



Welcome to December's edition. Thank you for your support throughout 2016! We wish you a Happy Festive season and hope you get some rest and relaxation with friends and family.

Our office will be closed over the Christmas period on Thursday 22 December, reopening Tuesday 3 January 2017. During this period, please call 1800 141 400 for emergencies. Your emails will be answered first week of January.



Michelle Marinovic, President

Dear Families and Friends,

The last few months have been very busy and just flown by. I would like to sincerely thank each member of our team for all their efforts and I look forward to working with you in the new year. We are very grateful for our amazing friends who have helped us in our fundraising efforts and in raising awareness of Leukodystrophies this year. I would like to acknowledge the individuals and their families who live with the challenges of Leukodystrophy every day, your strength and resilience keeps us going. Finances have been a challenge this year but we continue to support our families as best we can. Thank you Sr Julie for sharing your story, you are such an inspiration to us.

I wish you the very best for the festive season, may you spend quality time with those you care about and may 2017 bring you all health, happy times and courage.

Take care, Michelle 0417822161



Bronwyn Byrne, Office Manager

As I think about 2016 and the myriad of tasks we have endeavored to achieve, gratitude and Inspiration come to mind. Thank you to all those who have helped us achieve, including our Committee and Family Advocate, to those who have asked for help and who have received that help. It is what we are here for. Thank you to our grant benefactors and marvelous donors and fundraisers who allow us to keep giving. I am always eternally grateful for the inspiration I receive from remarkable people like you.

Our milestone database is up and running. If we have not contacted you or you have some changes, please notify us. I'm always happy to take your calls or you can email me.

Women with ALD have their very own private Facebook page. Should you wish to join, please contact our office. Katie & Josie Cincotta attended the **Women With ALD Forum**. Katie, a freelance writer, has published her mum's story online <https://medium.com/@KatieCincotta/the-genetic-lottery-ddaff0bd3fed#.584u54ao7>

Next year one of our main focus areas will be to lobby for new born testing for ALD. Thank you to Ruth McGowan for heading this up.

17 August 2017 – another milestone being the **25th Anniversary** of our group now known as Leukodystrophy Australia. Thank you Sr Julie Thomas OAM, our auspicious Founder. If you have any ideas about what form a celebration should take, or where, please let us know.

Best Wishes to All, Bronwyn



Renee and Thomas enjoying the benefits of St George Foundation help we have been able to give in 2016. Quote from mum, Angie: *"I have been wanting to send you a couple of photos of my kids with funding you previously helped us with, sorry it's taken so long, they do keep me busy but guess better late than never. The SMILE on their faces says it all. Thanks so much it has helped heaps!"* Thanks a bunch Angie for sharing, so lovely to see.



Our hearts and prayers go out to the families of Mark Fernandez who died 21 November aged 7 and Rayan Mougharbel who died 30 October 2016 aged 13.



Beautiful Rayan



Mark Alexander Fernandez - 19/11/2009 - 21/11/2016

"Our beautiful son, Mark, was diagnosed with Pelizeaus-Merzbacher disease when he was 9 months old. We were advised that his life would be short but we were not quite prepared for how short it would be as he had been doing so well. We aimed to make the most of our time with Mark and make him as happy and loved as we could.

In return, Mark brought such incredible love and joy to our hearts. He was the brightest star in our lives and each moment we had with him was precious and dear to us. He inspired all who met him.

Mark did a lot in his short life. He had graduated from Kindergarten and he had started at Belmore School this year where he was blossoming. He was engaging in all his classes, was loved by his teachers and therapists and making a lot of new friends. We were extremely proud of how well he was doing with this big change to his life. He was even taking the school bus all by himself. He looked so little up there on the bus but he was well looked after by the Bus Crew who befriended him.

Mark had a great love of music, Charley Bear and the Wiggles. He loved to go for bike rides and walking in the park with his 2 dogs, Hector and Archie. He loved playing on his swing with Dad and most importantly playing Dinosaurs and Roars with Dad just before bedtime.

Mark answered to many names, all given with love - Marky Mark, Marky Bear Pants, Nugget, Bug Bug and Markysauras. Mark's smiles and laughter would always bring us great happiness. We loved his cheekiness, he was our gorgeous young man and we loved him dearly. Mark passed away in the early hours of the morning at home.

Thank you to Sister Julie, Earl, Bronwyn and Bede and all at Leukodystrophy Australia for your support at this time and over the past few years." Brett & Marylou



Long Walk for Leukodystrophy Thank you to Englishman, David who saw John as they were both travelling. Although David saw John quite some months back, his sentiments ring ever more true the closer John comes to safely home Jan 2017.

