EDITION: SPRING 2021

Unifying Support and Genetics

Thalassaemia and Sickle Cell Australia

COVID-19 Vaccination Information for Thalassaemia and Sickle Cell Anaemia Patients

Produced by clinicians from Monash Health, Royal Melbourne Hospital & Western Health

COVID-19 is a highly contagious virus that has high hospitalisation rates as well as mortality, particularly for those with underlying medical conditions which make them more vulnerable. Both Thalassaemia and Sickle Cell Anaemia have been designated as vulnerable conditions in the context of risk for hospitalisation and death from COVID-19. Vaccines are the best available defence against severe COVID-19 disease and death.

The Thalassaemia International Federation has categorised "highest risk" and "high risk" Thalassaemia patients with any two of the following:

- Over the age of 50 years.
- Transfusion dependent.
- Non-transfused with haemoglobin less than 70g/L for more than 2 years.
- Receiving iron chelation therapy.
- Splenectomised persons or persons with asplenia.
- Other medical conditions - diabetes, heart disease, lung disease.

Therefore, all international advocacy groups for haemoglobinopathies including Thalassaemia International Federation (TIF), the American Society of Haematology (ASH) and Cooley's Anaemia Foundation, strongly recommended that all haemoglobinopathy patients be vaccinated against COVID-19.

COVID-19 Vaccines

There are currently 2 types of vaccines available in Australia; MRNA vaccines (Pfizer BioNTech COVID-19) and viral vector vaccines (AstraZeneca), which have been modified so they cannot grow in humans. Both vaccines are extremely effective at reducing hospitalisation, severe disease and death. This has been demonstrated in large clinical trials involving tens of thousands of participants. Additionally, both vaccines are extremely safe and have been given to millions of people globally with overwhelmingly very limited severe side effects.

Currently, anyone aged over 12 years is eligible for COVID-19 immunization.

Is COVID-19 immunization recommended for people with Thalassaemia and Sickle Cell Anaemia?

COVID-19 vaccines are NOT contraindicated and strongly encouraged for adults and youth, including those who have had COVID-19 infection. Parents, carers and family members of those with Thalassaemia and Sickle Cell Anaemia also need to be vaccinated to avoid passing it on to affected family members. As you are aware, Victoria is currently experiencing large numbers of COVID-19 cases. Indeed, hospitalisation rates, ICU admissions and numbers of patients requiring ventilator support are increasing. It is therefore imperative that you, as well as your family and friends get vaccinated as soon as possible. It is the most important health measure you can take to protect yourself, your family and your community from severe illness and death from COVID-19.

2021 Annual General Meeting with Special Guest, Peter Bol

Scan to RSVP

AGM 2021

THALASSAEMIA AND SICKLE CELL AUSTRALIA

Oct 28, 2021
7 pm - zoom

Special Guest: Peter Bol

Olympian and TASCA Ambassador Peter Bol will be sharing his inspirational story and participating in a short Q&A.

DON'T MISS OUT!

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TASCA acknowledges Australia's first peoples as the traditional owners and custodians of the land on which we meet and provide our services to those effected by genetic haemoglobin disorders. We pay our respect to them and their cultures, and to elders both past and present.

Visit **TASCA.org.au/store** to check out the great range of TASCA branded items and show your support. 100% of the profits go right back to help us supporting, advocating and educating!

Thalassaemia and Sickle Cell Australia acknowledges the support of the Victorian Government.

Chair's Address

The last 3 months have been an interesting time for us at TASCA with Victoria plunging in and out of lockdown. Despite this, we have continued to actively provide support, education and advocacy to our community. One of the highlights from this period includes meeting with members of Thalassaemia and Sickle Cell Society of NSW, to work together towards a new advocacy goal, campaigning for equitable access to T2* MRI scans to improve iron overload outcomes in patients.

We have also made ground in improving awareness of Thalassaemia to mental health care providers, through presenting at an Australian Psychological Society webinar.

Finally, we are proud to announce the TASCA Small Grants in Honour of Sotirios Katakouzinos and Maria Kastoras. The Small Grant program is open to all TASCA members and is intended to improve the wellbeing of patients and families through small equipment purchases. (More information is available on Page 3).

TASCA has spent much of our lockdown time working on the new Strategic Plan. Our Secretary, Pat Bollard, has worked intensively with the committee and staff to develop a mission statement and goals that will serve as a direction for TASCA's work within the community.

Our 3 year plan will continue to focus on the core areas of education, support and advocacy within the parameters of our mission statement. In addition, however, it will reflect our growing commitment to support patients, families and clinicians in other Australian states.

