

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.



Thank you to our **Ambassadors Gary Smokey Dawson OAM, Matthew Lavery**, golfers, supporters, donors, family members as you supported The Charity Challenge golf events in NSW and Victoria, and the Gala Ball in Sydney. Your continued support is vital to our organisation and deeply appreciated.



Kellie Panton, President 0458 083 883

A very good and busy last quarter to 2019 saw some amazing events held. Our Sydney Golf day at Long Reef was very successful. **Dinner for Derek** was fabulous. I was fortunate to attend this event run by the Lyons family who have done an amazing job to bring so many people together to raise money for research, for our organisation and to raise awareness for Leukodystrophy. A great tribute to remember a husband, father and friend. Well done and thank you Tracey, Michael, Ashlee, Sean and Declan.

The **Charity Challenge Gala Ball** in Sydney was a great night. I met some of our fabulous family members and the people who help support the Charity Challenge group. I stayed with Earl and his amazing family. This family is inspirational in their spirit and love for each other. Thanks to all in making this event a spectacular success.

Our **Melbourne Golf day at Woodlands** - Bron tells me Sr Julie was present and it was a great day, for golfers and guests featuring a performance by family member Alessio Dilettoso, highlighting his **Safe in Sound** music experience with Robbie Avenaim, a program we offered in 2019 and will continue to offer in 2020 <http://www.safeinsound.com.au/faq/>
A special thank you to Nicholas Rizzo and Bianca Bed Linen for your ongoing sponsorship, donations and participation in this annual event at Woodlands.

Each year these **Charity Challenge** events in **NSW and VIC** are free to all our family members to come for lunch, to meet each other, and simply enjoy. Next year we hope to meet more of you – please come 2020!

In order to obtain funds for the continuation of our organisation and for financial support to our families, grant writing kept us busy. This has proved most competitive and we thank the “brains trust” who volunteered their time to assist Bronwyn submit these grants – Jacklyn Vick, Dr Helen Brown, Dr Kylie Agllias, Terry McGill, Earl Schonberger, our Family Advocate Anne Patricia. Thank you Bronwyn for the hard work you have been doing on this one.

I hope you all have a safe and happy Christmas and we will have a great new year bringing about good ideas on how to fund-raise and bring about more awareness of Leukodystrophy. Please let us know if you can assist.



Alessio the rock star!



Winners @ Woodlands



Grinners at Woodlands



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

In this edition, you will find our stories celebrating compassion, kindness and generosity in support of our leukodystrophy families. They are volunteers, fundraisers, supporters, our Committee, our Ambassadors, and other partner networks – heartfelt thanks; we could not do it without you.

Welcome to our fantastic new Committee members, Dr. Dominik Fröhlich, Postdoctoral Research Fellow, University of New South Wales and part of Massimo's Mission, and from SA Phillip Marks, Business Development Manager, ZAP Fitness elected in September. Your valuable input will add great diversity to our discussions and business in 2020 as we support families living with Leukodystrophy. Should you, our families, have input whether it be via constructive feedback or you wish to volunteer, please contact me. Always happy to talk!

In addition, the very big news - a dream we have always wished for – a clinical and research program in childhood Leukodystrophies – **Massimo's Mission** has opened at Royal Children's Hospital Melbourne. Massimo's Mission will be including Australian patients of all ages for research into undiagnosed Leukodystrophies. **See page 3** for this exciting advance in both research and recognition for a much needed leukodystrophy specific clinic, a first in Australia. Well done Damiani family, the scientific team and all supporters; it has been such a long haul – you are extraordinary. Thank you Greg Hunt, Federal Health Minister for your foresight in the importance of genomics and the huge change in direction this is, in giving hope to well deserving people living with all kinds of disease.

Networking with peak bodies has proved invaluable. Attending the **Australian Genomic Health Alliance Conference** and the **Melbourne Genomics Symposium** we are thrilled to learn of the availability, expedience and precision in many cases, to achieve diagnostic outcomes via the world of genetics and genomics; preventing much suffering around protracted testing, potential misdiagnosis or no diagnosis even. We attended important forums and workshops over 2019. Held at Royal Children's Hospital, these meetings provided education in the changing landscape of healthcare and the opportunity to offer feedback and inclusion moving forward on the needs and feelings of our families on a range of topics.

