



25 Years of Caring & Support



Kellie Panton, President

It has been a very busy period, with the Golf days and the Ball. I was very fortunate to be able to go to the ball in Sydney. There were so many wonderful people to help raise money for some very great causes. I also took Phillip, our 24 year old son with me. Phillip has Undiagnosed Leukodystrophy of a very slow progression. It was also nice to watch him have a good time, meeting new people and having a dance.

Our son is at Uni and we very early on, made the decision to let him do as much new stuff as possible. Phillip is now going to New Zealand on a Contiki Tour (by himself). I will let you know how he goes, and how I go, letting him go.

The first few months of being President have gone fast, they have been busy but rewarding and I hope that we can achieve more great things next year.

As we come closer to Christmas, it is a great time of the year for family and friends to get together. It is a time of year so many of our families will be without a loved one, so we take this opportunity to say we are thinking of you all.

I would like to thank the members of our board for their hard work and for Bronwyn and Anne Patricia's hard work.

It will be great to have a small break and energize for the year to come. I wish all our families a Merry Xmas and a great New Year.

Warm wishes Kellie 0458 083 883



Dear golfers, families, supporters, donors, guest speakers and The Charity Challenge, Leukodystrophy Australia, gives heartfelt thanks to each one in your support of the Charity Challenge Leukodystrophy Australia Golf Day at Woodlands in December, the Golf Day at Macquarie Links in October, and the Gala Ball at the Hyatt in Sydney in December. Woodlands was a momentous day with record attendance. It was wonderful to have our three Ambassadors, and our Founder Sr Julie Thomas, under the one roof. Thank you John Olsen, Smokey Dawson and Matthew Laverty. We are so blessed! The illustrious winners were **FIS Financial Planning** @ Macquarie Links, and **Allianz** @ Woodlands.

Links to the golf day photos:

<https://www.dropbox.com/sh/p2mqr66rxg521yc/AABUrJu1MkXdIBdF4HSQyEaa?dl=0>
https://www.dropbox.com/sh/ecw2sf1de5ofk34/AAD-obyB2PUBuGilt_q_aXLda?dl=0



Bronwyn Byrne, Office Manager

As each year rolls around some of us make resolutions and lofty goals we want to achieve in the forthcoming year. We also reflect and give gratitude for the year that was and the people in it. That is you!

2017 sees further integration with our state of the art database generously designed and supported by Tonic and our amazing volunteers Jenny Vick and Amy Ruscigno. Jaclyn Vick thank you for your encouragement and input with grant writing. We have been successful with Coopers Brewery SA – thank you! For the effort and enthusiasm into fabulous fundraising events – notably gargantuan **Long Walk for Leukodystrophy** and outstanding Dinner for Derek – John Olsen and Tracy Lyons, you are remarkable. RMIT and students for PR and website development. To our incredible supporters and donors, and our families - 25 years supporting people living with leukodystrophy! We thank Sr Julie Thomas, our illustrious Founder, and our marvelous Committee – where would we be without them!

Returning to my reference to lofty ideas, we are very optimistic 2018 brings a better year for all. Serious, exciting work is well underway in many areas of research right here in Victoria, encompassing across our nation and the globe. Thank you to all those hard working, incredible people who are doing great work with research around genomic medicine and the entities who are funding them! We take heart in you and others like you in the hopes for better outcomes for our Leukodystrophy families. Please look at our updates from **AGHA**, and newspaper article, with comments by **GSNV**.

♥Blessings to all at Christmas♥ 1800 141 400

Samantha, mother of Jackson, shares their incredible family story (excerpt only): Jackson and I have been in Italy since mid-August. Mackenzie, Ashlee and my mum and sister joined us at the end of September. During Mackenzie’s treatment isolation in Perth, we spent many days talking about the things we would do when she was discharged. One of the things we had said we would do when she was well enough was go to Disneyland. We did not know if she would be cleared (medically) to travel, but by some miracle she was and was able to join us in Milan. We got to fulfil her wish to go to Disneyland in Paris before Jackson’s treatment commenced. It was one of the most special experiences of my life.

