



**Michelle Marinovic, President**

Dear Families and Friends,

I hope this message finds you well and that you have had a good summer and are looking forward to autumn. As usual, there has been much activity and I would like to thank the committee and all our volunteers for your contributions.



My husband Emil and I attended the Geelong Australia Day Family Fun Day at Ripplside Park, which was organised by the same fantastic team of Lions Club members who supported John in his recent Long Walk across Australia. It was a great day, with John and his trusty cart 'Wilson' wandering around the park amongst thousands of people while Lions (and Emil) shook the cans to continue to raise money. This all led to John finally getting his long hair and beard shaved off after growing it throughout his walk. We look forward to acknowledging John's massive achievement at the event in May - come along if you can – more info to follow.

Another milestone event we are organising this year is to mark our 25th birthday. We are thinking of how to mark this occasion and welcome your suggestions. One very moving feature of the 20year Conference was the Remembrance Quilt, with names of loved ones passed, lovingly embroidered into the quilt. If anyone would like a loved one who has passed away to be woven into this special quilt, please contact Bron.

As always, our thoughts go out to anyone going through challenging times and particularly families affected by the recent storms and flooding in Queensland. It was great to see the family day in SA a great opportunity for families to get together and share stories.

Take care, Michelle 0417822161



**Bronwyn Byrne, Office Manager**

2017 sees me working from the Byron Bay region over the next 3 months. Happily, this came about because I had a granddaughter born just last month and I am here to bask in the glory of this new life. I would love to hear from families in the region. Should you wish a chat, please give me a call. You are all doing a wonderful job as parents and nurturing yourself is just so important. Please make time for this. Here is a wonderful article I just read <http://www.sourcekids.com.au/single-post/2017/03/29/The-grace-of-grief-why-special-needs-parents-shouldnt-be-afraid-of-the-darkness>

Warm regards Bronwyn 0418 755 994

♥A belated Happy Birthday to Sr Julie in January – marvelous as ever! ♥



**RARE DISEASE DAY 28 February 2017** In honor of Rare Disease Day, Katie Cincotta has written a little story about John Olsen's Long Walk for Leukodystrophy, which she has published across her social media accounts: Facebook

<https://www.facebook.com/254287881441839/photos/pb.254287881441839.-2207520000.1488261314./670106336526656/?type=3&theater>

Instagram <https://www.instagram.com/p/BRCycumDLs4/>

To our SA Families who attended the **Family Gathering on Sunday 26 March at The Watermark**; we are so happy you had a great day catching up on new and old acquaintances – thank you for attending. *We hear a morning tea may follow later in the year, so if you could not make the luncheon, there may be another opportunity – go SA families!* A big thank you to Shilandini, Rohanna, Elisha and Alma for your fabulous support and the photos. What a gorgeous bunch! We look forward to your feedback – please drop us a line.



**The Australian Genomics Health Alliance (AGHA)** is a national research program committed to the integration of genomic medicine into Australian healthcare. **AGHA** research is focussed on the infrastructure of health delivery in a genomic age: mapping and evaluating existing systems, building on current networks, and piloting national approaches to drive whole-of-system change. Work starts in the clinic – building evidence of the benefits of genomic testing through Clinical Flagships in Rare Disease and Cancer.

**AGHA** Brain Malformations and Leukodystrophies Flagship, led by **Richard Leventer** and **Paul Lockhart**, plans to prospectively recruit 50 paediatric Leukodystrophy patients through a national network of clinicians over the next two years, and further plans to link to existing functional genomics research. It is anticipated this will provide a significant number of children with a precise genetic diagnosis for their Leukodystrophy. For more information, please visit <https://www.australiangenomics.org.au>



## **Save the Date Saturday 19 August 2017:**

**AGM & 25 Year Celebration** 17 August officially sees us operating for 25 years. Thank you Sr Julie Thomas OAM, our auspicious Founder; who has given so much to so many♥

To celebrate we will combine our **AGM with a Celebration Dinner on Saturday 19 August**, comprising **4 very interesting guest speakers**, including Australian Genomics Health Alliance (AGHA) **Rick Leventer**, clinical lead of the Brain Malformations and Leukodystrophies Flagship, including **Tiffany Boughtwood**, Program Manager AGHA.

We are also delighted to have our past Family Advocate for almost 5 years and ex-President for 2 years, **Pam Joseph**, speak about her Thesis entitled:

Parent-carers' perspectives on their relationships with complex service systems. - [http://sydney.edu.au/education\\_social\\_work/about/staff/profiles/pam.joseph](http://sydney.edu.au/education_social_work/about/staff/profiles/pam.joseph).

One of our three fabulous Ambassadors for Leukodystrophy Australia, the astonishing **John Olsen**, will speak about his Long Walk for Leukodystrophy. We do hope you can make it. More details to follow.





