



25 Years of Caring & Support



Kellie Panton, President

0458 083 883

It has as always, been a very busy time. Christmas has come and gone so quickly. I have been encouraged by your family stories and I would like to share our recent story with you. After a very successful four-week treatment with NeuroPhysics therapy in Robina late last year, my eldest, Phil, who had been wearing AFO's for 8 years, happily came home without them. Ever since, he has been doing the gym program they set for him and has been doing well. We are looking at returning to do a refresher course later this year. His Baclofen pump had been replaced and unfortunately, this set him back a bit. After a hard year, it was agreed Phil could have a holiday by himself with Contiki. He chose to go to New Zealand. Phil had a wonderful time, did a lot of walking and looking at the beautiful scenery.

It was not as smooth as we would have liked. In Melbourne, his luggage was left behind, leaving him without clothes for 2 days. Worst of all he had his crutches with his bags – you guessed it – they also were left behind. On arrival, he was wheeled to his bus and wished a good time. That is, once he rang me to find out which bus he was to catch. I booked it and printed the paperwork, putting it 'safely' in his bag.....He did arrive at this hotel, and with the help of the bus driver and the hotel manager, made it to his room. The tour guide came to see him to find out what was going on – he must have thought he was getting a guy on his tour who needed one on one care the whole time. The hotel manager bought a set of crutches for him so he was able to get around before his own arrived from Aus.



Phil really enjoyed his trip, and is now planning another. I on the other hand, am not looking forward to it. I am glad and proud he is out seeing the world, being able to make all his dreams come true, but I worried the whole 10 days!

I wish all our families a good year.



Bronwyn Byrne Office Manager

toll free 1800 141 400 or 0418 755 994

8 March saw International Women's Day: Congratulations to all our champion women out there for the courage, care, dedication, love and persistence you are showing our families and friends living with leukodystrophy. You are amazing! Please take some time for yourself. See page 5, section on Cara, is just one example where respite may assist. Please call us should you wish to discuss Respite.

This year sees Leukodystrophy Australia in the fortunate position of engaging two fabulous science students as volunteers, via GSNV, to help populate our database; and I have the great pleasure of working with them. We want to thank GSNV and our volunteers Amy Ruscigno (pictured) and Lucas Mitchell. Some of you may receive a courtesy call along the way, or please feel free to call us.

Please note our change of postal address only:

P O BOX 850 MORNINGTON 3931



The **2018 Rare Disease Day** theme slogan is *'With research, possibilities are limitless.'* Rare Disease Day takes place on the **last day of February** each year, with the main objective to **raise awareness** amongst the public and decision-makers about **rare diseases and their impact on patients' lives**. Patient organisations, politicians, carers, medical professionals, researchers and industry gathered in solidarity to raise awareness of rare diseases.

<https://www.rarediseasedayaaustralia.com.au>

Following a Rare Voices symposium at GaRDN in WA, was an Awards Ceremony. Nominated by Di Murphy, our very own Angela Famiano received the **Rare Voices Australia Advocacy and Patient Support Inaugural Award** in recognition for the extraordinary difference she has made through advocacy and patient support in genetic and rare diseases in WA. Congratulations Angela!



The amazing Sue Scott for her hard work in advocating and promoting Cystinosis won the Award overall.



The **Great Illawarra Walk** is back – **March 17 & 18, 2018** - bigger and better than ever. This year all money raised will be going towards Saving Chloe Saxby, a 9-year-old girl who was diagnosed three years ago with a type of Leukodystrophy - Vanishing White Matter Disease. Doctors at Illawarra Health Medical Research Institute (IHMRI) are working on a cure, with promising stem cell research taking place, however funding is urgently required to speed up this process.

- To register for the 2018 event www.greatillawarrawalk.com
- To find out more about Chloe and her story www.chloesaxby.com.au



We trust this message finds everyone well in 2018. The past two months have been a blur and we are still in shock at the unexpected passing of Massimo. It was an incredibly difficult Christmas without him. Massimo was the anchor of all our lives, in so many ways, and we still feel terribly lost without him. It is going to take a long time to adjust to our new normal.

