



President's Message

Dear Families and Friends,

Firstly, I would like to thank you all for placing your trust in me to lead our organisation as President. I commit to doing so with a collaborative and considered approach to continue the vision Sr Julie set out to provide assistance and information to those affected by Leukodystrophy.

It was wonderful seeing many of you at our recent events - the Women with ALD Forum, the AGM and the Family Gathering Dinner. I am reminded how important shared experience is for our wellbeing and hope you find these opportunities valuable ways to connect with other members and partners. I look forward to seeing you in the future.

I have been part of this committee for a number of years now and am continually impressed by the commitment of the team and wish to thank the previous committee for their time and achievements.

For those vacating their posts, Angela, Brett, Donna and Pam we wish you all well in your future endeavours and in particular Pam for her leadership and integrity as President. Big shoes to fill, we will miss you, but I am grateful for Bron, Earl and Kellie's continued service and we are also excited to have Elisha, Deb and Jenny join us so we have a great team.

I would also like to acknowledge our office manager Bronnie for all her efforts in working with each of our committee members on various projects, events and support and generally being the glue that keeps us all together.

We are also very lucky to have our family advocate Ann providing such valuable support and advice to families.

It has been a long winter which can make life with Leukodystrophy just that bit tougher, so may spring bring you and your loved ones' sunshine and brighter days. Perhaps you (or someone you know) fancy a round of golf, like classic cars or enjoy following the amazing John Olsen on his Long walk...

Take care, Michelle 0417822161



Greetings to our Families & Friends living with Leukodystrophy

We have a very exciting and packed issue for you this time around. I do hope you enjoy the read. Please drop me a line for feedback, to change your contact details or to have a chat.

Our AGM was well attended thank you! We saw the departure of Pam Joseph as our President of 2 years. Prior to this Pam was our Family Advocate for 5 years. Pam has been an outstanding contributor to Leukodystrophy Australia and we thank her for her wisdom and kindness. Also departing Committee was Angela Famiano who for 5 years worked tirelessly for our group on family events, forums and our Facebook. Angela continues as a volunteer for our WA families, Facebook and in support of women with ALD. Thank you Angela. Donna Lourensz retired for the 2nd time from Committee. Thank you to Donna who actively contributed with heart and dedication for many years and was with Sr Julie from the very early days and so an integral member. Donna will stay on as a volunteer for Peer Support. Our Treasurer Brett Fernandez also retired. We thank Brett for his contribution, not an easy gig when you already have so much on. You are all highly valued.

We welcome our new President, Michelle Marinovic whose empathy, style and skill will bring a fresh new approach and keep us on our toes. We are looking forward to working with Michelle and other new Committee Deb Letica from WA, Elisha Wijethunge from SA and Jenny Vick from Victoria. It is so lovely to have a spread of people across most states now. Thank you to our new Committee and to those who remain, Kellie Panton from Tasmania and Earl Schonberger from NSW – you are all fantastic and we do not exist without you.

Warm regards Bronwyn 1800 141 400



WE NEED YOU!

Book a table for lunch, get a team together or come on your own

<u>The Charity Challenge Annual Golf Day @ Macquarie Links NSW</u>	<u>6 October 2016</u>
<u>The Charity Challenge Gala Ball @ The Sydney Hilton</u>	<u>12 November 2016</u>
<u>The Charity Challenge Annual Golf Day @ Woodlands VIC</u>	<u>7 December 2016</u>

It's time, it's actually well overdue. Please think seriously about how you can help. Maybe you or your contacts can offer [sponsorship, prizes, donations, play golf or enter a team](#). As usual our families are invited for lunch on the golf days – we would love to see you, it's always a great day. This is the major annual fundraiser run by our wonderful Ambassadors Gary Smokey Dawson and Matthew Laverty who donate the proceeds to keep our group going. Without them, we would not exist. If every family could come up with one way to help, we would have a smashing hit on our hands. Please consider. Bronwyn and Earl are always here for you to talk to should you have any ideas or contributions around these events.

Please call or email **0418 755 994** or **info@leuko.org.au**

You can register for golf and/or lunch only via our website

<http://www.leuko.org.au/events?n=3>



Long Walk for Leukodystrophy

Our Trojan Ambassador, John Olsen has made it to Alice Springs! Congratulations John and thank you to Lions Club of Corio Bay and others who have supported John along the way with supplies, donations and good cheer. But for John there is still a long way to go, being only halfway there. At this point he should reach Cape Leeuwin in December..... such a long walk, taking our name and message right across Australia!!

