

President's welcome

Welcome to our 'Bumper Issue' September 2015 Newsletter. September is 'Leukodystrophy Awareness Month', and we are talking to as many people as we can about leukodystrophy and its impacts.

The last 12 months has seen some very important and positive changes in our organisation, and I look forward to celebrating them with you in the edition. The Committee looks forward to the next 12 months being characterized by consolidation of these changes and continuing to build a strong foundation for our future.

Please take a few minutes to look through the articles below, and don't hesitate to contact Bronwyn in our office, or any of the Committee members, if you have any questions or would like us to offer support or assistance in any way.

Pam Joseph/President, 2015/2016

Annual General Meeting

This year we decided to change the venue of our AGM to Mary McKillop Aged Care, in Hawthorn East, and it proved to be an excellent choice, with our every need catered for by Camille and her team. We are extremely grateful to the Sisters of St Joseph for their generosity and hospitality.

The 2014/2015 Committee informed those present of progress in designing our new website and revised logo, and use of the name 'Leukodystrophy Australia'. Those present voted to apply to Consumer Affairs Victoria for this name also to become our incorporated name, completing a significant amount of work over the past few months. We are particularly indebted to Earl Schonberger for his energy, enthusiasm, and creativity in transforming our ideas into reality.

The new Committee of Management was voted in, and we say an appreciative farewell to Karen Keable, who leaves the role of Treasurer, and an equally warm welcome to Brett Fernandez who steps into that role. All other positions return unchanged.

In addition to the 'business' part of the meeting, we were delighted to have the opportunity to hear two very interesting presentations. Rick Saunders and his mum Coralie showed us a slideshow and shared their experiences of attending the MLD Conference in America recently, and Michelle Marinovic gave us some insights in the NDIS. This was followed by afternoon tea and a chance to meet each other and make new friends.

Although AGMs are not generally a popular way to spend an afternoon, I can highly recommend ours! I hope you will be able to join us this time next year.

Meet your 2015/2016 Committee

The Committee of Management works hard to keep Leukodystrophy Australia running, but we are spread around Australia and mostly in contact via email or telephone. You could probably walk past any of us and maybe not even know! So below we have given a little introduction to each of us. Each of us brings a range of things to our committee roles, but we've identified one 'superpower' to show what a varied bunch we are. We hope this helps you to feel like you have got to know us a little bit, and that you will feel comfortable to contact any of us via the ALDS office if you would like to chat further about anything to do with Leukodystrophy Australia as it is now, or as you would like to see it in the future.



Pam Joseph (President)

I first heard about leukodystrophy through a friend (Bede), whose son Peter has a leukodystrophy. Bede sang in a choir with my husband. I was later employed as the Family Advocate and stayed involved after I left that position because I wanted to keep contributing to this wonderful group in some way. When I'm not doing Committee work, I'm at Sydney Uni doing a PhD in Social Work.

Pam's superpower: Writing policy documents.



Michelle Marinovic (Vice President)

Michelle joined the Committee in 2013. Michelle and her husband, Emil, live in Geelong and are our resident NDIS 'experts'. Not only do they live in one of the first NDIS areas, but Michelle has a professional interest in the NDIS and shared some of her knowledge with us at this year's AGM.

Michelle's superpower: Understanding the NDIS.



Bronwyn Byrne (Secretary & Office Manager)

I am the lucky Office Manager of Leukodystrophy Australia, formerly Australian Leukodystrophy Support Group. I say lucky because I love this job, particularly the contact I have with our people and families living with leukodystrophy and the amazing and various ways our group can support. My first contact was as a volunteer with my sister and former Office Manager, Robyn Loh. Lucky me again, not only do I have a wonderful sister, but she has been a marvelous mentor to me in this privileged position.

Bron's superpower: Putting the 'fun' in 'fundraising'.



Brett Fernandez (Treasurer)

Brett first contacted our group when his young son was diagnosed with a leukodystrophy, and since those early days he and his family have been active supporters of many of our events.

Brett's superpower: Managing finances.



Angela Famiano (Committee Member WA)

Angela lives in WA and has been on the Committee for several years now. Angela is a qualified counsellor and specialises in the areas of father and carers needs. Angela has worked hard at building up a strong network with government and non-government support services in the state. Angela is an advocator of individuals with disabilities and has a driven passion in raising awareness and promoting research of all types of leukodystrophies. Angela is a carrier of the X-linked adrenoleukodystrophy gene, her father passed away from the disorder in 1988. *Angela's superpower:* Connecting with others.



Donna Lourensz (Committee Member Vic)

In 1996 I was handed a pamphlet when my son was diagnosed with infantile MLD. On this day I was introduced to the term leukodystrophy and ALDS which back then was essentially Sr Julie. My daughter too was diagnosed and I joined the committee. When I was unable to continue my commitment my friends supported me by stepping onto the committee in my place. The ALDS has always held a special place for me and I deeply value the people who have been dedicated to its growth. There continues a huge amount of work to be done so I rejoined the committee to help in any way I can. I look forward to our future growth and support. *Donna's superpower:* Being a role model of hope & encouragement to other parents.



