



newsletter / summer 2022



Hi all and welcome to our 30th Anniversary newsletter.

Is it just me, or has the year flown by faster than ever? 😊

Just when the last few months were starting to look better from a Covid perspective, at time of writing, we're staring down a bit of bumpy patch at the moment (at least here in NSW). Please all stay safe.

There were many highlights for Leukodystrophy Australia over the second half of the year, below being some of the significant ones.

The committee is excited to announce that in July, we successfully recruited the organisation's first full-time Family Advocate, Jane O'Neill, a very experienced Social Worker and with the right credentials to build on the fantastic foundations of what Anne Patricia (for seven years), Kylie Agllias and their predecessor (and past President) Pam Joseph were able to lay. Operating for some time on two days a week of family advocacy, we were somewhat limited in touch points with all of our members, but in a full-time role, Jane has the time to be able to reach out, hear from and support more members. Please see Jane's introduction in the Family Advocate section below and feel free to reach out to her if you or your loved ones might need any advice or support, or just to say hi. We wish Jane all the best and look forward to grow our supports and services to our members. We would like to thank and acknowledge Anne and Kylie for their work, particularly Anne's epic seven years as Family Advocate for Leukodystrophy Australia.



In the last newsletter, we announced a generous bequest from Sister Julie's dear sister, Janet Hudin and that we had named our 30th Anniversary in Janet's memory. Though we were heavily restricted by numbers (due to Covid) in our capacity to be able to formally celebrate the 30th Anniversary, we were thankfully able to arrange and hold a 50 person

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President's Report cont.

event at a function room with thanks to St Vincent's Care (where Sister Julie lives) in Hawthorn, Melbourne. Thank you also to volunteer Bridget Smithers who was so generous in planning and supporting the running of the day. A number of past committee members and long-term connected stakeholders of the organisation together with friends of Sister Julie shared an afternoon to connect and reminisce over the history of Leukodystrophy Australia (formerly known as the Australian Leukodystrophy Support Group). It was a memorable and enjoyable afternoon and we were blessed to be able to celebrate this event with our founder.

We are thrilled to have received a further donation from The Co-Group Limited to allow us to part-subsidise the costs of our full-time Family Advocacy program. With thanks to the board of directors of The Co-Group for their recognition of the importance of our Family Advocate.



In October we returned to Long Reef golf club in Sydney (after being unable to participate in an event there in 2021). With thanks to Gary 'Smokey' Dawson and Matthew Laverty (Ambassadors of Leukodystrophy Australia) for continuing to have Leukodystrophy Australia as one of their favourite causes and part of their Charity Challenge Golf series.

Congratulations to victors and great supporters, Tacca Industries. Bridget Smithers again jumped on board and introduced the event to many colleagues who entered teams and sponsored the event and she also arranged a number of prizes for the day. With special thanks to Ian Carr and Shaun Standfield of the IA Foundation for a fantastic donation of \$10,000, gold sponsorship by ICT Infrastructure and sponsorships by Tacca Industries, Atlantic Plumbing, Lawrence & Hanson and Reece and ongoing support of Steve Brady from Ardent Insurance Solutions. The golf day was a special and enjoyable day during which we also recognised the memory of long term supporter Paul Smithers who we greatly miss.

We had the Leukodystrophy Charity Challenge Melbourne event on December 7 at Woodlands Golf Club. We'd like to thank Enza Dilettoso, family member and long term volunteer who has again stepped up in promoting the event and sourcing prizes. Special thanks to generous supporter Nicholas Rizzo of Bianca (www.bianca.com.au) and also Mario Romano (Steritech) and Sally & Stephen Damiani OAM (Mission Massimo) for sponsoring teams on the day.

Over the last 6 months we have lost multiple friends/members who were affected by Leukodystrophy. Our thoughts are with their families and friends and we stand with them in keeping the memories of their loved ones strong.

I would particularly like to acknowledge Penny and Gary Lawler, Mackenzie and Tom following the loss of their dear son and brother, Jake – they reached out to their friends who in turn were collectively very generous with their financial support of Leukodystrophy Australia in Jake's memory.

Finally, we recently held our Annual General Meeting and I would like to congratulate our 2022 committee who have all nominated again for the 2023 committee. Thank you also to our great volunteers who supported us during the previous financial year. With great thanks to Vice President Dominik Froehlich, hard-working Treasurer Kate Fernie, Secretary Susan Stenning and past Family Advocate and committee member Kylie Agllias for remaining with our committee for another year. We have entered the 2023 Financial Year with Leukodystrophy Australia in a solid position and primed to be more impactful to our members.