Right now we have a unique opportunity for our Leukodystrophy Australia families and individuals. You can help by sharing the below link via Facebook, Twitter, or just talk out loud about it, as we all try to garner momentum, in support and donations for John in his quest to raise awareness of Leukodystrophy and to assist the families of Leukodystrophy Australia. <https://www.youtube.com/watch?v=n-mgRZ8ILms> Should you have any contacts in media, please send them the link too. **A Media Release to accompany the video** is available shortly from Bronwyn or it can be downloaded www.info@leuko.org.au Long Walk Page.

A very big thank you to South Australians, **Mark Hosking from Global Music Revolution and Scott Parslow from Dreamcoat Media** for having the vision, drive, creativity, and kindness in making this video. You dropped everything - family and work for 4 days, to go out into the desert to meet John and shoot footage. Then you came home and put it all together, with a little help from us and Lions Club Corio Bay. We will always be grateful to you wonderful men.



Sr Julie's Biography

There has been a slight hold up to the finishing touches of Sr Julie's biography but we are working on this and copies will be coming into print and available soon. We will keep you posted!



Family Gatherings SA & Vic

2 exceptional events, one a luncheon in South Australia held at the Watermark Hotel, Glenelg, and the other, a dinner in Victoria, following our AGM at Kildara in Malvern. The number of families attending well exceeded previous events, and this is most heartening as we come together in our efforts to support one another living with Leukodystrophy. Thank you to Shilandini Wijethunge and those who helped organize these standout events and to those who attended - we all had fun and so many new connections have been made.

Leukodystrophy Australia is seeking a Treasurer

This position is a voluntary position, requiring an understanding of Bookkeeping, but does not necessarily require a formal qualification.

We use Xero accounting and have a great accountant who is marvellous support to our group. But we need a Treasurer to assist in quarterly reporting, preparing the annual budget, attendance of Committee Meetings, co-authorising of financial transactions and liaison with the Office Manager and President. Awareness of the impact of Leukodystrophy would be beneficial.

For more information, please contact Bronwyn, 0418 755 994 or info@leuko.org.au

Leukodystrophy Australia is seeking the help of Volunteers for events in each state, and for IT Support.

For more information, please contact Bronwyn, 0418 755 994 or info@leuko.org.au



Women with ALD Forum

12 August saw our first Forum for Women with ALD - a lovely workshop at the Larwill Studio, Royal Children's Hospital, Melbourne. This was a small, interactive group, and for many of whom this was the first opportunity to discuss similar personal experiences.

We had the honour of guest speakers from Genetic Services Victoria - Adrienne Sexton, Lisa Wragg from the Victorian Continence Resource Foundation, and Ellie Praver who conducted a research project around the effects of being a carrier of the X-linked Adrenoleukodystrophy gene.

During the forum we also watched the Webinar conducted by ALD Connect in relation to women with ALD <https://youtu.be/BwdZoFhWo9M>

Participants expressed their wish to remain connected with each other, to which two methods were agreed upon.

Firstly, an implementation of an email mailing list. If you are a confirmed or suspect you are a carrier of the X-linked ALD gene, you are most welcomed to join the mailing list. Please let Angela know pandang70@hotmail.com

Secondly, a private Facebook page has been set up for women to communicate and share information relating to ALD. This is totally private to the participants and is not overseen by Leukodystrophy Australia, but we will be interactive in our ongoing connection when requested.

If you wish to be part of the mailing list or be a member of the private Facebook page, please send your contact details to Bron via info@leuko.org.au or directly to Angela pandang70@hotmail.com

The Forum was run by Pam Joseph, assisted by Angela Famiano. A big thank you to both these great women.



Lisa Wragg

GRANTS

The following grant money has almost been expended. How lovely it has been to be able to assist you. The imminent task ahead now lies for us to apply for more Grants. Should you have anything you would like us to assist you with or you may be really good at grant writing and like to volunteer, please contact Bronwyn or Anne.

Cops for Kids SA	SA Children Living with Leukodystrophy	\$15,000
Slater & Gordon	Family Advocacy Program	\$10,000
St George Foundation	Quality of Life Program	\$41,100
Turi Trust	Living with Leukodystrophy	\$1,500



Anne Patricia – Family advocate

Hello everyone,

Where has the time gone? I have been employed with Leukodystrophy Australia just over twelve months. I am very grateful to the committee for my employment status. I feel blessed to work alongside so many wonderful, innovative, generous, loving and courageous families. I enjoy assisting families on many levels and I feel privileged to be witness to their amazing stories. I love my role and thank you to all who support me ☺

I enjoyed travelling to Melbourne and attending the AGM and Family Gathering. Meeting new families and connecting with those I have engaged with over the past twelve months was fabulous. We had a lovely time sharing stories, laughing and eating some great Melbourne food. Thank you Bronwyn for organising such a rewarding event.

