

Providing information and support for the Leukodystrophy Community

People rarely remember what you say, but they will remember how you made them feel. In the case of a life-long chronic disease, our holistic approach encourages individuals and families positively in their life-long journey with Leukodystrophy.

Our Hero! John Olsen receives an OAM for Walking the Walk for Leukodystrophy

Awarded the Medal of the Order of Australia as a part of the Queen's Birthday Honours 2019 - Kerry John Olsen for his service to the community through charitable initiatives receives his OAM at Government House on 20 September 2019.



Kellie Panton, President

0458 083 883

A big warm hello to everyone, I hope you are all keeping warm. Here in Tasmania, it was a very cold -4 the other day.

We have great news! Our ambassador John Olson receives an OAM 20 September 2019. We are so happy, along with the support of Brian Edwards and Corio Bay Lions Club to be a part of his recommendation. Congratulations John you deserve this accolade.

- In 2004, John walked from Cape York to Wilsons Promontory, Victoria, and from Devonport to the southern tip of Tasmania.
- In 2008, John began his walk at the most westerly point, Steep Point, Western Australia and ended at Australia's most easterly point, Cape Byron, NSW.
- In 2016, we saw John's transcontinental adventure 'The Long Walk' begin at Cape York ending in Cape Leeuwin the Southwest corner of WA mainland.

John met many interesting and wonderful people along his journeys, and raised awareness about Leukodystrophy. John was kind enough to donate his proceeds (\$70K) to our organisation. We are indebted to John for his motivation, passion and compassion towards our cause, which is to support our members. Thank you, John you are inspiration to all of us at Leukodystrophy Australia.

Bronwyn our Office Manager and Anne Patricia our Family Advocate organized and attended our Melbourne Family Gathering in March. The Family Gathering gave families and individuals the opportunity to enjoy long conversations in a relaxed atmosphere, forming new supportive relationships. Sister Julie attended and enjoyed time with current and new families.

I am looking forward to catching up with some of our members at our AGM in September. Please come and join our great guest speaker and family member, Dr Chloe Stutterd and others.



Our thoughts go out to our bereaved members. We are always here for you. Deepest condolences to the families and loved ones in the passing of Steven Pratt 19 May, Kyra Mckinlay 5 June and Beau Stevenson 7 June.

From my home to your home, I send a huge warm hug to help get you through the chilly months.



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

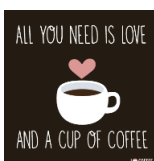
Our shared experiences across the spectrum are our most enriching, doors open, light comes in. It is a privilege to be a cog in this kindness. There are bright and beautiful people within and around Leukodystrophy Australia looking after their loved ones in the most caring of ways. There are others who are doing all they can in support with fundraising, wellbeing and research – anything connected to Leukodystrophy. We thank all people sincerely and we urge you to rally your support where you can. Please see the **Diary Dates** below. We really need your help, - small, large or just be there. We would love to see you.

Recently we had the privilege of an invitation, along with other support groups, to take part in the production of the **GSNV Lived Experience Videos Series**. The purpose was to develop an understanding of how well the health system is serving the needs of the individual, to collate responses and identify where the gaps are; to address and point out those gaps experienced, to policy makers and health professionals.






Thank you to our families who took part, our Founder, Sr Julie Thomas OAM, and to GSNV for this amazing opportunity. The Lived Experience presentation will take place in September; date TBA, @ Royal Children's Hospital. You are all invited! So come along for the unveiling. Please call me should you have interest. In addition, if you living remotely or interstate, the Series continues in 2020 via podcast. We will be sure to let you know your chance to share and connect from wherever you are!

We are looking to hold a **Morning Mingle** in Victoria, Melbourne University Masters of Genetic Counselling students setting. If you would like to have a morning tea near you, this Leukodystrophy mums, dads, grandparents and carers too.



facilitating a chance for families and two to meet and speak in an informal and friendly is a great opportunity for 'mingle' with other Please contact me via phone or email.