A final and ratified copy will be presented at the Annual General Meeting in October.

All members will have, by now, received notifications regarding our Annual General Meeting to be held on October 28th, 2021, via zoom.

I would like to encourage members to attend this important event, to have a say and to contribute to TASCA's work. Please ensure that your membership is current and feel free to nominate (financial) members to join us in our ongoing efforts.

Another victim of COVID-19 lockdowns, the Sooshi Mango concert previously advertised to be held in August was rescheduled by the event organisers to November 2021, then rescheduled again to February 2022.

As a result, we have cancelled our attendance but will look forward to hopefully being able to attend this hilarious event at a future time.

Keep Safe,

Peter Verveniotis

Staff Changes

It is with great sadness that we will be farewelling Sam, our Health Promotion Officer, in October 2021.

Sam has been an integral member of our team, always been willing to go the extra step and has shown compassion and dedication to the Thalassaemia and Sickle Cell Community, to patients, their families and carers, as well as to medical professionals.

Sam has continued to showcase the important work that TASCA provides by engaging with stakeholders, the Department of Health, the Department of Education and many community organisations.

Committee Update

Farewell to Jane from MIU

We caught up with Jane Grimshaw, a familiar face at the Medical Infusion Unit at Monash Health. Jane reflects on her years serving as the Ward Clerk at the unit and looks forward to the challenges that lie ahead in her new appointment at the Lung and Sleep, Immunology and Allergy clinics.

To everyone at the Medical Infusion Unit:

I started working in MTU (now MIU) four and a half years ago. I came into the unit as I wanted to have regular set hours. When I was interviewed, I was asked if I knew anything about Thalassaemia, to which I replied: No.

However, I spent the next four and half years learning and growing to understand what Thalassaemia and Sickle Cell was. I met wonderful people, who, through no fault of their own, have this condition. I watched the children grow as well as the adult patients; I learned how they coped with transfusions.

Life was always interesting in the unit, people with their different and dynamic personalities, we always celebrated the children's birthdays, and acknowledged milestone birthdays of the patients. I formed lovely bonds with some wonderful people, and I miss the interaction with our patients and staff.

I loved working with the caring staff of the unit, and we are a great team who support one another.

I have now been in my new role for a month, and working in the Lung and Sleep, Immunology and Allergy clinics is another huge learning curve. I am fortunate to work with another great team, who are willing to support and guide me.

I would like to wish all the patients and staff the best, especially at this difficult and crazy time with COVID.

I do miss the unit and the faces who I have come to know well, and care for too.

Kindest regards always,

Jane xoxo

Membership Renewal Reminder

A reminder to all TASCA members who recently received membership renewal invoices in the post. Membership Renewals are now due and need to be paid if you intend to participate in this year's Annual General Meeting, Thurs 28th Oct. Please do not hesitate to contact our office if you wish to confirm your membership status. By becoming a member or renewing your membership:

- you can help support TASCA and it's 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 disorder.

TASCA Small Grants in Honour of Sotirios Katakouzinos & Maria Kastoras

TASCA is pleased to announce the availability of a new Small Grants program. It is named after Sotirios Katakouzinos and Maria Kastoras, to honour the memory of two past presidents of TASCA who championed the wellbeing of the genetic haemoglobin disorder community.

The TASCA Small Grants program is intended to improve the quality of life and wellbeing of patients through a small grant to fund equipment or other non-perishables for treatment centres.

Who is eligible to apply?

- Haemoglobin disorder patient / carer.
- Current financial TASCA members.
- A social worker on behalf of an individual patient / parent / carer.

What may be funded?

- Entertainment systems for treatment centres.
- Medical equipment unable to be funded by hospitals.
- Furnishings (small).
- Other non-consumable items that would improve the comfort and wellbeing of patients while receiving treatment.

What is the maximum value of the grant?

- TASCA will fund equipment to the value of $750.

For more information and to apply.
Visit www.tasca.org.au/tasca-small-grant

Key Dates: Grant Applications Open - 01/10/2021
Submissions Close - 12/11/2021

TIF Update - TIF e-Academy

The Thalassaemia International Federation (TIF) has launched a new video to promote the TIF e-Academy established in 2017. TIF e-Academy's purpose is to provide 'current, verified information for Thalassaemia and other Haemoglobinopathies globally'. All courses on offer have been developed and reviewed by eminent international medical experts with extensive experience in treating patients with Thalassaemia and Sickle Cell Disease.

Key courses include: Thal e-Course for Patients and Parents (available in 7 languages), eThalED Course for Medical Specialists (available in 3 languages) and SCD e-Course for Healthcare Professionals. Courses on TIF e-Academy are free, self-paced and available to patients and healthcare professionals through a registration process.

