



# Thalassaemia

## A U S T R A L I A

*Unifying support and genetics*

Thalassaemia Australia Winter 2015 Volume 10 Issue 21

Quarterly

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Thalassaemia Australia Inc.  
ABN 85 502 428 470  
333 Waverley Road,  
Mount Waverley VIC 3149 Australia  
Phone: +61 3 9888 2211  
Fax: +61 3 9888 2150  
info@thalassaemia.org.au  
www.thalassaemia.org.au



## TIF receives WHO award

One of the most prestigious honours of the world health organization (who) has been granted to the thalassaemia international federation (tif)!

We are extremely proud to announce that the prestigious Dr Lee Jong-wook Memorial Prize has been granted to the Thalassaemia International Federation (TIF) for its outstanding global contribution in the field of public health. The award ceremony was held during the 68th World Health Assembly (68th WHA) on 21 May 2015, in Geneva.

The prize was received by Dr Androulla Eleftheriou, TIF Executive Director. Mr. Panos Englezos, TIF President and Mr. George Konstantinou, Assistant Secretary of the TIF Board of Directors were also present at this formal occasion.

TIF's success through the years since its establishment in 1987, undoubtedly underlines and demonstrates the significant impact of patients/ parents' organisations can have on the promotion of policies and programmes, disease specific, but also health oriented ones.

The empowerment of patients and parents across geographic, cultural, religious, social and linguistic borders and their transformation into equal partners with

national and international health bodies in their journey has been our major success and will continue to constitute the main focus of work.

TIF was privileged to be working in official relations with WHO since 1996 promoting and contributing to many of its programmes, disease specific and public health ones, as an important pillar of its activities.

TIF's Board of Directors and the global haemoglobinopathy family across 63 countries worldwide express their most sincere appreciation to those who have shown confidence and have recognised its impact and value clearly reflected through the receipt of this prestigious award.

We express our continued and full commitment not only to keep but to strengthen the momentum across the world in many ways through enhancing our contribution to the relevant programmes of WHO.

Information courtesy of Thalassaemia International Federation (TIF)  
[www.thalassaemia.org.cy](http://www.thalassaemia.org.cy)

# Thalassaemia Australia Inc.

## Committee of Management 2015

### Executive

<b>President</b>	Sotirios Katakouzinou
<b>Vice-President</b>	Dr. Jim Vadolas
<b>Secretary</b>	Agnes Nsofwa
<b>Treasurer</b>	Preston Nsofwa

### General Committee Members

Anastasia Katakouzinou  
Bessy Mougou  
Joe Ravidia

## Committee meeting dates for 2015

Committee of Management meetings begin at 7.30pm and are held at the Thalassaemia Centre, 333 Waverley Road, Mt Waverley 3149 or the Murdoch Childrens Research Institute, Royal Children's Hospital, 50 Flemington Road, Parkville 3052.

Tuesday 21 July	Tuesday 20 October
Tuesday 18 August	Tuesday 17 November
Thursday 17 September	Thursday 17 December

We currently have a few vacant positions on the Committee. If you would like to join us, please contact Sotirios Katakouzinou – President on 9888 2211 or email [info@thalassaemia.org.au](mailto:info@thalassaemia.org.au).

Dear Members and Readers, if you would like to receive your newsletter via email, rather than in the mail, please contact Thalassaemia Australia at: [info@thalassaemia.org.au](mailto:info@thalassaemia.org.au) or Thalassaemia Society of NSW at [coordinator@thalsnw.org.au](mailto:coordinator@thalsnw.org.au) to update your records!



The information in this Newsletter is provided by Thalassaemia Australia Inc. for educational and information purposes only. It is not a substitute for professional medical care and medical advice. The contents express the opinions of the authors who alone are responsible for their views expressed. Thalassaemia Australia does not accept any legal responsibility for their contents.

## RESEARCH

### Bluebird Bio's sickle cell gene therapy working for French boy

A pioneering gene therapy for sickle cell disease is working well so far for a 13-year-old French boy with the hereditary blood disorder, researchers said on Saturday, in a boost for the technology to fix faulty genes.

He is the first patient with severe sickle cell disease (SCD) to be treated with Bluebird Bio's LentiGlobin BB305 product, which the U.S. biotech company believes could cure the disorder.

SCD is caused by a mutated gene, resulting in abnormal red blood cell function. Patients suffer anemia, painful obstruction of blood vessels and, in some cases, early death. Bluebird's gene therapy treats the condition by extracting blood stem cells and then adding a working version of the malfunctioning gene. Results presented at the European Hematology Association meeting in Vienna showed the French patient has not needed a life-sustaining blood transfusion for more than three months and his body was producing 45 percent so-called anti-sickling hemoglobin at six months.

