



Christmas Greeting 2015

Welcome to our Christmas Greeting for 2015. My word for this time of year is always 'intense': the sounds, the activity, the food, but most of all the emotions. While some things are winding down and people are looking forward to a holiday and a break from routines, other things continue to happen regardless, and this can be both a blessing and a challenge.

As you will see from the information contained in this newsletter, 2015 has been a busy and varied year for us here. We started the year as 'Australian Leukodystrophy Support Group'. We end it still with that as our incorporated name but we take a fresh new image into the new year, as you will see from our name and logo at the top of this page. Thank you to everyone who has had input into this process. We have endeavoured to retain the rich heritage of the group over the past 23 years, while responding to new opportunities in the way we present ourselves to the wider community. Importantly, we have not lost what makes us 'us' as a group – everything we do remains focused on supporting families affected by leukodystrophy, raising awareness, and encouraging research into this group of conditions and their impacts.

This year, a research project undertaken by Ellie Praver highlighted the particular issues faced by women who have been diagnosed with X-linked Adrenoleukodystrophy. Ellie completed this study as part of her Master of Genetic Counselling studies at the University of Melbourne. In 2016, we are planning to hold a special forum for women who have this diagnosis, whether or not they have symptoms of the condition, and we also hope to set up some specific support networks for women in this situation. Angela Famiano and I will be working together on this and would love to hear from you if you are interested in being involved in any way. If you would like more information, please contact me on 0417 358 061.

Meanwhile, we have been able to provide financial assistance, information and emotional support to many families throughout 2015. I would like to extend a very sincere thanks to Bronwyn Byrne and Anne Patricia for all their efforts in supporting families through the year. I would also like to acknowledge the wonderful work of our Committee of Management. I hope they are all able to have a good rest over the next few weeks – they have certainly earned it!

Whatever this season holds for you, I hope that you are able to find times of peace and blessing. Although the routine work of the office will stop while Bron has a well-deserved break from Monday 21 December to Monday 18 January, we will be able to respond to urgent issues if they arise. Please email or ring the office and leave a message, and either Anne or I will get back to you as quickly as we can.

My best wishes to you for the remainder of 2015 and into the new year, and I look forward to continuing our important work together into the future.

Pam Joseph (President)

Greetings and welcome to the last Newsletter for 2015. The year has been huge for **Leukodystrophy Australia**. We hope you like the new name and all it encompasses both new and old. Our Vision remains the same - 'To Provide assistance and information to those affected by Leukodystrophy and to support research into Leukodystrophy'. On reflection, and with thanks to the collaborative effort of our group, we have achieved this outcome in 2015, in the winning of several Grants to aid and assist our families in a multitude of ways over a 12 month period. We hope you will come forward for assistance, we are here for you and thank those who have already been in touch. A huge thank you goes to the benefactors for these wonderful Grants:

♥ ConnectGroups WA

♥ Cops for Kids SA

♥ Slater & Gordon

♥ St George Foundation

♥ Turi Trust

♥ GSNV

Special thanks must go to the continued support of all the people who donated - small and large, those who supported via our memberships, to the individuals who helped along the way with events of all descriptions and sizes, and to our administrative support and fantastic volunteer Committee, to Sr Julie who continues to inspire.

Our illustrious Ambassadors Gary Dawson and Matthew Laverty of The Charity Challenge Golf Day events once again held 2 days for the benefit of Leukodystrophy Australia at Woodlands and Macquarie Links. Our office is most grateful and indeed exists because of you - thank you is just not enough. The events were also very well supported by the incredible Earl Schonberger, our wonderful and fervent volunteers Enza Dilettoso, Jenny Vick and Marylou Fernandez - we can't thank you enough! Other supporters and people we could not do without were of course the players, sponsors and donors. We look forward to growing these events and seeing more families attend too, it's a great day out. Here is a link to all the photos (Golf and Lunch) – each photo can be downloaded:

<https://www.dropbox.com/sh/l7s2x9filrkaux3/AABQxQsuy80xtggyCw2SENCa?dl=0>

Please help The Charity Challenge help us by supporting the Art Union Raffle which is still open. One ticket is all you need! Please see last page for details.

