



Thalassaemia and Sickle Cell Australia

Unifying Support and Genetics



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Connect with TASCA: Latest News and Updates

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TASCA acknowledges Australia's first people as the traditional custodians of the land on which we meet and provide our services to those affected by genetic haemoglobin disorders. We pay our respects to them and their cultures, and to Elders both past and present.

Stay connected, stay informed, and look forward to our monthly newsletters!

TASCA MONTHLY



Pat Bollard

Chairperson
Thalassaemia and Sickle
Cell Australia

From our Chair

As we steadily prepare for the following festival season, TASCA continues to pursue opportunities for advocacy and community support.

These are outlined within this edition of our newsletter, however I would like to highlight a recent meeting involving TIF and organisations in the Asian & West Pacific regions. Our meeting included representatives from China, the Philippines, Malaysia, Vietnam, Hong Kong, New Zealand, Indonesia and Singapore. We had a very successful meeting and plan to meet again in the new year to establish a regional network of Thalassaemia organisations. Our ever-reaching goal is to create a strong, inter-connected community focused on strengthening best practices for all.

Our 2025 AGM was very well attended and I want to thank everyone for their participation and support.

Through our connection with the Genetic Services Network Victoria (GSNV) and Melbourne University, we are extremely fortunate each year to host Masters of Genetic Counselling Students in their final placement. Sarah Bainbridge and Eleanor Fuller, this year's students, have completed a very successful project, aimed at young patients, which will be published in due course. I would personally like to thank both Sarah and Eleanor for their

diligence, enthusiasm, commitment and dedication to their work. I wish them both the very best of luck in their future endeavors.

Finally, in recent weeks, I met with the Brisbane Lion's Club of Chinese group to discuss TASCA's work in advocacy and education. Following on from that meeting, the group made a significant financial contribution and have undertaken to help with fundraising in Brisbane. A sincere thank you to Ella Luong, whose tireless support of TASCA transcends state boundaries.

As always, if anyone wishes to discuss any matter or raise any concern with me, please do not hesitate to get in touch at info@tasca.org.au or by phone at (03) 7015 5637.

A handwritten signature in black ink, appearing to be 'Pat Bollard'.

TASCA MONTHLY - TASCA Updates

TASCA'S 2025 AGM

TASCA's 2025 AGM took place on Monday, 20th October. We would like to thank everyone who took the time to join us as we presented TASCA's work and achievements over the past year.

A special thanks to **Prof. Sant-Rayn Pasricha** and **Dr. Robert Sertori** from the Walter and Eliza Hall Institute of Medical Research, who delivered an insightful presentation on their work in the field of Thalassaemia and Sickle Cell disease.

TASCA is proud to support WEHI's ongoing research and look forward to deepening our collaboration in the year ahead.

The TASCA 2025 AGM Minutes are now available on our website. Please contact info@tasca.org.au for more information.

Trial Team

Healthier mothers, healthier babies: iron trial could transform pregnancy care worldwide

07 January 2025



WEHI helps spearhead changes to global anaemia guidelines

28 March 2024



More donors are required to keep blood supply stable



Can Cultured red blood cells fill the gap?

MOORLEIGH COMMUNITY VILLAGE OPEN DAY

The TASCA team set up an interactive stall in our office at Moorleigh Community Village, in celebration of the **2025 Senior's Festival**.

A wonderful day was had, raising awareness of Thalassaemia and Sickle Cell Disease, the importance of blood donations and handing out cookies to those who stopped by to say hi!

We would like to extend a sincere thanks to our wonderful committee and staff members who volunteered their time.

Interested in volunteering for similar events? Become a TASCA volunteer by completing this [form](#). We welcome volunteers from all walks of life. You just need a passion for improving the community and helping others!