"(This) is cause for optimism as we expect levels of anti-sickling hemoglobin of 30 percent or more could significantly improve and potentially eliminate the serious and life-threatening complications associated with sickle cell disease," said lead investigator Marina Cavazzana of Paris Descartes University.

Two other patients with a related blood disorder called beta-thalassemia remained transfusion-independent at 16 and 14 months respectively.

Bluebird had already reported success with beta-thalassemia patients for a shorter period of time.

Shares in Bluebird have doubled this year on growing hopes for its gene therapy drug pipeline and the latest results may shore up confidence further, although analysts said data from more patients was needed to better understand the treatment's potential.

Gene therapy is currently undergoing a renaissance following a series of setbacks in the late 1990s and early 2000s, and several large drugmakers are now buying into the field. The medical approach has the potential to revolutionize a number of diseases caused by faulty genes, ranging from blood disorders to eye problems to heart failure.

But producing gene therapy products is extremely complex and the \$1 million price tag for the first such drug approved in Europe, from Dutch firm UniQure, highlights the quandary facing governments and insurers as to whether they will offer value for money.

**Source:** Ben Hirschler, Reuters, June 13 2015,

<http://uk.reuters.com/article/2015/06/13/us-health-genetherapy-bluebird-idUKKBN0OT0B620150613>

If you have an event or story you would like publicised please send the details to the newsletter editor at:

333 Waverley Road,  
Mount Waverley VIC 3149

Ph: 03 9888 2211  
Fax: 03 9888 2150 or email  
[info@thalassaemia.org.au](mailto:info@thalassaemia.org.au)

Please include the date and time of the event; a description in 20-30 words; venue address; any costs involved and a contact name and phone number and/or email address for public enquiries.

This newsletter is supported by an unrestricted educational grant from Novartis Oncology.

All content presented in this newsletter has been independently prepared by Thalassaemia Australia.



## RESEARCH

### Bluebird Bio trialling thalassaemia gene therapy in North Star Study

*Dear patients, family members and members,*

An ABC Report in January highlighted the first beta-thalassaemia patient to receive gene therapy for this condition in Australia. The patient from Sydney, Stacey Wong aged 26, is one of 8 patients worldwide to have received this breakthrough treatment.

This investigation is part of bluebird bio's Northstar Study to treat beta-thalassemia major and severe sickle cell disease. This treatment uses a modified virus to deliver the functional human beta-globin gene into patient stem cells ex vivo (outside the body) and then return the modified stem cells to the patient, ideally getting patients to manufacture their own beta-globin.

#### The company has set up three clinical trials:

- 1) HGB-204 Study is a phase 1/2 study designed to evaluate the feasibility, safety and efficacy of LentiGlobin product in the treatment of subjects with beta-thalassemia major. The study is designed to enroll up to 15 patients. Patients will be evaluated for safety and efficacy post-transplant.
- 2) HGB-205 Study is a phase 1/2 study designed to evaluate the safety and efficacy of LentiGlobin drug product in the treatment of subjects with beta-thalassemia major and severe sickle cell disease. The study is designed to enroll up to 7 subjects. In only sickle cell disease patients, efficacy will also be measured based on the number of vaso-occlusive crises or acute chest syndrome events.
- 3) HGB-206 Study is a phase 1/2 study is designed to evaluate the safety and efficacy of LentiGlobin product in the treatment of severe sickle cell disease in the U.S.

New data presented at the recent American Society of Haematology Annual Meeting in Orlando, Florida, showed the first four patients treated with bluebird bio's LentiGlobin BB305 therapy remain transfusion-free after at least three months follow up, confirming the functional treatment for the disease. This treatment resulted in sufficient hemoglobin production reducing or eliminating the need

for transfusion among beta-thalassemia patients who would otherwise require chronic blood transfusions. These data consisted of the first five patients treated in Bluebird bio's ongoing Northstar Study and the first three subjects from its earlier study.

LentiGlobin product has so far been well tolerated, the company said in a recent report, with no gene therapy-related serious adverse events observed. The company is now working to complete enrolment in 2015, targeting 22 patients in total. The plans are to start working with experts, patient groups and authorities to map out a regulatory path for the treatment, Chief Medical Officer Dr. David Davidson said.

I have been in contact with Stacey's doctor in Sydney (Dr. Joy Ho), who is quietly confident about this therapy. While it's early days for Stacey, it is encouraging to see from the ABC report, that Stacey has recovered from her stem cell transplantation and doing well, but it is too early post-transplant to draw any meaningful conclusions on clinical efficacy. We wish Stacey all the best and hope to see more of Stacey in the near future. Dr Joy has also confirmed that a second Australian patient has now been recruited to the NorthStar clinical study.