Jackson went into isolation on October 7. He had Chemotherapy (high dose Busulfan) from October 9 – 12 October and on Friday October 13 2017 he received his new cells – gene therapy. His own cells were extracted via a leukopheresis machine one month prior. They were sent to a lab and modified to supra express the ARSA enzyme that his tiny body does not currently produce. An inactivated version of the HIV virus was also added to the cells to help it cross the blood brain barrier. It is quite amazing to think that the bag pictured below contains 17million cells that will hopefully allow his body to fight this disease and hold it off – it truly is liquid gold.



17 million cells



Mackenzie & Ashlee Paris, Disneyland.



Discharge Day



Jackson now

Samantha says: If anyone would like to follow this journey, we have a private Facebook Page, you’re welcome to follow: [Kenzie N Jackson’s Journey](#)

Dinner for Derek

What an amazing event! Congratulations and thank you to Tracy Lyons and her gorgeous 3 children on this incredible night in honour of husband and father Derek Lyons. Family and friends rallied at Heidelberg Golf Club in celebration of the very big-hearted Derek, dearly loved and adored by all. The event raised \$15,200 of which Leukodystrophy Australia will distribute a large portion to research and retain a smaller portion for our general funds in supporting families. <http://www.vipphotobooth.com.au/portfolio/dinnerforderek/>

The story goes further: VACC, employers of Michael Lyons, eldest son of Derek, have done an article on Michael and the fundraiser, raising more awareness on Leukodystrophy. Here is the link

<http://www.autoapprenticeships.com.au/Presscentre/LatestNews/tabid/155/aid/63/Default.aspx>

It goes on: Some of Derek's mates since attended the Charity Challenge Leukodystrophy Australia Golf Day at Woodlands – it was so great to see them again. Heartfelt thanks to Tracy, Westy and all the amazing crew for your continued support.



Tracy Lyons centre and friends



Westy and the gang had a good round for Leukodystrophy Australia!



The Brain Malformations and Leukodystrophies (BML) Flagship of Australian Genomics, led by Richard Leventer and Paul Lockhart, has been actively recruiting in 2017. The project is now open for LD recruitment in VIC, NSW, SA & QLD, with WA to follow imminently. 45 children are already in the process of enrolment into the BML Flagship from across Australia, and the diagnostic rate to date from genomic testing in this cohort to date is 63%.

The Leukodystrophies component of the project collaborates with Adeline Vanderver, Program Director of the Leukodystrophy Centre for Excellence at the Children's Hospital of Philadelphia, building upon the existing flagship team members (paediatric neurologists, clinical geneticists and laboratory geneticists nationally) who have the clinical, imaging and genetic expertise required for the ascertainment of patients and subsequent study of LDs.

Members of the Australian Genomics Brain Malformations and Leukodystrophies Flagship look forward to a productive 2018, increasing clinical and genetic understanding of these diseases, and helping our participating families reach a diagnostic resolution.

For more information about the study or enrolment, please see australiangenomics.org.au or email australian.genomics@mcri.edu.au



Government Funded Genomic Testing: DNA sequencing will be offered to patients suffering rare and mystery conditions under an Australian-first program to be rolled out in Victoria. The testing is not yet available on Medicare, however the Victorian government have put \$8.3 million towards to fund this testing for children and adults with rare conditions. This funding is targeted to public patients who are not eligible for research trials or specialist programs. The four-year funding is expected to provide full genetic sequencing for about 80 patients a year who have conditions so rare they cannot be diagnosed through previous methods. This testing could save people years of uncertainty and the thousands of dollars which is currently needed for this test to be carried out overseas.¹

To order to access this testing, you must be seen by a genetic health professional located at one of the clinical genetics services in Victoria (*the funding is for Victorian patients*). A genetics doctor will, generally, carry out a full examination before discussing whether this type of testing is appropriate for you or your child. Although this testing is helping find the underlying cause for a significant number of people with rare disease, it is important to remember that this testing may not be the right test for everyone. **GSNV** contact: 8341 6315 email info@gsnv.org.au

<http://www.heraldsun.com.au/news/victoria/free-genetic-sequencing-funded-to-diagnose-victorian-patients-with-mystery-illnesses/news-story/e55899cb9fe6cd416e13df33834c00ee>

THANK YOU!

