Thalassaemia and Sickle Cell Australia

Unifying Support and Genetics

*Cover Image from Sickle Cell Disease Association of America Inc.

CONTENTS

Connect with TASCA: Latest News and Updates

Phone: (03) 7015 5637
Email: Info@tasca.org.au
Address: Room 44, Barry Neve Wing Moorleigh Community Village Bentleigh East, Vic 3165 Australia

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

I would like this opportunity to thank Peter, Karen and Jo for taking charge at TASCA while I have been on leave. The role of Chair involves very hands-on oversight of the day-to-day workings of the office as well as event planning, staffing, meetings, liaising with patients, health care providers and stakeholders. The Executive Committee have done a fantastic job in my absence and I sincerely thank them.

It is with great sadness that I inform our community that our Secretary Karen has tendered her resignation effective immediately. Her wisdom, professionalism, great sense of humor and engagement with patients will be greatly missed. On behalf of the Executive Committee and Board of Management I want to sincerely thank Karen for her 6 years of service, wish her well in all future endeavours and look forward to seeing her at our events.

In light of Karen's resignation, Peter will take over the role of Secretary and will be replaced as Vice Chair by Stani. Jo will remain as Treasurer. I look forward to working closely with the new Executive Committee.

This newsletter contains updates on the 3 major awareness days on TASCA's calendar – International Thalassaemia Day, World Sickle Cell Day and World Blood Donor Day. We have been very busy raising awareness of these key days by engaging with patients, families and health professionals.

My thanks to all who have participated in these events.

This month's newsletter contains information and a request for participation in a survey being conducted by the University of Sydney on the subject of high-cost gene therapies, with a view to presenting the analytics to federal government agencies and research authorities in the hope that these may become more accessible and viable for both Thalassaemia and Sickle Cell Disease patients. Participation in this survey is brief and totally voluntary, however I believe it is vital for our members and their families to undertake the survey, as it will help our decision-makers determine appropriate courses of action based on feedback from you – the target audience. I urge you to scan the barcode and complete the survey.

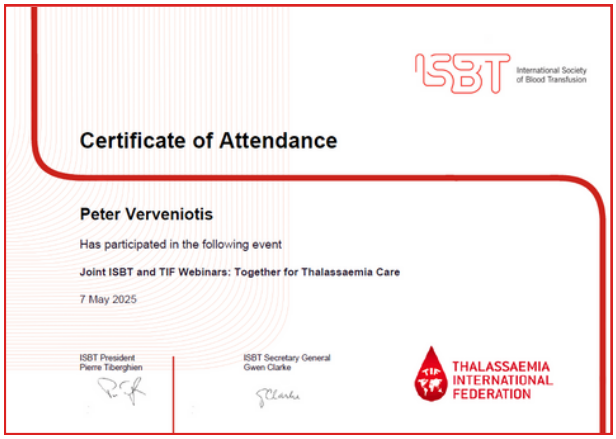
TASCA MONTHLY

TOGETHER FOR THALASSAEMIA CARE

To celebrate this International Thalassaemia Day (May 8th), the TASCA team attended a series of two international webinars, hosted by the **International Society of Blood Transfusion (ISBT)** and the **Thalassaemia International Federation (TIF)**.

With guest speakers from around the globe, this inspiring series explored current practices and challenges in transfusion care in Thalassaemia patients.

Bringing together patient perspectives and expert knowledge, our team is privileged to have been apart of these meaningful and forward-looking discussions to improve the overall care and promote best practices worldwide.


Certificate of Attendance

Peter Verveniotis

Has participated in the following event

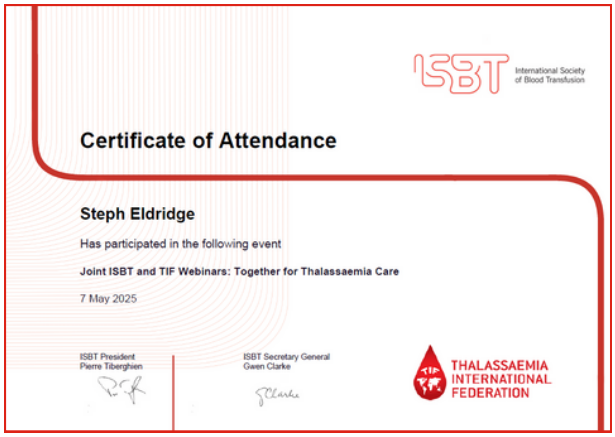
Joint ISBT and TIF Webinars: Together for Thalassaemia Care

7 May 2025

ISBT President Pierre Tiberghien

ISBT Secretary General Gwen Clarke

THALASSAEMIA INTERNATIONAL FEDERATION


Certificate of Attendance

Steph Eldridge

Has participated in the following event

Joint ISBT and TIF Webinars: Together for Thalassaemia Care

7 May 2025

ISBT President Pierre Tiberghien

ISBT Secretary General Gwen Clarke

THALASSAEMIA INTERNATIONAL FEDERATION

If you didn't get a chance to view the webinar live, **scan the QR code below** to watch the recording.