A special thank you as always to the amazing Sister Julie whose friendship, staunch support, positivity, encouragement and advice I greatly value.

Many thanks to all our generous donors throughout the year including regular supporters Talya and Adam Chimes (of Chase Gallery) and Paul Ryan of EnergyConsult.

Wishing everyone a happy and safe Christmas and holiday period and we look forward to reaching out to and hearing from our members over the coming months.

Earl
0477 550 977

Family Advocate's Report



Hi everyone.
My name is Jane O'Neill and I am the new full-time Family Advocate for Leukodystrophy Australia.

I understand

that Anne has let many of you know that she is retiring from her role and a new Family Advocate will be coming onboard to support our Leukodystrophy families, community and members. We are so happy that the organisation has now been able to increase the Family Advocate position to full-time after it being a part-time role over the past ten years.

I know you will miss Anne very much after her seven years of dedicated work as your Family Advocate. Over the past few weeks, Anne and I have been working closely together so I can quickly learn the role to be able to support you well and become a strong advocate for our Leukodystrophy families and members.

Just a little about myself: I am a qualified Social Worker with twenty-three years of experience in providing support and advocacy for parents, caregivers, children and young people who are experiencing challenging life circumstances. I have worked in both non-government and government organisations in providing disability support, community health services,

family support, stakeholder engagement and community education.

I feel very grateful to have the opportunity to work with Leukodystrophy Australia and I'm really looking forward to meeting each of you over the phone, online and/or in person over the coming months as I settle into my role.

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

Hours of operation:

Monday to Friday 9am-5pm.

Hours may differ at times and the phone is checked regularly.

Phone: 0418 790 059 or

Email: advocate@leuko.org.au

A message from Sister Julie



Greetings to All

I am sure we are happy to feel some warmer days after a rather severe winter; at least I felt that way (maybe being older I found it COLD! ☺)

August 20th was a very special occasion given to me to mark the 30th anniversary since Leukodystrophy Australia began in Australia.

I was truly overwhelmed by those who did so much to recognise this day. I am extremely grateful to our President Earl Schonberger who planned so much behind the scenes, along with Bridget Smithers who arranged so much to make the Conference Room at Mary MacKillop nursing home appear colourful and cheerful 🌸🌸.

Many travelled from Sydney & even from W.A.

I conclude by making it known that I will always remember this day.

Best wishes to each one.

Sincere greetings,
Julie Thomas CSB

Telephone 0412 535 113

Address 4 King Street East Hawthorn 3123



Leukodystrophy Australia have been proud to work with Safe in Sound throughout 2021. Safe in Sound is 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". Readers can view footage of the concert series at <https://youtu.be/4ryob6zi7GE>



Families interested in participating in 2022, please contact our Family Advocate: advocate@leuko.org.au
Mobile 0418 790 059.

One percent.
One step closer.



By donating just **1% of the commission** from your major property sales, you can make a world of difference to families living with Leukodystrophy.

What is Leukodystrophy?

Leukodystrophy is not one thing. There are over 50 Leukodystrophies that are rare, genetic disorders that affect the white matter of the brain and spinal cord. They are degenerative disorders that lead to the deterioration of the body's neurological functions.

Leukodystrophy occurs in approximately 1 in 7,000 births. Due to the rarity of the disorder, it can often be difficult to diagnose, but it is fatal, with no known treatment or cure.

Leukodystrophy Australia has been set up to assist children and adults living with the disorder, their families and carers, to lead their best lives and continue the pursuit for a cure.

How can you help?

Leukodystrophy Australia are asking Real Estate Agents and Property Developers to **donate 1% of the commission** from major sales to the charity in order to continue to support the affected and pursue new treatment options.

Every 1% received will bring us one step closer to finding a way to combat this terrible disorder.

If you're interested in supporting this cause, please register your details below and we will contact you. Alternatively, you can always contact us using the information below

REGISTER NOW TO HELP

1800 141 400 (Toll free)
info@leuko.org.au

WWW.LEUKO.ORG.AU
1PERCENT.ORG.AU

We are very excited to announce our new fundraising 1PERCENT campaign

Everyone can help. If you know real estate agents or property developers please tell them about 1PERCENT. Share with your local agencies. If you are selling your house, you may elect to ask the agent to donate 1PERCENT.

