



## newsletter / spring 2021



Dear families and supporters of Leukodystrophy Australia,  
Welcome to the Spring edition of our newsletter,  
Melbourne put on a great weather over the past week.  
I hope you are getting a chance to get out for fresh air  
during these unfortunate times. I'm sure the lockdowns  
will be over well before summer starts.

We have a few events planned over the next couple of  
months, we are yet to know whether these will go ahead.

The Western Australia Family Gathering is an exciting opportunity to meet other  
families and connect over lunch. If you haven't already registered we encourage  
you to do so asap.

We are also pleased to see a great number of membership renewals, thank you!

We hope you enjoy reading the newsletter and look forward to seeing you at our  
virtual AGM.

**Hala Raghieb, President**  
**0411 625 775**  
[president@leuko.org.au](mailto:president@leuko.org.au)

### Events & Meetings

<b>8 October</b>	<b><u>Charity Challenge Leukodystrophy Australia Golf Day</u></b> Long Reef NSW
<b>30 October</b>	<b>Family Gathering Western Australia</b>
<b>20 November</b>	<b><u>18th Charity Challenge Gala Dinner</u></b> Hyatt Regency, Sydney, 6:30pm
<b>8 December</b>	<b><u>Charity Challenge Leukodystrophy Australia Golf Day</u></b> Woodlands

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## A message from Sister Julie

I know that many of you know about Janet, my sister's death, on August 15th. Janet had been unwell for a short time, and I wish to make it known to all that she was beautifully cared for; all staff were very kind and gentle with her. She very often said, "Aren't they

so kind and good". I seldom heard her complain, which is wonderful!

Everyone has been very kind to me and they are aware that I am by myself. Janet was very kind and extremely generous to me. Naturally I miss her very much, but I am grateful she is free of suffering and pain and now enjoying God's

presence. I have many happy memories of her; she frequently checked if I was OK.

I would like to express my thanks to all who have been in touch with me in the last fortnight. The different ways that LA people have sent me messages of sympathy; I have tried to answer some, but I am struggling to be in touch with all! I need a private secretary.

Best wishes to all & my sincere gratitude to everyone.

**Julie Thomas CSB**

**Telephone** 0412 535 113

**Address** 4 King Street East Hawthorn 3123

## Family Advocates' Report



**Anne Patricia**  
0418 790 059



**Kylie Agllias**  
0418 755 994

With this newsletter we welcome the warmth of Spring, and hope that it brings some sunshine to our members, families and supporters. September

is also Leukodystrophy Awareness month, which encourages us to think and talk about leukodystrophy and rare disease, especially with people who may not be aware that such conditions exist, or understand the impacts they bring. With this in mind, we are really pleased to introduce two more of our members in this newsletter. Thank you to Nathan and Josie for their stories. We will continue to bring these stories, as well as introductions to our staff and committee members, in upcoming editions, on Facebook and on our website.

We would also like to welcome individuals and families who have

joined us since June. It has been a privilege to meet, and work with, you at this time. We hope that you will feel supported by the collective strength of the Leukodystrophy Australia community.

Finally, we send special acknowledgement to those experiencing ongoing lockdowns. The interactions we are having with families consistently highlight the additional burden Covid-19 carries for some, especially when they are restricted from attending allied health appointments and facilities such as hydrotherapy pools. Please reach out to us if we can support in any way.

**September is  
Leukodystrophy Awareness  
Month**



One percent.  
One step closer.



By donating just **1% of the commission** from your major property sales, you can make a world of difference to families living with Leukodystrophy.

#### What is Leukodystrophy?

Leukodystrophy is not one thing. There are over 50 Leukodystrophies that are rare, genetic disorders that affect the white matter of the brain and spinal cord. They are degenerative disorders that lead to the deterioration of the body's neurological functions.

Leukodystrophy occurs in approximately 1 in 7,000 births. Due to the rarity of the disorder, it can often be difficult to diagnose, but it is fatal, with no known treatment or cure.

Leukodystrophy Australia has been set up to assist children and adults living with the disorder, their families and carers, to lead their best lives and continue the pursuit for a cure.

#### How can you help?

Leukodystrophy Australia are asking Real Estate Agents and Property Developers to **donate 1% of the commission** from major sales to the charity in order to continue to support the affected and pursue new treatment options.

Every 1% received will bring us one step closer to finding a way to combat this terrible disorder.

If you're interested in supporting this cause, please register your details below and we will contact you. Alternatively, you can always contact us using the information below

REGISTER NOW TO HELP

1800 141 400 (Toll free)  
info@leuko.org.au

WWW.LEUKO.ORG.AU  
1PERCENT.ORG.AU

## We are very excited to announce our new fundraising 1PERCENT campaign

Everyone can help. If you know real estate agents or property developers please tell them about 1PERCENT. Share with your local agencies. If you are selling your house, you may elect to ask the agent to donate 1PERCENT.

