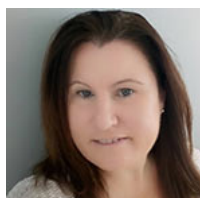




newsletter / winter 2020



It is a very different time for our families, as it is for the rest of the world. Covid 19 has forced us to make some challenging and positive changes to our lives. Whilst we wait for a vaccine it is imperative we continue to foster our family, friends and other relationships.

We continue to search for Grants, and as many small Non for Profits, we will continue to be positive in being there for our members. Our Family Advocate is retiring at the end of August, but will be there in a volunteering capacity for our members.

The new web-site has been launched and it looks great. Bronwyn, Anne and others have devoted a lot of time in its development. We would like to share your stories. If you have a story you wish to share, please feel free to send this through to Bronwyn.

On behalf of the Lyons family, we donated \$6000 to leukodystrophy research. This donation was a very generous offer made by the family and shows their devotion towards leukodystrophy research.

The 2020 AGM will be a Zoom meeting on 5 September, where all members are welcome to join. Zoom lets supporters call in on the phone if you don't have access to a computer. No need to create an account or username to take part.

Our thoughts go out to our bereaved members and those who are finding the new normal under Covid 19 hard. My heart felt wishes to all members and the community at large at a time that is effecting us all in so many different ways.

Kellie Panton, President

Events & Meetings

| | |
|-----------------|---|
| 5 September | AGM meeting / via Zoom, 3-4pm / Register in advance for this meeting: zoom.us/meeting/register/tJAAtcumppzpkE9wZetmWrzW1rZL5XrTCWZ-F |
| 2 October | Charity Challenge Leukodystrophy Australia Golf Day / Long Reef NSW thecharitychallenge.com/events/australian-leukodystrophy-support-group |
| 8 November | Running for Ryder / give.everydayhero.com/au/running-for-ryder-1 |
| TBA | South Australian Family Gathering |
| 21 November TBA | Charity Challenge Gala Dinner / Hyatt Regency, Sydney, 6.30pm |
| 9 December | Charity Challenge Leukodystrophy Australia Golf Day / Woodlands, 8am-3pm form.jotformpro.com/charitychallenge/leukovic2020 |
| 5 December | Special Children's Christmas Party / See page 2 for details |



It is with joy and gratitude we bring you our first newsletter for 2020. Sorry it has taken so long – it's all my fault! However, I do hope you have been keeping abreast of things via our **Facebook**. Much of my time has been taken up with developing our new website leuko.org.au. We hope you find it a useful reference and interest for

yourself, your friends, carers, supporters, teachers, colleagues, doctors and allied health; because this is our aim as we endeavour to support you. Thank you to those who have already used the Feedback form on the Contact page. We are acting upon and are truly obliged.



Part of the joy and gratitude is the enlistment of our new Newsletter volunteer, Dimitra Minuzzo, for whom we are most grateful. We hope the format is easier for you and that we may be more on time. You can read more about Dimitra and her lovely family on page 5.



And a very big thank you and welcome to Abby Tennant our volunteer website editor, who comes to us from the GSNV Volunteer Program – thank you GSNV yet again supporting the support sector. Abby is a biomedical science graduate and looks forward to being involved in other LA potential projects in the future. How lucky we are to have two fabulous new volunteers this month!

The state and federal governments have provided LA much valued financial assistance via their various stimuli and this thankfully looks set to remain, allowing our support to continue.

I'm very sad however to be losing our very supportive, dedicated and hardworking colleague, Anne Patricia, Family Advocate. Anne has also become a good friend and mentor to me. Anne will be retiring at the end of August; but true to her giving nature, or is it she just can't let go of any of us,

Anne will stay on for a while in a volunteer capacity. Anne has been outstanding in her dedication in assisting families who will miss her dearly. Thank you Anne for who you are and all you do. Go well into the future.

LA is not yet sure how or when we replace Anne, but it is first and foremost in our minds and efforts.

