue, Collaroy, NSW
Wed 4 Dec	**Charity Challenge Leukodystrophy golf day at Woodlands Golf Club** White Street, Mordialloc, Victoria

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From the Leukodystrophy Australia Team cont.

President Earl Schonberger also enjoyed meeting Leukodystrophy Australia members, families and supporters at the Charity Golf Challenges at Long Reef Golf Club NSW on 6 October and the Woodlands Golf Club VIC on 6 December. We thank everyone who attended these events to support Leukodystrophy Australia.

We are now in the planning stages for 2024 family gatherings in other states across Australia with the next events to be held in New South Wales. We will send out invites to those events as soon as we have arrangements in place. Jane is looking forward to meeting many more of our members and families through the gatherings this year.

The Team at Leukodystrophy Australia

Family Advocate Feature

2023 NDIS Review information

The Independent Review of the National Disability Insurance Scheme report and recommendations were formally released on 7 December 2023 following a year long enquiry into the scheme. The report totaled 329 pages, contained 26 recommendations, and detailed 139 supporting actions for implementation over a five-year transition period.

We appreciate that many of you will not have the time to be able to fully review this report but will be keenly interested in the detail relating to yourself or your loved ones. I have compiled the following website links to organisations which have summarized these recommendations and actions and hope these may be informative and helpful resources for you:

Easy Read Booklet prepared/endorsed by the NDIS Review Team & the Department of Social Services: https://www.ndisreview.gov.au/sites/default/files/resource/download/a-better-ndis-recommendations-actions.pdf

Australian Government- NDIS Review Facts Sheets and FAQs: Working together to deliver the NDIS | NDIS Review

DSC: https://teamdsc.com.au/resources/ndis-review-recommendations

Public Interest Advocacy Centre Ltd - Sydney: https://piac.asn.au/2023/12/19/explainer-understanding-the-ndis-review/

Request for Information about adverse experiences with the NDIS scheme

Through my role in supporting individuals and families affected by leukodystrophy, I have observed there to be a significant lack of consistency in people's experiences and outcomes when applying for funding under the scheme.

Leukodystrophy Australia is keen to know if you are having difficulties in accessing NDIS funding or if the level of funding you/your family members/person you are caring for is not meeting your/their disability support needs adequately.

We would like to understand more about the number of people experiencing barriers to accessing the support they require through the NDIS scheme to determine the need for systemic advocacy on behalf of people living with leukodystrophy conditions at a State and Federal Government level.

Please email or call me to discuss your situation if:

- NDIA has declined your application to access NDIS funding,
- you have been accepted into the scheme but are experiencing significant challenges/adversity due to the level of funding approved under the scheme.

I will work with you to determine the most helpful type of assistance Leukodystrophy Australia may be able to provide you such as: advice, information, consultation and advocacy with your health and support professionals, linking you with disability advocacy services to support you through NDIS appeals processes.

You will also see information below about the NDIS Review Live Q&A being held on Thursday 21 March 2023 – facilitated through the Child and Family Disability Alliance. For families caring for a child or young person with leukodystrophy, you may find this event helpful.

Please don't hesitate to reach out to me at any time if you would like to chat or need any assistance. I would love to hear from you.

Family Advocate/Social Worker: Jane O'Neill

Hours of operation: Monday to Friday 9am-5pm
(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

Leukodystrophy Australia Membership – how to join or renew your membership

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 organization relevant. Please initiate or renew your 2023-24 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 it on.

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

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 Jane O'Neill on:

Phone: 0418 790 059

Email: advocate@leuko.org.au

News and Events

Our Work with the Neurological Alliance Australia (NAA)

Leukodystrophy Australia is a proud member of the NAA (Neurological Alliance Australia), a growing collective of 21 national not-for-profit peak organisations to represent adults and children living with progressive neurological or neuro-muscular conditions in Australia.

The Alliance works collaboratively to identify and systemically advocate for opportunities that will promote improved quality of life for people living with these conditions and funding to support research.

During 2023, Leukodystrophy Australia consulted with our NAA partners on the following position papers:

- Submission to the Joint Standing Committee on the NDIS General Issues Inquiry
- Submission to the consultation on improving alignment and coordination between the Medical Research Future Fund and Medical Research Endowment Account
- Submission to the Health Technology Assessment Policy and Methods Review
- Submission to the Treasury Measuring What Matters consultation
- Pre-budget submission for the 2023-24 and the 2024-25 Federal Budgets
- Submission to the Australian Bureau of Statistics 2026 Census topic review

These documents can be reviewed at **https://neurologicalalliance.org.au/**

One percent One step closer

We are renewing our promotion of the One Percent campaign.

Turn your property transaction into a meaningful cause!

