Thalassaemia and Sickle Cell Australia
*Unifying Support and Genetics*

## CONTENTS

# 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

**Peter Verveniotis**

Vice-Chair
Thalassaemia and Sickle
Cell Australia

# From our Chair

Welcome to another year! I hope everyone had a chance to relax or enjoy some time with family and friends. As you may be aware, I am the Acting Chair while Pat enjoys a well-deserved break with her family.

I'm excited to welcome two new members to our board: Stani and Moyez. Their expertise in genetic blood disorders, community education programs, awareness, engagement, and advocacy will be valuable assets to our team.

This year, we'll be updating and reviewing our strategic plan for the next three years. It will continue to focus on the core areas of education, support, and advocacy within the parameters of our mission statement. This plan will serve as a roadmap for TASCA, setting clear direction, goals, and a strategy for achieving them.

TASCA is reaching a milestone of 50 years! I had the pleasure of sifting through many photos and albums over the break and met up with Libby Reid to assist me in identifying the many patients who attended the old Queen Vic. Libby was the transfusion charge nurse at Queen Victoria Hospital and then at the Medical Therapy unit at Monash Health. She worked with Thalassaemia and Sickle Cell patients over many years. It was such a beautiful meeting—we shared stories, and she also gave me insight into what it was like in the early days. Sally and I have interviewed her, and this will be featured in our anniversary book, which we are preparing.

In 2025, we also hope to offer presentations to community groups. We're already in the process of contacting some leads. These presentations will not only be educational but also include a Q&A session where community members can ask questions to patients.

We will continue visiting hospitals and engaging with the children, in particular, to ensure we maintain our connection with the community. We're also planning to roll out another round of small grants this year—one in May and another in November, in honour of Sotirios Katakouzinos & Maria Kastoras. Our Small Grants program is designed to enhance the standard of living and well-being of patients by providing a modest grant to support the purchase of equipment or other non-perishable items for treatment centres. Last year, we provided two grants to patients, and we hope to continue supporting our community through these initiatives. More information can be found on our website, **at this link.**

Please feel free to contact me at peter@tasca.org.au or by calling the office at 03 7015-5637 if you'd like to chat or volunteer at any time throughout the year. I encourage everyone reading this, and all our members, to actively participate in the vital work TASCA is striving to accomplish. Your contributions are essential to our progress. Take care, everyone, and enjoy reading our first newsletter of 2025!

TASCA MONTHLY

# MEET TASCA'S NEWEST COMMITTEE MEMBERS

## MEET MOYEZ

Dr. Moyez Jiwa is a distinguished Professor at the University of Notre Dame Australia, with over 30 years of international healthcare experience. He is a leader in healthcare innovation, and the Editor-in-Chief of The Journal of Health Design and host of The Health Design Podcast. With 2,841 citations and an H-index of 31, he continues to contribute significantly to healthcare research and innovation while maintaining an active clinical practice as a GP in Melbourne CBD.

DR MOYEZ JIWA

## MEET STANI

STANI GOMA

Stani Goma is a registered pharmacist with extensive experience across diverse settings, including hospital, research, and Aboriginal health. Born and raised in the Congo, he brings a deep understanding of the challenges faced by people living with Sickle Cell, which aligns closely with the mission of TASCA.

In addition to his healthcare knowledge, Stani brings extensive experience in community engagement. As a respected radio host and cultural curator, he has dedicated himself to fostering cross-cultural connections and raising awareness on critical issues.

## TASCA MONTHLY

50 YEARS

# CELEBRATING 50 YEARS OF TASCA

## HELP US SHARE OUR STORY

As we approach our 50th anniversary in 2026, we're excited to reflect on the impact TASCA has had in the lives of those affected by Thalassaemia and Sickle Cell in Australia. To mark this milestone, we're working on a commemorative book that will celebrate our rich history and the vital role we've played in raising awareness, supporting individuals, and advocating for change.

This book will tell the story of TASCA's journey and the impact we've had over the years, and we need your help to make it complete. We're looking for personal stories, photos, news articles, and any other memorabilia that illustrate the history of Thalassaemia and Sickle Cell Australia, formerly known as the Thalassaemia Society of Victoria. We are also looking for volunteers who would like to assist with preparations.