Earlier today, Illumina dedicated its clinical genomics laboratory in San Diego to Massimo. Jay Flatley, Francis deSouza and Ryan Taft all gave touching tributes to Massimo on the impact he has had within the Illumina and rare disease communities globally. Massimo will now forever be watching over every genome sequenced through this laboratory each with its own unique story of hope.



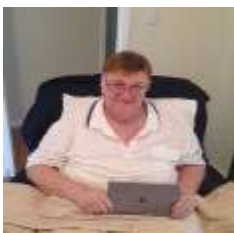
Massimo and his mission will always be remembered as an enduring example of courage, persistence, love and teamwork. Massimo showed us all what the very best of humanity can achieve working together to achieve a common goal. Stephen, Sally, Marco and Leonardo.



*Dedication in honour of Massimo Damiani.
Massimo's legacy will live on in Illumina as we work*

to fulfil our mission. This lab is dedicated to Massimo Damiani, one of the first children to benefit from whole-genome sequencing. We will always remember - and deeply feel - the passion and love surrounding Massimo. Dedicated January 2018

stephen@missionmassimo.com | **m** +61 410619173 | **w** www.missionmassimo.com



Thank you to Coopers Foundation in awarding a General Giving Grant to LA. Johanna and Chris: "We are grateful for the support we receive through Leukodystrophy Australia and we would like to thank Coopers Brewery for their funding to allow Chris to receive a new iPad which he thoroughly enjoys to watch TV programs etc., as he is confined to bed and a chair most days. In addition, I was privileged to have respite for two nights, where I felt completely relaxed and had time to myself. Once again, thanks to Coopers Brewery, without the generosity of company's like yours this would not of have been possible. You have made two people very happy.

Geshan (below) has also been a beneficiary of the **Coopers Grant**, receiving a backup generator in case of power outage. As SA residents, this is most comforting for the family and vital support for Geshan.



INVISIBLE SHADOW - Our family visit back to Sri Lanka

I am not the best when it comes to writing, especially in English, but I like to share our wonderful journey. We travelled from South Australia to Sri Lanka as a family of five at the end of November 2017 after 4 years to see extended family. As you can imagine, travelling locally with Geshan who is 17, is a challenge, so travelling overseas! Well anything is possible when you think positively.



We had a wonderful time in Sri Lanka spending time with Geshan's' granddad, aunties, extended families and friends. All were very excited to see Geshan after a long time, this youngster grownup to be young man. In addition, we travelled all around the country in our own van as well as public transport; bus and train with Geshan. See Geshan and Elisha enjoying nice shot of **scotch on rocks** in the public train! Just kidding, its tea in Elisha's hand and Geshan is nil oral.

You may think what so special about travel in public transport or in a van. Okay, to start with van or public transport does not have wheelchair access, so heavy manual handling. Our hired van is good had only one-step, whereas bus and train had 3-4 steep steps. However, good thing is always ask for help, "ASK YOU SHALL RECEIVE"; there are lovely people in Sri Lanka who were really amazed to see Geshan out in the public. Therefore, it was a matter of asking for help; do not get disappointed if one say "no", there are 10 others to say yes. In fact, four strong men to first floor of a restaurant where they had no escalator or lift had lifted Geshan on his wheelchair.

You may wonder where I am going with this. Is it about our holiday or what? I just wanted everyone to know because we have a young man with special need; it will not stop family fun, or whatever you wanted to do. Yes, we have to PLAN, plan and plan...but can achieve. As time goes on, we will have limitations of what we did 4 years ago cannot do the same today, but now or this moment is precious before it become past. Also knowing the limitations and work around can address controllable obstacles. Therefore, you have time to address unplanned rocks in your journey. We had huge rocks too, that is for a future newsletter.