You can help us in the following ways:

- Planning on selling your property? Consider asking your real estate agent to contribute to people affected by Leukodystrophy by donating 1% of the sale (equal to roughly half of their commission) to Leukodystrophy Australia.
- If you know real estate agents or property developers, please tell them about our One Percent campaign.
- Share information about this campaign with your local real estate agencies.
- Every 1% received will bring us one step closer to finding a way to combat this terrible disorder

For more information and to register: **https://www.leuko.org.au/support-us/1percent/**

Congratulations Nathan on your Big Ride success!!

After 6 days of riding, overcoming many challenges Nathan completed the marathon ride on his handcycle all the way from Woorim Bribie Island to Victoria Point on the Moreton Bay Cycleway.

He and his key worker and trainer Matt rode 136 KM's over 6 days (23-30 October 2023), to raise awareness of his rare genetic disease, Pelizaeus- Merzbacher, and to raise funds to purchase an accessible van for his transportation.

Nathan's family, friends, and team at Holistic Horizons had an emotional time as they joined him for a celebration as he rode into the finish line. (Ref: Nathan's Facebook page)

Well done Nathan!! Another amazing achievement and we appreciate your ongoing commitment to raising awareness of leukodystrophy conditions.

If you would like to find out more about Nathan's fundraising efforts to purchase a desperately needed van, please visit **https://www.gofundme.com/f/nathan-mcdowell-ride-for-life**

FREE to Leukodystrophy Australia families

Leukodystrophy Australia is proud to work with Safe in Sound, an exploratory music concert series for persons living with disability and their families/supporters. The Safe in Sound team focuses on creating music that explores sound to stimulate the listener. Drawing on their experience in sound art and improvisation, they encourage focused listening and enjoyment for people with disabilities, family and carers. Artistic Director Robbie Avenaim said "We believe improvised music can stimulate joy and encourage mindfulness for the listener, and contribute to a well-balanced life through engaging with art. We aim to engage families and carers to both supervise and take part in developing new methods of stimulation, entertainment and communication".

SAFE IN SOUND

Readers can view footage of the concert series at **https://youtu.be/4ryob6zi7GE** and through the Safe In Sound Website: **https://safeinsound.com.au/**

Families interested in participating in 2024, please contact our Family Advocate Jane through:

advocate@leuko.org.au

Mobile: **0418 790 059**

In Memoriam:

Anthony Williams

In Loving Memory of
Anthony James Williams
29/01/1964 - 01/01/2024
Aged 59 Years

We wish to express our sincere condolences to Anthony's family and friends and particular his wife Tania and their children. We know that Anthony will be deeply missed by all who knew and loved him. We send our love and caring thoughts to his family.

Thank you to Anthony's family and friends who donated to Leukodystrophy Australia in honour and in loving memory of Anthony to help others living with leukodystrophy conditions.

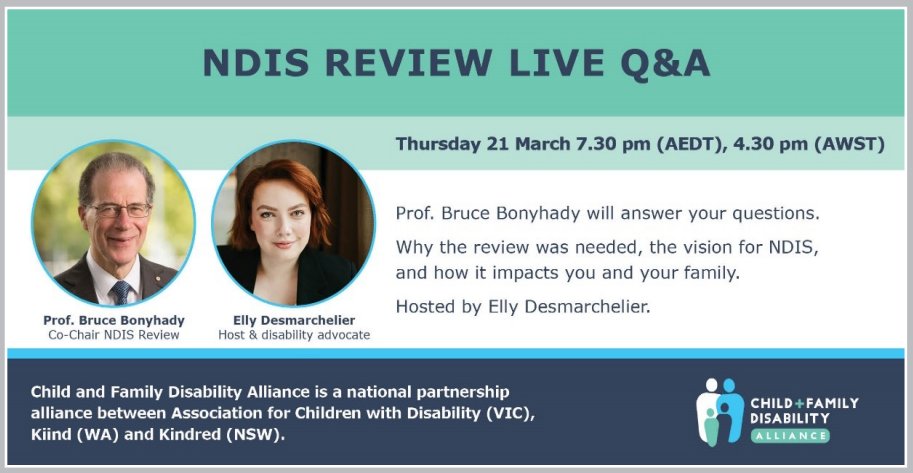
Child & Family Disability Alliance – NDIS Review Live Q&A

The Child and Family Disability Alliance welcomes Leukodystrophy Australia families from across Australia to attend their online event on 21 March 2023.

We thank the Association for Children with a Disability (VIC) for extending this invitation to our organisation.

You can register for this event through this link:

https://bit.ly/QAbruceACD



The Lion King, Simba Strava Art in honour of Zack Lush

Hi all,

From 1 March to 30 April, in honour of Zack Lush's strengths and teachings of life, we will be walking, running, rolling (cruising) and riding approximately 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 just 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, a legacy to all that had the privilege of knowing and loving him.

The Strava Art is to bring the community together to raise awareness of Leukodystrophy and those living with a disability and raise funds for Leukodystrophy Australia. Further information and to donate can be found at Leukodystrophy.

Thank you to Pete Stokes who will be helping out with the Strava art route and coordinating everyone's efforts.

