



# newsletter / winter 2022



Welcome to our winter Newsletter. 2022 has been a busy and eventful year. We've had some ups and downs over the past approx. 6 months, several of which I will share with you in my report. This is off the back of a difficult 2+ years for most and certainly for Leukodystrophy Australia, impacted financially and also in terms of our ability to support members as we would have had hoped.

Starting with an important upcoming milestone for the organisation – this being the Leukodystrophy Australia

30th Anniversary. On 17th August 1992, our founder and life member, Sister Julie Thomas CSB OAM launched the organisation – back then, known as the Australian Leukodystrophy Support Group Inc. A small event involving current and past committee will be held to mark this important milestone and with the hope that COVID –19 concerns begin to ease, our aim will be to plan for state –based events to recommence over the coming 12 months.

August also marks 12 months since the passing of Sister Julie's dear and caring sister Janet, who through her support of Julie, was a staunch supporter of the organisation. On behalf of the committee and members, we are most grateful in announcing and acknowledging Janet's generous bequest to Leukodystrophy Australia. The 30th Anniversary will be named in Janet's memory:

'Leukodystrophy Australia 30th Anniversary in memory of Janet Hudin'.

Continued on page 2

#### **Important Anniversary**

17th August 2022 30 years.

**Leukodystrophy Australia celebrates 30 years**On Monday 17th August 1992, Sister Julie Thomas CSB
OAM launched the Australian Leukodystrophy Support
Group Inc.

#### Contents

President's Report	1
Upcoming Events	1
A message from Sister Julie	2
This is Your Space	2
Family Advocate Report	3
Safe In Sound	3
Next Big Ride for Nathan	4
The Australian Leukodystroph Clinical and Research Program (Massimo's Mission)	
new website	4
One Percent	5
Advocate for X-linked adrenoleukodystrophy (ALD)	5
Determining Average Time to Transplant in X-Linked Adrenoleukodystrophy	5
A research project for individu with a Leukodystrophy OR the parents/guardians/carers towards clinical trials	als ir
Life, Love and Loss: A podcast for families caring for a child who is dying	6
Disability Gateway	6
NORD News	6
Social Worker Feature story	7
Membership: Renew today	7
Meet our Families: Geshan	8
	9





#### President's Report cont.

Kylie Agllias, Social Worker who shared Anne Patricia's Family Advocate role over the last few years has unfortunately resigned due to other commitments. However, we are excited that Kylie expressed interest in and has joined the committee, adding an important skillset and level of professionalism.

2022 was to be a record-breaking year for long term hero and ambassador of Leukodystrophy Australia, John Olsen OAM. John, backed by the Geelong Corio Bay Lions Club, commenced his fourth Long Walk across Australia - 'Another 10 Million Steps for Leukodystrophy' in April this year, with the hope of important funds to be raised for Leukodystrophy Australia. Under a week into the walk, in extremely hot conditions, John suffered what appeared to be heatstroke. John was taken to a local clinic and then to Broome Hospital, upon which it was discovered that he had suffered a minor stroke. Further clinical follow-ups confirmed the diagnosis and this unfortunately spelled the end of John's walk. While John is extremely disappointed in this outcome, he has already achieved so much with his past walks and we salute his achievements and wish John a good recovery. We'd also like to thank John's supporters from the Geelong Corio Bay Lions Club, sponsors of equipment and services associated with the planning of John's walk, donors and importantly, Mark Hosking from South Australia, one of our family members who spent valuable time and money in the planning, including flying up to Broome in prep for the start of

We would like to thank those who donated toward the walk and a future initiative in the spirit of The Long Walk (though not a walk across Australia, but we have some ideas) is not out of the question. If any members or supporters have marketing expertise and are interested in helping to craft an alternative fundraiser, please contact us.