Kellie Panton Committee Member (Tas)

Kellie joined the committee in 2014 and has worked tirelessly to raise awareness, funds and support in Tasmania, as well as joining the Melbourne committee members to support events there when possible. Kellie's positive approach always encourages the rest of us on the committee, and she is the epitome of the 'quiet achiever'. *Kellie's superpower:* Bringing together families who would otherwise be isolated by distance or circumstance.



Earl Schonberger (Committee Member NSW)

Earl is the longest-standing member of the current committee and brings a deep knowledge of the impacts of leukodystrophy on a family, as well as invaluable skills in IT, fundraising, event management, and liaison with the corporate sector. Earl is based in NSW, but with his widespread golf event commitments (not usually playing) he gets around! *Earl's superpower:* IT and event manager extraordinaire.



♥ *We extend our condolences and deepest sympathy to the family and friends of Helen Hart who passed away on 20 August 2015. Helen is survived by her 4 lovely children. Our support will always be there.*

A big hello to you on this strange but typical spring day, from your **Office Manager**. We have had sunshine and hail today - so Melbourne. We have had an incredible time recently, being successful in our applications of the following grants and we thank all those involved, Committee, Family & our Benefactors:

1	6 January	GSNV	\$200	Scienceworks Family Day
2	20 May	Cops for Kids	\$15K	SA children with Leukodystrophy
3	27 July	Connect Groups	\$2300	2 x WA events
4	21 August	St George Foundation	\$41.1K	Quality of Life Project (mixed for mainly families, and a little staff)
5	7 September	Slater & Gordon	\$10K	Living with Leukodystrophy (Family Advocacy Program)

The above is for you, please come forward if you think we can assist - we're here to help ♥

We still **need big help** however for our group and its day-to-day function. Our wonderful Ambassadors, Garry Dawson and Matthew Laverty of The Charity Challenge, have organised this amazing chance to assist all the charities under their umbrella including ours. We ask you help them to help us. Please pass the following great fundraising opportunity around to your family and contacts: <http://winalexus.com.au/32>



Go on line for your opportunity to win a Lexus IS 250 Luxury (worth \$61,161 includes on road costs) as well as other great prizes and support Leukodystrophy Australia:

Our golf days are rolling around very quickly and I want to thank our volunteers Enza (2 years now), and Jenny and Marylou, who have come on board to assist in the success of these 2 events. Your help is priceless thank you!! Our families are invited for lunch and to enjoy a lovely day out. Please let us know ASAP.

<http://bit.ly/sydneygolf2015>

<http://bit.ly/melbournegolf2015>

For these 2 golf events, we are seeking support in the following ways which you or your colleagues, family and friends may be able to assist:

👉 players, single or a team

👉 sponsors (tailored packages available)

👉 donations

👉 prizes

👉 Any ideas or discussion required, please call - Bronwyn 0413 750 365 or mail@alds.org.au

We've just had a fantastic **Family Gathering in SA** and by all accounts everyone had a fun time. Thank you to Shilandini in organising this event with only a little help from me. You made this happen and you have ensured our families are connected and know we are really there for them. We love the photos too and are very happy everyone wants to do the same thing next year. Well done on choosing Watermark as a wonderful venue for all to enjoy. Thank you to our families who attended ♥

SA FAMILY GATHERING @ WATERMARK

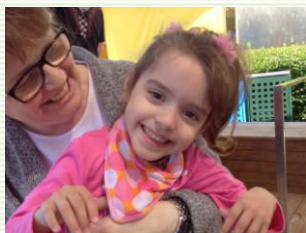


Shilandini, Geshan & Sally



Susie, Patrick & Joseph

VIC FAMILY GATHERING @ SCIENCEWORKS



Debbie and Amber



Jayden, Keith, Bailey, Linda, Sr Julie
& Bron



Jenny, Donna, Debbie, Enza, Marylou



Salv & Alessio

Our **Family Gathering @ Scienceworks in Vic** last Sunday was also a stunning success. It was great to meet new people and mingle with the known! Thank you for coming ♥

It's all happening! Next we have our **Family Gathering in WA @ Niche Centre, Nedlands**. If you need any assistance with attending these events which are all free to you, please let us know. It's not too late to rsvp - so come on!

Please send us any pics and a little news you would like to share with others. We love hearing from you.

I'd like to thank another volunteer, Donna Bradley-Robinson who will help me with fundraising as we begin our bequest program and possibly another event next year - time permitting! Thanks too can not be overstated to Karen Keable our past Treasurer. You put in an incredible 18 months and it was a sheer delight working with you. Best wishes in everything you do Karen ♥

Our new website depicting our new name **Leukodystrophy Australia** will be live very soon. Meanwhile all our contacts remain the same and you can still link in to www.alds.org.au SO watch this space!