Diary Dates

| | |
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| August 15 @ 6.30pm Queens Park Golf Club, Queens Park Rd. Newtown | The Lions Club of Geelong Corio Bay is having a very special evening for Leukodystrophy Australia's ambassador Mr. John Olsen OAM, to celebrate John receiving the Order of Australia Medal in the Queen's Birthday honor list. Leukodystrophy Australia families are invited to celebrate this magnificent milestone, to meet John, say thank you, enjoy. RSVP Morrie Pieper , President Lions Club of Geelong Corio Bay on 0430 279 808 asap. |
| August/ September TBA | Morning Mingle Coffee morning with Masters of Genetics Counselling Students – Melbourne. |
| September 6  | Melbourne Storm vs Cowboys @ Melbourne Storm 7.55pm. Please call LA for free tickets. |
| SAVE THE DATE September 7 1-4PM NORTH MELBOURNE | LA AGM - guest speaker/s TBA includes Dr Chloe Stutterd, VCGS, AGHA @ Our Community House, North Melbourne – Saturday 7 September. (Notice will also be sent separately). Please RSVP ASAP. Everyone welcome for an informative catch up. |
| September all month | Leukodystrophy Awareness Month – Greyhound Racing South Australia multiple events and races over September. |
| September 15 | Sunday Mail City Bay Fun Run – Running for Ryder & Leukodystrophy Australia. Log in to pledge support for all our individuals and families. https://give.everydayhero.com/au/running-for-ryder |
| September 26 5pm- 10.30pm | South Australian Family Gathering SA. This exciting event will be paired with GRSA Annual Go Blue for Leukodystrophy Fundraiser Night at Chasers Restaurant 55 Cardigan St, Angle Park SA 5010 Email invite with all details will be sent separately. Doors open 1hour early for LA families only. |
| October 4  | Charity Challenge Leukodystrophy Australia Golf Day @ Long Reef NSW: Get a team together or come along and join a team to play, seek out support from your friends, family or colleagues, buy a sponsorship, donate prizes, come for lunch which is free for LA Members. https://form.jotform.com/charitychallenge/leukosydneygolf2019 |
| November 16 | Dinner For Derek II @ Heidelberg Golf Club, Lower Plenty. Another night bigger and better than ever, includes three course meal, beer/wine, lots of prizes & silent auction to raise funds for research and to assist those living with Leukodystrophy today. Email Tracy Lyons for bookings, auction items contribution dlyons48@bigpond.com or kindly make a donation https://inmemory.gofundraise.com.au/page/TracyLyons0 |
| November 23 | Charity Challenge Gala Dinner , Hyatt Regency Sydney @ 6.30pm. https://thecharitychallenge.com/events/16th-charity-challenge-gala-ball-2019 |
| December 4  | Charity Challenge Leukodystrophy Australia Golf Day @ Woodlands – Wednesday @ 8am-3pm. Get a team together or come along and join a team to play, seek out support from your friends, family or colleagues, buy a sponsorship, donate prizes, come for lunch which is free for LA Members. https://thecharitychallenge.com/events/australian-leukodystrophy-support-group-golf-day |

For information on Leukodystrophy Australia www.leuko.org.au, events, volunteering, joining Committee, please contact Office Manager, Bronwyn Byrne 0418 755 994, or email info@leuko.org.au



Safe in Sound is Back!, with an all new concert series for 2019-20.

We will be contacting families shortly across NSW and VIC, offering families one off visits FREE!

For more info contact info@leuko.org.au or info@safeinsound.com.au



What have you been up to? Care to share?



Happy Birthday beautiful April!

April Williams, diagnosed with Metachromatic Leukodystrophy MLD about 18 months ago, has met her hero several times through the Crows Children's Foundation, and the pair caught up again after training a few Wednesday's back. Tex Walker said April was an inspiration for him and the rest of the team. "I've been lucky enough to meet April a half-dozen times now and she's a lovely little girl with a massive smile. She always smiles when she sees us," he said.



Could April have had a better birthday! So grateful to receive a disability vehicle from Variety to enable us to get April out and about so much easier and make life as full as possible. Go Crows and Variety SA.