For further information visit the TIF website:

www.thalassaemia.org.cy.

Watch the Thal eCourse Intro Video

THALASSAEMIA INTERNATIONAL FEDERATION

Australian Research into New Treatment for Beta Thalassaemia

Hudson Institute researchers have developed a new gene therapy strategy to treat Beta Thalassaemia, an inherited disorder where the body doesn't make enough haemoglobin in red blood cells.

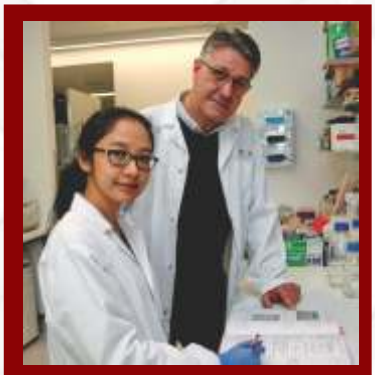
Researchers from the Hudson Institute led by Dr Jim Vadolas found the lack of haemoglobin in Thalassaemia is caused by two issues – a mutation in the beta globin gene, and too much alpha globin, which is toxic to red blood cells.

Dr Vadolas' team used viral gene therapy – a process where therapeutic genes are delivered into blood stem cells by a virus – to simultaneously deliver the therapeutic beta globin gene and limit the production of excess alpha globin.

The goal of this research is to improve the quality of life and save lives by finding new treatments that improve haemoglobin production in Beta Thalassaemia patients.

This research was conducted in the laboratory. The next step, requiring significant investment, would be to deliver the therapy to patients.

Article by Hudson Institute



Dr. Tiwa Nualkaew and Dr. Jim Vadolas

Why is this study important? Dr Vadolas' research group investigates the causes and consequences of severe anaemia in blood disorders, particularly in people who have a mutation in the beta globin gene.

These disorders lead to altered production of both haemoglobin and red blood cells, causing serious life-threatening complications soon after birth.

For more than two decades, researchers have been investigating gene therapy strategies to treat inherited red blood cell disorders including Beta Thalassaemia and Sickle Cell Disease. Recent clinical gene therapy trials have proven reliable for the treatment of milder forms of the disease. However, for patients with severe forms of Beta Thalassaemia, gene therapy has not been as effective.

Is a vaccine coming soon for Hepatitis C?

A vaccine to protect against infection from Hepatitis C could be in use within 5 years, says Professor Sir Michael Houghton, 1989 Nobel Prize winner for Medicine and Physiology, along with three other scientists who discovered the Hepatitis C Virus (HCV).

"While the advent of directly acting antivirals (DAAs) to cure Hepatitis C has given us a huge weapon to turn the tide on this pandemic, there is no doubt that a vaccine is required to help the world reach its' ambitious target of reducing new Hepatitis C infections by 90% and mortality rates by 65% by 2030," explains Sir Michael, speaking at the at a major European gathering of Clinical Microbiology and Infectious Diseases scientists and clinicians this year. Although the COVID-19 pandemic has slowed down many areas of medical research, Sir Michael states that emerging technologies from the pandemic such as recently developed RNA and adenovirus vaccines, have helped scientists better understand ways to reproduce immune responses to protect the body against Hepatitis C.

Sir Michael believes that if clinical trials are successful, Hepatitis C vaccines could be rolled out to the population as early as 2026. Such vaccines, Sir Michael reasons, would not only reduce hepatitis infections, but make great health economic sense, doing away with costly hepatitis treatment through its prevention.

Australia can't wait to eliminate hepatitis!
Learn more on Hepatitis Australia's website:
www.hepatitisaustralia.com

Advocating for the Inclusion of Iron Overload MRI Scans in the Medical Benefits Scheme

TASCA has begun preliminary meetings with clinicians and Thalassaemia and Sickle Cell Society of NSW, to work together and advocate for the inclusion of MRI scans required to assess iron overload in patients, in the Medical Benefits Schedule (MBS). The MBS lists the medical services covered by Medicare and includes an MBS fee for each service. This is the amount (or benefit) the Australian Government thinks the service should cost. The schedule also includes the rebate rate claimable for each service.

MRI procedures are an important part of iron management in transfusion dependent patients. Currently, these are funded by hospitals. We believe that this has the potential effect of patients receiving less frequent scans, due to health services prioritising based on the patient's severity of iron overload and hospital budget constraints. We hope that our efforts and collaboration with clinicians, ThalNSW and other stakeholders to add annual MRI scans to the MBS for transfusion dependent patients will improve access and health outcomes.