*Image sourced from ISBT

CELEBRATING A MILESTONE: PETER'S 5 YEARS OF SERVICE

A big congratulations to TASCA's Vice-Chair, Peter, on reaching a remarkable milestone—five years of dedicated service on the Blood Management Committee at Monash Health!

The Monash Health Blood Management Committee is a vital body that plays a central role in ensuring the safe and effective use of blood products across all Monash Health sites. Meeting monthly, the committee reviews adverse events, monitors incident reporting, and develops improved transfusion protocols, all with the goal of enhancing patient safety and care.

As a consumer advisor, Peter represents the voice of patients and their families living with blood conditions. His lived experience and insights contribute meaningfully to the committee's discussions and decision-making, helping to shape policies and initiatives that aim to improve patient outcomes.

We are deeply proud of Peter's unwavering commitment to advocacy and patient-centered care, and we're thrilled to see his contributions being recognised.

Thank you, Peter, for your passion, dedication, and service!

TASCA MONTHLY

SCHOOL PRESENTATIONS

We're currently preparing for the upcoming school terms with a range of educational presentations and programs. If you know anyone who might be interested, please reach out!

We offer a free genetics presentation to schools across Victoria and an online session for other states. Our presentations can be customised to serve as an introduction or a revision of key topics in science and biology. We also offer community presentations to other interested groups.

To book a session with our Health Promotion Officer, Sarina, simply complete the booking form here

JOIN OUR LIFEBLOOD TEAM!

We're proud to be part of Lifeblood Teams, the group donation program from Australian Red Cross Lifeblood.

Aside from saving lives through blood donation, Lifeblood Teams is about friendship, a little healthy competition and being part of something bigger than yourself. It's a unique opportunity for all of us to band together and give something more powerful than money.

Donated blood can be used to help people in all sorts of life-giving ways. The need is constant and the person receiving it could be fighting cancer or going through a difficult pregnancy, or they could be someone who relies on regular transfusions to stay healthy — or even, stay alive. Now that's something worth uniting for!

There's nothing like knowing you've genuinely helped someone, and we'd love to share that amazing feeling with you.

Register and join the Thalassaemia and Sickle Cell Australia Lifeblood Team here, or find out more by contacting us.

Australian Red Cross Lifeblood®

Thalassaemia and Sickle Cell Australia
Unifying Support with Genetics

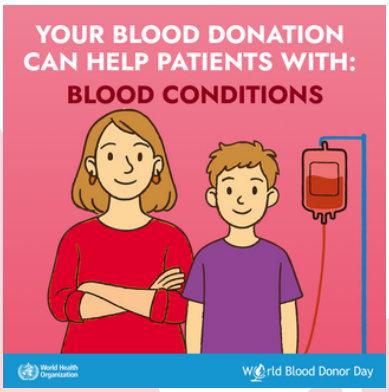
TASCA MONTHLY

World Blood Donor Day

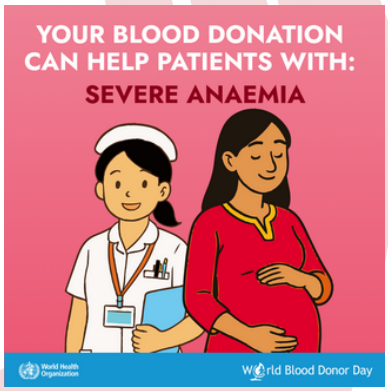
Give blood, give hope: together we save lives. 14 JUNE 2025

*Image from WHO

Every drop counts. World Blood Donor Day is a day where everyone from across the globe joins forces to celebrate the many individuals who donate blood, and to raise awareness on the critical need for blood donations and how they have a direct impact on patients' lives. This year, the World Health Organization (WHO) proudly presented the theme for this year: **"Give blood, give hope - Together we save lives."**



When you donate, you're not only saving lives, you're building stronger, more resilient communities. You're part of something bigger!