A very special mention of Anne Patricia, Social Worker and Registered Nurse - our Family Advocate for seven

years. Anne's final official Family Advocate Report is in this Newsletter. Anne has invested her heart and soul in support of those affected by Leukodystrophy, their families, working with multiple stakeholders and all-round service to Leukodystrophy Australia. Anne has announced her retirement, which will allow her to focus on her family. We are grateful for Anne's work for Leukodystrophy Australia and we will miss her in her role, but she has indicated she would like to remain connected with the organisation and hopefully ultimately join our committee. We wish Anne well!

I'd like to acknowledge donors to Leukodystrophy Australia over the past 6-12 months – your support has been critically important for us. One donation in particular by The Co-Group Limited has allowed us to be able to extend the Family Advocate role to full-time (initially planned to be a 1-2 year contract) and we are currently going through the recruitment process – we will announce further details when we have an update. Once the new Family Advocate role is filled, we anticipate further increased connectivity and outreach to more persons affected by Leukodystrophy, their families and the ability to work with more stakeholders.

Thank you to the board of The Co-Group for their support and understanding the importance of the Family Advocate to our organisation.

To the families who have lost loved ones in the recent past, we share your grief as part of the wider Leukodystrophy family and we remain here for you.

I'd like to thank my fellow committee members and also our volunteers who all play important parts in the running of Leukodystrophy Australia. As we move through our 30th year since Sister Julie founded the organisation and in an improved financial position, we plan to be able to provide continued and increased support to those affected by Leukodystrophy.

Earl 0477 550 977

# A message from Sister Julie

Greetings to All. I am sending you warm greetings hoping you are as well as possible.

I trust you are all as well as you can be and all the brave people have all the Medical help that is available, together with being able to have the equipment you need.

Those who live in Queensland I hope you are not experiencing too much rain. The reports we have seen on T.V look rather a big concern, so hopefully you will not have more 'Rain Bombs'. In Vic we have had very little rain!!

Many sincere thanks to all who are doing great work on the Committee; you are keeping all who are affected in different ways know what to do for assistance. Sincere greetings,

Julie Thomas CSB
Telephone 0412 535 113
Address 4 King Street East Hawthorn 3123

# 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.

Anne Patricia 0418 790 059 Email advocate@leuko.org.au







## **Family Advocate Report**



We have now moved into Winter and no matter if you are down South in the snowfields or up North where it's warmer, enjoy this magical time of year.

I love this time of year drinking hot chocolate, watching movies, knitting and walking along the beach with my beanie and jumper on. I hope you can experience some wonderful times during your busy schedules.

Thank you to Shilandini, Geshan's mother for sharing their family story in this newsletter. I am certain our families and others will enjoy reading this heartwarming story.

New families continue to contact Leukodystrophy Australia (LA), many of whom find out about us from internet searches. It is wonderful to have a webpage which shows LA's contact details, valuable resource for GP's, allied health professionals and families. LA is always interested in ways we can assist our LD community and others. If you have any constructive feedback or ideas for our website, we are open to suggestions.

LA sends a very heartfelt acknowledgement to those families who have and continue to experience hardship due to the floods in Queensland and NSW. We have you in our thoughts. If there is anything LA can do to assist you, please don't hesitate to reach out to us. One of LA's main goals is to reach out, connect with and assist our families.

This year Leukodystrophy Australia will celebrate 30 years of supporting families and others impacted by leukodystrophy. We are fortunate Sister Julie is never far from the phone to mentor us and to send her love and blessings to all our families. Sister Julie never forgets those who assisted her to bring Australian Leukodystrophy Support Group (ALDS) to fruition, many remain loyal supporters and friends of Sister Julie and LA.

Thank you Sister Julie, for giving our families a space where they can be listened to and supported.

Angela Famiano, our LA WA Representative will be calling families over the following months to update your details on our database. Please feel free to take some time and have a chat with Angela.