To find out how, visit [leuko.org.au/support-us/1percent/](http://leuko.org.au/support-us/1percent/)

### SNUG Retreat for Leukodystrophy Australia Families

The **SNUG** project has invited our families – those who have a child with leukodystrophy – to attend a residential retreat in **Lake Macquarie, NSW**, from **Friday 25th February to Monday 28th February, 2022**. The whole family attends the retreat together and a program of activities is designed so that EVERY attendee can participate. All accommodation, meals and activities are provided.

The retreats:

- Aim to create a relaxed environment for families to build on their strengths, improve resilience, and develop friendships and support networks with others who are experiencing similar challenges.
- Focus on identifying and celebrating the skills and strengths of ALL family members – parents, children with special needs, and their siblings.
- Provide a wide range of activities over 4-5 days which are designed so that all can participate – including music therapy, art therapy, physical activity and outdoor recreation, craft, sensory play, and parent discussion.
- Are supported by a team of trained volunteers.
- Are the only retreats of this kind in Australia.

**SNUG** is coordinated through the Family Action Centre at The University of Newcastle and is assisted by the **Steve Waugh Foundation**.

If you are interested, or require more information, please contact:

**Kylie Agllias** 0418 755 994 Email [info@leuko.org.au](mailto:info@leuko.org.au)  
Or email **Liz** at **SNUG** directly: [snug@newcastle.edu.au](mailto:snug@newcastle.edu.au)





## Meet our Families: Josie's Story

This is Josie, pictured with her loving family, and her little dog (Poppy). Josie has X-linked Adrenoleukodystrophy and she is a valued member of Leukodystrophy Australia. Josie says that "the simple act of talking, listening and sharing our stories makes us feel less alone, less forgotten, better able to face the daily struggles". Her story - from diagnosis to living through Covid-19 - has been documented beautifully by her daughter. Josie's story can be accessed on the Leukodystrophy Australia Website.

See *The Genetic Lottery* by Katie Cincotta. [Our People, Our Stories | Leukodystrophy Australia](#)



## Meet our Staff: Anne Patricia, Family Advocate

### Why do you like working for LA?

I feel privileged working beside our families, I find them selfless, kindhearted, humble and wonderful advocates for their loved ones.

### If you weren't a Social Worker and Registered Nurse, what might you do professionally?

A dramatic actress with a degree in Ancient and Modern History majoring in Archaeology. An archaeological expedition to Israel would be fabulous.

### What is your favourite movie?

Adult: *Wuthering Heights* (1939), starring Sir Laurence Olivier and Merle Oberon.

Children's: Walt Disney's, *Snow White and the Seven Dwarfs* (1937).

### What is your favourite TV show?

*Law & Order: Special Victims Unit* (SVU) starring Mariska Hargitay and Christopher Meloni. To be on *Bargain Hunt* is one of my dreams; you never know what interesting items you would find to auction.

### What book are you reading now?

*The Amazing Story of Forgotten Hollywood Star Mary Maguire*. Australia's Sweetheart. Plus, the children's version of 'Little Women' with my Granddaughter Acacia (Mooshi).

### Of those close to you who has been your inspiration?

My parents, maternal Grandmother, Godmother, Mr Stephens my teenage Minister, my modern history teacher Miss Anne Slattery, my husband Peter, and my friends.

### If you had a choice of one leisurely experience on your days off work, what would it be?

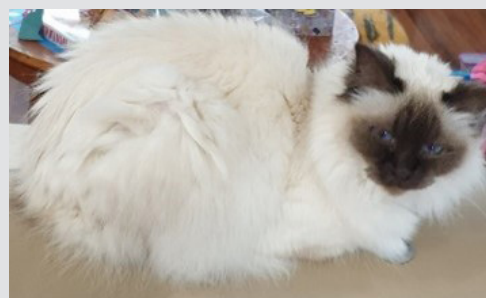
I love going to live theatre and musicals, amateur or professional.

### What is your dream holiday?

Great Britain, across to Israel with a special trip the Garden of Gethsemane, Italy to eat pasta, Germany to eat Black Forest cake in the Black Forest and across to Russia to visit the Tsars Palace and then find a restaurant and eat oysters with Russian caviar.

### What meal do you cook best?

Fish stir fry with Thai peanut and chilli sauce for Peter and I. Smoked salmon and caviar bow pasta with garlic creamy sauce for Mooshi and I.