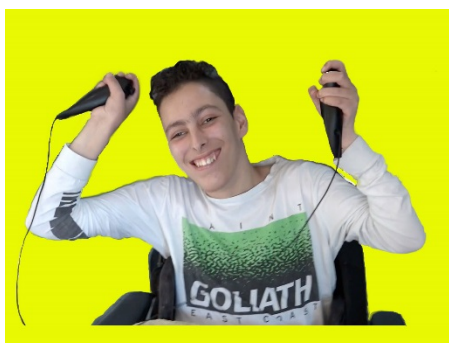
April and Ryder became friends after meeting at the Leukodystrophy Australia Family Gathering in SA 2018. They keep in contact via Facebook, and enjoy seeing each other at their birthday parties. They also have a love of chocolate frogs!

Happy Birthday beautiful boy!



Ryder's dad Michael is running in the Sunday Mail City Bay Fun Run – Running for Ryder & Leukodystrophy Australia. [Log in to pledge support for all our individuals and families.](https://give.everydayhero.com/au/running-for-ryder)

<https://give.everydayhero.com/au/running-for-ryder>



Happy Birthday Gorgeous!

Coming up Alessio Dilettoso performing at the **Jolt Sonic Festival 2019** September 21 & 22. **Safe in Sound** will present Alessio, who will be performing solo at Australia's biggest experimental festival in Melbourne for persons with a disability.

<https://www.joltarts.org/home>

It is a big couple of months for Alessio who is turning 18 in August



Anne Patricia, Family Advocate

advocate@leuko.org.au

0418 790 059

A big hello to everyone on this cold winter evening. I had a wonderful day joining Bronwyn and some of our family members at our Family Gathering held at Melbourne Museum. We had beautiful weather and most importantly, I felt privileged to meet up with current and new families from Victoria and interstate. When I reflect on some of the things the children said I can't help but laugh, they brought a warm and fun-loving energy to the afternoon. Sister Julie was in good spirits and she was eager to speak with all the families, as they were to her. She enjoyed herself immensely and she remains such an inspiration to us all. Thank you to the GSNV

Volunteer Program and the volunteer Genetics Students Lucas Mitchell and Claire Trumble who lent a hand on the day - you were a big hit too as people loved speaking with you.



The Disability Expo at Melbourne in March this year was a privilege to attend. The event was fruitful for me in relation to networking, meeting families impacted by rare diseases and viewing many pieces of equipment used in the disability and ageing sector. If you have any questions in relation to equipment, please contact your Occupational Therapist or Physiotherapist.

Accessing Genetic Counsellors

Genetic Alliance Australia have recently had discussions on delays in clients seeing a Genetic Counsellor.

A meeting held recently at Genetic Alliance Australia found that some of their group's members experience long delays. Delays of over 365 days is noted in the National Health Genomics Policy Framework 2018-2021, so this has been known when the report was being written. This is a great concern to our members and for people who have not yet begun a Genetic Health process.

It would be helpful if any of our families would like to call me in relation to the positive and negative experiences you may have had in accessing a Genetic Counsellor. With your permission, I may then pass the information onto Genetic Alliance Australia.

This information would be of assistance, particularly to gauge delays - is it only in NSW? Or more widespread? Once Genetic Alliance has more clarity about this issue, they can then formulate a request to State and Federal bodies to address delays - staff/ funding/ training. I would appreciate your feedback in relation to the above within the next 3 weeks please.

I did some quick benchmarking this week and when I called each State the average time to access a Genetic Counsellor was 6 months and can take anywhere up to 18 months. (I have not contacted the Territories yet). One Genetic Counsellor advised me that due to an increase in Genetic testing, the Genetic Counsellors have an increased client load, but they lack resources.

There are private Genetic clinics and to engage a Genetic Counsellor is on the average \$175 for an initial assessment and then post Genetic testing there is a follow up fee determined by the clinic. Private funds or Medicare does not cover the fee.



I will be attending our AGM on 7 September 2019; I am looking forward to meeting those of you who will be there.

Enjoy the crisp winter mornings.

