

# Thalassaemia and Sickle Cell Australia

**Unifying Support and Genetics** 



## **CONTENTS**

- From our Chair Pg. 2
- 2025 Greek History & Culture Seminars - Pg. 3
- **Uni Stalls -** Pg. 3
- School Presentations Pg. 4
- **R U OK?Day -** Pg. 4
- Meet our Newest
  Committee Member Pg. 5
- Join Healthdirects'
  Engagement Group- Pg. 5
- Introducing: Spleen Australia - Pg. 6
- Therapeutic Goods Administration survey: your chance to have your say - Pg. 6
- Join the WEHI Consumer Program - Pg. 7

# 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!



Pat Bollard
Chairperson
Thalassaemia and Sickle
Cell Australia

#### Dear all

Welcome to another edition of TASCA's newsletter.

I would like to firstly inform our community of changes to our Committee of Management. It is with great sadness that we farewell Cameron, committee member & patient representative. Cameron has always approached his role with enthusiasm, commitment and dedication advocating for patients and their families. His own family and work commitments have meant that he has made the difficult decision to step down. I sincerely thank Cam for everything he has achieved in his time with TASCA & wish him every success with his future endeavours.

Our new committee member is Dr Sherouk Fouda, who joins us from Darwin Hospital. I take this opportunity to warmly welcome Sherouk to our community & look forward to working closely with her.

As we enter Term 4, our secondary school presentations for 2025 are nearly over. My sincerest thanks to Nathan who, as the newest Health Promotions Officer, approached these tasks with confidence and enthusiasm within a week of beginning his role with TASCA.

Our collaborations with various research projects & organisations continues and

# From our Chair

requests for patients' input are featured on both our website and our social media. I urge all members to take advantage of opportunities to get involved in the provision of feedback as this will help inform future research & funding directions.

A very big thank you to Dr Jim Vadolas who recently delivered a very engaging and informative presentation - Thalassaemia Uncovered: Understanding the Condition, Recent Advances and Hope for the Future - as part of a series of events at the Greek Community Centre. Always a dedicated supporter of TASCA, Jim entertained and educated the large audience.

Preparations for our 50<sup>th</sup> anniversary commemorative book are coming along nicely. I would like to thank Madi, our creative writer, and Oscar for their hard work and dedication in seeing this project to fruition. I would like to remind everyone to keep their calendars free May 2026 to join us in celebrating 50 years of TASCA.

And lastly, TASCA's AGM will be held on October 20<sup>th</sup> at 6.30PM. You can RSVP your attendance **here**. For more information, you can contact our office at (03) 7015 5637 or at info@tasca.org.au. We hope to see all our members there.

## 2025 GREEK HISTORY & CULTURE SEMINARS

The Greek Community of Melbourne are hosting a series of free seminars at the Greek Centre, all of which are open to the general public.

The 'Greek History and Culture Seminars' tell the history of Greece and Greek culture, and how these have helped contribute to the formation of Western civilisation.

Thursday 4<sup>th</sup> September, TASCA members Pat, Peter, Stani, Nick, Nathan, and Steph were fortunate to attend the 'Thalassaemia Uncovered' seminar, presented by long-time TASCA member and friend, Dr. Jim Vadolas.

Dr. Vadolas delivered an insightful presentation on the history of inherited blood disorders, with a focus on Thalassaemia and Sickle Cell Disease. Exploring medical advancements over the years, Dr. Vadolas highlighted the significant breakthroughs that have helped to improve the lives of those living with a genetic blood disorder.

You can find more information on upcoming seminars **here**.



#### **UNI STALLS**

This September, TASCA Staff members Nathan and Steph, and Genetic Counselling Placement Student, Eleanor, attended Deakin's 'Self Care Week' event, Swinburne's 'Sustainability Market Day', and RMIT's 'Wellbeing Week'.

The TASCA team set up an interactive stall to raise awareness about Thalassaemia and Sickle Cell Disease, and promote the importance of blood donations.

Thank you to all the students and volunteers who stopped by our stall to say 'hello'!









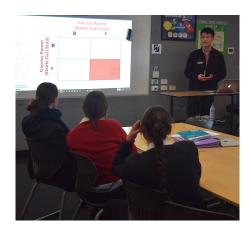
#### **SCHOOL PRESENTATIONS**

August and September have been a busy month for our Health Promotions Officer, Nathan, as he travels around Victoria, delivering our *free* genetics presentation to VCE Biology and Science students.

At TASCA, our commitment to community education and engagement remains at the heart of our mission. From regional classrooms to metro schools, Nathan has been engaging with students to spark curiosity, facilitate meaningful discussions around haemoglobinopathies, and raise awareness for these conditions, including Thalassaemia and Sickle Cell.

We're extremely grateful for the warm welcome we have received thus far, and look forward to continuing our efforts in the weeks ahead.