In support of small not for profit organisations, to benefit in shared learning, knowledge, development of resource sharing, brainstorming, practical outcomes and camaraderie that sustains us, the **Genetic Services Network Victoria** has shown great wisdom and a will in making this happen and continue to happen. Just one of the great and varied outcomes has been the **Lived Experience** series of videos where personal stories are valued and shared. Please see page 3 to view video links.

Since joining, the **Neurological Alliance Australia** our collective voice has included three Submissions to lobby government. 2020 will include input to further Submissions, and exploring opportunities for potential collaboration around research and financial sustainability for support organisations is on the Agenda 2020. Should you wish to provide input, please contact me.

Gleefully, circumstances have allowed us to pick up again, the development of our new website with Practice Edge, due for completion April 2020 or earlier.

Enjoy our news, and we wish you a peaceful, safe and happy Christmas and New Year as together we work toward leading our best lives. We return Monday 13 January when emails will be answered, or simply call 1800 141 400 for quick response.



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 Ryder Edwards, 14 August, Sebastian Burnet, 6 September.



SHOUT OUT TO WESTERN AUSTRALIA FAMILIES

Society for the Study of Inborn Errors of Metabolism have granted LA funds to hold an information event in 2020. This is an opportunity for families to come together to hear guest speakers, and to make new connections. The event is planned 1st weekend in April 2020. More details to follow.



Safe in Sound is Back for 2020 with an all new FREE concert series. Interested families please contact us. For more info contact info@leuko.org.au or info@safeinsound.com.au



Massimo's Leukodystrophy Mission has commenced!

Massimo's Mission, a clinical and research program in childhood Leukodystrophies has commenced. The Federal Health Minister, Greg Hunt announced a commitment of \$3 million over three years to fund a research consortium to "close the loop from genetic diagnosis to clinical treatment" for Leukodystrophies.

The announcement was made on the one-year anniversary of the passing of Massimo Damiani who had a rare form of leukodystrophy known as HBSL. The cause of Massimo's Leukodystrophy was found in 2011 through a collaboration between the Royal Children's Hospital and the University of Queensland together with collaborators from the Netherlands and the USA.

At that time, Massimo was the first patient in the world to have a novel genetic disorder diagnosed through the use of trio whole genome sequencing, where his entire genome was compared to that of his parents, Stephen and Sally Damiani. Stephen and Sally have always been at the forefront of raising funds for research and advocating for children with Leukodystrophies.

Massimo's Mission is being led by Associate Professor Richard Leventer from the Royal Children's Hospital (RCH), the Murdoch Children's Institute (MCRI) and the University of Melbourne Department of Paediatrics, together with Dr Cas Simons from the MCRI, Professor Ernst Wolvetang from the University of Queensland and Professor Matthias Klugmann from the University of NSW. Massimo's Mission is administered through the Leukodystrophy Flagship of the Australian Genomics Health Alliance.

The research begins with patient recruitment for genomic diagnosis, moving to disease modelling and pre-clinical testing with the promise of human clinical trials for novel treatments. A dedicated Leukodystrophy Clinic has just commenced at the Royal Children's Hospital / Victorian Clinical Genetics Services, and with funding from Massimo's Mission has been able to employ a clinical geneticist, research coordinator and post-doctoral scientist.

Adults with Leukodystrophy please note: Massimo's Mission will be including Australian patients of all ages for research into undiagnosed Leukodystrophies.

In terms of clinical care and the leukodystrophy clinic based at the RCH in Melbourne, this is only open to paediatric patients. A paediatric patient is generally considered a patient who is still attending school, or up to 18yo.