I have resigned from my Family Advocate role after 7 years, this was not an easy decision to make and I reflected on my decision for many months. I turned 60 this year and after many months of reflection, I decided it was time for me to resign from my role as Family Advocate. I have to now focus and give more of my time to my family. My beautiful granddaughter requires constant care and attention and there is regular advocacy work I must achieve for her. I will be joining the LA Committee sometime later in the year, so I haven't left LA entirely.

I am crying as I write this because all the families and individuals I have worked beside have touched my heart. I will be forever grateful for their patience, kindness, compassion and sharing their stories and knowledge. I believe people come into our lives to teach us numerous lessons, so we can go out into the World and share our love and knowledge.

Thank you to Sister Julie OAM, all the wonderful LA families, previous and current Presidents, Committee members, individuals and service providers I have engaged with over the past 7 years. I am a richer person for having been in your presence.

I will graciously hand over to the next social worker and of course wish them well in their endeavours.

Anne Patricia. 0418 790 059

Love the chill of Winter and stay safe.

#### Safe In Sound

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.







## **Next Big Ride for Nathan**

Nathan McDowell will be riding a custom-built hand cycle long distance from Kingaroy on Wednesday, 29th June for a 9.00am start from South Burnett Rail Trail, Kingaroy and arriving into Suttons Beach, Redcliffe Peninsula on Saturday, 2nd July around 12.30pm. (celebration between 11.30am to 3.30pm)

All welcome to celebrate with the Holistic Horizons Support Services Team, Nathan and Nathan's family on Saturday 02nd July between 11.30am to 3.30pm. We will be selling sausage sizzle, drinks, raffle tickets with all proceeds going to Nathan's cause. CASH ONLY PURCHASES

We have a LIVE MUSICIAN for entertainment. Nathan would dearly love to see you all there, some familiar faces and some new friends as well. BYO Chair, picnic rug, fold out blanket and hat, sunscreen)

Nathan is raising awareness for his rare genetic terminal disease, Pelizaeus-Merzbacher Disease (PMD). Nathan is 32years old and living with Cerebral Palsy and Spina Bifida as well as PMD. Nathan would love you all to join him for a celebration on Saturday 2nd July when he rides into Redcliffe.

Leukodystrophy Australia has donated funds for Nathan and his team to purchase riding jackets, which they will wear on their current and future rides. LA wishes Nathan and his team all the best on their ride.

Please rsvp to <u>julie@holistichorizons.com.au</u> if you are attending or would like to help in anyway.

UPDATE - Nathan completed his ride successfully! Keep an eye out for next year's ride. You can still donate at the link below.

Supported by Holistic Horizons Support Services

You can support Nathan by donating to his GO FUND ME PAGE:

https://www.gofundme.com/f/nathan-mcdowell-ride-for-life?

Please follow RIDE FOR NATHAN here at his Facebook Fan Page for live updates of his ride this week from Kingaroy to Redcliffe: https://www.facebook.com/nathansbigride/

#### NATHAN'S MOTTO:

'WHEELS GIVE ME LIFE, WHEELS GIVE ME FREEDOM'





# The Australian Leukodystrophy Clinical and Research Program (Massimo's Mission) new website:

#### ww.leukonet.org.au

Leukodystrophy Australia exists to provide information, support and advocacy to individuals and families affected by leukodystrophy, to raise awareness of this group of conditions, and to encourage leukodystrophy-related research.

The Australian Leukodystrophy Clinical and Research Program (Massimo's Mission) has a dedicated white matter clinic and cutting-edge research programs, and their mission is to ensure that every family has the appropriate

support and resources needed to navigate the various diagnostic and therapeutic options available.

They recently launched their website: <a href="https://www.leukonet.org.au">www.leukonet.org.au</a> which provides helpful information and resources for families including patient fact sheets on the common leukodystrophies. You can sign up through the website to be involved in their research studies such as the patient registry and natural history studies. There is also information about the White Matter Disorders clinic in

Melbourne and how you can be referred for a clinical opinion and/or genomic testing. If you have any questions, please visit the **contact us page** and send us an enquiry and we will respond as soon as possible.

