



newsletter / summer 2021



Welcome to our summer 2021 Newsletter. For those who haven't seen my name or who have not met or spoken to me, I've been on the committee for too many years to recall 😊 and nominated for the President role at the recent AGM.

As this is the first newsletter since our AGM, I'm making mention of a number of recent updates. I'd like to thank last year's president Hala Raghib and our fellow committee (Kate Fernie – Treasurer and Dominik Froehlich who stood

in as interim President just prior to the AGM) for their sterling efforts through the particularly challenging times of COVID-19 and during which fundraising activity was significantly impacted. The committee had to make some difficult organisational restructuring decisions due to funding shortfalls. Together with Anne Patricia, who temporarily took on the role of Committee Secretary in addition to her Family Advocate responsibility and Kylie Agllias also as Family Advocate, everyone worked very hard behind the scenes to reset operations.

I'd like to acknowledge past Office Manager Bronwyn Byrne for her service to the organisation for many years.

Welcome to our new Committee Secretary, Susan Stenning and also thanks to all of our volunteers for the important work they do.

We have a number of plans in store for the coming year and will provide updates as they become finalised. This coming year represents a significant milestone for Leukodystrophy Australia as we will celebrate 30 years of operations since Sister Julie founded The Australian Leukodystrophy Support Group Inc on 17 August 1992 - a significant upcoming milestone and congratulations and ongoing thanks to Sister Julie for her foresight, passion and ongoing support of our organisation.

Thank you also to Angela Famiano for hosting the recent and successful WA family gathering – more info in this newsletter.

Leukodystrophy Ambassador John Olsen, who many will recall previously walked solo across Australia multiple times (most recently 2016/17) having raised important funds for the organisation, has announced his plans to yet again walk across Australia, this time North West (commencing Cape Leveque in Western Australia) to South East (finishing near Cape Howe around the Victoria & NSW border). The walk will see John (now a sprightly 70 years young!) spend some time making his way through South Australia. John hopes to commence his walk

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President's Report cont.

around late April 2022 with the important support of Geelong Corio Bay Lions Club. We thank John and his support crew and will bring you updates and plans as we get closer to April.

If anyone would like to reach out to me on any matter, I'd welcome your contact.

Please enjoy reading through the Newsletter (thank you to our team, particularly Kylie and Dimitra for putting this together).

Wishing a happy Christmas and Festive season and a safe and Happy New Year to all who celebrate these festivities and peace and happiness to all.

Earl
0477550977

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 or Kylie 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.

Anne Patricia 0418 790 059

Kylie Agllias 0418 755 994

Email info@leuko.org.au



A message from Sister Julie

Greetings to all,

Congratulations to the committee for organising and presenting a wonderful 2021-2022 AGM on Saturday 20th November 2021. I was pleased to see everyone via Zoom and to know the staff and committee are working hard to support our families.

I am especially pleased and would like to thank Earl Schonberger for taking on the role as President. I have known Earl for approximately 28 years and know his lovely wife Debbie, daughter Jessica and son Ariel. Earl is a kind and caring man in every aspect of his life. LA is privileged to have him as their President.

I was thrilled to know that Kate Fernie will be the Treasurer again in 2022 and that Dominik will fill the role as Vice President. It is wonderful that Susan has taken on the role of Secretary. You are all a tremendous support to each other.

We have been through many challenging times of late and I am grateful to the social workers Anne and Kylie who continue to support families emotionally, financially and advocate beside them, when necessary. Family work is why LA exists, it is such important work. To show kindness, caring and compassion to others in times of their need is vital so they remain hopeful, supported and not judged.

For those of you who can have a holiday after COVID lockdowns for 2 years I wish you all the happiness and joy. For others who can't have a holiday, enjoy what you can with family and friends.

I wish you all a happy Christmas filled with peace and love.

God bless each and every one of you.

