

Kellie Panton, President

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Hello to our existing members and welcome to our new families. With the Christmas tree finally down and the Easter eggs in stores, the year is flying. Happy International Women's Day. We have so many extraordinary women surrounding us - special mothers, grandmothers, sisters, and friends, all doing an amazing job.

Leukodystrophy Australia has been busy organizing a family gathering in Melbourne - **31 March 2019 @ Melbourne Museum**. We hope to see many of you there. This is just one of the items of support we have been able to pass on to our members, courtesy of the **Soulful Rhythms** fundraiser held by the wonderful **Shirdi Sai Sansthan Melbourne Temple**.

We are always working on Grants to hold more gatherings, amongst other things. If you are in an area you feel a Family Gathering would be great for you, please feel free to let us know info@leuko.org.au

28 February saw **Rare Disease Day 2019** raising awareness across the globe. Thank you to all those who contributed, sharing their photos, videos and stories – this includes **Robbie Avenaim** of the very innovative **Safe In Sound**. I painted my face for rare disease day, - and yes, people asked why I had colored nails and I told them all about the rare disease, Leukodystrophy. May have to do it every month....



Bronwyn Byrne, Office Manager

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Friday 8 March marks **International Women's Day** – “Joyful Greetings” to the entire unique, courageous, smart, hardworking but most of all kind women in the world, who have made life just that much easier for us through their toil and tenacity over the centuries and more recently! Lucky me, I have met and engage with many women within and around Leukodystrophy Australia. As I reflect more broadly, I realize, we still have a way to go - it is a big gig no matter where you exist! So let us all take a breath for ourselves, rest and feel good when we require and let the great work continue toward further equality, kindness, medical breakthroughs, wellness and lots of fun together.

There are many interesting stories and events marking International Women's Day 2019. Recently I came across **Little Dreamers** Australia who have been publishing in celebration of young carers they support, both male and female who through no choice of their own, find themselves in a caring role. Take an awesome peek. <https://littledreamersonline.com/>

Another tempter, a wonderful young woman I know – **Sarah Cannata** who works for **Rare Voices Australia**, now there's a great bunch of women. However in addition, Sarah has her own website and I encourage you to check out the amazing short stories brimming with inspiration. <https://www.thiswomancan.org/>



One last word from me on another great woman many of you will remember. **Pam Joseph**, our past Family Advocate and President. Pam's PhD is about to be published and she has kindly submitted a synopsis for us to share. *See page 5.*



Family Gathering: Please join Leukodystrophy Australia, **Saturday 30 March 2019** in the cafe. Our Family Advocate, Anne Patricia & Office Manager, Bronwyn Byrne are attending. We will meet for lunch (free for you) from 12.30pm or come anytime, we'll be there until 4pm. This is a great opportunity to catch up with families you may already know, make new connections, and for us to meet you. Please see Facebook or email

info@leuko.org.au for further details.



Genetic Services Network Victoria has a new logo – we love it, and we have really enjoyed and appreciated working with them over the past 12 months.

2018 was a very big year in these various collaborations centred at Murdoch Children’s Research Institute, with many support organisations, including us. In 2019, we continue the opportunity via support group events and conversations run by GSNV in the key areas of Ageing, Transition, NDIS, Mental wellness, Familial impact, and Navigating the health system.

Through their work and these collaborations, GSNV are also increasingly aware of the challenges of finding reliable resources and this has led to the development of **THE GENETIC LINK** to help provide easily accessible, useful and reliable information in one place. The Genetic Link online repository houses a wide selection of resources for people impacted by genetic conditions and those who support them – support groups, carers, health professionals and the general community <https://www.thegeneticlink.org.au/support-groups/>



Undergoing or considering genomic testing? The www.genomicsinfo.org.au website has launched – sharing a whole range of easy-to-understand **GENOMIC RESOURCES** for you.

The resources cover basic genetics and genomics, genetic and genomic testing, genetic counselling, insurance, pharmacogenomics, data sharing, cancer genomics and guidance on discussing genomic test results with family. The website also features a news and events section, information on genetic services and referral for testing.



Leukodystrophy Australia is delighted to report, Robbie Avenaim’s Safe in Sound Concert Series continues into 2019 whilst being received with much enthusiasm by our families in both NSW and Victoria in 2018/19. It is hoped, the program will expand to other states. Should you be interested, wherever you live, please

let us know. [@SafeInSoundConcerts](http://www.safeinsound.com.au) Thank you to all who contributed the heart-warming testimonials, here is just one:

“From Robbie’s first Sound Art performance with Jess, she was absolutely connected to the sounds and she had amazing engagement for extended periods. Bringing the Sound Art to Jess was extremely important because she is permanently bedridden and cannot leave our house, completely dependent upon the typically limited variety of activities normally brought to her.