#### R U OK?DAY

As TASCA marked R U Ok?Day on Thursday 11<sup>th</sup> September, we want to remind our community that you don't need to wait for a special day to ask 'R U OK?', you can ask any day, because life's ups and downs happen *every day*.

Take a moment to reach out to your friends, family, and even yourself. You don't need to be an expert – just a good listener! By starting a conversation, you could help save someone's life.

To our wonderful TASCA community: thank you for your continued support — for each other, and for us. We're always here for a chat and a kind word when you need it.

Need help starting the conversation? **Here** is a helpful step-by-step guide.



# MEET TASCA'S NEWEST COMMITTEE MEMBER

## **MEET SHEROUK**

Dr Sherouk Fouda is an experienced Medical Science professional and currently the Medical Laboratory Science Course Coordinator at CDU university. Sherouk is deeply engaged in improving care and awareness around genetic blood disorders. She believes that her expertise in liver disease, metabolic stress, and cellular signalling can help inform better diagnostic, therapeutic, and educational strategies in the broader context of genetic and metabolic illnesses.

Sherouk is committed to promoting better communication between clinicians and the wider public and sees education and awareness-raising as key to improving outcomes for patients. She looks forward to bringing these strengths, her research experience, scientific rigour, and collaborative mindset, to the TASCA team, with the shared goal of advancing care, support, and innovation in the Thalassaemia community.



DR SHEROUK FOUDA

#### JOIN HEALTHDIRECTS' CONSUMER ENGAGEMENT GROUP

Healthdirect Australia is inviting people from across the community to join their Consumer Engagement Group.

Their goal is to help every Australian stay healthy with access to trustworthy health advice, information and connection to care. The best way to achieve this is to design services alongside the people who need and use them. When community representatives share their experiences, insights and ideas, they help Healthdirect create services that are more accessible and easier to use for all Australians.

By joining, you'll be part of a network of enthusiastic and generous community members who are passionate about making a difference. You'll have the opportunity to share your perspective, help shape the future of our services and be reimbursed for your time. Click **here** for more information, or register your interest **here**.

#### **INTRODUCING: SPLEEN AUSTRALIA**

# Have you had your spleen removed, or have you have been diagnosed with a non-functioning spleen?

People living without a functioning spleen have a lifelong risk of serious infection. These infections, whilst rare, can progress quickly and sometimes lead to sepsis, a lifethreatening condition.

That's where **Spleen Australia** comes in. Based at The Alfred Hospital in Melbourne, this service has been supporting patients for more than 20 years in Vic, Tas, QLD and WA.

#### Why Register with Spleen Australia?

- People without a spleen face a 50 times higher risk of sepsis – but the good news is that much of this risk can be prevented.
- The service is **free** for patients living in Queensland, Victoria, Western Australia, and Tasmania.
- Health care providers can register their patients, or patients can register themselves.
- Registration can be completed online: <u>www.spleen.org.au</u>, or call us 9076 3828

#### **Preventing Severe Infections**

- ✓ **Education** understanding your risk and what to do in an emergency
- √ Vaccination ensuring all recommended vaccines are up to date
- ✓ Antibiotics providing tailored daily and emergency plans

#### What Do Patients Receive?

- A personalised education session and information booklet
- An individualised vaccination and antibiotic plan
- A medical alert card
- Access to a dedicated telephone support service for ongoing advice



#### THERAPEUTIC GOODS ADMINISTRATION SURVEY: YOUR CHANCE TO HAVE YOUR SAY

The Therapeutic Goods Administration (TGA) is seeking feedback on the current usage of paper information included with injectable medicines.

This consultation aims to understand whether the paper copy of the Product Information (PI) document is helpful for patients and carers when it is included in the packaging of injectable medicines that they administer themselves.

The survey relates to the PI only and not to any other leaflets that may be present in injection packaging (such as instruction leaflets or Consumer Medicines Information leaflets).

Have your say **here**.

# Join the WEHI Consumer Program and help improve medical research!

# Have you experienced a haemoglobin condition, or cared for someone who has?

By sharing your experiences and knowledge, you can help shape and improve medical research.



### You will:

 Attend four meetings per year (in person or online)

#### WEHI will:

Provide ongoing support and training workshops

### Join WEHI as a Consumer

WEHI is seeking consumers with lived experience of haemoglobin conditions to join our Consumer Partnership Group.

Interested? Contact:

## Katya Gray

WEHI Consumer Program Manager 0408 525 122

consumers@wehi.edu.au

For more information, contact: (03) 7015 5637

■ info@tasca.org.au



Thalassaemia and Sickle Cell Australia Unifying Support with Genetics

## CALENDAR

10<sup>TH</sup> OCTOBER
WORLD MENTAL HEALTH DAY

12<sup>TH</sup> - 18<sup>TH</sup> OCTOBER
NATIONAL CARERS WEEK

## **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.



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 Moorleigh Community Village, Barry Neve Wing 92-94 Bignell Road, Bentleigh East VIC 3165 Australia T: +61 3 7015 5637