Julie

Julie Thomas CSB

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Family Advocates' Report



Anne Patricia
0418 790 059



Kylie Agllias
0418 755 994

The festive period can be a strange mix of increased busyness, accompanied by moments of stillness, allowing us time to reflect on our work, our relationships, our triumphs, challenges, and our future. As we (Anne and Kylie) reflect on our work at Leukodystrophy

Australia across 2021, relationships feature primarily.

We have engaged with many individuals and families this year, providing information, financial assistance, emotional support and reassurance. We have maintained ongoing relationships, welcomed newcomers, and re-connected with members from the leukodystrophy community. We have also experienced times when we felt we couldn't do enough or give enough to the people we work with, and we have had to sit with, and learn from, those uncomfortable feelings. As such, we have reflected on the losses that many have endured this year, including the loss of loved ones, and we extend our care and condolences to

all affected. Importantly, we would like to acknowledge those of you who have allowed us into your lives this year, and thank you for the lessons you have taught us about leukodystrophy, love, commitment and resilience.

We would also like to acknowledge the support we have received from our professional and skilled committee of management, and group of volunteers, whose dedication to this community is inspiring and unwavering. Thank you.

Finally, we hope that this newsletter brings you some joy as our families, members, committee members and volunteers share some of their news.

Wishing you all peace, love, good will and all the blessings of Christmas.

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/



Australian Government



Disability Gateway
Connecting you to information and services

Disability Gateway

The Department of Social Services has developed a way to improve access to information for people with disability, their families and carers, by creating the National Disability Information Gateway. The new Disability Gateway is your first step in finding information and services within Australia.

Welcome to the Disability Gateway |
Disability Gateway



NORD[®]
National Organization
for Rare Disorders

NORD News

The National Organization for Rare Diseases offers an array of information that may be of interest to readers, including a podcast called NORDPOD, and YouTube Channel.

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

In Memoriam



To the families of those who have passed away in 2021, we wish you peace, comfort and love. We hope you will have time to share and reflect on memories of those who you love and remain forever in your hearts.



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 Anne Patricia on advocate@leuko.org.au

Mobile 0418 790 059.



Upcoming Events: Celebrating 30 years

Covid-19 has affected the way we have operated, and the events we could hold, in 2020-21. As vaccination rates increase and state borders re-open, we hope to bring you more events and celebrations. Excitingly, this appears to have happened at the most ideal time, because next year we will be celebrating a very special 30th birthday. Leukodystrophy Australia – previously Australian Leukodystrophy Support Group Inc (ALDS) – was established on the 17th August, 1992.

We look forward to sharing more in 2022.

Caring for yourself over the Christmas period



Christmas time means different things for many people. Traditionally we celebrate the birth of Jesus Christ, attend Church services,

and have the opportunity to relax on holidays and spend quality time with family, friends and others.

However, for some Christmas can be a time where our mental health may be impacted due to financial strain, family issues and the expectations put on us by society to spend time with family members or others you would normally avoid. For some there is social isolation, loneliness, bereavement, grief and loss associated with a new diagnosis, loss of dreams and future plans and the ongoing impact of living with a leukodystrophy.

Implementing strategies to minimise stress levels during this period may assist you, such as surrounding yourself with supportive family and

friends at gatherings, via the phone, emails and social media, limit gifts and buy only for children or have a Secret Santa. Remain self-determined and be realistic about who you wish to have contact with, find a quiet space and nurture yourself even if you only have a few minutes. Take a deep breath, join a community gathering and call someone who will listen to you from a compassionate place, without judgement.

Whatever this Christmas holds for you, we hope that you can find times of peace and tranquillity to care and look after yourself, because you are special.

Anne Patricia (Family Advocate)

Western Australia Family Gathering: Success!