**Long Walk for Leukodystrophy END of WALK CELEBRATION & FUNDRAISER**

You are invited to Lions Club of Corio Bay **END of WALK CELEBRATION**. Meet John Olsen - *the man who walked, 5,800kms across Australia*

DATE:	<b>27 May 2017</b>	RSVP:	13 <sup>th</sup> May 2017
COST:	TBA		<a href="mailto:morreipieper@gmail.com">morreipieper@gmail.com</a> or 0430 279 808.
VENUE:	TBA	<u>This is a pre invitation or 'Save the Date' with more details to follow</u>	
TIME:	6-30pm for 7-00pm start.		
DRESS:	Neat casual.		



On Saturday **17 June 2017**, Geelong Supercats Basketball Club

will hold a fundraising event before & during the two basketball games for the **Long Walk for Leukodystrophy**.

Prior to the start of the Men's game, there will be a power point presentation on the big screens as well as an introduction of John & his faithful cart, Wilson.

The women's game starts at 5-00pm & the Men are at 7-00pm, at the Arena in Victoria Street, North Geelong.

During the game members of the Geelong Corio Bay Lions Club will be shaking cans to raise much needed funds.

These games are of high quality as the Supercats are part of the SEABLE League, the second highest league in Australia. For further information, please contact Morris Pieper, Chairperson, Long Walk for Leukodystrophy Committee:

0430 279 808 or [morriepieper@gmail.com](mailto:morriepieper@gmail.com)

Thank you John Olsen as you continue your amazing fundraising for Leukodystrophy Australia. We believe the tally is \$56,500 – over half way now to your goal, which you are still working so incredibly hard at. Thank your extraordinary man! Thank you amazing donors. **Please donate now to The Long Walk** [www.leuko.org.au](http://www.leuko.org.au)



**Anne Patricia – Family advocate**

Hello everyone, for those of you who may be unaware I work from my home office in Cardiff NSW. This is a growing, thriving suburb of Newcastle. Some new families may be unaware that I can offer service provision via phone calls and Skype sessions across Australia, emails and at times outreach visits.

Recently I have been fortunate to conduct outreach visits in areas of NSW and I would like to thank those involved for their hospitality, sharing their stories and allowing me to meet their beautiful families. I'd like to thank the committee for allowing me to engage in face to face meetings with families as these sessions bring a whole new perspective to the professional relationship.

My hope is I will have the opportunity to meet more families over time whether it be via our events such as family gatherings, fundraisers, the AGM or outreach visits.

I have an enjoyable, rewarding social work role because I work with a supportive committee and Bronwyn. Importantly I have the privilege of working beside fabulous families whether briefly or extensively.

Please note I have changed my working hours and now work Wednesdays each week and every second Tuesday (commencing 21-March 2017) 8.30am to 5pm. My contact details: 0418 790 059 and/or: [advocate@leuko.org.au](mailto:advocate@leuko.org.au). Enjoy the beauty of autumn, warm regards Anne

---

**CLINICAL TRIALS** We are aware there are many trials taking place around the world right now. Should you wish to look <https://clinicaltrials.gov/>

---

**Thank you!** To **GSNV** for the \$1000 **Margaret Sahhar Grant**. We are so proud to be the recipient of this inaugural Grant, which we will use for further development to our Locus Database, with the help of two fabulous volunteers, Jenny Vick and Lisa Pap. Thanks girls♥

Thank you Margaret Sahhar, you have been incredible support to our organisation over many years on a number of fronts and in your retirement, you are still giving. We hope you enjoy your well-deserved retirement☺

Other people to thank for your very kind donations that keep us going:

- ♥ AAI Limited
- ♥ Aged Care Developments
- ♥ Atlantic Plumbing
- ♥ Jardine Lloyd Thompson (JLT)
- ♥ Long Walk for Leukodystrophy donors
- ♥ Private Donors

**GRANTS** This year, as with many other years, our major focus is to write grant applications. It is a very big task and we are truly grateful for the amazing help we are receiving from our volunteer, Jacklyn Vick who is sourcing and helping to write grants to benefit our families. Yey Jac ♥ We cannot thank you enough.

We also need help from you. Please let us know if you are looking to buy equipment or require services, educational needs or other more general support such as for transport costs to appointments. This information is vital in helping us source the right grants and keeps us on track in our Vision and Mission to assist families living with Leukodystrophy.

Contact Bronwyn [info@leuko.org.au](mailto:info@leuko.org.au)

or Anne [advocate@leuko.org.au](mailto:advocate@leuko.org.au)

**There is other news however:** In searching for grants to resource the ongoing operations of Leukodystrophy Australia, we often come across grants that are only applicable for individuals or organisations that members are associated with (e.g. schools) to apply for. Since these are not applicable for Leukodystrophy Australia to apply for, we will therefore be regularly notifying our members of these grants across Australia.