To find out how, visit leuko.org.au/support-us/1percent/

Our Work with the Neurological Alliance Australia (NAA)

Leukodystrophy Australia is a proud member of the NAA (Neurological Alliance Australia), a collective of twelve 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.

Within this Alliance, we continue to work on Position Statements, submissions and responses to Government hearings and consultation papers related to issues affecting people living with neurological conditions in Australia.



NORD News

NORD'S NATURAL HISTORY OF METACHROMATIC LEUKODYSTROPHY STUDY

Metachromatic Leukodystrophy research needs YOU! Get involved in progressing innovation by enrolling in NORD's HOME Study and challenging others to do the same.

About Us - NORD (National Organization for Rare Disorders) (rarediseases.org)

NORDpod™ - NORD (National Organization for Rare Disorders) (rarediseases.org)

National Organization for Rare Disorders (NORD) - YouTube

30 year LA event

LEUKODYSTROPHY
.org.au AUSTRALIA

30th
ANNIVERSARY
IN MEMORY OF
JANET HUDIN

On the 20 August 2022 we held our 30 year anniversary for LA at Mary MacKillop Conference room Hawthorn East. This is on the site of the residential care facility where Sister Julie lives. We had a wonderful turn out with 45 previous and current committee

members and Sister Julie's supporters in attendance. The anniversary was in honour of Sister Julie's beloved sister Janet Hudin, who sadly passed away on the 15th August 2021.

Janet assisted Sr Julie with her dream of developing and seeing the Australian Leukodystrophy Support Group (ALDS) come to fruition 30 years ago. Janet would attend many events and was a generous donor to LA, she continued her support to Sr Julie and LA throughout her lifetime. She is dearly missed.

There were many old faces and new faces such as, Jane O'Neill our new Family Advocate. Sister Julie was full of good cheer and was busy chatting with everyone and having the time of her life. There were many stories to tell and memories were reflected upon during the afternoon. We loved hearing from Sister Julie about her humble beginnings with ALDS and John Olsen's stories about his Long Walks. Sister Julie was so grateful to everyone on the day, particularly Earl who organised the event and Bridget and Rika who created a beautiful space for us.

A heart shaped award was given to Sr Julie for her service to LA and John Olsen our wonderful Ambassador received an award in the shape of a foot. As you can imagine they were both thrilled.

Everyone enjoyed themselves during the afternoon and many people re-connected or connected for the first time.

A sincere thank you to all those who attended and created a warm, inviting and friendly space. Sister Julie was extremely grateful to everyone who attended to make this day special for her.

Some photos from the day:



Meet our Families: Alessio's 21st

We were absolutely thrilled to celebrate Alessio's 21st birthday on Sunday 21st August 2022.

Furthermore, it was our youngest cousin's 1st birthday so it was a double celebration!

Alessio had his favourite Pokémon's on his passionfruit and raspberry coulis cake and we all had a wonderful day cheering on our boys 21st trip around the Sun. What a blessing.

We always said to Alessio once he turned 21 we would consider a dog for him. We welcomed 'Artillery' our Greyhound dog into our home on the 9th October 22. We love him, he is smart, gentle and kind and he loves to sleep! We are so happy that Alessio adores him, it is such a pleasure to see the smile on my family's faces and Artillery knows he is loved.

Love Enza, Salvatore, Alessio, Danilo and Savio.

xxxxoooo



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 and often overlooked by the medical profession (rememberthegirls.org).

Remember the Girls Podcast



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 Jane 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.

Jane O'Neill: 0418 790 059

Email: advocate@leuko.org.au

In Memoriam

Leah Blair

21 February 1963 to 23 July 2022

It is with great sadness that we were informed by Leah's sister that she passed away this July.

Leah was always up for a chat and a laugh. She loved her Terrier dog Oli, he was a wonderful companion for many years. Leah adored cats and dogs and was always interested in the work the RSPCA carried out to support animals.

We send our heartfelt condolences to Leah's family, friends and LA supporters.



Jake Lawler

30 April 1993 to 3 October 2022

Jake was 29 years of age when he passed away. He was the much-loved son of Penny and Gary and big brother of Tom and Mackenzie. Jake was dearly loved by his family, friends, Carers and everyone who knew the happy, smiley and loving person he was.