The RCH / MCRI are recognised as a Clinical Centre of Excellence amongst the leading centres internationally which make up the Global Leukodystrophy Initiative. For further information see www.theglia.org, or contact:

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Clinical Research Coordinator

Massimo's Mission Leukodystrophy Program

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Melbourne Genomics
Health Alliance

Melbourne Genomics' Education team has produced an [interactive infographic](#) on the genomic sequencing process - highlighting the types of tests available, pre- and post-test guidance and including downloadable learning resources for health professionals. You may wish to pass this to your GP. This free online resource is now live and available for health professionals. You may wish to pass on to your GP. www.melbournegenomics.org.au/professionals/learning



The **Lived Experience** is a continuing program and open to others of which in future we will be reaching out to you on this. Thank you to our participants and to the **GSNV**. Here are 3 Leukodystrophy stories:

- Brothers, Victor and Max McDonnell: <https://www.youtube.com/watch?v=tt1Yd7USekc>
- Our Founder Sr Julie Thomas: <https://www.youtube.com/watch?v=wc0RjBj2MyU>
- The support group leaders perspective: https://www.youtube.com/channel/UC7TwaPxgrVLeow0-UdyH-oA?view_as=subscriber



Anne Patricia, Family Advocate

advocate@leuko.org.au

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Everyone at LA have been working hard this year so we can continue to support individuals and families with current up to date information, support and advocacy to those affected by leukodystrophy; raising awareness of the impacts of this group of conditions; and to encourage ongoing leukodystrophy related research. Thank you to Bronwyn who is always searching for appropriate grants, networking with appropriate agencies and for her ongoing support to the Management Committee and myself.

As I write my LA Newsletter extract tonight, I feel very overwhelmed and saddened that due to ongoing personal issues, reluctantly, I have had to resign my position as Family Advocate. My last day of official employment will be 29th April 2020. My extended resignation time will allow me to say goodbye to those individuals and families I have worked beside over the past 4+ years. Even though I have resigned from my position, I will certainly be happy to assist LA anytime if they require my support.

I can remember with fondness when I initially arrived on the first day of my orientation, I was warmly welcomed (via phone) by Bronwyn Byrne our Office Manager. I drove to Sydney to attend orientation with Pam Joseph our previous Family Advocate and then President Pam Joseph. Immediately I felt invited to work in a nurturing and supportive environment where I would evolve professionally and personally. I was not wrong! Bronwyn and I have had an ongoing positive and respectful professional relationship right from the beginning and I have appreciated all her support and everything she has taught me over the years. The previous Presidents Pam Joseph, Michelle Marinovic and our current President Kellie Panton have always been open, supportive and professional. I have been fortunate reporting to inviting, warm and knowledgeable Presidents during my time at LA. Sister Julie has always been giving in providing mentoring and offering advice to me particularly in the early days of my employment.

Working beside the previous and current LA Management Committee has been extremely rewarding. I have noticed from my early days that each person on the Management Committee has the core of the service at their heart, in providing a unique, professional, supportive and transparent service to assist those impacted by LD. I have always been impressed by the passion and energy of the Management Committee therefore I feel LA will continue to be uniquely positioned as the proactive national peak body for Leukodystrophy. How wonderful for our families.

When I reflect on my role many wonderful memories flood back to me. I could write for hours about these but to summarise; I feel a sense of gratitude for the knowledge you have imparted to me, the respect awarded to me and allowing me to step into your lives and work beside you throughout your LD journey. Everyone I worked with has inspired me with his or her care, resilience and strength to move through even the most challenging moments. I have always believed the Universe holds many wonders for each of us and my hope is that one day whether in my lifetime or not there will be a cure found for each Leukodystrophy.

I feel very blessed to have worked in such a caring, supportive, nurturing and compassionate organisation. I will think of you often and miss you all very dearly.

I wish all of you a sense of joy, peace and safety throughout the Christmas period and throughout the summer holidays. I hope you find quiet moments to reflect on those who are no longer present in your lives, either via bereavement, distance or other reasons. May you all experience some wonderful warm moments to hold onto during this period and cherish them always.

I am taking annual leave from the 19 December 2019 and will return on 28 January 2020. However, during this period I will be around to respond to voicemail messages. Please do not hesitate to call if you wish to speak with me.

Stay safe, cool and most of all find time for some fun over the summer holidays.
Warm regards, Anne Patricia.



Sr Julie Thomas CSB OAM

0412 535 113



Greetings to All, I am fully aware this time of the year is very busy for many, but at the same time it can be sad for those whose loved is no longer with you. It can help if we try to remember they are no longer suffering, but have peace and happiness.