Warm regards to all, cheerio for now, Bronwyn

Thanks Angela for this useful tip for Leukodystrophy updates called Google Alert. Here's how:

Go to <https://www.google.com.au/alerts>

Type in what you would like to have alerts to (i.e. leukodystrophy)

Then you can set up the alerts (how often you receive the alert, which language, which email the alerts go to)

Then press Create Alert

Repeat for further alert subjects. (yes it's that simple) 😊



Dr Adeline Vanderver, Stephen Damiani, Rick Leventer

Dr Adeline Vanderver visits Melbourne

On Tuesday 25th August several families affected by leukodystrophy attended a seminar at Murdoch Children's Research Institute featuring presentations by Dr Rick Leventer (RCH), Stephen Damiani (Mission Massimo) and special guest Dr Adeline Vanderver (Director, Myelin Disorders Clinic, Children's National Health System, USA). While in Melbourne, Dr Vanderver attended the HBSL (tRNA) Synthetase Scientific Summit and spoke at Grand Rounds and the Paediatric Neurology conference on the following day.

After the presentations, many of us were able to chat informally with Dr Vanderver. It was very exciting not only to have the opportunity to speak with such an eminent specialist in the area of leukodystrophies, but also to hear her message of the importance of strong links between clinical, research and patient organisations such as Leukodystrophy Australia. We are actively pursuing opportunities to join global networks so that, together, we can work towards improved understanding, diagnosis and treatment and, we sincerely hope, a cure for the distress caused by currently unidentified conditions.

Genetic Disorder Awareness Week

Pam Joseph represented Leukodystrophy Australia at the launch of the annual Genetic Disorders Awareness Week, hosted by Genetic Alliance (formerly Association of Genetic Supports Australasia). The event was very well attended by a wide range of support groups, many of them representing rare genetic disorders. This year, leukodystrophy had a prime focus, as Stephen Damiani spoke about his family's experiences in searching for a diagnosis for Massimo. Stephen's book, 'Cracking the Code' has recently been released by Random House Publishers.

Rare Disease Day 2016

Rare Disease Day in 2016 will be held on Monday 29 February – a rare date! How do you think Leukodystrophy Australia could celebrate this day and raise awareness? We'd love to hear your creative ideas, and even more than that, we'd love you to put your hand up to be involved in planning our activities! Just send Bronwyn a message (mail@alds.org.au) or call her at the office (1800 141 400) and register your interest (and ideas!)

Young Carers Bursary Programme

The 2016 Young Carer Bursary Programme will deliver 333 bursaries worth \$3,000 each to assist young carers up to 25 years old. The aim of the bursary is to encourage young carers to continue studying by relieving the financial pressure to work a job in addition to their caring role. For more information go to: <http://bursaries.youngcarers.net.au/>

A message from Angela in WA

On Friday 25 September, Bron and Angela will be stallholders at the annual **ConnectGroups Self Help and Support Groups National Awareness Day Expo** in the Perth Cultural Centre.

This is a great opportunity to showcase the many self help and support groups in WA to the general public in Perth. **ConnectGroups** is one of the WA non-government organisations with which Leukodystrophy Australia has a positive and supportive connection. **ConnectGroups** (in conjunction with the WA Health Department) have provided funding for two WA family events this year as well as providing a full scholarship for Angela to attend their three day Conference and Gala Ball.

The 2nd event is **Saturday 26 September**, and it's not too late to RSVP! A **Family Activity Day for WA Families**, hosted by Angela and Bron providing an opportunity for families to come together, have a chat with our Office Manager, Bron, and design a family keepsake with Angela. Should they wish, families will be given the opportunity to provide an insight to what it is like to have leukodystrophy in their life, as a advocacy project. The intent is to give medical personnel, researchers and the general public a better understanding of what leukodystrophy means beyond the medical literature. If you are not able to come but would like to be part of this project, please contact Angela angela.f.counselling@gmail.com

Cracking the Code - An Evening with Stephen Damiani (OAM)

On the evening of the 12 August we had the wonderful opportunity to host an evening with Stephen Damiani. In 2008 Stephen and Sally started the quest to diagnose their son's type of leukodystrophy and the workings of the organisation they have established began <http://www.missionmassimo.com/> Those attending the event were ALDS WA family member, a researcher from the Eastern States of Australia, two allied health professionals (physiotherapist and psychologist), Genetic and Rare Disease Network staff, representative for Lyme Disease and general public. Stephen graciously gave of his time to privately chat with families and other audience members before and after presenting his personal story which was engaging and entertaining, as well as inspiring. This encouraged a group discussion allowing our families to discuss their experience with a leukodystrophy.

During the day of the 12 August, I and a WA family member were present for the final **Newborn BloodSpot Screening Consultation Workshop**. The purpose of the workshop was to discuss the policies contained in the policy framework, the beneficiaries of screening and the potential harms/risks of newborn screen. We were able to provide feedback as consumers among many medical clinicians, in particular researchers. A report is currently available

http://www.genomics.health.wa.gov.au/docs/Consultation_workshop_feedback_report_12Aug2015.pdf

The final report of the Newborn BloodSpot Screening Consultation will be available shortly <http://www.genomics.health.wa.gov.au/nbspf/index.cfm>

Bron and I are looking forward to seeing some of our families this weekend's gathering at The Niche, Take care, **Angela/WA Committee Member 2015/16**