***Please find below grant details for you, our members to review and consider applying for:***

### **Disability Equipment Grants - WA Members**

This program seeks to assist West Australian individuals with permanent disabilities. It is income-assessed and aims to help people who would not otherwise be able to afford the equipment or services.

Grants are available for a range of assistive technology / equipment including:

- Assistive Technology (AT) for People with Vision Impairment (maximum grant: \$5,000)
- Air Conditioners: (maximum grant: \$1,500)
- Vehicle Modifications: (maximum grant: \$12,000)
- Assistive Technology (AT) for People with Communication or Physical Impairment (Maximum grant: \$5,000)
- Essential Independence Assistive Technology (maximum grant \$10,000)

Program administrator

Independent Living Centre WA

Closing Date

This program is open on an ongoing basis.

Contact

Telephone: 1300 885 886

E-mail: [ilcgrants@ilc.com.au](mailto:ilcgrants@ilc.com.au)

Web: <http://ilc.com.au/funding/disability-equipment-grants/>

### **Equipment for Living Grants – WA Members**

Equipment for Living Grants (EFL) are available to assist eligible people to obtain vital equipment not currently available through the CAEP or other support programs. The grants

will provide essential items that enable individuals with disabilities to have increased participation within their homes and communities.

The maximum individual grant is \$5,000.

The following is a list of examples of equipment that may be considered:

- Wheelchairs for community access or as an alternative to a primary mobility device
- Specialised car seats and occupant restraints
- Electrically adjustable beds or specialised beds. e.g. Bariatric beds
- Alternative seating or seating to facilitate transfers
- Standing frames where CAEP funding is not available
- Environmental controls and other emerging technologies
- Assistive communication technology or mainstream technology with inbuilt accessibility features
- Specialised equipment for recreation
- Equipment for alternative living arrangements e.g. Shared custody
- Items to support client safety outside the home
- Small home modifications where CAEP funding is unavailable

Program administrator  
Independent Living Centre WA

Closing Date  
30 June 2017

Contact Us

Telephone: 1300 885 886

Email: [eflgrants@ilc.com.au](mailto:eflgrants@ilc.com.au)

Web: <http://ilc.com.au/funding/equipment-for-living/>

**Disability Inclusion Support for Queensland Kindergartens (DISQK) – QLD Members**

This program aims to assist sessional kindergarten program providers in supporting children with diagnosed or suspected disability to fully participate in a kindergarten program. If this program is suitable, please liaise with your kindergarten to apply.

Funding categories are:

- \$2,000 (Primary): Support universal access

- \$5,000 (Targeted): Support to maximise program participation and self-management

- \$8,000 (Intensive): Support to facilitate engagement in the program

Program administrator  
Department of Education and Training  
(DET)

Closing Date  
30 September 2017

Contact Us

Telephone: 07 3328 6720

Email: [disability.inclusionsupport@det.qld.gov.au](mailto:disability.inclusionsupport@det.qld.gov.au).

Web: <http://deta.qld.gov.au/earlychildhood/service/grants/disability-grant.htm>

**Youngcare** <https://www.youngcare.com.au/our-work/at-home-care-grants/> providing funding for equipment, home modifications and emergency respite care to enhance the quality of life for people aged 18 - 65 with high care needs and their carers. Should you need assistance, we are happy to help. See below for submission dates per state.



## Leukodystrophy Australia is seeking a Treasurer

This position is a voluntary position, requiring an understanding of Bookkeeping. 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, but not necessary.

For more information, please contact Bronwyn, 0418 755 994 or [info@leuko.org.au](mailto:info@leuko.org.au)



## You can support now:

**Leukodystrophy Australia, our Ambassadors Gary Dawson OAM & Matthew Lavery, as the Charity Challenge Golf Days for 2017 in NSW and Victoria approach.** We are looking for donations as prizes, sponsorships, players. Please think of anything or anyone you know who may be able to assist, or who plays golf and may wish to attend a fabulous day at either **Macquarie Links International Golf Club in NSW on Thursday 28 September 2017** or **Woodlands Golf Club in Victoria on Wednesday 6 December 2017**. It sounds a long way off, but it is vital we prepare now. If every person could assist in just one way, this would make a huge difference – so come on, please rally – we need you! Remember, these golf days keep us afloat!!

Please contact Bronwyn [info@leuko.org.au](mailto:info@leuko.org.au) or call 0418 755 994, or Earl Schonberger 0439 790 151.

Please look at our website, [www.leuko.org.au](http://www.leuko.org.au)

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