Pictured: Our Birman cat Cadbury sitting on our lounge watching Acacia crafting



## Meet our Committee Members: Dominik Froehlich



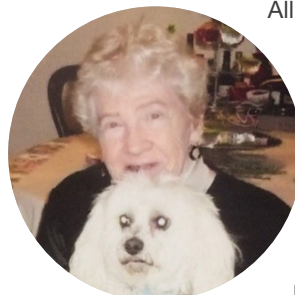
Dominik joined the Leukodystrophy Australia committee in 2019. His interest in leukodystrophies developed through his profession – he is a neuroscientist and works in the Translational Neuroscience Facility at the University of New South Wales in Sydney.

Dominik is of German heritage and relocated to Australia in 2014 after completing his PhD at the University of Mainz in Germany. As a neuroscience researcher he is aspiring to understand how the brain works – in its normal, physiological state but also when diseased. Since he started working in Australia in 2014, his research mainly focused on the white matter of the brain and specifically on leukodystrophies.

The current emphasis of his research is on the leukodystrophies Hypomyelination with Brain stem and Spinal cord involvement and Leg spasticity – short HBSL and Canavan disease. To advance the understanding of these devastating conditions, Dominik and his team are developing genetic disease models, which will help unravel the underlying pathophysiology and disease mechanism and will be instrumental for the development and testing of novel experimental therapies.

A second arm of his research is focused on establishing innovative new gene therapy strategies for the treatment of leukodystrophies. This line of research has delivered promising results, which – one day – hopefully will make a difference for people suffering from leukodystrophies.

## In Memoriam



All of us at Leukodystrophy Australia (LA) would like to acknowledge the passing of Sister Julie's beloved sister, Janet Hudin. Janet passed away peacefully on the 15th August 2021, she was 91 years of age.

Janet was beside Sister Julie when she founded the Australian Leukodystrophy Support Group (ALDS), now known as Leukodystrophy Australia, over 29 years ago in Melbourne. Janet was a wonderful supporter of LA and so kind to the families she encountered over the years.

Sister Julie and Janet were fortunate to live together over the past few years at St Vincent's Care Services Hawthorn. They shared many special moments together and their love for each other is timeless.

Janet is now with our Lord and knowing Janet is with Him provides much comfort for Sister Julie, her family, friends and others. Our love and Prayers are with Sister Julie and all others who knew and loved Janet.

**In loving memory of Janet Hudin:**

**7th September 1930 – 15th August 2021**

Janet pictured with her dog Tiffany (Tiff)



**NORD®**  
National Organization  
for Rare Disorders

## NORD News

The National Organization for Rare Diseases offers an array of information that may be of interest to readers, including a podcast called NORDPOD, and YouTube Channel. Registration is now open for the NORD Rare Summit 2021, a virtual event run October 18-19. This multi-stakeholder event, brings together participants spanning the rare community, including rare disease experts and leaders from patient advocacy groups, government, industry, and academia to discuss the most current and critical topics related to rare diseases and orphan products.

Use this link to register:

**[Personal Information - 2021 Virtual Summit \(cventevents.com\)](https://cventevents.com)**



Australian Government



**Disability Gateway**  
Connecting you to information and services

## Disability Gateway

The Department of Social Services has developed a way to improve access to information for people with disability, their families and carers, by creating the National Disability Information Gateway. The new Disability Gateway is your first step in finding information and services within Australia.

**[Welcome to the Disability Gateway | Disability Gateway](#)**



## Making meaning of complex losses

As human beings, we often strive and struggle, to make meaning of our lives. Researchers increasingly understand that meaningfulness is a vital element in our health, well-being and quality of life. However, there are certain experiences that are almost impossible to make meaning of. For example, the diagnosis of a rare disease, like a leukodystrophy, brings a series of interconnected losses that potentially undermine one's ambitions and expectations for life. The person who is diagnosed, and indeed the family system in which they reside, is forever altered. This type of experience is referred to as an ambiguous loss, where people are physically present but psychologically changed, and where closure is elusive. I would also suggest that this is a disenfranchised loss, where there is a lack of social awareness and understanding about the nature and

extent of the person's experience. There is minimal acknowledgment that (i) loss has occurred, and (ii) losses will continue to occur across time.

Since commencing at Leukodystrophy Australia, I have been witness to the rich, courageous and important ways that families work to make meaning of their experiences. These have included: creating and giving to community; through faith, spirituality and ritual; by raising awareness and seeking recognition; and, through the psychological acceptance of ambiguity.

While we still have much to learn about living with ambiguous loss and disenfranchised grief, we know that these strategies are vitally important. We can also be certain that connectedness is core to resilience and reaching out is a sure sign of strength.