Robbie initially began by listening to what we thought might be the right type of sound triggers for Jess’ enjoyment and he then proceeded to improvise with his ‘bag of tricks’, ultimately identifying the types of sounds that Jess enjoyed.

In a follow-up session with Jim, Jess was super chilled and relaxed with different types of sounds. It gave us great joy, and excitement, to take a back seat, as audience members, and watch Jess have so much enjoyment and relaxation. Her smiles & laughter, together with far less usage of the suction equipment normally very regularly required by her, demonstrated to us that with this form of stimulation, there are untold wellbeing benefits waiting to quantify. It would be interesting to be able to formally/scientifically measure the impacts of this Sound Art on more people suffering from degenerative neurological and other similar groups of diseases in order to come up with different approaches to improving their wellbeing.” — **Earl & Debbie Schonberger (Jess’s parents)**



Family Advocate

advocate@leuko.org.au

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A number of clients have contacted me recently in relation to sourcing appropriate housing for their loved ones. Appropriate housing is one of the many unmet needs for our clients and others living with a disability. I have researched some websites of assistance to those who wish to explore housing options. It is always best to gain accurate and updated information from the housing providers themselves, though I am always here to assist where I can.

The **NDIS** may be able to provide extra assistance to scheme participants, such as a Local Area Coordinator to make contact and discuss the person's needs with housing providers, and funded support co-ordination to assist sourcing appropriate housing options.

NDIS housing information

<https://www.ndis.gov.au/participants/housing-and-ndis>

For those clients 65 years and under wishing to access an Aged Care facility, NDIS is the initial provider to contact.

Young people entering Aged Care

<https://agedcare.health.gov.au/programs/younger-people-in-aged-care/younger-people-entering-aged-care-new-entrants>.

All providers I have had conversations with were generous with their time and pleasant to speak with so please do not hesitate to give them a call if you have any questions.

Housing websites

National

<https://www.thehousinghub.org.au/>

ACT

<https://www.nsw.gov.au/services/services-by-need/people-with-a-disability/housing/>

Northern Territory

<https://nt.gov.au/wellbeing/disability-services/contact-the-office-of-disability>

NSW

<https://www.nsw.gov.au/services/services-by-need/people-with-a-disability/housing/>

Queensland

<https://www.youngcare.com.au/what-we-do/housing/>

Tasmania

<http://possability.com.au/services/accommodation/>

Victoria

<https://housing.vic.gov.au/ndis-contacts-and-help>

Western Australia

<http://www.housing.wa.gov.au/currenttenants/publichousing/livingwithadisability>

Clients over 65 years of age

An Aged Care assessment is organized by an Aged Care Assessment Team (ACAT, or ACAS in Victoria) and is required for a person who needs to be approved for Government-funded services including; an aged care facility, home care, transition care or respite. Several aged care homes no longer provide respite (If you require respite then call individual facilities to find out if they provide respite). <https://www.myagedcare.gov.au/eligibility-and-assessment/acat-assessments>

Rural and remote

For those living in rural and remote areas, appropriate housing and home care services are limited and families often don't have wide choices with which service providers, housing options or Aged Care facilities they may access. Families often have no choice but to travel long distances to visit their loved ones. This places a huge strain on families and it often helps if the facilities have family gatherings so families may build rapport with staff and other residents' families. These peer support networks often provide families with some peace of mind knowing their loved one is being supported by other caring people.

Deciding on housing

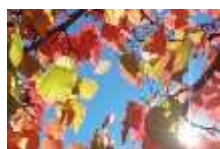
When exploring housing options, try to make the time to visit the house or facility several times to gain some insight into the culture, environment, staff and the care provided. It is not only the aesthetics of the building you should be considering, it is the care offered to your loved one, the quality of the food, daily menu, access to your or other medical officers, the provision of internal or external allied health and palliative health care professionals, internal and external social activities. As a previous RN in charge of community housing and residential care facilities, I have always encouraged people to chat with other family members and residents and ask questions. Staff are often willing to answer questions and if they don't know they should be directing you to someone who does, such as the house or facility manager.

In September, Prime Minister Scott Morrison announced a Royal Commission into Aged Care. You will be pleased to know that young people in Residential Aged Care facilities and the issues related to this cohort are a high and early priority for the Royal Commission.

I hope this brief information may assist some of our families. If you ever require support in relation to housing or anything else, or even just want to pick up the phone to have a chat, please feel free to give me a call and I will do my very best to support you.