Despite cancelling our 2020 event due to a Covid-19 lockdown, and state border controls in 2021, we were able to hold a successful - although modified - Family Gathering on October 30th, 2021. The event was held in Perth at St Catherine's on Park, in the suburb of Nedlands. It was hosted by one of Leukodystrophy Australia's valued members, Angela Famiano. Angela graciously, and skillfully, took on this role when the Family Advocates were unable to attend due to border closures.

The day commenced with virtual messages from the Leukodystrophy Australia Committee and Family Advocates. Speakers from two local organisations (Carers WA and People With disabilities Western Australia [PWdWA]) presented on topics including caring support, local services, disability and self-advocacy: Good discussion ensued.

The event also included an exploratory musical experience by a group of local artists, facilitated through the Safe in Sound program. This program creates music that explores sound to stimulate the listener, hence encouraging participation and much enjoyment for the audience as they witnessed the star of the show, a Leukodystrophy Australia family member, Melissa, alongside the SIS musicians.

Importantly, families were provided with welcome bags including information about our organisation, important resources and self-care items. Families were offered the opportunity to connect and support each other through sharing their experiences, successes and losses prior to the commencement of the day's planned agenda, over the lunch time period, and while enjoying the fresh air in the garden courtyard and grassed area. Furthermore, a variety of creative activities were offered in the afternoon, including a photo booth with fun props, card games, colouring and learning the Japanese art of gold repairing (Kintsugi).

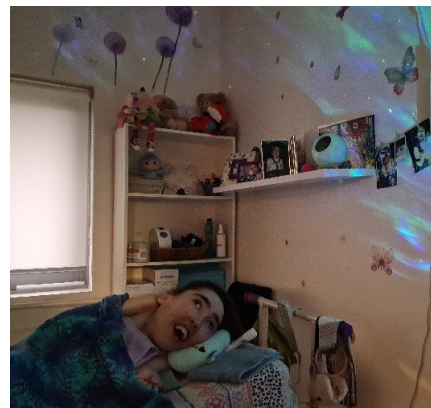
Plans are being made, through our on-ground representative, Angela Famiano, to develop these existing linkages across time, engage in networking with services and programs within the area, and to participate in training opportunities. This will assist with the planning and development of future activities and peer support, ensuring service provision is community informed and led.

Kylie, Anne, Angela



Meet our Families: Jessica's Room

Jessica, celebrated a significant milestone in November, turning 30 years of age. Jessica has Canavan Disease and was diagnosed shortly after birth. Jess has been bed-bound for the last 16 years, so activities need to be brought to her with a focus on multiple sensory stimulation. As you can see from the photos below, her room was amazingly decorated (by her support workers and family) and this included lights and sound and Jess got great enjoyment out of celebrating this occasion with her family.



Meet our Volunteers: Abby Tennant (Website)



How did you become involved with Leukodystrophy Australia?

I became connected with Leukodystrophy Australia through the Genetic Support Network of Victoria during lockdown in 2020 and have been volunteering ever since as the editor of the LA website.

What do you like about your work with LA?

I was really happy to find a volunteer position that I was able to do remotely while I had been stood down from work and it has been an enjoyable challenge learning some new skills. Despite not having had the chance to meet anyone in person I thoroughly enjoy being part of such a wonderful organisation.

What is your favourite book?

The Seven Husbands of Evelyn Hugo by Taylor Jenkins Reid. A captivating and unexpected story about the life of a fictional Hollywood star.

What is your favourite TV show?

Dark. A twisty, generational time travel story on Netflix with a very satisfying conclusion.

If you had a choice of one leisurely experience on your days off work, what would it be?

Reading a good book in the sun with my cat Bonnie and a cup of earl grey tea.

What is your dream holiday?

Canadian national parks in summer time are at the top of my list!

What do you cook best?

Over lockdown I started baking bread, a hobby that requires a lot of patience and time, but I had plenty of that! The ones that went down best with my family were my cinnamon rolls and focaccia bread.