On December 4, there was the Annual Golf day at Woodland, Mordialloc. I must say I am amazed to see so many attend the function including a big number from Sydney. Many of you do know Earl Schonberger who has been on the Leukodystrophy Committee for well over 20 years. He came from Sydney and naturally, I was delighted to see him.

A big debt of gratitude to Bronwyn Byrne who is our outstanding Office Manager. Bronwyn is a very kind, gifted and thoughtful person; making so many functions and occasions go so successfully.

I wish you all a happy and joyous Christmas and a successful 2020.
Warm regards and best wishes, Julie



Special guest Sr Julie with Bron and Earl @ Woodlands

What have you been up to?



It is widely known if you want something done, you ask a busy person. As such, I am constantly in awe of the families with whom I have the privilege to interact, marveling at achievements and the courage in their day to day, as shown in caring for their families. Every now and again, I get the chance to spend some extra time making it even more special. One such occasion was the **'Because She Can by Marina Brbot'** book launch featuring our very own Melbourne mum of three boys, Enza Dilettoso. Enza not only can, she does. I was so proud and happy, on this balmy Melbourne night overlooking the Melbourne skyline, to be amongst 30 extraordinary Melbourne women achieving amazing feats in their everyday lives, to share in the celebration as Marina's book officially launched.

Congratulations Enza on your amazing journey so far!

Enza graciously shared more of her story at the Charity Challenge Woodlands Golf Event, and the book chosen by one delightful golfer as a prize to share with his family. Leukodystrophy Australia will be meeting with Marina Brbot next year, to promote the importance of giving to organisations such as LA, and the importance of women collectively supporting one another.

<https://www.marinabrbotbook.com/>



Because She Can by Marina Brbot @ Melbourne book launch with Enza Dilettoso



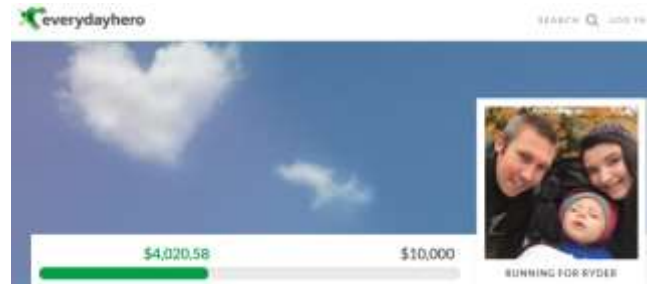
Enza with 3AW's David Man



For the many donations received throughout the year, large and small – Thank you, you made a difference!

Donations of \$1000 or more gratefully received:

- All Souls' Opportunity Shop
- Anonymous and other donors
- Dinner for Derek
- Energy Consult Pty Ltd
- Fire Fighters Charity Fund
- Greyhound Racing SA
- Hala Raghieb
- Insurance Advisernet Foundation
- Jake Chimes
- Julie Thomas OAM
- Lions Club of Cowaramup
- Lucas Hofmann
- Lysosomal Diseases Australia
- Michael & Lauren Edwards
- Michael Doran
- The Charity Challenge



Dinner for Derek II - Lyons family Tracy, Declan, Sean, Ashlee & Michael



Dinner for Derek II – Damiani's, Kellie, David Green, Bron, Dilettoso's

Kindly sponsored by **Greyhound Racing South Australia**, and family members Lauren and Michael Edwards via fun run - **Running for Ryder - The SA Family Gathering 2019** held at **GRSA** was a warm and engaging experience of which we all enjoyed. Attendance was 34! Some were new members, others renewed acquaintance. It was so lovely to bring our SA families together.

We acknowledge the sad passing of little Ryder just one month before the event to Krabbe Disease. This cheeky boy we met last year at the Mawson Lakes Family Gathering, is deeply missed. Our hearts go out to Lauren and Michael Edwards who are just such wonderful, brave, selfless, generous people. Heartfelt gratitude to you from all who attended and Leukodystrophy Australia.



What a year it has been! On behalf of the team at Leukodystrophy Australia, we wish everyone a very Merry Christmas and happy holidays! We thank you for your continued support and look forward to being in touch again in 2020. We are closed Friday 20 **December**, reopening on **Monday 13 January**. Our phone line is always open – **1800 141 400**.