GSNV Update

TASCA continues to be involved with the Mental Health Working Group facilitated by the Genetic Support Network Victoria (GSNV). The group consists of representatives from Genetic, Undiagnosed and Rare Disease (GUARD) groups as well as psychologists and genetic counsellors. The role of the group is to lead the review into the suitability of current resources and services for the GUARD community and to develop a strategy for making recommendations for systemic and immediate support for our community.

The group has developed a strategic plan and is in the process of prioritising projects to maximise impact on the community.

As a result of our association with the working group, GSNV invited TASCA to speak at a webinar organised for the Australian Psychological Society. The webinar, titled "A Day in the Life of Thalassaemia" was part of a larger series designed to raise awareness of genetic conditions to psychologists who provides mental health services to the rare disease community. TASCA's Vice-Chair Robbin Vissakodeti spoke about his lived experience as a parent in a Sickle Cell and Thalassaemia family. The webinar was recorded and made available to psychologists interested in learning more about Thalassaemia and Sickle Cell.

gsnv
Genetic Support Network Victoria

R U OK? Day, SEPTEMBER 9

"Every day is #RUOKDay. Every day's the day to start a conversation that could change a life"

A national initiative, R U OK? Day is held on the second Thursday in September every year. This year TASCA helped spread the message, by hosting two Zoom drop-in sessions, encouraging everyone to participate in social media post activities and sharing tips and suggestions on how to respond to family members, friends and co-workers. You can learn more at: **www.ruok.org.au**

THERE'S MORE TO SAY AFTER R U OK?™

Vicky's Special Birthday Gift

My name is Vicky, and I just celebrated my 50th birthday on 19 June. Coincidentally 19 June is International Sickle Cell Day which is also the chronic illness my son was born with. My husband Peter and I are the proud parents of two wonderful boys. Christian our eldest, lives with Sickle Cell Beta Thalassaemia and was diagnosed just before his second birthday. Christian lives a relatively normal life and just recently transitioned from Westmead Childrens Hospital where he was under their care since the age of 2 and is now at Prince of Wales in Randwick under the care of Doctor Kidson-Gerber.

Christian is 19 years old and is a strong, tall, handsome and outgoing young man who lives with consideration to sickle cell disease but is definitely not limited by it. He is studying Business at University, loves playing soccer and has a strong circle of friends and cousins who are extremely important to his wellbeing.

Christian currently undergoes monthly red cell exchange through apheresis and is managing his health by looking after what he eats, staying well hydrated and listening to his body when he feels tired. That is not to say that he does not experience the odd crisis here and there. Those periods where he has a crisis are difficult, but we support him and make sure he knows that we are there to get him through the physical and mental challenges he experiences.

I celebrated my birthday with 70 friends. I decided I did not want any gifts for myself and instead asked my friends and family to donate to Thalassaemia and Sickle Cell Australia. Sam from the society was very helpful in setting up QR codes so that people could scan directly to the organisation. My family and friends raised close to $3500 and as a family we are beyond grateful for the love and generosity they showed us.

We would like to thank all our family and friends who donated, no matter how big or small, to the cause and to Sam from the society for helping my vision come to fruition. We also would like to thank all the medical staff and professionals for their care of Christian for the past 17 years and who have advised and guided us in our journey thus far. And finally, to all the other sickle cell warriors out there, you are always in our thoughts and prayers. Be safe during these trying times.

Thanks to all,

Vicky Valensise

Thanks Vicky!

Ella's Birthday Wish

Ella Luong, a passionate TASCA member has once again encouraged family, friends and colleagues to celebrate her birthday by raising funds for our organisation. Thank you Ella for your ongoing generosity and support. We wish you all the best with your campaign and a Wonderful Birthday with many happy and healthy returns.

Happy Birthday Ella!

Prologue of "IRON BOY" by Arthur Bozikas

October 1986

Where was my wife? I found myself sitting alone in front of the obstetrician, who my wife, Helen, and I had met for the first time only minutes earlier.

But now Helen was gone. After another quick look around the doctor's plush office, I excused myself and went out to search for her. Surely she wanted to hear what the doctor had to say?

After dismissing her unusual behaviour as a possible toilet dash, I was stunned to find her outside in the carpark next to our car. She was in hysterics, crying and shaking uncontrollably.

'What's up sweetheart, are you alright? Is the baby okay?'

'I'm not going back in there, I'm not!' Helen screamed through her tears.

'No, of course not, why? What happened honey?' I was confused and now very concerned.

'You know why, you heard him! I'm not terminating our baby!' Helen burst into tears again.

'What?' I said in disbelief. This was news to me. Apparently, I had been more distracted than I'd realised as I had missed the doctor's words.