Dr. Jim Vadolas, at the Murdoch Children's Research Institute, who is currently studying the LentiGlobin BB305 gene therapy vector in his laboratory, is indeed very excited by this breakthrough treatment. "I've been following this technology throughout my career. It has taken over 15 years for beta-thalassaemia gene therapy to reach clinical trials. However, after some initial setbacks in the field, it's encouraging to see gene therapy finally making significant advances in the clinic.

Although it's still early days for beta-thalassaemia gene therapy, it's very important for this treatment to undergo adequate evaluation for safety and efficacy over the next few years. While the future is looking much brighter, it's important for patients to remain compliant with their recommended treatment and monitoring.

## To Australia and beyond...

TIF has initiated a new endeavour, a motivational new project called the Australian Blood Project.

This article appeared in the TIF Magazine – Issue 65 Oct 2014

Australia has a significant number of thalassaemia-affected people, which is increasing as migration patterns change. However, the exact number of affected people is unknown as well as the severity of each case. Little is known about their long-term complications and outcomes. Although different centres currently manage the same disease, they do not follow a common protocol, and there is a need to determine which strategies work best for patients.

In this context, we are delighted to share with you that TIF has been invited to join a grant application which is to be submitted to the National Health and Medical Research Council (NHMRC) of Australia, with the aim of creating a national Haemoglobinopathy electronic registry in this country. The invitation was sent by a group of haematologists led by the Head of the Transfusion Research Unit at the Department of Epidemiology and Preventive Medicine (DEPM) in Australia, Dr Erica Wood.

#### The aims of the national Haemoglobinopathies electronic registry are to:

- Provide an important framework for future research to improve patient care
- Be used to help to plan health care services for the future
- Bring together a network of Australian health care professionals with a special interest in haemoglobinopathies, for sharing ideas.

The Registry is the first step of a major project to ensure that all Australians with a Haemoglobinopathy continue to receive the best possible care. Further details about this project will follow in our next TIF Magazine.

**Source:** TIF Magazine – Issue 65 Oct 2014



## Farewell to

### Jim Demetriou and Helen Kosmarikas

Thalassaemia Australia would like to thank Jim Demetriou and Helen Kosmarikas for their hard work and many contributions to our organisation.

In his role as the community educator, Jim reached out to many different communities, sharing with them what thalassaemia is and what it is like to live with the condition. He was much loved by those he spoke with.

Helen's business knowledge has been invaluable to Thalassaemia Australia and her dedication to the organisation is very much appreciated.

We would like to wish them both all the best in their future endeavours.



## IN THE NEWS

### Government to transform Australians' e-health records system to 'opt-out' model

On 10 May 2015, the Government announced that it will rename the personally controlled electronic health record (PCEHR) scheme as "myHealth Record" and adopt an opt-out model after completion of limited trials. Health and aged care providers should ensure that their IT infrastructure can interface with "myHealth Record" and adequately meet the technical requirements of the new e-health system.

#### Implications for health and aged care providers

Importantly, health and aged care providers (and other organisation having access to electronic health records) should ensure that their IT infrastructure is sufficiently robust to maintain the privacy and security of health records to which their staff will have access.

Providers may need to mix technology, contracts and employment policies to ensure that they are sufficiently capable of assuming responsibility for the information they collect from patients and customers in the course of delivering services.

Information about the current PCEHR can be found at the eHealth website. This could be used as a guide to providers to plan systems for myHealth Record. But providers should bear in mind that the Government intends to revise the myHealth Record system to "become more user-friendly and to better reflect the needs of health professionals, including better alignment with existing clinical workflows". The Government has not set a timeframe for when information about myHealth Record will be published.

#### December 2013 review recommended switch to "opt-out" model

The previous Government introduced the PCEHR scheme as an "opt-in" model. However, an independent review commissioned by the current Government found that less than 10%

of Australians had adopted PCEHR since it was launched in 2012. The review recommended that the Government changes the model to an "opt-out" model to encourage large-scale take-up of electronic health records. The Government released the results of the independent review via the Government's eHealth website.

In the 2015 Budget, the Government allocated \$485 million over four years to the roll-out of the myHealth Record system. The Government predicts that when the system is fully operational, it could save up to \$2.5 billion per year, with State and Territory Governments collectively saving an extra \$1.6 billion per year.