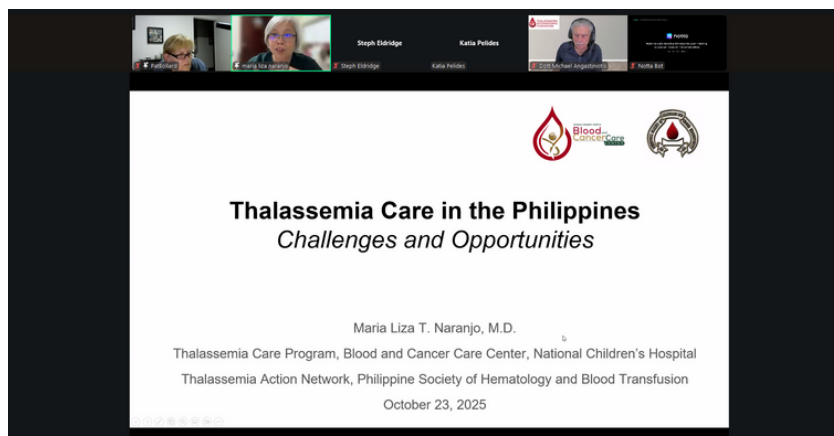


TASCA MONTHLY - TASCA Updates

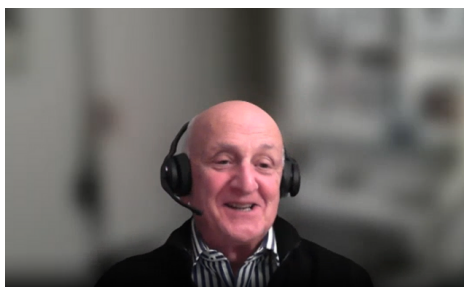
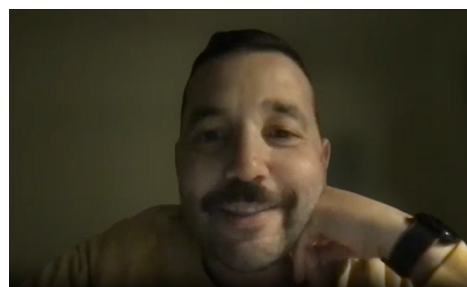
TIF ASEAN & WEST PACIFIC NETWORK MEETING

This past month saw exciting progress in the development of the **TIF ASEAN & West Pacific Network of Haemoglobin Disorders**. Joined by various doctors, health professionals, patients and patient groups, TASCA members Pat Bollard, Peter Verveniots and Dr John Malios exchanged stories and lived experiences of Thalassaemia care and challenges faced in Australia and shared their hope for the future.

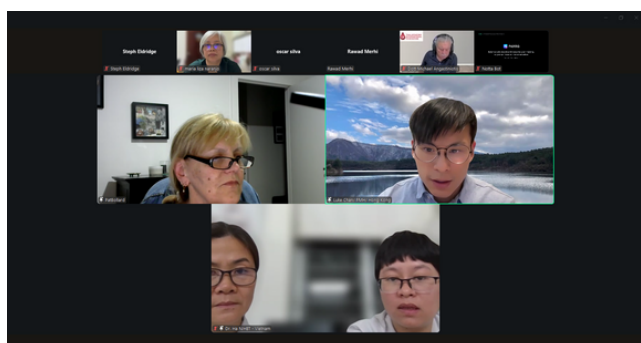
We would like to extend our deepest gratitude to TIF for establishing this connection and look forward to collaborating and sharing ideas with other countries in our region!



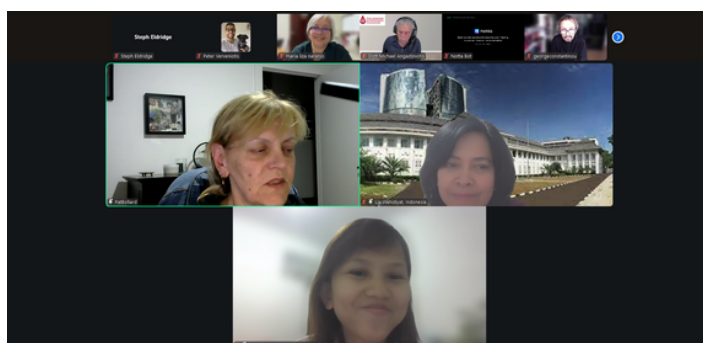
*Philippines Thalassaemia Care Presentation by Dr Maria Liza Naranjo



*TASCA Members Pat Bollard, Peter Verveniots and Dr John Malios



*Dr Luke CHAN Ka-lok - Hong Kong and Dr Nguyen Thi Thu HA & Dr Nguyen Thi Chi



*Dr Lia Wahidiyat and Thalassaemia patient Natasha - Indonesia

TASCA MONTHLY - TASCA Updates

NORTHERN HOSPITAL

During October, our Health Promotions Officer, Nathan and Administration Officer, Steph visited Northern Hospital to meet with Haematologist Dr Vanessa Manitta and patients. The meeting provided a valuable opportunity to learn more about the hospital's services and facilities available to support individuals living with Thalassaemia and Sickle Cell conditions.



*Northern Hospital Staff and patient with their new Apheresis Machine

During their visit, Nathan and Steph were also able to connect with patients and gain a better understanding of their care experiences. It was encouraging to see the level of commitment and care provided at the Northern Hospital team, which has the capacity and expertise to support individuals in Melbourne's northern suburbs.

