

## Inside the February 2018 e-Newsletter:

- **Parramatta Picnic**

- **The blood type you didn't know you had**

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**Issue 3 Feb 2018**

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MailChimp



**Thalassaemia**  
**Society of NSW**

## **Our 40th Year Anniversary**

A special welcome and thank you from the President

This year marks the 40<sup>th</sup> Anniversary of the Thalassaemia Society of NSW and I want to pay special tribute to the wonderful people who have dedicated their time to establishing and contributing to the success and longevity of the Society for these past 40 years.

We will be forever grateful to the foundation members for their determination, passion and commitment for establishing the Thalassaemia Society back in 1978. On behalf of all the members, past and present, we owe you our gratitude and heartfelt thanks.

Since that foundation, the Thalassaemia Society of NSW has been a pillar of support for many patients and their families and friends as they have come to grips with understanding and managing the impacts of Thalassaemia and Sickle Cell Anaemia in

their daily lives. The Thalassaemia Society of NSW has supported people through some of the toughest of times and it has been at the centre of education and advocacy.

Over the past 40 years, the Thalassaemia Society of NSW has raised huge amounts of money for medical research, medical equipment, social & respite activities and resources to improve the treatment centres for patients. All this success has been achieved from the many people that have donated and volunteered their time and energy to our important cause for over 40 years. I want to thank each and every person who has dedicated their time either by serving on the Committee, volunteering at our functions and events or donating generously to our cause. Our success has been built on the back of your efforts and commitment and I wish to pay tribute to you.

As we enter our 40<sup>th</sup> Anniversary, I believe it is more important than ever that we unite and work towards growing and supporting the Thalassaemia Society. In order to continue to succeed and to honour those who have given so much in the past, I ask for your support and assistance in helping make this year a big year of celebration and to help us in our plans as we try to improve and grow the Thalassaemia Society of NSW into the future.

**Founding Members and Supporters**

<b>With Thanks and Gratitude</b>	Dr Vasili Berdoukas	Professor Ron Trent
Dr Bau	Dr Sandy Robertson	Dr Boyd Webster
John & Angela Dimitrakas	Elizabeth Karamihalis	Niki Lanpitsi & Jane Lampitsi
Mary Lathourakas	Alex & Effie Margaritis	Fred & Maria Matsas
Jim & Kitsa Michalopoulos	Peter & Ellie Phontos	Sotiris & Mark Tirris

**A peaceful bull, crazy goat and a fuzzy doggy had our families laughing at the movies**



Thanks to all the families who came along to our recent Holiday movie event. Ferdinand was the movie and it was a lovely story with a peaceful message ... All our families loved it !!! Next time we hope to get more families to come along.

## Family Fun and Games at Parramatta Picnic



We were lucky - we had a beautiful day, sandwiched between two blustery, rainy days - and a great time for our Family Picnic on December 3rd. Thanks to all the families who made it a great day and who brought a huge variety of treats to share. To the volunteers, thank you so very much ... your help was amazing.

Thanks to Ady and Grainne – the CNCs at Westmead & Sydney Children’s Hospitals – for your help and organising support and a special thank you to Christine Luna and to her family for their superb fundraising and organising work.

A special mention to Phil & John who sweated it out in blazing sunshine to cook up a huge bbq. It was lovely to meet a large family group from Canberra, and two doctors - Tatjana and Juliana - from Westmead Children’s Hospital who came to enjoy the day with the families. Thank you to the businesses who donated services or gave discount. For a list of supporting businesses and more picnic photos, please visit our Website.



## The blood type you didn't know you had!

Sometimes it takes a rare occurrence for us to understand the commonplace. In world-leading research, Blood Service scientists have worked with colleagues in Thailand to uncover a blood group that until now has hidden in plain sight.

Apart from the commonly known ABO and Rh blood groups, there are hundreds of possible variations in blood type, encoded in our genes and reflected in small changes on the surface of red blood cells.

Accurate matching of these blood groups is particularly important for people who require frequent blood transfusions, such as those with diseases like thalassaemia or sickle cell anaemia. Frequent transfusions with blood that is not a perfect match may lead to the development of harmful antibodies. This is what happened to one patient in Thailand and it is his antibody that begins our story.

**To read this full fascinating story visit:**

<https://thalnsw.org.au/?q=blood-type-you-didnt-know-you-had>

Thanks to David Rosetto, Community Relations Officer, **Australian Red Cross Blood Service** for this article.

**Support Thalassaemia Australia [Red 25 Group](#) Blood Initiative**

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## Coordinator update

Since July we've spoke with 1,200 people to raise awareness of carrying the genetic trait for haemoglobin disorders, and remember, the simple **blood test** to know if you carry the trait is covered by **Medicare**.

Some people have told us that their GP stated the test costs several hundred dollars. The GP may be referring to genetic analysis which is different and more detailed. The blood test is the first step, and probably a sufficient step for most people. It is covered by Medicare. The need for further analysis would be discussed after this test. Make sure to ask for the following:

- A full or Complete Blood Count
- Ferritin studies
- A Hb EPG (Haemoglobin Electrophoresis) check

As well as working on some projects with Spleen Australia and Genetics Alliance, I have been updating our website - **Why not check out our new & updated pages:**

[Child & Family](#) : [Info for Patients](#) : [Getting a Test: What you need to know](#)

Finally, we had a successful awareness stand at the Greek Festival Sydney with over 250 people visiting the stall and asking questions or giving their support including a visit from the Greek Consul General. Congrats to the Greek Orthodox Community of NSW on a great festival.