THE GENETIC LINK provides easily accessible, useful and reliable information in one place. The Genetic Link online repository houses a wide selection of resources for people impacted by genetic conditions and those who support them – support groups, carers, health professionals and the general community <https://www.thegeneticlink.org.au/support-groups/>



Undergoing or considering genomic testing? The www.genomicsinfo.org.au resource covers basic genetics and genomics, genetic and genomic testing, genetic counselling, insurance, pharmacogenomics, data sharing, cancer genomics and guidance on discussing genomic test results with family. The website also features a news and events section, information on genetic services and referral for testing.

Post-stroke Health & Well-being - CADASIL PATIENT SURVEY. If you have had a stroke or CADASIL stroke, you are invited to participate in a research project seeking to understand the impact of stroke in your life, what types of treatment and care you have sought and received following a stroke. You can participate in two ways.

1) Online survey

If you have had a general stroke, please complete this General stroke survey

<https://redcap.research.uts.edu.au/surveys/?s=TYLHXNMA8T>

If you have CADASIL and have had a stroke, please complete this CADASIL stroke survey

<https://redcap.research.uts.edu.au/surveys/?s=JF98MM4KKX>

2) Interview

If you have CADASIL and have had a stroke, or you cared for such a person, the research team would like to talk to you to learn how your health is affected, and about your experiences of care.

As a token of appreciation for your valued input, a **\$25 gift card** is offered. If you are interested in participating, please contact Lichin Lim at poststrokestudy@uts.edu.au



Carrier Screening Research Project. If you or your child has a genetic condition, you are invited to participate in a research project seeking to understand your views about reproductive carrier screening. The aim is to identify which types of conditions adults, with personal or familial experience of a genetic condition, believe should be included in reproductive carrier screening programs. You possess important knowledge and valuable insight from your personal experience. Your views can help inform future reproductive carrier screening programs. If you would be happy to participate <https://redcap.mcrci.edu.au/surveys/?s=HMPYT3D99P>



ConnectGroups
helping support groups & individuals

We are coming to WA in 2020! Details TBA. Thank you ConnectGroups & Lottery West.



Thank you GRSA! The amazing Greyhound Racing South Australia are this year, for the second year in a row, supporting **Leukodystrophy Awareness Month** during September. Various events include donation boxes around the venue, "Chasers Goes Blue for Leukodystrophy" night - date TBA, including inviting guests, Ryders Race and some naming of races. If you have any race name ideas, please email Bronwyn info@leuko.org.au. Do try to get along and join the fun in awareness raising during September at GRSA for Leukodystrophy. Last year was a great success!

Funds raised will support the **Family Gathering 15 September @ 12noon**. Venue TBA. So please, all our SA Members, we want to see you - **Save the Date!**

There is more! GRSA employee and LA family member, **Michael Edwards** is running in the City to Bay Fun Run <https://give.everydayhero.com/au/running-for-ryder> - all funds so kindly donated by Michael and Lauren to Leukodystrophy Australia.

Please support this event by joining the team in running, making a donation, or walk the run with Lauren Edwards and young Ryder in his stroller. You can see Michael, Lauren & Ryder on page 3.

Thank you to family members, Brodie and Ann Marie Lush of Lush Marketing for your wonderful marketing support of Michael and Leukodystrophy Australia in the City to Bay Run <http://www.lushmarketing.com.au/>. We are looking forward to seeing you all in September.



More than ever, we are looking for golfers especially to play in The Charity Challenge Golf Days for Leukodystrophy. Without golfers and the Charity Challenge team, we cannot survive as an organisation. Please tell your family, friends, business networks and register now.

The dates - 4 October @ Long Reef NSW and 4 December @ Woodlands - both beautiful courses.

We are also seeking donations of prizes, sponsorship; and for our families to attend as our guests for lunch and a chance to meet. It is always such a great day, so do come along. Please see the **Diary Dates** links on page 2 of this Newsletter, or call our office and speak with Bronwyn 0418 755 994.