TASCA encourages members and community members living in the north to consider connecting with Northern Hospital for their ongoing care and consultations. We look forward to continuing conversations with Dr Vanessa Manitta and the broader team, exploring ways to collaborate and strengthen care pathways for patients in Melbourne's northern region.

TASCA'S GENETIC COUNSELLING PLACEMENT STUDENTS

A huge thank you to our wonderful placement students, Eleanor and Sarah, for completing their Master of Genetic Counselling placement with TASCA!

Over the past few months, they've brought creativity, kindness, and passion to every task — from hospital visits and school presentations to creating a beautifully written and illustrated children's storybook that helps young people understand Thalassaemia and Sickle Cell conditions.

The TASCA team is so grateful for their incredible contributions and will miss their positive energy in the community.



TASCA MONTHLY - TASCA Updates

LION'S CLUB OF BRISBANE CHINESE

Earlier this month, long-term Thalassaemia advocate and dedicated TASCA member, **Ella Luong**, delivered an insightful presentation about Thalassaemia to the **Brisbane Lion's Club (Lions Club of Brisbane Chinese)**, raising awareness about the condition, challenges faced by the community and highlighting TASCA's ongoing efforts to support and empower the community.

Thanks to Ella's passion, dedication, and heartfelt advocacy, the Brisbane Lion's Club has generously chosen to support TASCA's mission and initiatives. Their commitment marks a wonderful step forward in raising awareness and strengthening community connections.



*TASCA Member Ella Luong delivering her presentation on Thalassaemia



*TASCA Member Ella Luong (left) and Brisbane Lion's Club President Cheryl Yim (right)

We would like to extend our heartfelt thanks to both Ella and the Brisbane Lion's Club for their generous support and unwavering commitment to our cause. Together, we're helping to strengthen our community and advocacy work!



TASCA MONTHLY

OCTOBER: PLASMA AWARENESS MONTH



Hint: it has six letters. And can be used in 18 different life-saving ways. The answer? Plasma.

What is plasma?

Plasma is a part of your blood that holds all the other blood cells, and it is Australia's most-needed blood donation.

How is it used?

Plasma protects against chicken pox. It fights measles and tetanus infections. It treats immune deficiencies, helps prevent infections during bone marrow transplants and treats complications during heart surgeries. Those are just some of the incredible ways it can be used.

And Australia needs more of it.

In fact, a new plasma donation is needed every 33 seconds.

Will you be the answer?

If you've been thinking about donating, now is the time. Your donation could stop bleeding in critical moments. It could treat severe burns and protect unborn babies. Or, help a transplant patient celebrate another birthday. Step up and save lives with TASCA Lifeblood Team. *The answer is in you.*

Register and join the Thalassaemia and Sickle

Cell Australia Lifeblood Team [here](#), or find out more by [contacting us](#).



TIF GUIDELINES BOOKLETS - PRACTICAL SUPPORT FOR PHYSICIANS WORLDWIDE

The **Thalassaemia International Federation (TIF)** has released a new series of stand-alone booklets. With information from TIF's Guidelines for the **Management of Thalassaemia Syndromes**, these resources are essential in supporting physicians of all medical specialties, providing quick and convenient access to evidence-based recommendations for healthcare professionals on the treatment and management of Thalassaemia.

You can [download](#) the booklets now!



TASCA MONTHLY

HAPPY HOLIDAYS!

Christmas is right around the corner, and just like you, the TASCA team are getting into the festive spirit! As we prepare to celebrate with our families and friends, we're excited to share some of the special traditions that make this holiday season meaningful to us. Hear from some of our staff members about their Christmas traditions!

Madi, TASCA Creative Writer:

"I have 'Friendmas' with my closest friends in early December, where we do 'Secret Santa,' exchanging presents and cooking up a delicious roast lunch. Every year, we take in turns hosting. Then on Christmas Day, I have lunch with my mum's side of the family before attending dinner with my dad's side. Always a full belly!"

Steph, TASCA Administration Officer:

"December is always a busy, but festive, time for me. I always enjoy celebrating Christmas with friends and extended family, before having a quiet Christmas lunch on Christmas Day with my closest loved ones. We spend the morning exchanging gifts and finish the night off watching Christmas movies."

Nathan, TASCA Health Promotions Officer:

"In the leadup to Christmas, I like to get into the festive spirit by watching a few Christmas movies and going out with my family to see Christmas Lights. On Christmas Day, we have a big gathering with relatives and everyone brings a dish to share. We always finish the night off with Bad Santa, a tradition that gets everyone involved and laughing."