"I was lucky enough to meet John at the Ti Tree Roadhouse up in the Northern Territory (mid-August). Seeing him getting ready to move off, I could not help but ask what he was up to and where he was going. John gave me a quick overview of where, how and why he was walking, which was fascinating, especially for someone like myself being so far from home (I live near Oxford in the UK). To hear of what he was doing and for what is clearly a great cause was most humbling, on top of which he is a thoroughly nice guy too. As I made my own way by car up to the North West (via Karumba to Cooktown), I had to marvel at what John was doing and he wasn't even half way yet, especially given the heat (and the bugs and the traffic and the flies...)"



Please donate now to The Long Walk www.leuko.org.au

Should you have any contacts in media, please send them the link
<https://www.youtube.com/watch?v=n-mgRZ8ILms> Media Release also available.

Genetics Alliance Australia - new and further developments in the Genetics arena: November 2016. A timely report as Australia progresses towards providing clinical genome sequencing to the public has been released following the results of a twelve-month project looking into the perspectives and needs of Australian patients and families who are considering genome sequencing. <http://www.geneticalliance.org.au/genome.php?1>



Sr Julie Greetings

Greetings to All. It is amazing to think and realise that it is almost the end of 2016! It has been a very busy year and much has been accomplished.

Firstly, I want to acknowledge all that our Office Manager, Bronwyn Byrne has done and achieved in a quiet, efficient and thoughtful way. Bronnie is very kind and thoughtful the way she thinks of those who are in need, whether it be material, counselling, or company with someone who might have a loved one with a Leukodystrophy and would like to be able to share with one who is having similar emotions and heartache. Bronnie, was thoughtful in thinking of ways of Fund Raising. She would also think of how to assist families in every State.

This year, one of our Ambassadors, John Olsen from Geelong was wishing to do a Long Walk. At present he is "Walking" and will not finish until sometime in January. If one would wish to see where he is; look up: leuko.org.au/the long walk. You may also choose to make a donation in support of him and us.

John wished to do this in memory of his dear partner and friend Vida who died as a result of suffering from AMN. He has the wish and desire to raise money to assist anyone in need!

Many of us were aware that Marylou and Mark Fernandez have had the very hard time in the death of their only child Mark Alexander on 21 November. He had just had his 7th Birthday. Mark is now at peace and happiness with a loving God.

The present Committee asked Bronnie if she could approach me to write my Biography. With the great assistance of Dr Janet Pritchard, volunteer biographer with MND Victoria and Bronnie this has been done! The Biography is on our Website. If anyone who is interested in having a read of it would like to make a Donation, please be assured it will be put to good use and very much appreciated. Copies available from the office.

May Christmas bring Joy and Peace to All and many good wishes in the New Year: 2017.

Every good wish and many special blessings, Julie





Anne Patricia – Family advocate

Hello everyone, I have been grateful to all the families I have been in contact with over the past few months. You have been very patient and understanding when I have asked you pertinent information the organisation requires to ensure our database and other organisational processes are streamlined. It makes Bronwyn's and my jobs so much easier.

This year has flown by for me and I have had the privilege of working beside current and new families. I thought I would write some words down which I feel describe the wonderful families I have worked beside this year:

Strong, resilient, caring, loving, funny, encouraging, hardworking, clever, forward thinkers, motivated, observant, patient and giving. Thank you for being open and sharing your knowledge with me, you are great teachers!

The end of 2016 is almost upon us and my hope is that over the holiday season individuals and families will have people around them who are supportive, compassionate, caring, understanding and loving. Remain safe and I hope each of you find moments to nurture yourself. Warm regards, Anne Patricia.

My usual working hours are **Thursday 8.30am to 5pm** and I will be back on 12 January 2017. My contact details: **0418 790 059** and/or: advocate@leuko.org.au.



Leukodystrophy Australia is seeking a Treasurer

This position is a voluntary position, requiring an understanding of Bookkeeping, but does not necessarily require a formal qualification.

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.

For more information, please contact Bronwyn, 0418 755 994 or info@leuko.org.au



THANK YOU!

Gary Dawson OAM & Matthew Laverly Ambassadors to Leukodystrophy Australia

Gary and Matthew run a golf series called The Charity Challenge, a unique Corporate Golf Series in support of low profile Charities. Gary & Matthew ran their first golf event in support of the organisation in 2009 in Sydney. Since then, Gary & Matt have supported the organisation in many ways, not only via continued fundraising Golf Days, but also through the all-important networking of their Corporate Supporters. Their support has been integral in allowing the organisation to continue to do what it does, as well as awareness raising. The Sydney & Melbourne Golf days, and the Gala Ball were fabulous in 2016. Corporates, friends and supporters plus The Charity Challenge's own Ambassadors, Sponsors and golfers are thanked for their generous support.

Some of the highlights below from the Melbourne Golf Day below and for more photos:

https://www.dropbox.com/sh/4clz7oreyll4208/AADd7ArasGMJBm7EP4k_87nga?dl=0



Please take a look at our website, www.leuko.org.au
Catch up with our news, and let us know if you have any stories or information to share.



Peace and All Good Wishes to You