Sr Julie Thomas CSB OAM

0412 535 113

The official recognition of John Olsen by way of an OAM is just the most wonderful news, about a kind, generous, thoughtful, and wonderful benefactor to Leukodystrophy, who has walked 3 times across Australia, coast to coast, each time from a different start and finish point, over a period of 9 years. John Olsen OAM has a great ring to it and we will be brimming with excitement for our man and gentleman, John. Sincere thanks to Brian Edwards who rallied for this award.

I conclude by giving praise and offer my gratitude to Bronwyn who is very much at the helm of Leukodystrophy Australia and to the Committee Members who do so much to keep the organisation functioning and afloat. New blood is always welcome and required however, so hop on board if you can! Sincere greetings to all Julie.



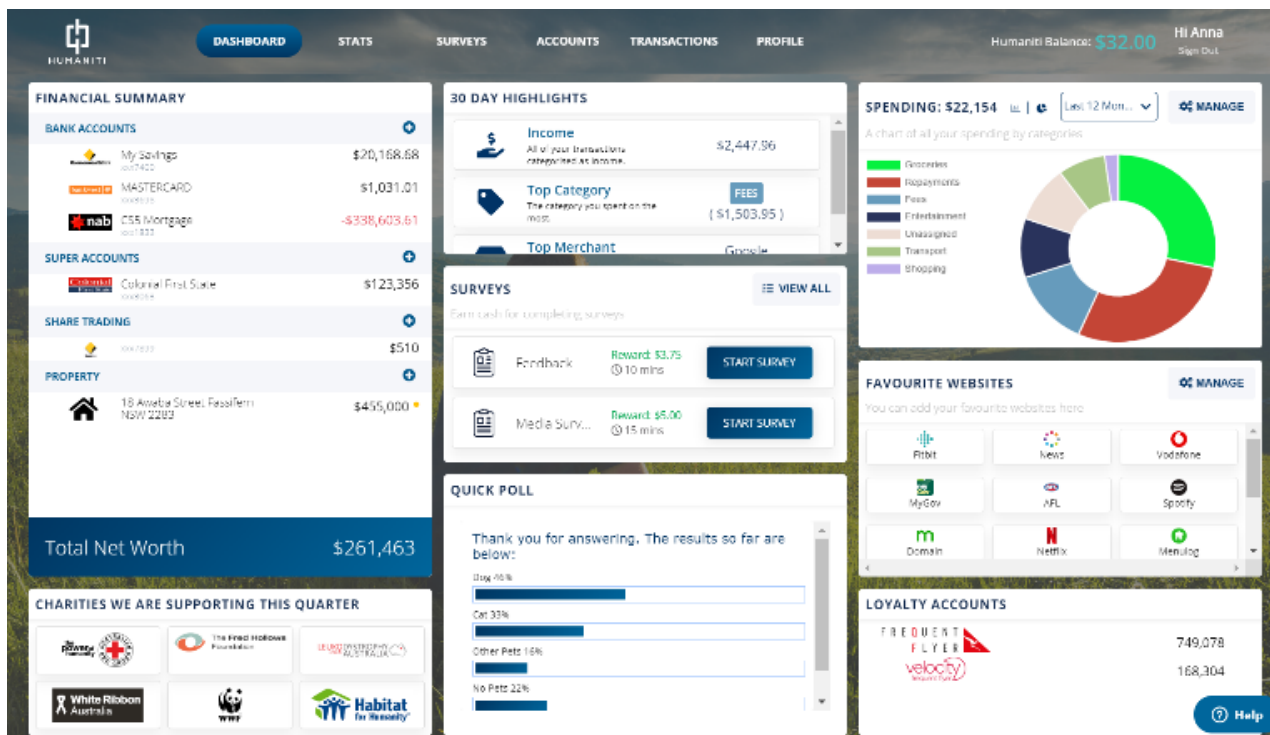
Leukodystrophy Australia is delighted to be partnering **Humaniti**, Australia's first personal finance tool, where you can see all your finances in one place, earn money when you participate in surveys, and donate to your favorite charity.

To help Australians *be more organized, plan a brighter future, be rewarded, and support meaningful causes*, Humaniti was established.