#### Government to run limited trials

The Government will run limited trials around Australia of the opt-out model, in conjunction with the State and Territory Governments. The Federal Health Minister will meet with her State and Territory counterparts to plan when and where the trials will be established. As part of the revisions to the electronic health records initiative, the Government will dissolve the National eHealth Transition Authority and replace it with an Australian Commission for eHealth from July 2016.

**Source:** Craig Subocz, Russell Kennedy Lawyers, May 13 2015

[www.rk.com.au/insights/government-to-transform-australians-e-health-records-system-to-opt-out-model/](http://www.rk.com.au/insights/government-to-transform-australians-e-health-records-system-to-opt-out-model/)

## IN THE NEWS



### Mapolo's Story

The Royal Children's Hospital is being forced to search nationwide for compatible donors for its sickest and most regular blood recipients.

Victoria's ethnically diverse population is driving an increase in some genetic disorders. Although blood compatibility is not based on race, genetically similar blood is the best choice for patients who need repeated or large volumes of blood transfusions.

For patients like six-year-old Mapalo Nsofwa, finding a close match for her three weekly blood transfusions is vital to protecting her health. Mapalo was seven months old when she was diagnosed with sickle cell anaemia, a genetic disorder that changes the shape of oxygen-carrying red blood cells.

RCH paediatric haematologist Dr Anthea Greenway said sickle cells looked like "bent bananas", which became stuck in blood vessels, blocking blood flow around the body. "It's one of the most painful conditions we know about," Dr Greenway said.

"It's a chronic long-term disorder that needs lots of treatment and follow-up." It is more common in people with African and the Middle Eastern

backgrounds, where the affected gene is more common. With the RCH clinic seeing a sharp increase in affected patients in the past decade, it is establishing a national register to capture how many patients have the condition, to plan for future treatment needs. Dr Greenway said ethnically matching blood donations to regular recipients reduced the likelihood of adverse reactions.

"There are the superficial A-B-O blood groups, but when you look at it in more detail there are layers and layers of levels of matching," she said.

"If someone develops a reaction it's difficult to find blood that's a good match. Sometimes that involves an Australian-wide search to find a blood donor, something that we now have to do reasonably frequently."

**Source:** Brigid O'Connell, Herald Sun, June 18 2015

[www.heraldsun.com.au/news/victoria/population-boom-means-a-shortage-of-compatible-blood-donors-at-royal-childrens-hospital/story-fni0fit3-1227404796724](http://www.heraldsun.com.au/news/victoria/population-boom-means-a-shortage-of-compatible-blood-donors-at-royal-childrens-hospital/story-fni0fit3-1227404796724)

### Mrs Mougos and Thalassaemia

The tireless efforts of Mrs Bessy Mougos and her supporters have continued with Mrs Mougos presenting Professor Don Bowden of the Monash Medical Therapy Thalassaemia Services Unit with a cheque for \$5,000.

Professor Bowden (right) and Mr Soti-rios Katakouzinis (left), President of Thalassaemia Australia, thanked Mrs Mougos for her untiring commitment and assistance in raising vital funds to support the care of Thalassaemia and Sickle Cell Anemia patients at the Unit.

The Unit caters for more than 170 patients and provides a world class integrated service for all affected by these haemoglobinopathies. The Thalassaemia Services Unit also provides specialist care for those who are carriers of these conditions known as Thalassaemia Minor.

If you require further information on these conditions or would like to help please call Thalassaemia Australia on 9888 2211 or the webpage [www.thalassaemia.org.au](http://www.thalassaemia.org.au)







## World Sickle Cell Day

Thalassaemia Australia wishes to give a huge thank you to the staff at the Royal Children's Hospital for helping us to put together a fun and special day to celebrate World Sickle Cell Day.

Arts therapist, Michelle Dixon, kept the children entertained as they waited for their appointment with Haematologist Dr Anthea Greenway. With colouring activities and model-making lessons, the day passed quickly for the children.

Whilst the children enjoyed a fun morning of crafts, we held an information table on the ground floor. We were delighted to meet with so many people curious to learn about sickle cell anaemia as well as about the work that we do.

Before long, it was time for the day to end but not before we had a piece of the delicious "sickle cell cake." Thank you to everyone who supported us and helped to put the day together.



## International Thalassaemia Day Melbourne

This year's International Thalassaemia Day was spent at Monash Medical Centre.

A central task of Thalassaemia Australia is to raise public awareness of thalassaemia and sickle cell anaemia. With the assistance of Carolyn Greely, we set up an information table to reach out to the patients and staff at Monash Medical Centre.

With increasing migration, more people know people who have these conditions or

who are carriers. We were delighted to inform those who approached the table about both conditions as well as to share about the work we do. The children, in turn, were delighted by the balloons.