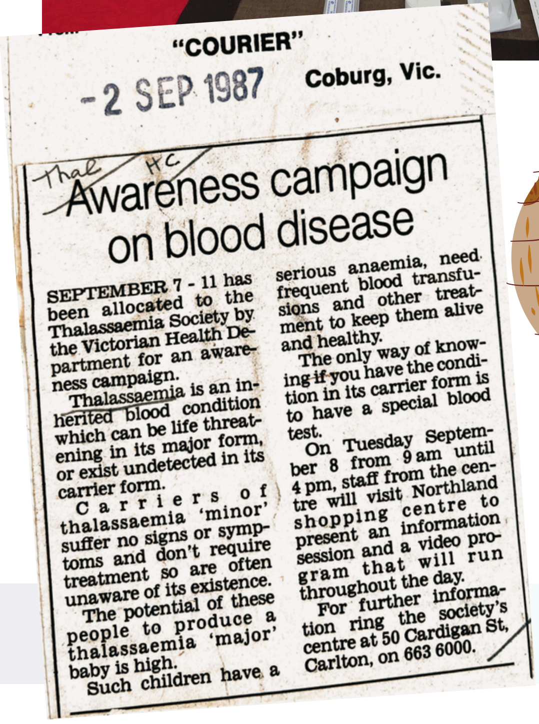
Whether you'd like to remain anonymous or be credited in the publication, we welcome your contributions in whatever way feels most comfortable for you.

We'll also be reviewing our photo archives and making every effort to identify individuals in the images and seek permission for publication where necessary.

If you have something to share, we would love to hear from you!

Please reach out to us with your stories, photos, or any relevant materials at:

**Expression of Interest Form (click this link)**
Contact Email: info@tasca.org.au
Contact Phone: (03) 7015 5637



"COURIER"

-2 SEP 1987 Coburg, Vic.

Thal HC

### Awareness campaign on blood disease

SEPTEMBER 7 - 11 has been allocated to the Thalassaemia Society by the Victorian Health Department for an awareness campaign.

Thalassaemia is an inherited blood condition which can be life threatening in its major form, or exist undetected in its carrier form.

Carriers of thalassaemia 'minor' suffer no signs or symptoms and don't require treatment so are often unaware of its existence.

The potential of these people to produce a thalassaemia 'major' baby is high.

Such children have a serious anaemia, need frequent blood transfusions and other treatment to keep them alive and healthy.

The only way of knowing if you have the condition in its carrier form is to have a special blood test.

On Tuesday September 8 from 9 am until 4 pm, staff from the centre will visit Northland shopping centre to present an information session and a video program that will run throughout the day.

For further information ring the society's centre at 50 Cardigan St, Carlton, on 663 6000.

# TASCA MONTHLY

## 5TH EDITION OF TIF'S GUIDELINES FOR THE MANAGEMENT OF TRANSFUSION DEPENDENT Β-THALASSAEMIA

In another stride towards advancing global understanding and management of thalassaemia, the Thalassaemia International Federation (TIF) is delighted to announce the release of the updated 5th edition of the **“TIF Guidelines for the Management of Transfusion Dependent β-Thalassaemia (TDT)”**.

This edition stands as a seminal resource that provides critical guidance and recommendations to healthcare professionals across various specialties, researchers and all stakeholders involved in the care of individuals affected by this severe genetic haematological disease.

## SCHOOL PRESENTATIONS

We're currently preparing for the year ahead 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 Promotions Officer, Sally, simply complete the **booking form here**

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This edition stands as a seminal resource that provides critical guidance and recommendations to hea

TIF /

## CALENDAR

**29TH FEBRUARY**
- Rare Disease Day

**8TH MARCH**
- International Women's Day

**17TH APRIL**
- World Haemophilia Day

**20TH APRIL**
– Volunteer Recognition Day

**25TH APRIL**
- World Malaria 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.

REGISTERED CHARITY
acnc.gov.au/charityregister

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.

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Sickle Cell Australia
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