This **World Blood Donor Day, June 14,** we would like to join Lifeblood in celebrating **National Blood Donor Week (June 9-15)**, and recognising donors from across the country. "*For the ones who give life*", we say thank you!

Thinking about donating?
Check your eligibility to donate blood here, and find a donor centre near you to donate today!

Stop the Drop
Check out Australia's blood supply levels here, and help us to 'Stop the Drop'.

TASCA MONTHLY

WORLD SICKLE CELL DAY

To celebrate World Sickle Cell Day, TASCA visited treatment centers across Melbourne to show support for Sickle Cell patients and raise awareness about the disease.

TASCA MONTHLY

WORLD SICKLE CELL DAY

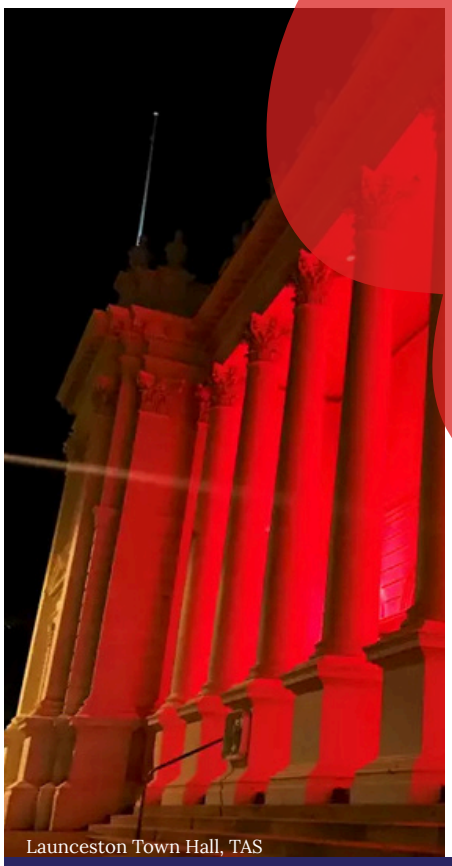
TASCA MONTHLY


Drum Theatre, VIC


Glen Eira Town Hall, VIC

TASCA LIGHT UPS

AAMI Park
Bolte Bridge
Brisbane Town Hall
Broadmeadows Town Hall
Canberra Times Fountain
City of Glen Eira (Town Hall Portico Entrance)
City of Greater Dandenong (Drum Theatre/Old Town Hall)
City of Launceston (Town Hall)
City of Perth
Civic Centre (Monash City Council)
Kangaroo Point Bridge
King George Square
Kingston City Clock Tower
Maryborough City Hall
Monash Park Tree
Mooroopna Water Tower
Newcastle City Hall Clock
Parliament House, South Australia
Point Bridge
Reddacliff Place Steam Sculptures
Story Bridge
Tasman Bridge
Unley Town Hall
Victoria Bridge
Victoria Park Lake
...plus many more!


Launceston Town Hall, TAS


Victoria Bridge, VIC

Drum Theatre, VIC

TASCA MONTHLY

WORLD SICKLE CELL DAY SPOTLIGHT: AN INTERVIEW WITH DR KYLIE MASON

We're excited to share a short snippet from our 50th anniversary interview with Dr Kylie Mason, a haematologist at the Royal Melbourne Hospital and Peter MacCallum Cancer Centre.

Dr Kylie Mason, a haematologist at the Royal Melbourne Hospital and Peter MacCallum Cancer Centre, has been looking after the Sickle Cell patients at Royal Melbourne for over 15 years! Realising that these patients needed to be looked after in specific clinical settings, with help from her colleagues and the fantastic nursing staff, they formed the haemoglobinography service and set up haemoglobinopathy clinics. Dr Mason feels most fortunate to be able to work with her patients to enhance their lives. "Being able to look after patients with haemoglobinopathies is a privilege."

Dr Kylie Mason

Can you give us a brief overview of what Sickle Cell is?

Sickle Cell is a common, inherited genetic mutation that affects red blood cells. The red blood cells are less able to carry oxygen around the body and they 'sickle,' which can block blood flow and cause the red cells to break down more rapidly. Those living with Sickle Cell are prone to ongoing challenges, from pain to strokes to problems with the body's bones and organs.

What are the most common treatments?

Currently in Australia, treatment options are limited. However, there are two common treatment methods available. Firstly, we have a medication called 'Hydroxyurea,' which increases the amount of Haemoglobin F (aka baby or fetal haemoglobin) present in the body. Having higher levels of Haemoglobin F decreases the likelihood of red blood cells turning sickle-shaped, the identifying characteristic of Sickle Cell disease, and reduces the risk of having a crisis.

