



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 February edition of TASCA's newsletter.

This month we attended our first trivia night as part of an ongoing commitment to community engagement. Held at the Bentleigh Social it was a fun night of camaraderie and testing of general knowledge. We will be participating in a monthly event and I encourage all to check our social media platforms or contact the office for details, date, time & location.

As part of our support of, and collaboration with, various research organisations, we were invited by staff at the Walter and Eliza Hall Institute (WEHI) to a tour of their facilities and a discussion of their current research program. Steph, Nathan, Jo and I were welcomed by lead researcher Dr Santa Rayn Pasricha and his

staff, with whom we look forward to extensive collaboration throughout this year.

This year we have launched an action plan document for parents to use at their child's school, in order to support effective learning and ongoing social inclusion. If any parent is interested in this resource, please contact the office or you can view them on our website [here](#).

A gentle reminder to everyone about the 50th Anniversary event and book launch to be held on May 24th. If you haven't already, please book your (free) tickets [here](#). We are very excited about this and proud of the work the organisation has undertaken in the last 50 years.

Thank you to everyone for the ongoing support of our work.



TASCA MONTHLY

VICTORIAN NEWBORNS THE FIRST TO RECEIVE FREE SCD SCREENING

Premier Jacinta Allan and Minister for Health Mary-Anne Thomas have announced the addition of **Sickle Cell Disease (SCD)** to the **Newborn Bloodspot Screening (NBS) Program**, a first for the nation.

The Hon. Mary-Anne Thomas explains that this inclusion to the program will ensure “that all Victorian babies” living with SCD “can get the care they need sooner”.

For more information about which conditions are screened for in the NBS program, view the information page [here](#).

INTERNATIONAL THALASSAEMIA DAY 2026

Each year, **International Thalassaemia Day (ITD)** is a day to come together and raise awareness, strengthen advocacy and amplify the voices of those living with Thalassaemia.

We are proud to announce that the Thalassaemia International Federation (TIF) has released the theme for this year’s ITD:

“Hidden No More: Finding the Undiagnosed, Supporting the Unseen”

Across the globe, many individuals are still only discovering Thalassaemia during pregnancy or early childhood, when earlier screening tools and timely care exist and can make a great difference. Simultaneously, many of those living with Thalassaemia remain invisible to the rest of the world, lacking the recognition and support they deserve.

Through the ITD2026 campaign, TIF seeks to

“bring those who have remained invisible into the spotlight”, working to strengthen community and their commitment to ensure that “every individual is seen, heard, and valued”.



INCORPORATING PATIENT DATA IN HEALTH TECHNOLOGY FUNDING DECISION

We are pleased to announce that TASCA will be supporting Professor Tracy Merlin, Dean of the School of Public Health, Adelaide University, and her team, in their MRFF funded project: “Societal, Health and Patient Experiences in HTA (SHAPE HTA)”.

Working with local and international patient engagement and lived experience experts, Tracy and her team will work towards developing a framework for evaluating highly specialised technologies that incorporates patient reported outcome data and uses new analytic techniques on routinely collected registry data.

For more information, read the media release [here](#).

TASCA MONTHLY - Easter Page

MAKE A HANDPRINT BUNNY CARD

Turn your handprint into an easy, yet festive, Easter card to wish your family and friends a Happy Easter!

You can view the visual step-by-step guide [here!](#)

What you will need:

- A4 Craft paper
- Acrylic paint and a paintbrush
- Googly eyes
- Satin bow

How to:

Step 1. Begin by folding a sheet of A4 Kraft Card in half.

Step 2. Paint your hand using white acrylic paint. Do not paint your thumb.

Step 3. Place your hand paint-side down onto the card. Press your hand down firmly, then remove your hand to reveal your handprint. You can fill in the handprint using a paintbrush and some white acrylic paint.

Step 4. Next, once the paint has dried, stick on two wiggle eyes.

Step 5. Paint on the bunny's features. You can always add a pastel satin bow to the top of the bunny's head.

Step 6. To finish, using a cotton bud, create colourful dots around the bunny.



TASTY EASTER BARK

A simple and delicious Easter treat. The best thing about this recipe is that you can add any toppings that you like!

View the original recipe, and find other Easter recipes [here](#).

Ingredients:

- 300g milk chocolate melts
- 125g pkt small candy-coated Easter eggs
- 1/2 cup marshmallows
- 1 tbsp coloured sprinkles

Method:

Step 1. Line a large oven tray with baking paper.

Step 2. Place the chocolate in a heatproof bowl over a pan of simmering water. Cook, stirring occasionally, for 5 mins or until chocolate melts and is smooth. Pour the chocolate onto baking paper and spread out to a 4mm-thick 25cm x 32cm rectangle.

Step 3. Sprinkle with the Easter eggs, marshmallows and sprinkles. Stand at room temperature for 1 hour or until set. Cut into large shards to serve.