**Kylie Agllias (Family Advocate)**



### Family Gathering planned for Western Australia

**A Family Gathering**, will be held on **Saturday, 30th October, 2021**. The event will be held at **St Catherine's on Park, 2 Park Road, CRAWLEY, Western Australia, 6009**.

We are currently finalising our arrangements, so thank you if you have already confirmed your attendance. If you wish to attend, and have not been in contact, please do so today.

We are hoping to make it a joyous, memorable and fun day for all.

**Anne Patricia** 0418 790 059

**Kylie Agllias** 0418 755 994

Email [advocate@leuko.org.au](mailto:advocate@leuko.org.au)

### In Memoriam



Rose Alafaci was a very good friend of Sister Julie's. Sadly, Rose passed away on the 21st July 2021. She was 91 years of age. Rose is now in God's care. We would like to send our condolences and heart felt warmth to Rose's family, Sister Julie, her friends and all others who knew and loved her.

"Rose has been a wonderful woman, in many ways. The most vivid memory I have of her is deciding how to raise funds for Leukodystrophy. Many years ago, we had functions at the Dining Rooms at the Caulfield Racecourse. Rose, together with her husband Rock, would arrive with many goods she made as prizes and a variety of Raffles. It was obvious she spent many hours preparing in different ways, so people were able to purchase different items to win a Raffle.

Rose is remembered by many as being an outstanding Benefactor to Leukodystrophy Australia.

I feel a little guilty and sad that I did not know until it was too late that Rose was very ill and is now at peace. I trust that some will remember her wonderful goodness and her gracious kindness." Sister Julie Thomas.

**In loving memory of Rose Alafaci:**  
**12 October 1929 – 21st July 2021**

## This is Your Space

Do you have a story to tell, or a contribution to make, to Leukodystrophy Australia's Facebook page or Newsletter? Please make contact with Anne or Kylie to discuss. It is really important that we represent and share the range of experiences and requirements of our members.

We would love to hear from you.

**Anne Patricia** 0418 790 059

**Kylie Agllias** 0418 755 994

Email [info@leuko.org.au](mailto:info@leuko.org.au)



## Meet our Families: Nathan's Big Bike Ride — Raising Awareness of Rare Genetic Conditions



At 30 years of age, Nathan McDowell lives with Pelizaeus-Merzbacher Disease (PMD) and Cerebral Palsy and he is wheelchair bound. His diagnoses have not stopped him from following his heart and completing a long-distance ride on his hand cycle.

On March 8th to March 13th, 2021, Nathan rode 120 kilometres from Noosa

to Sutton's Beach in Redcliffe Queensland. Matthew Bell, Nathan's support worker, assisted him in his preparation and cycled beside him all the way. The journey was not without challenges for Nathan, but he powered forward with a determined mind and spirit.

Nathan has a supportive, loving family, including his father Gavin, stepmother Robin and his sister Danielle. The staff at Holistic Horizons; Matt, Julie and others, are proud of Nathan and are always willing to assist him work towards his goals.

Thank you, Nathan, for raising funds and awareness for Leukodystrophy Australia and other rare genetic conditions. We appreciate your kindness and generosity.

Nathan is planning another ride in 2022 so keep an eye out for him on his Facebook and his GoFundMe page. Let's all get behind Nathan!

Dreams do come true and what an inspiration Nathan is to all of us.

Nathan's Big Ride was sponsored by Holistic Horizons, and supported by The Breakfast Club Redcliffe.

**Anne Patricia (Family Advocate)**



## The Australian Carer's Survey

Hello, my name is Monique Garcia. I am the mother of Nathan, who suffers from two rare diseases. Nathan is the catalyst for me to undertake my PhD at Edith Cowan University. My research seeks to understand the impact of caring with regards to health status. Participating in this survey ensures your voice is heard! Participation is completely voluntary, and you are free to withdraw at any time. As a carer, I sincerely thank you for your interest and potential involvement.

You can access more information, ethics approval and the survey here:

[www.thenathanproject.com.au](http://www.thenathanproject.com.au)

## Have you forgotten to renew your membership? It's not too late

Members are the essence of our organisation. Leukodystrophy Australia works with its members to achieve goals that benefit all people living with Leukodystrophy, with a specific focus on individuals and families living their best lives. Our members are vital to raising awareness of leukodystrophy, writing grant and policy submissions and keeping our organization relevant. Please initiate or renew your 2021-22 membership today. Applications can be found on our website, [Membership | Leukodystrophy Australia](http://www.leukodystrophyaustralia.org.au). Or contact us directly and we will forward it on.

Thank you