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

Another busy month has come and gone as we continue to work towards greater awareness, advocacy and education.

I would like to begin by expressing my sadness at the passing recently of a valued member of the TASCA community, Mr John Blias, and extend our condolences to his wife, daughter and family.

Recently, we have had a change in staffing, farewelling Sarina our HPO and welcoming Nathan Chong to the team . We wish him well in this key organisational role and are excited for him to be a part of the community.

In addition to Madi Lalor who is leading the 50th anniversary book project, I would also like to welcome Oscar Page, who will be assisting her in this exciting milestone publication.
Our office is definitely vibrant and filled with enthusiasm!

We continue our collaborative work with both TIF and TASCANZ, as well as our support of various research grant requests for MRFF (Medical Research Future Fund) which provides funding for health research and innovation.

Please continue to engage with our socials, newsletter and website for all news and activities conducted by our wonderful team. As always, if you would like to get in touch please do not hesitate to contact me or the office via email at **info@tasca.org.au** or by phone at **(03) 7015 5637**.

Pat Bollard
Chairperson

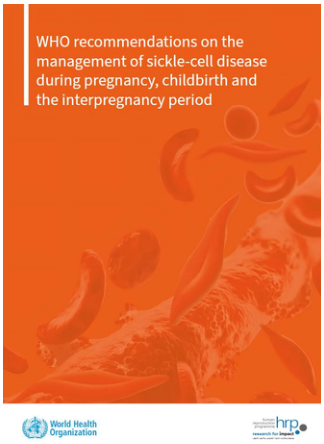
TASCA MONTHLY

WHO ISSUES FIRST GLOBAL GUIDELINE ON SICKLE CELL DISEASE IN PREGNANCY

The World Health Organisation (WHO) published its first-ever global guideline on the management of sickle cell disease during pregnancy.

Pregnancy naturally places extra demands on the body, and for women with sickle cell disease, these demands can significantly increase health risks associated with sickle cell. They face a greater risk of maternal mortality, 4 to 11 times higher compared to mothers without sickle cell disease, and have a greater likelihood of experiencing obstetric complications, such as pre-eclampsia.

In addition to working to improve maternal and newborn health, this guideline emphasises the need for respectful, personalised healthcare practices to suit women's unique needs and preferences, whilst also addressing the importance of tackling stigma and discrimination in the healthcare system.



WHO recommendations on the management of sickle-cell disease during pregnancy, childbirth and the interpregnancy period

World Health Organization

Curious to know more?

Read the full guideline here.

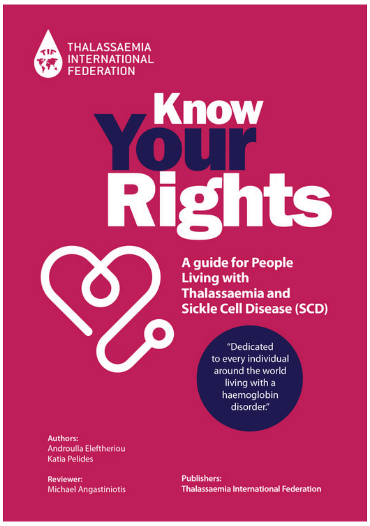
NEW EDITION ALERT: 2ND EDITION OF TIF'S ESSENTIAL PATIENT GUIDE

We are pleased to announce that the Thalassaemia International Federation (TIF) has released the updated 2nd edition of their guide: **"Know Your Rights: A Guide for People Living with Thalassaemia and Sickle Cell Disease (SCD)"**.

This revised patient guide is a powerful resource for patients, caregivers, and health professionals, outlining the fundamental rights of those living with a haemoglobin condition, from access to quality health care, social support, and the right to a better quality of life.

Executive Director of TIF, and co-author of the guide, Dr. Androulla Eleftheriou, notes "*awareness of patients' rights is the first and most crucial step*" for positive patient experiences. Having access to quality healthcare and treatments are "*human rights*".

Whether you're a patient, caregiver, healthcare professional, or advocate, this guide is a vital tool in the journey toward equality, dignity, and better health outcomes.



THALASSAEMIA INTERNATIONAL FEDERATION

Know Your Rights

A guide for People Living with Thalassaemia and Sickle Cell Disease (SCD)

"Dedicated to every individual around the world living with a haemoglobin disorder."

Authors:
Androulla Eleftheriou
Katia Pelides

Reviewer:
Michael Angastiniotis

Publishers:
Thalassaemia International Federation

TASCA MONTHLY

MEET TASCA'S NEWEST STAFF MEMBER

MEET OUR NEW STAFF MEMBER

We would like to welcome Nathan to the TASCA Team!

MEET NATHAN - HEALTH PROMOTIONS OFFICER

Nathan is passionate about youth wellbeing and creating positive, inclusive environments that empower young people to thrive. With a background in Health Sciences and experience in youth sport, Nathan brings energy, creativity, and strong organisational skills to his work.

As a tennis coach and program coordinator, Nathan has supported the development of young people through sport, helping them build confidence, resilience, and a sense of belonging. In his role in administration, he has managed documentation and supported internal processes with attention to detail and a collaborative mindset.

Nathan is committed to TASCA's mission of supporting individuals and families affected by Thalassaemia and other blood conditions. He values connection, education, and community and is driven to create engaging experiences that meet the needs of young people from diverse backgrounds.

Outside of work, Nathan enjoys playing tennis, watching films, and discovering new places to eat around Melbourne. He is excited to contribute to a compassionate and dynamic team making a real difference in the lives of others.

IN MEMORIAM

We are saddened to share the news of the passing of John Blias, a much-loved husband, father, brother, son and member of our TASCA community, who passed away at the age of 49. Our thoughts are with his family, friends, and all who knew him during this difficult time.

LIVE&LEARN: SPOTLIGHT ON THALASSAEMIA

Last month, one of our dedicated members, Ella Luong, joined MissingSchools' Live & Learn webcast series for a heartfelt and insightful conversation with MissingSchools Co-founder and CEO, Megan Gilmour. Their conversation explored Ella's lived experience raising two boys with Thalassaemia.

Ella shared the challenges of balancing her sons' medical care with their engagement in school and their learning, and emphasized the importance of early planning, strong family support, and raising awareness on invisible illnesses and their impact on children's education.

Interested in watching the whole podcast?
Listen here.

CALENDAR

12TH AUGUST
INTERNATIONAL YOUTH DAY

11TH SEPTEMBER
RUOK? 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.

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