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## Healthy Tips

Each newsletter we will feature a good health section, whether about good mental, physical or emotional health or perhaps introducing some learning about thalassaemia or sickle cell

anaemia. In this edition, we highlight two initiatives:

### Active Kids Program NSW

The NSW Government will provide \$100 rebate through a voucher system to parents/guardians of school enrolled children for registration or participation in sport and fitness activities ... Visit: <https://www.nsw.gov.au/news-and-events/news/how-to-claim-the-active-kids-rebate/>

### Better Mental Resilience for 2018

Stress Less Tips is an initiative of WayAhead - Mental Health Association NSW. 10 easy-to-do 'Tips to Stress Less' are developed each year to help support mental health and good well being ... Visit: [www.stresslesstips.org.au](http://www.stresslesstips.org.au)



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## Some interesting articles

Some new articles and some we shared on Fb but you may have missed:

1. [What are the different phases of clinical trials:](#)

<https://www.verywell.com/what-are-the-different-phases-of-clinical-trials-2249410>

2. [CRISPR Therapeutics plans its first clinical trial for genetic disease](#)

[https://www.wired.com/story/crispr-therapeutics-plans-its-first-clinical-trial-for-genetic-disease/?mbid=social\\_fb\\_onsiteshare](https://www.wired.com/story/crispr-therapeutics-plans-its-first-clinical-trial-for-genetic-disease/?mbid=social_fb_onsiteshare)

and

3. [First human CRISPR study in the US could begin soon](#)

<https://www.engadget.com/2018/01/18/first-human-crispr-study-in-the-us-could-begin-soon/>

4. [www.yourgenome.org](http://www.yourgenome.org) - An interesting and colourful website to learn more about genetics and the implications for health and society.

5. [Difficult Choices: Would-be parents urged to screen for genetic disorders](#) - Sydney Morning Herald

<http://www.smh.com.au/national/health/difficult-choices-wouldbe-parents-urged-to-screen-for-genetic-disorders-20171004-gyuhq7.html>

## Upcoming Events

We had a great weekend of awareness raising and meeting old friends at the **Greek Festival**. We are planning events for International Thalassaemia Day as well as other patient & member events – please do watch this space, as the saying goes !

## What to do when you have a Temperature

We are sharing some useful patient advice from **Red Cell News** - the patient newsletter run by the CNC (Leanne Crnek) at POW Hospital: - **Thanks Leanne!**

If you have a temperature of 38°C with shaking and chills please seek medical advice and complete the following:

**- Desferal**

Stop administering Desferal

**- Deferiprone (L1)**

Stop administering Deferiprone and have an urgent blood test - Full Blood Count

**- Exjade**

Continue to administer

**If your spleen has been removed or you have Sickle Cell Anaemia**

Administer your first dose of home supply of emergency antibiotics

- Take Amoxicillin 3g (6 x 500mg tablets) - OR
- Erythromycin 1g four times per day - OR
- Roxithromycin 300mg daily
- Then seek medical attention immediately

**If you are unwell without a temperature, continue with chelation medication and see your GP.**

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**Book us** for an **awareness workshop or stand** at your workplace, school, community group or faith group.

**What is Thalassaemia? Could you carry the sickle-cell trait?**

email: [coordinator@thalnsw.org.au](mailto:coordinator@thalnsw.org.au)

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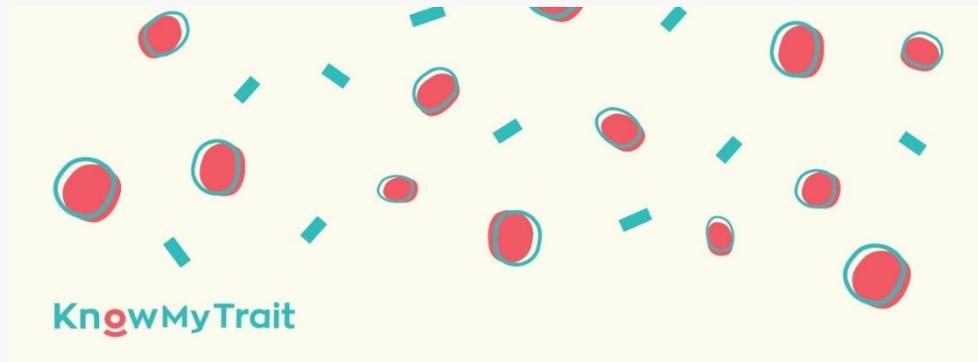
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[www.knowmytrait.org](http://www.knowmytrait.org)

The aim of the **Know My Trait** campaign is to engage a young and '*unaware*' community to learn about *potentially* being a genetic carrier of thalassaemia or sickle cell anaemia trait; and to provide steps on how to get a test and take informed action.

We say '*unaware*' as carriers have few symptoms and are often unaware they carry the trait.