Leukodystrophy Australia and Massimo's Mission collaborate and offer cross referrals so we may offer families the best possible outcomes during their LD journey.









# 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/



# Advocate for X-linked adrenoleukodystrophy (ALD)

Emma Hayes is a dedicated and fearless advocate for X linked adrenoleukodystrophy (ALD)

which stems from a family history with the disease. Her personal experiences with ALD catalysed her desire and interest to bring awareness to this disease and other X linked disorders. Emma is a member of the Young Adult Representative of RDLA (Rare Disease Legislative Advocates) and is heavily involved in ALD Connect, the patient organisation for ALD. Emma is currently working in Product Innovation at Carrum Health, a start-up healthcare company focused on bringing value-based care at centres of excellence to the marketplace. She has a Bachelor's degree in Chemistry from Saint Anselm College and a Master of Science degree in Technology, Entrepreneurship, and Innovation from the University of Notre Dame. Emma is committed to furthering her involvement in the healthcare world, specifically for rare diseases in order to ensure that healthcare is not given as a privilege but rather a right.

**ALD Connect** 

# Determining Average Time to Transplant in X-Linked Adrenoleukodystrophy

GLIA-CTN: <u>Time to Transplant in X-Linked</u> Adrenoleukodystrophy

Cerebral X-linked adrenoleukodystrophy (cALD) is a disorder characterised by the destruction of myelin (the insulation surrounding nerve fibers) in the brain. Survival and improved outcomes for cALD are associated with hematopoietic stem cell transplantation (HSCT) at earliest evidence of disease on magnetic resonance imaging (MRI).

In this study, researchers aimed to determine average duration between diagnosis of cALD and HSCT. Among 27 patients with cALD in the hospitals they evaluated, the team found that time to HSCT was greater than 3 months. They also noted differences in average time by race/ethnicity and by hospital. Authors state that these findings suggest an opportunity to reduce time to transplant in cALD.







### A research project for individuals with a Leukodystrophy OR their parents/guardians/carers towards clinical trials

Dear Leukodystrophy Australia team, I am a 2nd year Genetic Counselling student who is currently undertaking a research project with the Leukodystrophy and White Matter Disorders research team at MCRI in Melbourne.

Our project aims to explore the attitudes of individuals with a Leukodystrophy or their carers towards clinical trials, to help inform future clinical trial design. This is a qualitative study using interviews.

The Massimo's Mission team at the Royal Children's Hospital and the Murdoch Children's Research Institute would like to invite you to take part in an interview that aims to explore the attitudes of individuals with a Leukodystrophy OR their parents/guardians/carers towards clinical trials.

These interviews will provide us with further insight into any concerns you may hold regarding clinical trial participation, your motivations for clinical trial enrolment, your perception of the risks and benefits to clinical trials, and your understanding of the clinical trial process. Interviews are to be held via Zoom, Telephone or in person at the Royal Children's Hospital. Interviews will be conducted by Master of Genetic Counselling

student, Ella Wilson and will take approximately 30 – 60 minutes.

We plan to use this information to inform future clinical trial design, to ensure adequate recruitment of individuals with a Leukodystrophy into clinical trials. Further, this information will guide practice to support informed consent in the clinical trial process.

Participation in this project is voluntary. This project has received ethics approval from the Royal Children's Hospital Human Research Ethics Committee under reference #64193

If you are interested in taking part in this study or would like further information, please contact Eloise Uebergang (eloise.uebergang@mcri.edu.au, ph: 03 8341 6382) or Ella Wilson (ellalw@student.unimelb.edu.au) via email or telephone.'

Thank-you in advance for your consideration of this request, and please feel free to contact me directly on my mobile (0425371196) should you wish to discuss further.