*Other toppings to try:

- Shredded coconut
- Slivered almonds
- Dried strawberries



TASCA'S 50 Year Anniversary

1976 - 2026

RSVP BY 28 FEB

FEATURING TASCA'S 50-YEAR COMMEMORATIVE BOOK

24
MAY
2026



2PM - 5PM

Amora Riverwalk Melbourne

649 Bridges Rd, Richmond, VIC 3121
Event Pavilion 2 & 3

REGISTER NOW



Thalassaemia and
Sickle Cell Australia
Unifying Support with Genetics

50th Anniversary SILENT AUCTION

March 23 –
April 1



Place your bids for a chance to win:

- Luxury getaways
- Dining & experience vouchers
- Sports & entertainment prizes




Don't miss out! Save the date now!

*Auction link will be available closer to the date

 info@tasca.org.au

 Thalassaemia & Sickle Cell Australia

 (03) 7015 5637

 @tascaust



UNSW
SYDNEY



i2i UNSW
Implementation
to Impact

Was your child diagnosed with **Biotinidase Deficiency, X-Linked Adrenoleukodystrophy (X-ALD), Tyrosinemia Type 1, GAMT Deficiency or Sickle Cell Disease?**



If so, we'd love to hear from you...



Researchers from **UNSW Sydney** want to know your thoughts about:

- Possible changes to Australia's newborn screening programs
- Ways to best support parents and families



Am I eligible for this research?

You are eligible to participate if you are the parent/caregiver of a child (or children) currently under 18 years old, diagnosed with one of the following conditions: **Biotinidase deficiency, X-linked adrenoleukodystrophy (X-ALD), Tyrosinemia type 1, GAMT deficiency, OR sickle cell disease.**



What does participation involve?

A **30–45-minute telephone or video-call interview** on the following topics:

- Your experiences with newborn screening
- Your experiences receiving support after your child's diagnosis
- Your opinions about possible changes to newborn screening programs
- and the impact on parents and families

Please let us know if you would prefer to complete the interview in a language other than English



If you are interested...

Please email: neoscreen@unsw.edu.au
OR follow the following link:

<https://redcap.link/7r13w3p6>

OR scan
this QR
code:



Living Without a Functioning Spleen: Translating Guidelines into Everyday Care

Tuesday, 17 March 2026

Online via Zoom

Patients living without a functioning spleen are at lifelong risk of severe, rapidly progressive infection, including overwhelming post-splenectomy infection (OPSI) and sepsis. Despite well-established guidelines, many patients in the community remain unrecognised, incompletely vaccinated, or not receiving appropriate antibiotic prophylaxis.

General practitioners play a central role in identifying these patients, coordinating preventative care, and providing early safety-netting. This practical, case-based webinar is designed to support GPs and other healthcare providers to confidently apply current Australian recommendations and integrate Spleen Australia into routine primary care workflows.



Time					Topic	Presenter
AEDT (NSW, ACT, VIC & TAS)	AEST (QLD)	ACDT (SA)	ACST (NT)	AWST (WA)		
6.00pm	5.00pm	5.30pm	4.30pm	3.00pm	Delegate registration and login	
6.30pm	5.30pm	6.00pm	5.00pm	3.30pm	Setting the scene: why asplenia still matters in general practice	Dr Nenad Macesic
6.40pm	5.40pm	6.10pm	5.10pm	3.40pm	Asplenia and lifelong infection risk: what the evidence tells us	Prof Ian Woolley
6.48pm	5.48pm	6.18pm	5.18pm	3.48pm	When prevention fails: an OPSI case study	Sharon O'Brien
6.56pm	5.56pm	6.26pm	5.26pm	3.56pm	The patient perspective: what people living without a spleen need from their GP	Robyn Grima
7.06pm	6.06pm	6.36pm	5.36pm	4.06pm	Preventing infection in 2025: vaccines and antibiotics	Dr Sarah McGuinness
7.16pm	6.16pm	6.46pm	5.46pm	4.16pm	Translating prevention into everyday general practice	Dr Sarah Chu
7.24pm	6.24pm	6.54pm	5.54pm	4.24pm	Making it stick: identifying, registering, and supporting patients	Ella Brown
7.30pm	6.30pm	7.00pm	6.00pm	4.30pm	Q&A session	
8.00pm	7.00pm	7.30pm	6.30pm	5.00pm	Meeting close	

To register for this activity, simply:

- Go to www.cpd.inovating.com.au
- Login - if you previously used CPD HCP you can use the same email and password. If you have not registered for an Inovating event in the past, click on "Register here" and complete your details.
- Find the event and click on "Learn More"
- Click on "Register"



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CALENDAR

8TH MARCH

INTERNATIONAL WOMEN'S DAY

13TH MARCH

WORLD KIDNEY DAY

23RD MARCH

TASCA SILENT AUCTION OPENS

30TH MARCH

WORLD DOCTORS 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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