Another treatment option available is a red cell exchange, where a patient's red blood cells are exchanged with donor red blood cells via an Apheresis machine. Depending on the patient and their circumstances, a red cell exchange is completed every four to seven weeks.

The most important aspect of Sickle Cell treatment is that we stay on top of the symptoms, and that we are engaging in and practicing preventative care and supportive care for our patients.

How has treatment changed over the years?

The biggest change in Sickle Cell treatment that we have seen is the advancements in gene therapy, which is available overseas. Gene therapy works by modifying an individual's genes to either treat or cure diseases.

"We have the ability and technology in Australia to perform this," however the companies that

WORLD SICKLE CELL DAY SPOTLIGHT: AN INTERVIEW WITH DR KYLIE MASON

have licensed this technology have not yet made it available to Australia. Everyone is doing their part to not only obtain current gene therapies, but also to obtain clinical trials, so this is a 'watch this space.'

Another exciting treatment option that is emerging is Protein Kinase Inhibitors. Protein kinases play a role in many cell functions, including cell signaling, growth, and division. Blocking the functioning of these proteins with protein kinases inhibitors can help play a role in reducing the symptoms of Sickle Cell. Clinical trials of these agents are ongoing in Australia and overseas.

What are the biggest challenges that patients with Sickle Cell face today, do you think?

Sickle Cell is a lifelong disease, and individuals with Sickle Cell face the challenge daily to incorporate their symptoms and management into their everyday life. I think one of the biggest challenges for our patients is being able to maintain a happy, healthy lifestyle whilst maintaining good, proactive management of their disease.

How do you think stigma affects patients living with Sickle Cell and what can we do to reduce misconceptions and improve support for patients?

Stigma is a big issue for Sickle Cell patients, especially when it concerns diverse cultural groups. This is due to different cultures having different perceptions and views on Sickle Cell Disease, which may have an impact on a patient's experience.

In Australia, Sickle Cell is not well recognized. There is a lack of knowledge and understanding of Sickle Cell crisis and how it can cause a patient to be well one minute, and then in debilitating pain, unable to move and communicate, the next. This is especially true for employers and friends, who may not understand Sickle Cell and its symptoms.

It is important to have targeted information readily available that can be provided to employers, friends, and family to support our patients in their professional and personal networks. Educating these groups about Sickle Cell Disease and its symptoms can help reduce any misconceptions and stigma of those with Sickle Cell.

What is the most rewarding aspect of working in this area?

Being able to care for and support all my patients is wonderful. It's a great feeling, knowing that I can make a difference in their lives by managing their pain, or picking up problems early, or working alongside them to enhance their lives.

Looking after women with Sickle Cell and enabling them to have happy, healthy babies is a bonus!

THE UNIVERSITY OF SYDNEY

Thalassaemia and Sickle Cell Australia

Unifying Support with Genetics

PARTICIPANTS NEEDED

FOR RESEARCH STUDY

ABOUT THE STUDY

- Understand the preferences that patients, their families/carers and the general public have for different aspects of high-upfront cost gene therapies
- Help develop tools to support funding decision-making for these therapies by national committees (including the PBAC and MSAC)

WHO CAN PARTICIPATE

- Adults (18+) in Australia
- Individuals diagnosed with:
  - Haemophilia A or B (Factor VIII or IX deficiency)
  - Beta-thalassemia
  - Sickle cell disease
- Immediate family members or carers of individuals with the above conditions

WHAT PARTICIPATION INVOLVES

- Taking part in this study will involve completing an online survey.
- Completing an online survey (~15–20 minutes)
- You will be compensated for your time.

SCAN HERE

For more information:

Contact TASCA at info@tasca.org.au; or contact Professor Kirsten Howard via email at kirsten.howard@sydney.edu.au, or by phone: 02 9351 2587

This study has been approved by the Human Research Ethics Committee (HREC) of The University of Sydney [HREC Approval No. 2025/HE000195].

CALENDAR

MONTH OF JUNE
Pride Month

6TH – 13TH JULY
NAIDOC Week

25th JULY
Christmas in July

28th JULY
World Hepatits 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

Thalassaemia and Sickle Cell Australia
Moorleigh Community Village, Barry Neve Wing
92-94 Bignell Road, Bentleigh East
VIC 3165 Australia
T: +61 3 7015 5637
www.tasca.org.au info@tasca.org.au