Kindest regards, Ella Wilson Master of Genetic Counselling Student

The University of Melbourne, ID:1039987

# Life, Love and Loss: A podcast for families caring for a child who is dying

This five-part series focuses on the experience of parents of children who have died or are likely to have a short life. Despite advances in health care, children and young people still sadly die from a range of life limiting conditions. The parents in this series have been supported by palliative care teams to face multiple challenges in caring for their children. These parents bravely share the love and beauty of their children and the joy and sadness of their individual experiences. The parents in this series hope that their voices can support, inform, and better prepare other families who may need to face similar challenges. This podcast series is a collaborative project funded by the Quality of Care Collaborative Australia (QuoCCA) in partnership with The Royal Children's Hospital, Melbourne and the Victorian Paediatric Palliative Care Program. We warmly thank the parents who have generously taken part in this series.

PODCASTS: Life, Love and Loss (rch.org.au)





#### **Disability Gateway**

The national 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



#### **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







# Social Worker Feature story Anne Patricia, Family Advocate

I am often asked by parents and busy care givers what ideas can they use at home with their children around play. There is no right or wrong answer, it all depends on what fits for the family and particularly the children.

An important factor in a child's world is play. Play allows you to enter your child's world. Children process their thoughts, feelings, emotions, experiences, strengthen fine and gross skills, learn to problem solve and have fun. At the same time, you are connecting and fostering a healthy well-balanced relationship with your child. Be present for your child, listen and acknowledge them, build memories and never underestimate the power of play. These moments are precious.

#### Some ideas:

- Water play this can be explored indoors and outdoors, is a unique
  activity for children because it's always available, open-ended, and
  provides opportunities for extended learning. Such as fine motor skills,
  socialisation, language development imagination and problem-solving
  skills. Bubble bath or other non-allergic detergent to form bubbles and
  water paint, brushes and rollers are some fun things you may explore.
- Scrapbooking The handicraft element of scrapbooking is an enjoyable and soothing activity which can help to ease children relive and embellish happy memories, tell their stories as the trusted adult listens and can support them through this process.
- Drama therapy this therapy stimulates emotions, feelings, involves
  physical activity in the form of movement, and stimulates a child's
  imagination and spirit. It can be scripted by them or improvised. Try using
  props the children can make, costumes, boxes, puppets or toys.
- Make shapes make shapes from the clouds or the stars.
- Constructive games play board games, Uno or Snap, checkers or chess do a jigsaw puzzle.
- Music drum rhythms on pots and pans, dance and sing along to kids songs, buy a cheap mouth organ or recorder.

Have fun and create long life memories with your children, they are only little for a short time.

#### Some resources:

- · Google TED talks and 'Playing with your Children'.
- Connecting With Your Child Through Play: The Surprising Benefits of Parent-Child Playtime — Exchange Family Centre
- Special time & fun activities with kids | Raising Children Network

Kind regards, Anne Patricia.







# 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 2022-23 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







#### Meet our Families: Geshan





A big hello from Adelaide.

September to November 2021 were very special events for my son Geshan and our family.

In September Geshan become an Uncle for the first time to baby Josette. Geshan turned 21 years of age on the 6th October 2021. To celebrate his milestone birthday, we had a party with everyone who loves Geshan.

Geshan, granddaughter Josette and our daughter Elisha. Uncle Geshan loves his baby niece Josette.

I turned 50 myself on the 18th October and we had another fun party.

Geshan had completed his high school in 2020 during COVID lockdowns and he was due to graduate from the Adelaide East Education Centre in November 2020. Due to lockdowns and ill health Geshan could not graduate as we missed responding to the invitation that was never received. We requested to attend the November 2021 Graduation, but we were told by the school this was not to going happen because Geshan already graduated in 2020, and there was no place for him in the 2021 Graduation.

We were so upset and tried numerous times to liaise with the school's Principal and the Director of the local education office. We eventually went to the South Australian Government Department Ombudsmen who aligned with the school that Geshan could not attend the Graduation in 2021.