Open mind and believe in you make possible take you extra mile with **invisible shadow!** Below is a beautiful place we visited a temple on a mountain. We could not take Geshan this time as it was a steep climb (but I have a plan with others help to take Geshan to this mountain next time). It called "**Sri Pada**" (meaning Lord Buddha's foot) or "**Adams' Peak**". Please see the below photo how beautiful the surroundings. See the last photo, Elisha showed me the amazing image, which is the shadow of the mountain where we were. I have climbed this mountain 3 times before, never seen it. When we are in the midst of everything we cannot see our surroundings, but I believe there is unforeseen great power. For me it is the God or for some it is Universe. **Geshan and family, Shilandini Wijethunge**



Sri Pada



The parents and individuals who share their stories help us feel less alone on this journey, if you've got a story to share, please get in touch we have a whole country of people who would love to hear your story!



♥ A big and heartfelt thank you Gary Dawson, OAM & Matthew Lavery of The Charity Challenge, and all the wonderful people who contributed in the many ways it took to make our days at Woodlands in Victoria, Macquarie Links in Sydney, and the Gala Dinner in Sydney so successful. We would be lost without you! The fundraising achieved was \$26,055



Family Advocate

0418 790 059

Email: advocate@leuko.org.au

People often ask me what I do in a day's work for LA. Here is a brief snap shot of 'The Family Advocate's working day.' Waking at 6.30 am, I begin my morning routine, then it's off to work.

My usual working hours are Tuesdays & Wednesdays 8.30am - 5pm.

Individual advocacy:

- Contact medical officers and other service providers on behalf of a family.
- Identify service provision and other appropriate resources for a new family.
- Write a support letter.

System advocacy:

- Meet or correspond with local MPs, local councilors in relation to policy development.

Administrative tasks:

- Assess and prioritise my daily tasks and reassess as the day progresses.
- Read my emails and respond accordingly.
- Daily catch up with Bronwyn and discuss any matters, which need attention.
- Meet weekly with the LA President.
- Attend to any of the LA Committee's requests.
- Write reports for the committee.
- Work on a policy or procedure.
- Document in client notes and update the database.

Community education:

- Work on a presentation for an event
- Present at a LA event.

Education and training:

- Research the internet for referenced journal articles and other appropriate information pertaining to my role.
- Attend professional development so I may continue my Australian Association of Social Work membership.
- Attend clinical supervision.

Working alongside families:

- Have a conversation with a new family.
- Call families to say hello and see if there is anything, they may need.
- Receive calls from families and service providers.
- Provide emotional support.
- Assist with financial support.
- Attend events or outreach visits.

There are always many and different priorities to manage each day.

There is so much more to achieve.



Thank you to all the families for your ongoing support and encouragement; you provide me with the strength and resilience to continue in my role as Family Advocate. I will be on **annual leave from 16 April to 30 May 2018**. During my absence, please contact our Office Manager Bronwyn Byrne. *Enjoy the softness of autumn.*



Very Special Kids has launched a significant partnership with the Royal Flying Doctor Service @[RoyalFlyingDoc](#) which will enable families living with a terminally ill child the opportunity to access respite care, no matter where they live. <http://www.vsk.org.au/road-to-respite/>

Very Special Kids helps more than 900 families across Victoria who have a child with a life-threatening condition with ongoing support from diagnosis all the way through to recovery or bereavement. The free-of-charge family support services include counselling, advocacy, sibling support, bereavement support, networking and peer activities, trained family volunteers and specialist care at the Very Special Kids Hospice. Each family is supported in unique and varying ways according to their personal needs. The Very Special Kids Hospice is the only children's hospice in Victoria where families are offered access to planned and emergency respite, as well as end-of-life care. In addition to the children's hospice and main offices in Malvern, Very Special Kids is committed to providing family support across Victoria through offices in Brunswick, Ballarat, Bendigo, Hastings, Pakenham, Shepparton, Torquay and Port Fairy.