LA wishes to express our love and deepest sympathy to Jake's family, friends, and all of those who loved and cared for him over the years.



NDIA update re Portable Air Purifiers as a COVID-19 low-cost AT Item

Temporary inclusion of portable air purifiers as a COVID-19 low cost AT item

From 1 October 2022, some eligible participants may use existing **low cost AT processes** to purchase a **portable air purifier as a temporary COVID-19 support** measure where necessary.

We recognise that some participants will have disabilities that likely put them at increased risk from COVID-19 and of becoming very unwell from COVID-19 complications.

This change will allow some participants to use their existing core/consumable funding to purchase a portable air purifier (up to \$1,500 in value) as a low cost AT device in line with information **published on the NDIS website** and **Our Guideline – Assistive technology**.

Providers will need to use **03_090000912_0103_1_1 Low Cost AT – COVID19: Portable Air Purifier** to make payment requests for portable air purifiers as temporary COVID-19 support. Providers can backdate claims from 1 October 2022.

Identifying Patterns of Hematologic Abnormalities in Aicardi Goutières Syndrome

"Aicardi Goutières syndrome (AGS) is an inherited disease that is associated with early onset neurologic disability and systemic inflammation. Cytopenias—conditions in which there are lower-than-normal numbers of blood cells—are a potentially serious, but poorly understood, complication of AGS. As new treatment options are developed, it is important to understand the roles of the disease versus the treatment in hematologic abnormalities, allowing for better management of cytopenia.

In this study, researchers identified novel patterns of hematologic abnormalities in AGS. The team collected laboratory data throughout the lifespan from 142 individuals with AGS. Results showed that AGS results in multilineage cytopenias not limited to the neonatal period. Neutropenia, anemia, and thrombocytopenia were common. For patients on the treatment baricitinib, moderate to severe graded events of neutropenia, anemia, and leukopenia were more common, but rarely of clinical consequence.

Based on these results, authors recommend careful monitoring of hematologic parameters in children with AGS throughout the lifespan, especially while on therapy. Authors also note that AGS should be considered in children with neurologic impairment of unclear cause and hematologic abnormalities." Rare Disease Clinical Research Network, 2022.



Social Worker Feature story

Informal carers

Carers are people who provide unpaid care and support to family members and friends who are living with a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged.

Carers are an integral part of Australia's health system and are the foundation of our aged, disability, palliative and community care systems (Carer's Australia).

Many of our family members at LA are full or part time carers and they deserve to be praised and recognised for their patience, resilience, determination, advocacy and most of all the love they give unconditionally, not only to the person living with LD but to their family members, friends and others around them.

Informal care is normally provided by primary carers, and they are mostly women who have had to reduce their work hours, withdraw from employment, schooling or university to provide the hours of care to their loved one (currently 1:11 carers are under 25 years of age). Carers may experience financial burden, isolation, physical and mental health issues, breakdown in relationships, impact on their social life, grief and loss around the life they had hoped and wished for.

While there are supports in the community, they are often limited due to budget restraints and resourcing.

At LA we wish to embrace and support our LD families to the best of our ability. If you are experiencing challenges in your caring role, please contact our **Family Advocate Jane O'Neill** who will do her best to assist you.

Some current resources for carers are:

Carers Australia | The voice for carers across Australia

Young Carers Network | Carers Australia

Aboriginal & Torres Strait Islander Carers | Carers Australia

Culturally & Linguistically Diverse Carers | Carers Australia

Home | Carer Gateway

Palliative care and end-of-life care | Carers Australia

Centrelink Payments For Carers | Carers Australia

Little Dreamers Australia Supporting carers 4 years old to 25 years of age

The Nathan Centre

Monique Garcia is the Founder and Director of a wonderful new organisation called The Nathan Centre. The organisation aims to support families managing rare disease. Monique has created three Facebook groups that could be of interest to your members:

Rare Disease Kids Australia

<https://www.facebook.com/groups/332689378281950/about>

Rare Disease Palliative Care Australia

<https://www.facebook.com/groups/739138833866072>

Rare Disease Angels Australia

<https://www.facebook.com/groups/711530736855502>

<http://www.thenathancentre.com/>

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 2022-23 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. Thank you.

*Wishing you all a happy holiday season
and all the best for the New Year!*