You, our families and carers will be working so hard looking after your loved ones, made even tougher by the medical, financial and mental challenges of COVID. Just knowing your families are more vulnerable is challenging enough. How have you been coping, hunkering down, and doing your job? There will be highs and lows without a doubt. If you would like to chat or we can help, please give us a call or send an email leuko.org.au/contact-us/

COVID lock down has been a positive source of music discovery for me, and these lovely websites both for mediation and music, should you wish or have the opportunity to chill out for a little, is definitely worth checking out for the whole family:

soundcloud.com/maggiedentauthor/maggies-moon-meditation-for-mums

The ABC's Nature Track is your window to the amazing sounds of Australia:

abc.net.au/classic/read-and-watch/news/ambient-australian-soundscapes-in-new-abc-series-nature-track/12420284

Major news earlier this year was the opening of Massimo's Mission Leukodystrophy Program at Royal Children's Hospital. You can find an update from Clinical Research Coordinator, Eloise Uebergang on page 4.

Leukodystrophy Australia is honoured and deeply grateful to Dr Chloe Stutterd as our Medical Research Advisor. Immense thanks to Associate Professor, Rick Leventer, Eloise Uebergang and the team for their ongoing and enthusiastic support.

Bronwyn Byrne, Office Manager
0418 755 994 or Toll free 1800 141 400



Greetings, as we all try and live avoiding this nasty virus which seems to be rampant in Melbourne, does it not. We are all masked and need to keep our safe distance from each other.

I trust and pray those who are caring and nursing someone with a Leukodystrophy are still receiving the medical help you need to keep your heart and mind as peaceful as possible. I am confident given time everything will settle and some medicos will before too much longer find the correct antibiotic.

Anne Patricia, Bronnie has told me you are almost ready to resign your position. I know you have done all you can to listen and help those who need comfort, understanding when not too sure where to go, and you have shone light for many at the end of their dark tunnel. Sincere thanks Anne Patricia.

If anyone wants to speak with me. Please feel welcome to ring me on 0412 535 113.

Best wishes to all, Julie Thomas CSB OAM



We have been offered an opportunity to attend one of the free Christmas Parties held around Australia in November and December. We have invites available for Launceston, Perth, Brisbane, Melbourne, Adelaide, Canberra and Sydney. The invites are for children aged from birth up to 12 years.

If you are interested in attending, please contact Bronwyn at info@leuko.org.au



Over the past few months there have been women living with ALD contacting us in the hope of accessing support and some resources to assist themselves and their service providers. Here are some resources which may be of interest to our members or other interested parties. If anyone knows of any other appropriate resources, please contact Bronwyn or myself. They may then be download onto our website.

Remember the Girls



“Remember The Girls’ mission is to raise awareness of the many issues facing female carriers of x-linked recessive genetic disorders; to provide a forum for x-linked females to share their stories, ask questions, provide and receive emotional support, and develop friendships; and to advocate for increased attention of the medical community to the physical and emotional issues of females who carry x-linked disorders.”

rememberthegirls.org

ALD Connect



“Women with ALD can experience symptoms similar to men with AMN later in life. Symptoms vary in women, but many times include bowel and bladder dysfunction, pain in the extremities, and walking difficulties. Cerebral disease and adrenal insufficiency are rare in women with ALD, so symptom management is key. Until recently, women with ALD were recognized as “carriers”, who did not show symptoms of ALD, but with new research, women are recognized as actually having ALD, and thus receiving improved medical care.”

aldconnect.org/women/



A happy little Lush is Zack!

Workplace Giving

If just 10% of working Australians donated \$5 a week, an extra \$300 million would be raised every single year. And this is before employer donation matching is added in!