New CareSearch Portal

The CareSearch Project, a leader in the provision of evidence-based palliative care information, has launched its **new portal**. The interactive and revamped portal is designed to support everyone – patients, carers, health professionals, and ordinary Australians – to have conversations about death and dying and make informed palliative care decisions.

“We will all need palliative care at one point, and many of us will also care for a loved one who is dying. The new CareSearch portal is designed to help all Australians to prepare for their palliative care journey with trustworthy information and resources,” says CareSearch Director Professor Jennifer Tieman.

The new portal will help individuals, families and communities to start reflections and conversations about dying and death, which are important steps in planning and getting appropriate support. Resources to enable patients and carers to make informed decisions when facing the end of life are included, along with practical information to plan for ageing and caring for older persons.

A section to empower diverse and underserved Australians to get appropriate and quality palliative care and support is also featured.

Have you forgotten to renew your membership? It's not too late

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 2021-22 membership today. Applications can be found on our website, Membership | Leukodystrophy Australia. Or contact us directly and we will forward it on.

Thank you

Meet our Families: Johana and Ella

Johana and Ella had a great year in 2021 considering everything that was going on in Victoria. Johana completed her final TAFE course, she has now completed the Certificate I in Transition Education as well as the Certificate I and II in Work Education. Johana was surprised to find out that she had been nominated for student of the year in one of the categories at her TAFE. Even though she didn't win, she did receive a high commendation. Johana continues to love cooking and baking and hopes to find some work in hospitality next year.

Ella also completed her Certificate I in Transition Education this year and will continue TAFE next year. She also enjoyed attending pottery classes on Saturdays and hopes to continue with this next year.

Following months of online schooling and activities both girls were very happy to be able to return to campus and social outings with their support workers. They would both tell you that their biggest highlight of the year was attending Ability Fest in November, a wonderful musical festival organised by Dylan Alcott.

We are grateful for all the support the girls receive that allows them to continue to do the things they love.



Meet our Families: Cassie and Tyler



Hello to all our leukodystrophy families. My name is Cassie, and this is my son Tyler. Tyler was diagnosed with Metachromatic Leukodystrophy late infantile (MLD) when he was 2.5 years of age. He is now 10 years old, and the absolute apple of my eye.

It has been a dream of mine for years, to take Tyler to see the open spaces of our beautiful country, particularly Uluru. So I aimed to make it an adventure for my 30th birthday. People said to me, 'You can't travel with Tyler, it's too hard. What if you need medical treatment in the outback?'

Well no, it is not hard to travel with my gorgeous son. I just made sure I packed more than I really needed, particularly water and medicine. There are GP's and the Royal Flying Doctor Service, so there is medical care available in the outback! (Which we did need, Tyler must have been sick of driving, lol).

I began to organise our trip with my family in December 2020. I packed our wheelchair van to the brim, and we commenced our journey in June 2021. First we travelled through Western NSW, up into Queensland and across into the Northern Territory, destined to complete our journey to Uluru. Along the way to Uluru, we passed through and stayed at some amazing and interesting little towns. One of my favourites was Mount Ebenezer, a completely abandoned Roadhouse, that used to be fully functional, and is now left to ruin. Being there after reading the history was eerie, but fascinating.

Most people were generous and wanting to know our story. It was an opportunity to raise awareness about MLD: Of course no one had heard of the condition, and I hope we made an impact on those we met.

At Yulara, (half an hours drive from and closest accommodation to Uluru) we stayed at the Emu Walk Apartments, where everyone was friendly and we had a great time. We absolutely loved walking around the base of Uluru. The difference in the rocks colour, the texture, the scenery, and different areas the Aboriginal peoples used for women's business and mens business. We were in awe of this most gorgeous and spiritual place.

The entire trip took 5 weeks all up. We experienced almost every landscape our beautiful country has to offer...even snow on our last night away!

Would I travel with Tyler again? Absolutely! And who knows were our next journey will be.

Thanks for reading our adventure.

Cassie