This is a great opportunity for you and your broader network to access a most helpful tool, earn some extra \$\$, and be able to raise much needed money for our families.

Ben Dixon, the founder of Humaniti, has been associated with Leukodystrophy and the Charity Challenge events for over 15 years, and is very excited to be able to support us in this way.

Please feel free to log on and join Humaniti at www.humaniti.com



Please consider

Expression of interest – COMMITTEE

Leukodystrophy Australia

Leukodystrophy Australia is the national peak organisation representing all people impacted by Leukodystrophy. We share in the same vision to source a cure for Leukodystrophy worldwide. We collaborate internally and externally with all stakeholders to advance the care of our members.

Number of Paid Staff: 1.2

Number of Volunteers: 2-6

Community Segment: Health, Disability, Wellbeing

Current Board Size: 5

Board Meetings (frequency): Bi-monthly

Board Meetings Held: At night

State where Board Meetings Held: Teleconference from any state

Other Meetings/Events: AGM, other occasional events where possible i.e. Family Gathering

Local Government Area: Melbourne

Payment: Nil - honorary role

About these vacancies:

Leukodystrophy Australia (LA) Committee positions vacant – President, Treasurer, General Committee. People with skills to share: Governance, Finance, Medical, IT, Social Media, Networks, an interest in rare disease.

We are seeking experienced and committed qualified persons with an interest in maintaining an effective, professional and accountable Committee to oversee operations in our Mission to support and empower individuals and families living with the rare disease, Leukodystrophy, to live their best possible life.

As a specialist not-for-profit LA is the peak support organisation in Australia, providing information and support across all stakeholders, in a non-discriminatory and equitable basis to some of the most disadvantaged and isolated men, women and children across Australia.

We advocate for clients and educate stakeholders, operating holistically to empower and assist individuals and families and the common issues they face.

LA embraces innovation in responding to emerging issues in the health landscape. We are seeking enthusiastic individuals who align with our Vision, Mission and Values.

Vision

A World free of Leukodystrophy.

Mission

We assist in empowering people throughout their Leukodystrophy journey and beyond. We offer support, foster member connections, provide service linkages, education, and advocacy, and promote current trends in treatments and research.

Values

Leukodystrophy Australia are committed to the following values:

- **Respecting and recognizing our members' abilities, qualities, achievements and their lived experiences.**
- The rights and choices of members to have a say in their health and wellbeing.
- Collaboration with health professionals and other service providers to assist members in reaching their full potential.
- Rigid processes by which members, donors, beneficiaries and their financial contributions assist in sustaining service delivery.
- **Current multidisciplinary research in the hope for improved outcomes for members and finding a cure for Leukodystrophy.**
- Professionalism in all activities and a team environment.
- Service delivery informed by the principles of social justice, accountability, transparency, equality and equity.

LA is at the early stages of a new strategic sustainability journey. With a re-brand in 2015, plans for growth of services to meet our clients' needs and increasing client demand due to advancement in genomics, we see an increase in numbers diagnosed. Securing alternative sources of funding, and expanding our Family Advocate Program are areas of focus for the year ahead.

As we strategically look at succession planning, we would like to appoint Committee Members with significant financial and governance experience, other talented and varied to you skills, as we sustain our organisation into the future.

Please contact our Office Manager for further information, including Role Descriptions. Our Committee Vacancies (3). We encourage all candidates to apply. Our goal is to make everyone feel involved, respected and connected.

Please include in your expression of interest:

A cover letter outlining your interest in the position and relevant skills

A Curriculum Vitae (limited to 2/3 pages) outlining:

- Your contact details - phone and email.
- Your experience including relevant employment and volunteering, honorary positions held and qualifications.

Do you have further questions?

For a confidential discussion about the position, please contact:

Bronwyn Byrne 0418 755 994 or 1800 141 400

Please note: screening and interviews may take place prior to the advertised close date. As such, please submit your EOI as soon as possible.

Please send your Expression of Interest to Bronwyn Byrne info@leuko.org.au with the subject line **"Expression of Interest: LA Committee."**

Applications are acknowledged by email and treated in confidence. We look forward to hearing from you.