You can make a real difference by discussing

Workplace Giving with your colleagues, your employees or employer, in asking them to consider Workplace Giving to Leukodystrophy Australia and the important work we do.

leuko.org.au/support-us/workplace-giving

Leukodystrophy Australia

If you wish to engage with one of our women members living with ALD, please contact Bronwyn or myself and we will endeavour to connect you with a peer supporter. The team at Massimo’s Mission Leukodystrophy Program are currently documenting some information for women living with ALD and this will be downloaded onto the LA website and feature in our future newsletter.

COVID-19

COVID -19 has brought numerous unique and varied challenges for many of us during 2020. LA has some useful resources to assist our families.

leuko.org.au/coronavirus-resources/

My hope is you are all keeping as safe as possible particularly those who are living in the ‘hot’ spots.

We have all been through a huge learning curve this year and let us hope that a COVID-19 vaccine will be offered to us soon. Thank you to all the frontline workers who continually offer their services and are working tirelessly and selflessly throughout the pandemic.

Keep rugged up, safe and cosy during the Winter months.

Anne Patricia, Family Advocate

0418 790 059

advocate@leuko.org.au

New and Interesting Resources ALD Connect Webinar 21 July 2020

Physical Therapy for male and female AMN Patients around strength, sensory and range of motion. This can also be shared with your therapist

youtube.com/watch?v=RVN6wS-mTeo&t=1s

The 2020 United Leukodystrophy Foundation Virtual Conference

The Conference is over, but materials are available ulf.org/news/family-conference/

For our women with ALD, there was a presentation covering carrier/female patients of AMN that streamed live, but it is not published to YouTube as the research is still in preliminary stages and a video will be recorded once the data is finalized. The forecast for this could be the end of this year/early next year. There’s a gap, but it’s one that is beginning to be addressed.



Eloise Uebergang, Clinical Research Coordinator
Eloise.uebergang@mcri.edu.au
 03 8341 6382

Massimo's Mission Leukodystrophy Program Update

We are now recruiting:

- Undiagnosed children and adults Australia-wide for clinical and/or research based genomic testing.
- Diagnosed and undiagnosed children and adults Australia-wide for the **Australian Leukodystrophy Registry**. We will collect information from existing medical records with consent from the individual, parent or guardian. Being part of the registry does not require you or your child to do anything other than provide consent to access medical records.

It is very easy to be involved and we would love to hear from you! Please contact me or complete the survey through the link below and we will be in touch:

redcap.mcricri.edu.au/surveys/?s=33YKYRRMWE

Massimo was the first patient in the world to have a novel genetic disorder diagnosed through the use of trio whole genome sequencing, where his entire genome was compared to that of his parents, Stephen and Sally Damiani. Stephen and Sally have always been at the forefront of raising funds for research and advocating for children with Leukodystrophies. Massimo's Mission is led by Associate Professor Richard Leventer from the Royal Children's Hospital, the Murdoch Children's Institute (MCRI) and the University of Melbourne Department of Paediatrics, together with Dr. Cas Simons from the MCRI, Professor Ernst Wolvetang from the University of Queensland and Professor Matthias Klugmann from the University of NSW. The program is funded by the **Medical Research Future Fund** and is part of the **Australian Genomics Health Alliance**.

Leukodystrophy and other White Matter Disorders Clinic

This clinic commenced in 2020 and runs once a month as part of the Neurogenetics clinic at **The Royal Children's Hospital** in Melbourne. It is available for children with white matter changes of the brain to help provide advice for both parents and healthcare providers, offer accurate information and genetic testing where indicated.

During a clinic appointment you will see Associate Professor Richard Leventer: a paediatric neurologist who is an expert in human brain development and Dr. Chloe Stutterd: a medical geneticist who is an expert in the genetic causes of leukodystrophies and white matter disorders.

If you would like an appointment, please ask your GP or specialist for a referral.

Please feel free to contact me if you have any questions about the clinic.