I was fortunate enough to do some outreach visits while in Melbourne. I know life for many families is extremely busy and I appreciated the time families gave me. They shared their homes, their stories and their precious time. Thank you for your generosity.

Over the previous 12 months Pam has been instrumental in providing me with knowledge, training, guidance and support from a managerial and social work perspective. Thank you Pam - all the best in your future endeavours and am looking forward to reading your PhD.

Michelle a great big welcome as our new President. I look forward to working beside you in assisting our families on many levels.

My usual working hours are **Thursday 8.30am to 5pm** and I would love to hear from you. My contact details: **0418 790 059** and/or: advocate@leuko.org.au. If you have a matter which can't wait until the Thursday, please feel free to contact Bronwyn our Office Manager. Please note I will be on annual leave 15th September and returning on 6th October 2016.



Pam Joseph and her research supervisor, Dr Rosalie Pockett

As you may know, our past President, Pam Joseph, is studying for her PhD at the University of Sydney. In June, Pam attended the 8th International Conference on Social Work in Health and Mental Health, in Singapore. Pam presented a poster, "Creation of visual data to complement social work research", and an oral presentation entitled "Anonymity and consent: Confronting ethical dilemmas in social work research with small populations." Pam received a "Best Oral Award" for her presentation about issues of anonymity and consent. Pam is now busy completing her thesis, which focuses on the topic of parent-carers' perspectives on their relationships with complex service systems, and hopes to submit it for examination in early 2017. We wish you every success Pam.



Parental attitudes towards Whole Genome Sequencing (WGS) in Newborn Screening (NBS) in Australia

You are invited to participate in a University of Sydney Master of Genetic Counselling student research study to provide your opinions on the above issue. This study is being conducted by Tamara Mossfield (student researcher) under supervision from Associate Professor Veronica Wiley (Director of NSW Newborn Screening Programme).

As an Australian parent (over the age of 18), you are able to contribute to our understanding of parents' attitudes towards possible inclusion of new technology, Whole Genome Sequencing (WGS), in newborn screening programs.

If you are interested in participating in this study, please access the URL below:

<https://www.surveymonkey.com/r/NBSParents>

If you would like any further information at any stage, please contact Tamara Mossfield (tmos9793@uni.sydney.edu.au).

Thank You

- **QLSA** for your Olympic Fundraiser which raised \$3620 for Leukodystrophy Australia. Champion effort!
- **The Insurance Advisernet Foundation** for a very generous \$5,000 donation.



HMAS Albatross Show n Shine

Thanks to Glenn Smith, HMAS Albatross and others in their fabulous efforts to raise money for Leukodystrophy Australia and Juvenile Diabetes Foundation. Sunday 23 October, Fleet Air Museum, Albatross Road, Nowra Hill NSW. Register a car, or just come along and enjoy a day out with a difference. Cars, competition, music, and much more!

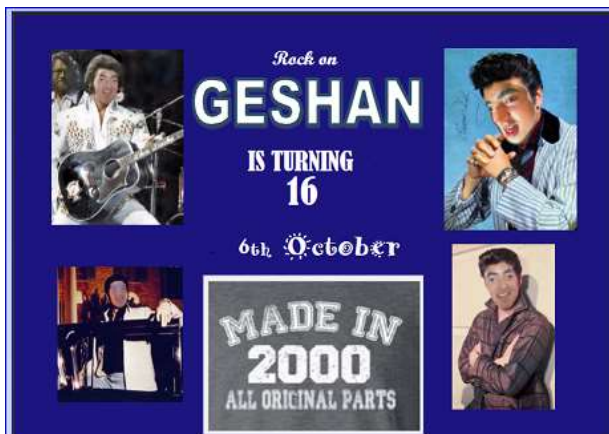
ENQUIRIES TO: THE EVENT CO-ORDINATORS

Stuart Walters 0410 577 296 wal250@y7mail.com

Glenn Smith 0427 476 427 albatrossshowshine.info@gmail.com

NEWS AND UPDATES: Will be advised via: <http://www.navy.gov.au/event/albatross-show-n-shine-2016>

Thanks Shilandini for this fabulous poster of gorgeous Geshan who is turning 16.



**Happy Birthday
Geshan with love
Leukodystrophy
Australia XOx**

Please take a look at our website, www.leuko.org.au

Catch up with our news, and let us know if you have any stories or information to share.