How do you and your family celebrate the holidays? Share your traditions, big or small —we'd love to feature your stories!



info@tasca.org.au

WEET-BIX™ CHRISTMAS SNOWBALLS

Looking for a healthy, but delicious Christmas treat? Try these Christmas Snowballs!

Ingredients:

- 8 Weet-Bix™, crushed
- 1 cup sultanas
- ½ cup cocoa
- 395g can sweetened condensed milk
- ½ cup desiccated coconut

Method:

Step 1. Place all ingredients, except desiccated coconut, in a large bowl. Mix well.

Step 2. Form mixture into 30 balls and toss in desiccated coconut until covered.



TASCA MONTHLY - TIF Updates

TIF ANNUAL REPORT 2024

A year of resilience and progress.

TIF have released their **2024 Annual Report** – highlighting a year's worth of resilience, innovation and progress in improving the lives of those living with Thalassaemia and other rare anaemias around the globe.

“Reflecting on 2024's achievements, we express our deepest gratitude to TIF's Members, healthcare professionals, partners, and supporters, whose dedication and collaboration make our shared progress possible. Together, we remain steadfast in our pursuit of a future where every patient enjoys the highest attainable standard of health and quality of life.”

You can read the full report [here](#).



**THALASSAEMIA
INTERNATIONAL
FEDERATION**

SICKLE CELL DISEASE: INFLAMMATION DURING MENSTRUAL CYCLE MAY TRIGGER PAIN CRISES

New research suggests that inflammation caused by the menstrual cycle may help explain why painful vaso-occlusive episodes occur more often during menstruation in people with Sickle Cell Disease (SCD).

For those with a menstrual cycle living with SCD, the findings from this research are crucial to better understand pain patterns and to break down barriers to personalised, holistic care.

Read more [here](#).

BOOSTING DONOR HEALTH: HOW IRON SPEEDS POST-DONATION RECOVERY

A recent study suggests that taking a course of iron supplements after a blood donation can drastically improve the recovery of iron stores and haemoglobin levels in blood donors. This reduces the risk of 'post-donation iron deficiency' – making the donation process safer and more sustainable.

Blood donors are vital for the Thalassaemia and SCD communities, so it is crucial that we look after our donors to maintain their health and improve long-term donor retention to keep up with the supply and demand for blood products.

Interested in learning more? Read more [here](#).

FREE ONLINE FITNESS PROGRAM

TASCA is Hosting Free, Online Fitness Sessions for all Kids & Teens Living with Thalassaemia and Sickle Cell



What is it:

TASCA is running fun, **free online fitness sessions** led by a fitness coach to help young people living with Thalassaemia and Sickle Cell stay active and healthy, from the comfort of your own home!



Who can join:

- Open to people living with **Thalassaemia and Sickle Cell**
- Suitable for all fitness levels
- No equipment needed



Program details:

- Start Date: **Wednesday 14 January 2026**
- Duration: **4 weeks**
- Time: 10am AEST
- Location: Online via Microsoft Teams



FREE

How to join:

- Step 1: Fill out the registration form [here](#) or scan the QR code!
- Step 2: Receive your confirmation email and join from any device.

Contact for more details:

healthpromotionsofficer@tasca.org.au



SCAN ME



This program is run by Thalassaemia and Sickle Cell Australia (TASCA) to encourage physical wellbeing for children and teens in care

CALENDAR

20TH NOVEMBER

UNIVERSAL CHILDREN'S DAY

3RD DECEMBER

INTERNATIONAL DAY OF
PERSONS WITH DISABILITIES

5TH DECEMBER

INTERNATIONAL VOLUNTEER DAY

CONNECT WITH US!

FIND TASCA ON SOCIAL MEDIA

@tascaust



BECOME A MEMBER AND SUBSCRIBE TO OUR NEWSLETTER

GIVE TASCA A VOICE AND BECOME A MEMBER TODAY

- You can help support TASCA and its valuable work.
- You can be inspired by stories about the people we support.
- You will be updated regularly on medical advances and clinical trials.
- You will be invited to member events and programs.
- You will belong to a community supporting people living with a genetic haemoglobin condition.
- You will be part of a community voice advocating for better access to medical care.



Your membership will support Thalassaemia and Sickle Cell Australia's important work.

As a not-for-profit organisation, we need the support of the community to provide ongoing education, support and advocacy for the benefit of those living with, or touched by, genetic haemoglobin conditions.



Membership is open to all interested individuals and organisations who want to support our mission.



**Thalassaemia and
Sickle Cell Australia**

Unifying Support with Genetics

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