PMD Natural History Study

We are still recruiting children and adults who have been diagnosed with PMD to the MCRI natural history study, led by Dr. Chloe Stutterd and Associate Professor Richard Leventer, in collaboration with the Children's Hospital of Philadelphia. This is to help understand how PMD progresses over time, which is necessary to accurately evaluate the effect of novel therapies.

We are collecting information from existing medical records with consent from the individual, parent or guardian. Being part of the study does not require you or your child to do anything other than provide consent to access medical records.

Please contact me if you would like to be involved or find out more information about the study.

Warm regards,
 Elle

SAVE THE DATE: LA AGM Saturday 5 September @ 3-4pm (via Zoom)

The meeting will be held via Zoom this year. This gives us a unique opportunity for as many as possible to attend. Meeting papers and the Annual Report will be emailed to you. Unlike other years, the meeting will be a simple happening, but we will have an opportunity for an update in leukodystrophy and Q&A.

If you have questions you would like answered, please email them leuko.org.au/contact-us/

PLEASE NOTE: nominations are open for all existing positions for our Committee

Please consider leuko.org.au/support-us/committee/

Fundraising and volunteering are important investments in our future. Our volunteer Committee of Management is one such area. Should you be interested, in the management aspect of our group, we would be most happy to talk with you. Any help you can give is, and will be, greatly appreciated!

Leukodystrophy Kid's Companion — Content Wanted!

Catie Becker, Massachusetts General Hospital Paediatric Neurology is excited to be putting together a Kid's Companion. It's a handout made just for kids about leukodystrophy. Catie is looking for children to help, and is especially thrilled to have input from Australia.

Here are a few options:

1. **Give a quote:** Your child can give a quote on what it feels like to have leukodystrophy in a sentence or two or in a picture.
2. **Tell your Story:** Want to write a little more? Kids can write their story (as a child living with leukodystrophy, sibling stories are great too!)
3. **Share your favourite book** that has helped you understand leukodystrophy or any challenges that have gone along with that.
4. **Author a section:** Up for a challenge? If you feel like writing a bit more you can answer one of these questions:
 - a. What is Physical Therapy like?
 - b. What is Speech Therapy like?
 - c. What is Occupational Therapy like?
 - d. Do you have pain? How to deal with pain.
 - e. What has helped you "take leukodystrophy to school?"

We hope to finish this book in the next two months. If you would like to be part of this we would love to include your child as an author. Please tell us your name as it will appear in the book and the child's age.

Here is are current draft and a video explaining the work we have done so far: [youtube.com/watch?v=fWADFi7nHjs&t=8s](https://www.youtube.com/watch?v=fWADFi7nHjs&t=8s)

If you are interested please email cbecker1@mgh.harvard.edu

Thanks, Catie



In January 2016 both our girls, Johana and Ella, were diagnosed with MLD (Metachromatic Leukodystrophy). Both girls underwent bone marrow transplants that same year at the Royal Children's Hospital.

Johana will be turning 21 this year and is completing her Certificate II in Work Education through Alkira at Box Hill Institute. Ella is 17 years old and in year 12, doing a modified VCAL.

The challenges following their diagnosis and treatment haven't been easy but we've been lucky to have had the support of family, friends and LA.

Dimitra Minuzzo



LEUKODYSTROPHY
.org.au AUSTRALIA

Running for Ryder
& Leukodystrophy Australia
Sunday Mail City Bay Fun Run

Sunday 8th November

Please support SA family members, Michael and Lauren Edwards as they courageously and generously fundraise again for Leukodystrophy families in the Sunday Mail City-Bay Run Adelaide to Glenelg. Their brave and beautiful baby Ryder lost his battle to Krabbe aged just two last year.

You can donate at give.everydayhero.com/au/running-for-ryder-1 or should you wish to join the team, please contact Michael 0420 512 876, or Bronwyn on 0418 755 994.

Last year funds raised enabled our fantastic SA Family Gathering, allowing families to meet for the first time, renew acquaintances, and for LA to meet families.

Everyone enjoyed!