It was October 1986, I was twenty-five years old, she was twenty-three and this was our first pregnancy. The sense of achievement of being a husband was still new, and soon I was to be a dad. The very thought was overwhelming, wonderful and scary. It sent me flying high with exhilaration, but then I would remember my medical condition and crash back to earth. The ensuing fear was crushing.

What if our child inherited my condition? Would I be responsible for denying both my wife and our child the chance of a normal life? Panic then manifested inside me, sending my thoughts spiralling out of control. I also now envisioned our baby being born with huge deformities that wasn't even related to my condition.

These misgivings had started the day we'd found out Helen was pregnant. After that, on a daily basis, worst-case scenarios constantly bombarded my mind, exhausting me.

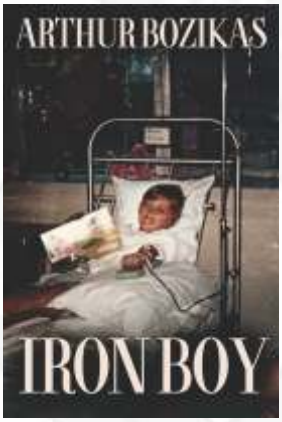
As I'd sat next to her in front of the obstetrician, I'd been assailed yet again by those tumultuous thoughts. Perhaps, if I had reined in my troubled introspection, I would have noticed her leave the room. But overwhelmed by my fears, I was oblivious.

'Look, I can't offer you anything else. Hello, your wife needs you!'

'Sorry, did you say something?'

'I SAID, your wife needs you!' The doctor practically shouting while pointing pretentiously over my shoulder toward the door behind me.

I was twelve when I was first told I wouldn't live past my twenty-fifth birthday. Born with a chronic blood disorder called beta thalassaemia major (Thal), the doctors said my body was unable to produce healthy red blood cells and therefore, I required regular blood transfusions to survive. Since then, it had only been the generosity of wonderful blood donors that had kept me, and others like me, alive. We are known as Thals.



OUT NOW ON amazon

About Arthur and "IRON BOY"

Arthur Bozikas was born with Thalassaemia major in 1961 before iron chelation was available and survival long into adulthood was slim. He has gone on to pursue tertiary education at the age of 40 and publish novels. Serving a long tenure as CEO of Self Advocacy Sydney, Arthur was awarded an Order of Australia Medal in 2016.

Iron Boy is a heart-breaking, gutsy and honest story about Arthur's fight back from the darkness, and of his will to survive and prosper against all odds. To date, he has had 8600 injections, 700 blood transfusions and 2200 blood packs.

Iron Boy is now available on Amazon in eBook and paperback.

Read the first 3 chapters here:

https://arthurbozikas.com/books/iron-boy/

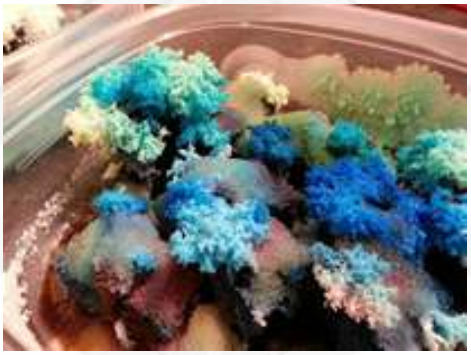
It's Springtime!

Spring Butterflies

Share your beautiful crystal gardens and butterflies with us by uploading to www.tasca.org.au/TASCAKidsSpring or post to Facebook / Instagram with #TASCAKids

More Kitchen Chemistry - Growing a Crystal Garden

(children will require supervision)



Ingredients:

- Water
- Ammonia
- Laundry Bluing eg. Bluo (Coles), be careful, it stains
- Salt
- Food Colouring - assorted

You will also need:

- 1 clear container (or disposable plastic plate)
- Several small pieces of porous material to grow crystals on eg. sponges, BBQ briquettes
- A small plastic cup to mix ingredients
- 1 plastic spoon

Method:

- Place your porous material on the bottom of your container.
- Mix 2 tablespoons of salt with 4 tablespoons of water in your cup, stirring to dissolve as much salt as possible
- Add 2 tablespoons each of ammonia and laundry bluing, mixing as you go. The mixture will be blue, watery sludge.
- Pour the mixture on top of the porous material. Make sure all the salt is poured over the items in your container.
- Let the container sit open to the atmosphere overnight.

The next day your crystal garden should start to bloom! To keep your garden in bloom, add 2 more tablespoons of salt on the second day, then half batches of the whole mixture from time to time. Make sure you pour the liquid into the base of the container, and not on top of the crystals.