



newsletter / winter 2021



Welcome to the Winter edition of our newsletter, I hope you had a wonderful Easter and enjoyed some quality time with your loved ones.

As you are aware, we made some changes to the way we operate our organisation and re-structured to allow us to deliver our mission to better support our members. We appointed a second Family Advocate and Social Worker, Dr Kylie Agllias. Dr Agllias has an impressive track

record within social work and has been an academic for a number of years. She has assisted us previously with grant writing. I encourage you to contact Kylie for a chat and to welcome her on board. Mrs Anne Patricia will continue to work with us. We've had some interesting meetings with companies currently recruiting patients in their clinical trials for different leukodystrophies. Unfortunately, those trials sites are based overseas and some of our eligible families may not be able to participate due to the COVID-19 travel restrictions. However, if you'd like to find out more about those trials please do not hesitate to contact our office.

I would love to hear from you and please feel free to contact me for a chat.

Hala Raghieb, President
 0411 625 775
president@leuko.org.au

Events & Meetings

8 October	Charity Challenge Leukodystrophy Australia Golf Day Long Reef NSW
30 October	Family Gathering Western Australia
20 November	18th Charity Challenge Gala Dinner Hyatt Regency, Sydney, 6:30pm
8 December	Charity Challenge Leukodystrophy Australia Golf Day Woodlands

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Greetings to All

I trust this finds you all as well as possible now that we have almost finished our pleasant weather and move into winter!

I have to say, I do not enjoy Winter weather, but I know I am fortunate that where I am living in Mary MacKillop Nursing Home. I am not

out on the cold days and we have heating which I really find comfortable; I know many people do enjoy Winter months.

Many people I will have not have had the chance of meeting. Since I am unable to attend any functions I do not meet anyone now, but that is how life is for me now. Please know that I am grateful to have had the opportunity during many years to have met different families in SA, NSW, WA, that is,

when I was able to travel. I will always remember everyone's kindness, generosity and thoughtfulness for many years and I always remember those who are diagnosed, or who have a dear family member, with this cruel illness.

I very often remember you in prayer and know that God does love each of us.

Thanks to the present Committee who have seen it necessary to make changes in different ways.

Best wishes to all.

Julie Thomas CSB

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Address 4 King Street East Hawthorn 3123

Family Advocates' Report



Anne Patricia
0418 790 059



Kylie Agllias
0418 755 994

As most of you are aware, the Family Advocate role has recently changed and we have two social workers employed (for 2 days per week). As such, we are both very pleased to be working together and writing this

joint report. The Family Advocate role continues to be one of great privilege, where we are engaged with families at some of the most challenging, confusing and traumatic times of their lives. We never take this engagement for granted, and feel continually inspired by the strength and resilience families show in the face of such adversity.

The Family Advocate role has shifted across time, and we have had much discussion about our priorities of late – as professionals and an organisation. As such, we will continue to offer our range of services, with a renewed emphasis on the important connections between Leukodystrophy Australia and its members/families. We want to

continue to bring families together for respite, fun and education, through events such as those mentioned in this newsletter. Most importantly, we hope that you will join us at an event soon.

Finally, the 2020 COVID-19 pandemic saw a dramatic shift in the ways that many of our families went about their daily activities, and while the vaccination regime is bringing us closer to some sort of safety, we are not quite there just yet. The cooler weather also brings its challenges for many families, impacting the ways that they can go about their lives and potentially interact with others. So, it is really important to recognize the isolation that some may be feeling. Please feel free to give us a call, we would love to hear from you.

Family Gathering planned for Western Australia



As you may be aware we had to postpone the Leukodystrophy Australia WA event in April 2020, due to the COVID-19 restrictions and the border closures. However, we are pleased to announce that we will be travelling to Perth and hosting an **all-day Family Gathering**, on **Saturday, 30th October, 2021**.

The event will be held at **St Catherine's on Park, 2 Park Road, CRAWLEY, Western Australia, 6009**. We would love as many of our WA families to attend our Family Gathering as possible: We are hoping to make it a memorable fun day for all. We are very excited to meet everyone, and we are currently planning some fun and exciting activities for our families.

If you are interested in coming along to create friendships, catch up with families you have not seen in some time, meet Kylie and I, and have a fun day with a nice lunch, **please email or call us ASAP** so we can have an idea of numbers and finalise our plans.

Anne Patricia 0418 790 059 **Kylie Agllias** 0418 755 994

Email advocate@leuko.org.au

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

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/

SNUG Retreats: Connecting Families

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.

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.
- 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.
- 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.

SNUG is coordinated through the Family Action Centre at The University of Newcastle and is assisted by the **Steve Waugh Foundation**.

The Family Advocates are currently in discussion with **SNUG** staff about potentially organizing an event for Leukodystrophy Australia.