Cara in South Australia provides support to **empower people for greater independence**. As the NDIS is rolled out to teens aged 15 to 17 from January 1, 2017 and then on to adults aged 18 to 64 from July 1, 2017 to June 30, 2018 (depending on where you live) everything at Cara will be available under the NDIS. This includes [Getaways](#), [Farm Stay](#), [Adults' Respite](#) and [Accommodation](#). Cara will work with you to meet your choices under the NDIS. Here's what some of the current NDIS children and teens are using: [Home & Community Support](#), [Kids Club](#), [Camps for Kids](#), [Children's Respite](#), [Specialist Services](#). Find out more 08 8347 4588, https://www.cara.org.au/about_us



For SA families who love music: A socially inclusive event for people with a disability and their friends every Third Sunday from 11:00 - 2:30 pm. http://www.thegov.com.au/index.php/gig_guide/gig/e83157



Are you in the early days of the journey with your child with a disability? The First Steps workshops are free and for parents of children with a disability in the early years before school. Find out more <http://www.firststepsworkshops.net.au/>

As part of their rural outreach program, **Genetic Alliance Australia** is hosting a genetics information and support services seminar. **Guest Speaker:** Michelle Stewart, Genetic Counsellor, Wagga Wagga Base Hospital. **Topics for discussion:** Genetics, NDIS Planning and fund management; siblings, accessing supports in the local area and more.

Saturday

Time:



7th April 2018

10am to 3.00pm.

Registration at 9.30am

Venue:

Commercial Club, 77 Gurwood Street, Wagga Wagga, NSW 2650

FREE

Lunch provided

This invitation is to all families and providers of disability services in the greater Wagga area. RSVP by 28 March so catering can be finalised. Please phone P: (02) 9295 8314 or (02) 9295 8359



Leukodystrophy Australia wishes to give a big thank you to Jacklyn Vick who regularly updates this section. Should you require assistance with a grant, please contact the LA office.

Please find below details on **GRANTS** for our members to review and consider applying:

Equipment and Home Modifications – SA Members

Purpose To provide equipment, home modifications and adult therapy services for people with disabilities.

Equipment: There are aids and equipment available that can help you maintain your independence. Equipment may help you with:

- Everyday tasks in the home
- Mobility
- Transferring and seating
- Bathroom, toileting and incontinence
- Communication and telephone access

Continence aids: Aids, equipment and support are available to help you maintain your independence with toileting and incontinence.

Home modifications: If you are having difficulty in and around your home, you might be able to get help with:

- Rails in and around your home
- Easy-to-use taps and switches
- Ramps
- Widening of doorways
- Alterations to your kitchen and bathroom

Contact

Email: DCSIDomCareFeedback@sa.gov.au

Phone: 1300 295 673

<http://www.sa.gov.au/topics/care-and-support/in-home-care/equipment-and-modifications>

Medical Aids Subsidy Scheme – QLD members

Purpose The Medical Aids Subsidy Scheme (MASS) provides funding for medical aids and equipment to eligible QLD residents who have a permanent and stabilised condition or a disability. The scheme helps people to live at home and avoid early or inappropriate residential care.

Overview Aids and equipment are subsidy funded on a permanent loan basis, through private ownership or the supply of consumables. If you pay for more than 50% of the cost of an item, you can choose to take ownership, rather than having a permanent loan.

Types of aids and equipment:

- Communication aids
- Continence aids
- Daily living aids and mobility aids
- Home oxygen
- Spectacles

Contact

Website: <https://www.health.qld.gov.au/mass/subsidy-schemes/mass>

Email: mass184@health.qld.gov.au

Phone: 1300 443 570

♥ Help support Leukodystrophy by circulating the following document across your networks:

Support children and adults with Leukodystrophy Through Workplace Giving

Workplace giving is where you can make regular donations through your pay cycle. You can give as much or as little as you want. **♥All donations over \$2 are tax deductible♥**



It's easy to set up – Just let Payroll know what amount you would like deducted each pay cycle and they will organise the rest!

You can also make one-off donations on top of your regular giving, and you can join or leave the program at any time.

Leukodystrophy Australia supports families', right across Australia, living with Leukodystrophy. We are not age specific.

We do this via advocacy, empowering people to connect with services such as NDIS, emotional and financial support, providing equipment, nutritional and medical expenses, respite, transport and education.

We are totally Not for Profit, receiving no government assistance. **All our services are free♥**

♥YOUR SUPPORT HELPS US MAKE A DIFFERENCE



Bronwyn Byrne/Office Manager