Our delightful Family Gatherings this year included TAS, SA, WA and VIC. It was so lovely to meet and share in these great days. Thanks to Kellie for organising the TAS event, to Shilandini for organising the SA event and Angela for the WA event which I was lucky enough to share in thanks to ConnectGroups WA. Through these days I am getting to know so many of you and that is indeed a thrill. If you have ideas to share around this, we would love to hear from you.

To the families of those who have passed, we wish you Peace, Comfort & Love. Our hearts are with you.

In the celebration of Christmas I wish you simple happiness and the sharing of joy with the people who mean much to you. To be successful by oneself in any task is very good. To succeed as a team is even better - Thanks Team and that means YOU! *Warm regards, Bronwyn Byrne Office Manager*



♥'Some of the 2015 Fun'♥



GESHAN'S NEW CHAIR THANKS: COPS FOR KIDS



SR JULIE & DONNA LOURENSZ @ SCIENCEWORKS FAMILY DAY: THANKS GSNV



LEUKODYSTROPHY AUSTRALIA AMBASSADORS MATT LAVERTY & GARY DAWSON WITH ENZA DILETTOSO @ CHARITY CHALLENGE BALL: THANKS TO ALL



MARIANNE FOSTER & ANGELA @ WA FAMILY ART DAY: THANKS CONNECT GROUPS



BEDE & SALVATORE @ WOODLANDS GOLF DAY



123 : 02 : 52 : 04
DAYS HRS MNTS SECS

Raffle Details

Art Union Operated under Permit number (GOCAU/1672).

All prize winners will be notified by email. Results will be published in the Australian Newspaper Friday 27th November 2015.

Tickets on sale until 8:00 pm 20th November 2015.

Net Profit from this raffle will be divided amongst the participating Charities supported by the Charity Challenge Golf Days in 2015 – see this year's events at www.thecharitychallenge.com *

• 1st Prize: The exhilarating Lexus IS 250 Luxury.

RRP (including on roads) \$61,161. A luxury sedan that seamlessly blends luxury and performance into one irresistible package. The captivating IS 250. Prepare yourself for a driving experience with an overriding focus on fun.

www.sydneycitylexus.com.au

Lexus supplied by Sydney City Lexus

• 2nd Prize: Fijian Great escape Holiday for 2 people.

RRP \$5,000

Package Includes:-

5 Nights Accommodation at the Sheraton on Denarau Island.

All transfers from Sheraton to Natadola.

Breakfasts Daily at Sheraton Denarau.

Four rounds of golf (2 rounds at Denarau & 2 round at Natadola Bay).

Closing Dinner (meals only).

\$1,000 airline voucher.

• 3rd Prize: Surreal Golfing Getaway for 2 people

RRP \$5,000

Package includes:-

3 nights at Australia's premier golfing destination with two of Australia's top 10 golf courses.

Prize includes Lost Farm accommodation at the course, Round of golf at Barnbouglie and Lost Farm.

Includes all transfers and \$1,000 airline voucher.

• Draw Date: 21/11/2015 10:00 pm

Additional Prizes

• Callaway golf sticks voucher.

RRP \$4,000

Package includes:-

\$4,000 Voucher to purchase Callaway golf products and custom fitting.



Quick Purchase

Enter in your details for a quick purchase, register to gain access to the full platform.

Select your tickets

☒ 1 x Ticket (\$20)

☐ 4 x Tickets (\$50)

☐ 10 x Tickets (\$100)

☐ 70 x Tickets (\$500)

Next: Contact Details >>

Transactions on the site are protected with up to 256-bit Secure Sockets Layer encryption.

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