- ♥ **Ambassadors Gary Dawson and Matthew Laverty - The Charity Challenge**
 - ♥ **Anonymous** donations
 - ♥ **BHP Billiton**
 - ♥ **Bindilee Day**
 - ♥ **Coopers Brewery Foundation** General Giving Grant 2017 @ \$15,000
 - ♥ **Daff** family
 - ♥ **Gordon Wardell**
 - ♥ **GSNV**
 - ♥ **Ian Carr** – Insurance Advisernet Foundation
 - ♥ **John Epta, Ewan Duckworth** - Tonic
 - ♥ **John Rymarz** – Quality Logistic Services Australia Pty Ltd
 - ♥ **Karen Keable**
 - ♥ **Lions Club of Geelong Corio Bay**
 - ♥ **Lyons** family – Dinner for Derek
 - ♥ **Paul Smithers** - Atlantic Plumbing
 - ♥ **Steve Brady**
 - ♥ **Val Gibson** – Inner Wheel West Harbour
 - ♥ **Zahid Arain**
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Our Founder, Sr Julie Thomas:

“Love and gratitude, Best Wishes to Everybody for Christmas & 2018”





Anne Patricia – Family Advocate

Hello everyone, the past few months have been extremely busy, and I have continued to spend time engaging with as many individuals and families as possible, some of whom have only recently received a diagnosis and others who have had varying changes to their circumstances. I am constantly inspired and in awe of the individuals and families, I work beside. People’s care, resilience and strength continues to inspire me.

I was fortunate to attend the Charity Gala Ball in Sydney and it was a privilege to meet many families face to face for the first time. We had heartfelt moments and enriching conversations with lots of fun in-between. Impressive was the venue, catering and the generosity of considerate donors.

The Christmas holiday season is soon approaching and this time of year has variable meanings for everyone. My hope is each of you have loved ones, friends or others around you to offer support and love throughout this period. May you find moments of laughter, happiness, tranquillity and strength through this period.

I am taking annual leave 27 Dec 2017 - 09 January 2018. Our office will close 22 Dec – 3 January 2018. My usual working hours are Tuesdays & Wednesdays 8.30am - 5pm.

Warm regards, Anne Patricia, Family Advocate, 0418 790 059 advocate@leuko.org.au.



LA offers our condolences to all those in the Leukodystrophy community who have been touched by bereavement this year.

To the Damiani family in the loss of darling Massimo 22.7.2008 – 15.12.2017, an angel on a mission. We send our deep condolences and prayers to you and all he touched.



Should you wish to join this page, for private discussion and friendship between women with ALD, please send a private message to Angela Famiano via [Facebook](#)



National Disability Insurance Agency

The Western Australian Government has announced its intention to join the rest of the country in the NDIS Scheme. The WA Rollout expects to be complete in 2020. People already connected to the WA NDIS scheme will transfer to NDIS in a phased approach from April - December 2018.

Leukodystrophy Australia Family Advocate is happy to help. Please contact Anne Patricia 0418 790 059 advocate@leuko.org.au.

NDIS Telephone 1800 800 110 - Facebook/NDISAus - Twitter @NDIS

For people who need help with English - TIS: 131 450

For people with hearing or speech loss - TTY: 1800 555 677

Speak and Listen: 1800 555 727



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

25 Years of Caring and Support

25 Years caring for those living with Leukodystrophy, we are proud of our achievements so far in supporting and honouring our loved ones. By pledging a flat donation of \$25 or a monthly pledge of any amount, you can help us continue in this support to individuals and families. <http://www.leuko.org.au/donate>

When shopping at Richies IGA, nominate Leukodystrophy Australia for donations – thank you!



When shopping at Richies and by using a Community Benefit card linked to Leukodystrophy Australia then Richies will donate money back to us. These cards/tags can be used ANY Richies store throughout Vic, NSW and Qld by our staff, supporters and their families.

If you would like to support us and you don't already have a CB card/tag please collect one at the registers next time you shop at ANY Richies store to use every time you shop. All you do is nominate Leukodystrophy Australia, it's that easy! This is an easy way for us to raise funds with no costs involved.

