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

Welcome to the latest edition of our newsletter.

As evidenced by our social media posts, we continue our affiliation with Deakin University, UNSW and other organisations seeking community input on a variety of projects aimed at improving opportunities for ongoing communication sharing on topics such as the use of AI in public health and health promotion, HTA research into costing and affordability of possible innovative treatments. I encourage all to engage with surveys as this is an excellent way to help influence future directions in the haemoglobinopathy space.

Who's enjoying the Biology Bites? A great way to initiate dialogue and inspire interest in the areas of genetic health.

TASCA's Father's Day silent auction is now live and I encourage everyone to support this great fundraising efforts. Don't forget you can also score some great gifts for the Father's in your life!

On that note, I want to take this opportunity to wish a very happy Father's Day to all the Father's in our community. I hope you are all celebrated with love.

To our community,

We at TASCA are aware of recent media reports regarding the issue of contaminated blood used to transfuse patients during the 1970s and 1980s.

The contaminated plasma products caused serious medical repercussions to many patients receiving blood.

This global incident was addressed in many countries, but has resurfaced in Australia due to recently declassified government documents.

In light of this, I want to take this opportunity to highlight that TASCA's remit is in the areas of awareness, engagement and education. We are not able to provide medical or legal advice, but would recommend patients who feel that they may have been impacted in any way should discuss the issue with their medical practitioners.

For more information, please refer to the following articles/statements:

- ABC News Story
- Australia Red Cross Lifeblood Australian Story Statement

TASCA MONTHLY

SCHOOL PRESENTATIONS

It's been a busy two months for Nathan, our Health Promotions Officer, as he travels around Victoria – delivering TASCA's free genetics presentation to Year 10 and 11 Secondary School 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.


Patterson River Secondary College

If you're a secondary school Biology and Science teacher, or a community group who wants to know more about Thalassaemia and Sickle Cell, there's still time for you to book your free presentation. Contact Nathan at healthpromotionsofficer@tasca.org.au or **(03) 7015 5637** to schedule your date and time.

MASTER OF GENOMICS AND HEALTH INTERNSHIP

We are pleased to introduce Jackson, a Master of Genomics and Health student at The University of Melbourne, who will be completing his internship with TASCA over the next few months!

MEET JACKSON - MASTER OF GENOMICS AND HEALTH

Hi all, my name is Jackson!

I am a second-year Master of Genomics and Health student at The University of Melbourne. I previously studied at Waurn Ponds in Geelong for my Bachelor of Science before moving back down the peninsula to be closer to my family.

Whilst pursuing my undergrad, I realised I was passionate about clinical genetics and cell biology, which led me to pursue my Master's degree. I am a huge advocate for genetic disorder awareness and have been involved in research within other similar organisations in the clinical space. I love all things genetics and providing people with knowledge they can use to empower themselves and those around them. I can't wait to start my time at TASCA and look forward to meeting the wonderful community!

TASCA MONTHLY

HELP SHAPE THE NEW NDIS SUPPORT NEEDS ASSESSMENT

The NDIS is introducing the new Support Needs Assessment. It will help decide a participant's funding and supports.

People with rare disease disability can take part in **paid testing**. This helps to make sure the assessment works for complex, multi-system conditions and people with high or changing support needs.

View the flyer.

Important: The testing is a practice session. It will not affect your current NDIS plan or funding. No plan or budget will be created or changed as a result.

Who Can Take Part

- Adult NDIS participants aged 18+, or
- Plan nominees of adult NDIS participants.

How to Take Part

1. Visit NDIS Engage – Test the new way of planning.
2. Read the Participant Information Pack.
3. Complete the Participant Consent form or call 1300 790 467.

Optional: Tell Rare Voices Australia You Registered

If you choose to, you can let Rare Voices Australia (RVA) know you've registered. RVA speaks up for Australians living with a rare disease. This includes Australians living with rare disease disability.

To let Rare Voices Australia know you have registered, complete this anonymous five (5) minute form.
No personal information will be recorded.

RVA will summarise the information we collect and show the NDIA:

- How many people with rare disease disability have registered.
- What types of rare diseases and conditions people have.
- Where there needs to be more targeted testing or training of assessors.

TASCA MONTHLY

INTRODUCING AUSSIE WHITE LION FOUNDATION

During late July, TASCA team members had the opportunity to meet with Ada Irorere and Garbi Irorere – founders of the **Aussie White Lion Foundation**.

The Aussie White Lion Foundation works to raise awareness of Sickle Cell Disease and support the individuals and their families affected by the condition.

During our meeting, both parties discussed the background and goals for our respective organisations, challenges faced by our communities, and potential collaboration efforts moving forward.

Sharing similar goals, we welcome this new partnership and look forward to collaborating with the foundation to help raise awareness and support our communities. Keep an eye on this space for more information.

You can read more about the Aussie White Lion Foundation here.

NEW WHO PUBLICATION: PAEDIATRIC DRUG OPTIMIZATION FOR SICKLE CELL DISEASE

The **World Health Organization** (WHO) has recently published a new priority-setting report, which identifies the areas of focus that should be prioritized for paediatric Sickle Cell Disease (SCD).

The paediatric drug optimisation (PADO) priority list for SCD includes the development of age-appropriate hydroxyurea formulations and a watch list for investigational therapies to guide future paediatric research.

Most importantly, the report includes key research priorities for the availability of safe, effective and child-appropriate treatments for children living with SCD.

You can view the report **here**.

TASCA MONTHLY

CUPPA AND CONNECT – INFORMATION SESSIONS

The **City of Glen Eira** is hosting a series of talks and workshops to support the healthy ageing community and carers of all ages in Glen Eira.

Sessions are held at venues across Glen Eira and online. During the series, experts will share practical information on topics including health and wellbeing, financial wellbeing, downsizing accommodation options, carer support, aged care navigation and more.

Anyone interested in Healthy Ageing, as well as our carers community, is invited to join in these informative sessions.

You can view all upcoming sessions **here**.

Click the tiles below to book your spot.

Financial wellbeing workshop
Friday 11 September, 11am–12pm
Caulfield Cup Room, Glen Eira Town Hall
The Smith Family will deliver a free Financial Wellbeing workshop for our community, designed to help us build confidence and security in managing our money. It will cover Scam protection, Digital banking and support in times of need, This workshop is delivered in partnership with ANZ's MoneyMinded program.
Note the presentation will be delivered as a webinar (online presentation) to the group at the Caulfield Cup room at Town Hall.
Bookings: www.trybooking.com/DMTTR

Healthy Brain. Healthy Body
Friday 27 November, 11am–12pm
Caulfield Cup Room, Glen Eira Town Hall
Did you know that longevity is 30 per cent due to genetics and 70 per cent due to your environment? Happy people live longer, have stronger immune systems and have improved coping skills. This one-hour information session will introduce you to the six factors of positive ageing so you can learn how to experience happiness and satisfaction at any age. This session is presented by Bolton Clarke.
Bookings: www.trybooking.com/DMTUG

CALENDAR

SEPTEMBER
HEALTHY AGEING MONTH

10TH SEPTEMBER
R U OK?DAY

17TH SEPTEMBER
WORLD PATIENT SAFETY DAY

19TH SEPTEMBER
WORLD MARROW DONOR DAY

29TH SEPTEMBER
WORLD HEART 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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