The banner is purple with white and blue text. On the left, it says 'GET BUILDING SDA'. In the center, it says 'National Conference 2019' with three house icons below it, and '22 March 2019 Melbourne'. On the right, it says 'Connecting NSW Events' with '1-12 April 2019' and 'Sydney, Dubbo, Wagga, Penrith, Tweed Heads' below it.



I am looking forward to meeting the families who will be attending our Melbourne Family Gathering 30 March 2019.

Kind regards, Anne Patricia, Family Advocate.
Enjoy the beautiful autumn leaves.



SOURCEKIDS DISABILITY EXPO

Source Kids Disability Expo in **Melbourne** on March 29-30, 2019 focused on children, youths and young adults up to the age of 25. This two-day event will bring together the latest disability **products, services and technology**, along with some incredible speakers all under one roof. With the **NDIS** continuing to roll out through Victoria - the Source Kids Disability Expo will be focused on giving people with a disability and their families and carers the opportunity to **find and try out** products and **talk** with providers at a crucial time in their NDIS planning process.



YoungCare At Home Care Grants are currently open in Victoria and Tasmania. Please take a look. If you would like assistance, please let us know or call Youngcare, they are most helpful. www.youngcare.com.au/what-.../grants/home-care-grants/



Did you respond to our **Survey 2018** emailed out by Kellie Panton, mid January 2019? **We would love to hear from you.** Please contact Kellie if you would like another copy sent kelliepanton@yahoo.com.au thank you!



I would like to wish all our families and individuals the very best in every way and that the season of Autumn will be pleasant weather for us. Once again a sincere thank you to all Committee members who work so generously without any fuss. **Julie csb OAM**

Parent carers' perspectives on their relationships with complex service systems: Summary of research project.



The study was about the ways that parents of children with high-level care needs understand their own relationships with a range of service systems. My interest in this area came about through my previous social work role with Leukodystrophy Australia (then ALDS). As I listened to parents talk about their experiences of dealing with service providers and systems, it appeared to me that this often took up a huge part of their lives, and came to affect the way they saw themselves too. I could find little academic literature that focused on parents' perspectives on this topic, and so this project came into being.

A total of 21 mothers and 6 fathers took part in interviews, across five Australian states. Some families lived in large metropolitan cities, while others were in regional or rural areas. The ages of the children they were caring for ranged between 2 years and 42 years at the time of the study, with a wide range of conditions leading to the children's increased support needs – some genetic or chromosomal, others acquired through injury or infection, and for many families, the causes of their children's conditions were unknown.

From the information parents shared, a strong theme of individual variation emerged. Some parents told of very positive experiences, where service involvement was an important and valued part of their lives, and relationships developed over the course of months or years in a mutually respectful way. Others shared examples of great stress and frustration, adding to the broader challenges they faced rather than alleviating them.

The analysis also showed that parents had very complex and individual views about their own identities. Many used specialised skills and knowledge as they cared for their children. At the same time, a lot of parents had service providers involved in their day-to-day lives, including in the home and family events, so that the usual boundaries between what we often term "informal" and "formal" care were less clear, and could be understood in many different ways.

The study showed that service systems are often designed in a way that fails to acknowledge or respond to the varied, often unusual, and maybe changing concerns of parents whose children need high-level care. It demonstrated the value of flexibility and continuity, so that providers and parents could work together and build trust in a mutually respectful way, sometimes over a long period of time. It also demonstrated the potential for more effective integration of services across sectors such as health, disability, education, community services and others. This was particularly so at times of transition from one service or sector to another, which often reflected the structure and function of services, rather than the unique life experiences of families.

The good news is that parents also shared examples of service providers and processes that were positive, and indicated the benefits not only for parents, but also for children and service providers, when this happens.

I have been sharing the findings of this study at conferences, meetings, and in conversation whenever opportunities arise, and will continue to do so. I am very happy to provide presentations to meetings of carer networks, service providers or others, as opportunities come up.

I am also preparing a number of academic articles for publication, and I hope in this way to make a contribution to the way parents' perspectives are understood, and maybe also to lead to further studies by other researchers.

Policy change often includes a submission process, in which interested people and organisations can express their concerns and priorities, and this research will help me to write submissions on relevant topics as the opportunities arise.

Finally, I am keen to speak alongside families, not over them. I hope that future research can occur in a way that increases parents' participation in every step of the project, from design to sharing of findings. I know that at some times in life, there is simply not time or energy to do this directly, and parents need someone to help get their voices heard. However, if people would like to be involved in future research in some way, whether small or large, I would love to hear from them.

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For information on Leukodystrophy Australia www.leuko.org.au, events, volunteering, joining Committee, please contact Office Manager, Bronwyn Byrne 0418 755 994, or email info@leuko.org.au