



**President's Message**

Hello everyone, it's lovely to be able to send you a greeting in our new-look newsletter. This is just one part of several related projects we've had on the go over the past few months. Together with our same-but-differed logo, a new website, and new email addresses, we are working hard to streamline our database and office processes so that we can be as effective as possible in meeting your needs.

Meanwhile, our primary purpose remains unchanged: to support people affected by leukodystrophy. Along with the rest of the staff and volunteers at Leukodystrophy Australia, I hope that you will feel welcome to contact us at any time if you need information or support, or if you would like to contribute to our work in some way.

As you will see later in this Newsletter, we are planning to hold our 2016 AGM on Saturday 13 August. I will be stepping down from the Committee at this AGM so that I can concentrate on finishing my PhD, and I know that the incoming Committee will be very keen to hear from anyone who is thinking about putting their hand up...be reassured that asking about it doesn't commit you! ☺

My best wishes to you,

Pam.

*Pam Joseph (President, Leukodystrophy Australia)*  
0417 358 061



## **Greetings to our Families & Friends of Leukodystrophy**

As 2016 rolls on, we must apologise for being so late in this newsletter, but it really has been busy! You are well aware of the daily challenges of living with Leukodystrophy, some of them seemingly insurmountable. Rest assured, we are here for you. Please email or call our office anytime, we are never too busy for you and welcome your contact.

Something very exciting has been the launch of our new website [www.leuko.org.au](http://www.leuko.org.au) We thank all those involved including the major volunteer on this project - Committee member, Earl Schonberger. Earl, thank you!! Please take a look, catch up with our news, let us know, if you have any stories, news or information you would like to share, and perhaps we could upload it. Please contact me on our new email address [info@leuko.org.au](mailto:info@leuko.org.au)

We are phoning all our families and individuals living with leukodystrophy to say hi and to check on contact details, so if you have not had a call yet, please expect to hear from me or from our Family Advocate, Anne Patricia. We look forward to supporting and speaking with you this 2016. Warm regards Bronwyn 1800 141 400

### **Invitation to participate in a research project**

Genetic Alliance Australia invites you to be involved in a project called "Australian patients and families' perspectives on genome sequencing".:

<http://www.geneticalliance.org.au/cmsAdmin/uploads/genome-sequencing-advert-v0-8.pdf>

### **Save the Date**

Our Committee of Management has set the date of **Saturday 13 August 2016** for our **AGM**, and we hope to see as many of our members and friends there as possible.

AGMs are a great way of getting together to share information and friendship, and to be part of the life of our support group. This year, the meeting will take place at 5pm and will be followed by a relaxed and informal dinner for those who can stay on. If you are a member of Leukodystrophy Australia, or if you or a family member is affected by a leukodystrophy (even if not a member of Leukodystrophy Australia) you are very welcome to join us. There will be no charge for this gathering.

### **Invites will be sent shortly. Meeting venue is Mary MacKillop, Hawthorn East.**

We encourage you to consider nominating for the new Committee of Management. To nominate, you must first be a member of Leukodystrophy Australia: membership is free to people affected by a leukodystrophy and their immediate family, a small membership fee is requested from other interested parties. For queries please contact Bronwyn at [info@leuko.org.au](mailto:info@leuko.org.au) or 1800 141 400.



## **Long Walk for Leukodystrophy**

13.5.16 at Elgoy National Park Ranger Base (Dixie Station)

Gavin and Kerri Enever: "We had a lovely morning with a truly inspiring man".