If you are interested, or require more information, please contact:

Kylie Agllias 0418 755 994 Email info@leuko.org.au

Or email **SNUG** directly at snug@newcastle.edu.au





Self-Care: Too much to ask?

Self-care is our commitment to attitudes and activities that protect our physical health and emotional wellbeing. Helping professionals often ask about our self-care practices; “how are you looking after yourself?”. As a practitioner, and an educator, I have realized that these types of questions often fall flat, they don’t always resonate with the crisis, the exhaustion and the lived experience of the person in front of me. People can feel like a ‘failure’ if they are not seen to be practicing self-care or ‘holding it together’. So, this is just a reminder that self-care is different for everyone, and especially for carers and people experiencing a chronic illness.

In most cases, self-care is not about meditating, exercising every day, or indulging in an hour long a bath with candles. Sometimes, self-care is simply taking time to breathe deeply, talking to someone about our feelings, or turning the phone off for 15 minutes. It is a small acknowledgement of our humanity and our need for peace.

Kylie Agllias

Meet our Members

10th June 2021: A very cold Winters day with lots of family warmth and love in the air.

I had the privilege today of meeting up and enjoying a warm delicious coffee with one of our LA families. Keith, his mother Sharen and his stepfather Phil decided to have a well-deserved holiday at gorgeous Nelson Bay, NSW. We met at Mayfield Wests Club (not far from where I live and not far from Nelson Bay), for a catch up. We all had an enriching experience, we laughed lots and talked about the wonders of nature and life experiences. I enjoyed hearing about the family’s holiday and their wonderful adventures.

One of Keith’s favourite hobbies is gardening and he has shared some photos of vegetables he has grown which would make your mouth water. I presented Keith with an orchid on behalf of LA. Keith can now add orchid growing to his gardening portfolio. Keith was thrilled with its beauty and ensures me there will be more orchids blooming next year.

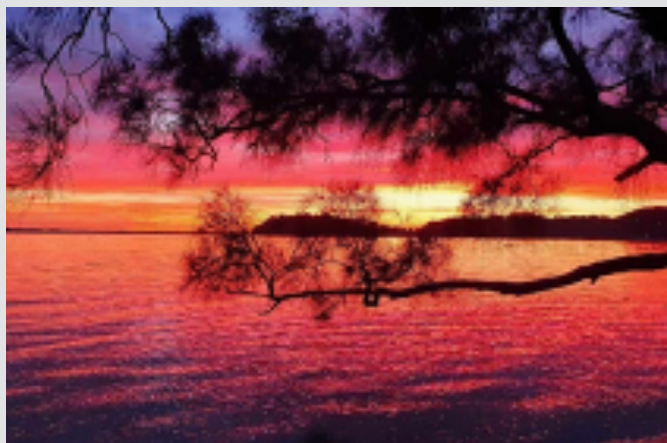
The family wished to share the delightful sunset they experienced during the week looking out from their holiday house. Keith also enjoyed a great sunny day quad biking with Phil. Sharen sat back and enjoyed the scenery and watched them having fun.



Keith, Sharen and Phil, I wish to thank you for a great morning, and allowing me to share your wonderful holiday experiences with our members at LA.

Thanks,

Anne Patricia





Safe In Sound is Coming to Tasmania

Leukodystrophy Australia are proud to introduce for the first time in Hobart, 'Safe In Sound 2021 live and online music concert series'. In the first week of July 2021, the Safe in Sound team will travel to Hobart to offer a FREE private 30 – 60 minute concert in their homes.

Safe in Sound is an exploratory music concert series for persons living with disability and their families/ supporters. Our team focuses on creating music that explores sound to stimulate the listener. Drawing on our experience in sound art and

improvisation, we encourage focused listening and enjoyment for people with disabilities, family and carers. Artistic Director Robbie Avenaim says "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".

View footage of the concert series here: <https://youtu.be/4ryob6zi7GE>

Families interested in participating, please contact Anne Patricia on advocate@leuko.org.au
Mobile 0418 790 059.



Membership: Renew today

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, on the '**Support Us**' page. Or contact us directly and we will forward it on.

Thank you



Memorial

Christopher Mark Bauerochse was born on the 7th April 1956.

Christopher was a well-known member of LA often attending our South Australian Family Gatherings.

Christopher passed away peacefully surrounded by his family on the 16th February 2021, he was 64 years of age. He was loved and adored by his family and many others, he will be sadly missed.

All of us at Leukodystrophy Australia send Christopher's wife Johanna, his children, grandchildren and others our warmth and love.



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. Additionally, the 2021 Living Rare, Living Stronger NORD Patient and Family Forum is an interactive virtual form to be held 26-27th June 2021. Topics include; The Sibling Experience, Coping with Grief and Getting Involved in Research.

Please note: All general sessions and breakout sessions will be recorded so that you may watch them at your convenience.

Use this link to register:

Overview - Living Rare Living Strong