I was in tears and anxious and one day Anne Patricia called me about another matter. When she heard about the graduation refusal, she began to explore options for us.

Anne was fantastic going to great lengths for Geshan and she contacted Earl Schonberger LA's current President. Stephen Damiani also wished to provide his support. Anne eventually contacted Paul Barbaro from the Disability Rights Advocacy Brooklyn Park SA. Paul was amazing and liaised continually between all parties. The school was hard and fast, Geshan could not Graduate!



Paul wanted us to go to the ABC Radio Adelaide and tell our story. Our family had long discussions with Anne and we decided the radio program would be a voice for Geshan.





I was so nervous, but Anne helped me to remember, I was Geshan's voice and the voice for others in the future.

I was interviewed by Ali Clarke at 0750 on Geshan's 21st Birthday (this was never planned) and I thought that was the end of the matter. Not at all, the ABC contacted the SA Premier and he intervened, finally the School offered a position to Geshan to attend his Graduation ceremony on 25th November 2021.

Geshan became unwell and was hospitalised on the 15th November 21 he was intubated. Our gorgeous son fought hard to get well enough to be extubated just prior to the Graduation. With permission from the doctors and taking his Bi-pap/ Oxygen and being late, having to navigate heavy traffic Geshan graduated on the 25th November 2021.

When Geshan heard his name he was looking around and knew this moment was all about him. What a wonderful moment for our son and through tears in our eyes we watched Geshan's dream come to fruition.

My message to everyone is no matter who you are or what challenges you face it is so important to ask for support from those you trust. Remain strong for your loved ones and if you can't initially find your voice to advocate for them ask for assistance. You will learn to get stronger and wiser over time. We all get tired and overwhelmed at times but our voice is that of our children's.

Thanks to Anne Patricia, Paul Barbaro and Ali Clarke ABC Radio Adelaide for assisting Geshan to Graduate.

Thank you Geshan, Shilandini and Rohana.







### In Memoriam



#### Clare White 15 September 1983 – 3 December 2021

Clare was a wife, mother, daughter sister and friend to many. Clare was kind, generous and a wonderful advocate for those impacted by leukodystrophy or other rare conditions. Clare always walked on the side of hope and always wished for everyone to have optimal health and wellbeing. Clare was a long term family member of LA, and she will be dearly missed.

The World has lost a wonderful, compassionate, strong and tenacious woman. Clare is dearly missed by many people.

#### Layla Rose "Bug" 2 January 2021 – 23 December 2021

Bug was born at just 32 weeks and right from the day she was born she had everyone wrapped around her tiny finger. She could light up a room and all her medical team loved her. Although she was tiny and couldn't physically move or communicate, she had tons to say and lots of judgemental looks to throw when someone doubted her. Bug lived until just 10 days shy of her 1st birthday and in that time, she taught so many people about Zellweger Spectrum Disorder and the vast differences in Leukodystrophy's. We will forever be thankful for Leukodystrophy Australia and their amazing support through our daughters short but impactful life.

Kind Regards,
Gabrielle Cronin.





### Gaelle Brooks 30 October 1950 – 20 April 2022





Gaelle passed away peacfully on Wednesday 20th April 2022. Gaelle was a long term family member of LA. She was always upbeat no matter what her situation was like and she loved to call for a chat and let me know how her cats were going. Gaelle never liked anyone fussing over her, her family would love Gaelle to be remembered for her humour, resilence and courage.

Gaelle was a great advocate for all those impacted by LD patricualry those women impacated by AMN. She loved to raise the consciounsness of LD wherever she went, particaulry around her local community on the Victiorian Peninsula at Warrnambool. Gaelle had her beanies embroided especially so people would question her about LD and LA. Gaelle will be sadly missed by us at LA and of course her loving family, cats, friends and her local community.

Our hearts go out to all the families whose loved ones have recently passed away. Please know LA is here for you if you require any support.

In kindness and compassion.

Anne Patricia.