Words cannot describe our wonderful Ambassador, John Olsen and the gratitude we have toward this brave man. John is also a 30+ year member of Lions and a member for the past five years of the Lions Club of Geelong Corio Bay. In April this year, John embarked on a monumental Trans-Australian walk, diagonally across Australia from Cape York to Cape Leeuwin in south-west Western Australia. He anticipates it will take him a little over five months. John has set personal goals but the primary purpose of this walk is to raise funds for Leukodystrophy Australia. John and Vida experienced firsthand the effects of Leukodystrophy His beloved Vida, died early in 2014. You can read more about John's walk, his motivation and his previous two monumental walks via [www.leuko.org.au](http://www.leuko.org.au)

We express our gratitude to the Lions Club of Geelong, for their long-standing support of John in his previous walks, and to the Lions Club of Geelong Corio Bay in the continuation of this marvelous support. Should you wish to speak with the Lions Club, please contact Ralph Patford, President, Lions Club of Geelong Corio Bay, Inc: [r\\_patford@hotmail.com](mailto:r_patford@hotmail.com) or on 0402 009 391. You can also contact our office and speak with Bronwyn.

Leukodystrophy Australia is the beneficiary of 100% of the proceeds. It would be most fair to say, if not for John's previous efforts and that of our other incredible Ambassadors, Matthew Laverty and Gary Dawson of the Charity Challenge, we would not be here today. Please donate and/or support John by passing on this message to your family, friends and colleagues - #wheresjohn

All fundraising will be paid into authorized "Gift Fund" – Trust Account at Westpac Bank, Long Walk for Leukodystrophy - BSB. 033679, Account No. 294455

There will be various radio interviews in collaboration with John Olsen, Lions Club of Corio Bay and Leukodystrophy Australia over the six months of John's walk. This provides us a wonderful platform for exposure. We would love some of our families to come on board and consider sharing their story via telephone link up with radio. If you would like to help us by taking up this opportunity, please call/email Bronwyn at our office.

**Thank you to Loretta Rouse for sharing your media savvy in support of John.**

Thank you Jardine Lloyd Thompson for donating \$5,000 to Leukodystrophy Australia.



**London Marathon**

Thank you to Josh Rymarz and Karen Keable for raising \$2,777 and for taking our message and name right across the world. You are fabulous!



**Run Walk Wheel**

A personal challenge for Peter Dempsey: Thank you Peter for undertaking fundraising through GoFundraise for Leukodystrophy Australia. We really appreciate your champion efforts and thank you and all those including your Dad, our Past President Bede Dempsey who got behind you to raise \$1,818 for our group. What a marvellous achievement!



**Sr Julie Thomas - Founder**

We are most grateful to Leanne Conway and the team at MND Motor Neurone Disease Foundation for agreeing to lend their fabulous volunteer Dr Jan Pritchard, to put together a biography of our incredible founder Sr Julie Thomas OAM. We look forward to more pictures and some interesting reading around midyear.



**GRANTS** - thank you to our grant beneficiaries without whom we would not have the wonderful job of helping our families. Thank you to Sienna in sharing your excitement at receiving your new Ipad, including apps for educational purposes, courtesy of **St George Foundation**. So good to see Geshan relaxing in his custom-made lounge chair courtesy **Cops for Kids SA**. Thank you for sharing your happiness Geshan, we are very glad to be a part of it.

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, I am very excited to finally write a few words in our newsletter. I have been calling families in WA, SA and NSW to introduce myself, explain my role as Family Advocate, ask for any changes to personal details and enquire if support or assistance may be required in some way. Recently I have been able to assist families in the following areas: financial assistance, linking families with appropriate services, advocating for families where appropriate and listening to their stories. I will continue to contact families over the coming months. **I will be in Melbourne for our AGM and will be available for family visits around this time. Should you wish a visit from me, please let me know.**

My usual working hours are Thursday 8.30am to 4.30pm and I would love to hear from you. My contact details: **0418 790- 059** and/or : [advocate@leuko.org.au](mailto: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 who will assist. Rug up for winter ☺ Warm regards, Anne Patricia.

**Men & Machines** have organised a **Motor Display** at this year's Camden Community Picnic. Funds raised will be donated to a local teenager who has recently been diagnosed with Adrenoleukodystrophy or ALD. Men & Machines is run and supported by the local (and some beyond) churches of the Camden / Narellan (Macarthur) region. Venue: Camden Equestrian Centre (enter via Exeter Street), Date: Saturday 28 May, Time: 11-3pm. **All welcome!**