If you would like to participate, please contact Ann Marie on ann_marie_lush@hotmail.com with your preferred distance, exercise method and date. We will be in touch to provide you the Strava route you will be completing.

Many thanks,

Ann Marie and Brodie

SNUG Retreats – Family Action Centre, University of Newcastle

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 through visiting the home page for Snug Retreats: **https://www.newcastle.edu.au/research/centre/fac/outreach/snug**

SNUG is coordinated through the Family Action Centre at The University of Newcastle and is supported by the **Steve Waugh Foundation** whose goal is to be 'somewhere to turn' for families of children with rare diseases.

The retreats aim to create a relaxed environment for families to build on their strengths, improve resilience, and develop friendships and support networks with others who are experiencing similar challenges.

The retreats:

- Focus on identifying and celebrating the skills and strengths of ALL family members – parents, children with special needs, and their siblings.
- Provide a wide range of activities over 4-5 days which are designed so that all can participate – including music therapy, art therapy, physical activity and outdoor recreation, craft, sensory play, and parent discussion.
- Are supported by a team of trained volunteers.
- Educate, train and support our volunteers (mainly undergraduate students of the University of Newcastle) in understanding the unique issues faced by families caring for children with rare medical conditions through our volunteer program.
- Are held approximately 6 times every year at Sport and Recreation Centre facilities in Lake Macquarie, NSW.
- Are the only retreats of this kind in Australia.

Future SNUG retreat schedule:

- **15 – 18 March 2024**
- **24 – 27 May 2024**
- **13 – 16 September 2024**
- **11 – 14 October 2024**
- **15 – 18 November 2024**

SNUG Retreats Connecting Families

STEVE WAUGH FOUNDATION

Manly Adolescent and Young Adults Hospice

The AYAH is a Public NSW Health Facility and is the first of its kind in Australia, offering respite care, symptom management and end of life care to adolescents and young adults aged 16-30 years with life limiting illness. The upper age has just been increased from 24 to 30 years which is wonderful news!

This specialised care extends to patients' families, including bereavement support, counselling and accommodation.

Having opened their doors to patients in February 2023, the AYAH have already had the opportunity to see the positive impact their service has on families who are going through very difficult times.

AYAH's holistic approach ensures the patients clinical needs are met, while also ensuring their stay is as enjoyable as possible within their physical and cognitive abilities.

You can find out more about the Hospice through reviewing the following links or through contacting the hospice directly via email:

Email address:
NSLHD-AYAHMANLY@health.nsw.gov.au

Facebook:
www.facebook.com/ayahmanly

Instagram:
Instagram.com/ayahmanly

Website address:
www.nslhd.health.nsw.gov.au/manly/Pages/default.aspx

Leukodystrophy Australia – new postal address

Please note that we have recently changed our mailing address to:

PO Box 248, Wahroonga NSW 2076

Research Update

VOLUNTEERS NEEDED FOR RESEARCH ON CADASIL

Invitation to Participate

Researchers at the Centre for Healthy Brain Ageing (CHeBA), UNSW Sydney are inviting individuals to join **AusCADASIL**, a study that will look at clinical and genetic features of CADASIL. We will recruit individuals who have a diagnosis of CADASIL, are suspect for CADASIL, are a first degree relative of someone with CADASIL, or a healthy control volunteer.

What is CADASIL?

Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy, or CADASIL, is genetic condition which causes strokes, and often migraines, and changes to cognition and mood.

We will use MRI, cognitive tests, retinal imaging, and blood markers to study the impacts of CADASIL.

This study looks at clinical and genetic features of CADASIL to better understand its progression and management.

This study might be a good fit for you if you are:

- Aged 18 and over
- Able to provide written consent
- Able to attend a study site in-person

This study might not be suitable for you if you:

- Are unable to participate voluntarily

If you participate, you will need to:

- Receive a screening phone call to confirm eligibility (10 minutes)
- Have a physical examination (30 minutes, optional)
- Have an MRI scan (1 hour, optional)
- Provide a blood sample (15 minutes)
- Complete some tasks (online and in-person) on thinking and mood (20 minute required, up to 2 hour full testing optional)
- Complete a survey about your basic medical and health history (25 minutes)
- Have an eye test (Only available at Sydney and Melbourne sites, 90 minutes, optional)
- Have genetic counselling (as appropriate; approximately 1 hour)
- Return for annual follow up of medical history and tasks of thinking and mood (1 hour, optional).
- Return after 3 years for a repeat MRI brain scan, eye test, and blood sample (3 hours, optional)

To express interest in participating or to learn more about this study, please contact Dr Danit Saks.

Email: auscadasil@unsw.edu.au
Phone: 02 9348 1658

Tests can be completed over multiple days at your convenience. **There are no costs associated with participating, nor will you be paid to take part. The study can assist with transport costs from a CBD railway station or parking costs on-site.**