Victoria			NSW	
Aspendale Gardens	East Bentleigh	Timboon	Ballina	Kyogle
Bairnsdale	Emerald	Towerhill Frankston	Bateau Bay	Nambucca Heads
Balnarring	Hastings	Wantirna	Boambee	New Lambton
Beach Street Frankston	Maffra	Wonthaggi	Broadmeadow	North Ryde
Beechworth	Mount Eliza	Yarra Glen	Cessnock	Port Macquarie
Bright	Mount Waverley	Yarrowonga	Coffs Harbour	Rutherford
Carrum Downs	Narre Warren		Elmore Vale	Singleton Plaza
Camperdown	Paynesville	Queensland	Erina	Spit Junction
Cobden	Ringwood North	Boonah	Erina Heights	Taree
Cobram	Rowville	Daisy Hill	Evans Head	Taren Point
Churchill	Sale	Logan City	Griffith	
Cranbourne	Seaford		Harrington Waters	
Diamond Creek	Somerville		Inverell	
Dromana	Sorrento		Kurri Kurri	

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

Community Living & Participation Grants – WA Members

Purpose: Community Living & Participation Grants provide up to \$10,000 for customised solutions that support people with disability to participate in family and community life.

Overview: People with disability can apply for equipment, resources, activities and projects connected to their particular social and recreational goals.

Community Living & Participation Grants cannot fund some things:

- Expenses considered to be part of an individual's usual cost of living
- Improvements or alterations to private property
- Upgrades to public facilities
- Retrospective expenses
- Fundraising activities
- Projects that require re-current funding
- Expenses outside of Western Australia (except equipment purchase of items unavailable from a Western Australian supplier)
- Equipment where there is an existing source of funding through government, hospitals or other grant programs
- Employment and education related expenses

Contact

Email: grants@nds.org.au

Phone: 08 9242 5544

Fax: 08 9242 5044

Postal: PO Box 184

Northbridge WA 6865

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

Telephone: 1300 885 886

Email: ilcgrants@ilc.com.au

Taxi Subsidy Scheme – QLD members

Purpose: The Taxi Subsidy Scheme provides an affordable and accessible transport option for people with a disability who experience profound difficulties using other modes of public passenger transport.

Overview: The Taxi Subsidy Scheme (TSS) subsidises taxi travel—half of the total fare, up to a maximum of \$25 per trip—for people with severe disabilities.

Eligibility - To be eligible you must be a permanent resident of Queensland and able to fully meet at least 1 of the 6 eligibility criteria listed on the website.

Contact:

Website: <https://www.qld.gov.au/disability/out-and-about/taxi-subsidy>

Phone: 1300 134 755

Leadership Scholarship – SA Members

Purpose: The fund is available to assist individuals living with disability to develop their leadership

Overview: This fund is available to assist individuals living with disability to develop their leadership. Scholarships are intended to meet individual access needs and to ensure that individuals living with disability have the same opportunity to participate in their chosen leadership opportunity as their peers. Grants are limited to a lifetime total of \$15,000 per applicant, and can comprise a number of smaller grants awarded over a number of years.

Grants must be for at least one of the following purposes:

- Access to further education such as TAFE, university or online studies; **or**
- Leadership programs such as the Leaders for Tomorrow or Women in Leadership Development (WILD); **or**
- Attendance of a conference or workshop which will inform a person's knowledge about a particular topic they are involved in; **or**
- Local, interstate or overseas research that supports a person's chosen field of academia; **or**
- Assistive technology, course enrolment fees and travel costs; **or**
- Other opportunities that arise and support a person in a leadership role and the values of the Trust.

Contact: Phone: (08) 8373 8333 Email: katieb@juliafarr.org.au Website: www.jfm.org.au

The Joseph Seridis Trust Fund - SA Members

Purpose

To assist young people with disabilities by providing equipment associated with enhancing daily living and independence.

Overview

The Joseph Seridis Trust Fund has been created in memory of Joseph Seridis by his parents. The trust is happy to receive applications at any time. The Trustees meet quarterly to consider applications.

Applications will be considered for:

- Young people with physical and multiple disabilities, aged from 16 to 30; and
- Who are on a government pension and/or who have difficulty purchasing suitable equipment; and
- Who have a high need for equipment that cannot be met through other supports such as the ILEP subsidy scheme; and
- Can provide a letter of support from a health professional.

Closing Date

This program is open on an ongoing basis.

Telephone: 08 8202 5149

E-mail: enquiries@jstf.org.au

Web: <http://www.jstf.org.au/index.html>

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.