## International Thalassaemia Day Sydney

This year to kick off our International Thalassaemia Day Celebrations the society held an information and awareness stand at Sydney Children's Hospital and Prince of Wales Hospital.

Volunteers and committee members manned the stand and raised the much needed awareness. We also made visits to the treatment centres at Sydney Children's Hospital and Prince of Wales Hospital, visiting any patients who attended for their treatment that day, yummy sweets were handed out to our patients and the wonderful staff who treat our patients on the wards.

Continuing our celebrations that evening at Michelangelo's Italian Restaurant which

saw 60 people attend our dinner celebration and show support. Thank you to everyone who showed support in attending the dinner which marked a significant day for the Thalassaemia Community around the world.

Again another big thank you to Nick, Pete and all the staff at Michelangelo's Italian Restaurant for the faultless food and service, we thank them also for their ongoing support to the Society.



International Thalassaemia Day – Jodi McKay MP – Member for Strathfield showing her support...It was lovely to see one of our local MP's and her staff member showing support, thank you!

# TA 2014 Christmas Celebrations

## Christmas Party for Special Children Moonee Valley Racecourse 2014

Held by Melbourne Party – Invites Thalassaemia Australia Inc.

Several of our patient families attended the Christmas Party for Special kids on the 14 December 2014.

A four hour stage show featuring many artists kept the children entertained. There were also activities such as merry go-rounds, jumping castles, face painting and much more. With all this fun had by the kids the food, drinks, and ice creams, were provided for free.

Of course no Christmas party is complete without Santa! Each child and their siblings received two beautiful presents. We would like to extend our gratitude to Melbourne Party for inviting our children to attend this wonderful event.



## Monash Children's Xmas Party

The MTU kids were invited to attend the Monash Children's Xmas party.

The event was hosted by the Child Life Therapy Unit and sponsored by TLC for kids. Various activities were available from face painting to the exceptional performance of Luigi Zucchini.

The comedy magic show by Luigi Zucchini had all the child and adults laughing and amazed by his incredible magical performance. The Big guy himself, Santa, made a visit and met with all the kids as he presented them with Christmas gifts.



## Frozen at MTU

Vermont Secondary College create paintings of scenes from the Walt Disney film 'Frozen'.

Art staff and students of Vermont Secondary College kindly donated their time and materials in creating the paintings of scenes from the Walt Disney film 'Frozen'.

Students also created paper snowflakes. The staff and students wish all the patients and staff of the Medical Therapy Unit a Merry Christmas and prosperous and healthy New Year 2015.





## COMMUNITY EDUCATION

# Committed to Education

Although thalassaemia and sickle cell anaemia are relatively rare conditions in Australia, the impact of these conditions is heavy for those who are affected as well as for those who support them.

It is for this reason that Thalassaemia Australia is committed to educating our community about thalassaemia and sickle cell anaemia. It is equally important to inform the public of the genetic nature of these conditions as well as to share about the experiences of those who live with them.

Throughout this half of the year, Thalassaemia Australia has been privileged to present at a number of venues. At schools, students displayed great interest during the presentations, especially regarding the biology of these blood disorders. They were also surprised by the financial and social costs associated with these conditions. Our community educators were able to impress on the audience the importance of being tested for carriage status.

We thank everyone who has invited us to give presentations and we look forward to continuing with this very essential task.



## DONATIONS

In Kind Support to Thalassaemia Australia Inc.  
On behalf of Thalassaemia Australia Inc. we would like to take this opportunity to thank the following people/organisations for their support over this half of the year:

- Pentana Solutions RITCH Foundation
- Soceity of Kontias Lemnos Saint Dimitrios Inc.
- Pampieriki Brotherhood of Melbourne and Victoria "Olympus" Inc.
- Sam Hall
- Kathy Balakis
- Philanthropic Society Nomou Kavalas Inc



## Hi, from Thian Ng

Hi everyone,

I am excited to join Thalassaemia Australia as their new office manager.



I first heard about thalassaemia when I was diagnosed as a thalassaemia carrier during a routine check-up with my GP and I knew little about the condition at the time. Since then, I had the great opportunity to learn more about the condition and to conduct research on it. As such, I am excited to be involved with a society that supports those affected by this condition.

I look forward to working with the members of the society as well as the medical professionals who look after them.

In my spare time I like to read, play hockey, knit and catch up with my friends.

## ThalTracker



A new app designed by, and for, patients with thalassaemia to help you live more healthy.

- Supports you with medication reminders
- Records blood test volumes and MRI results tracking and trending levels of iron overload
- Set your own goals for chelation medications and see how you are achieving this goal
- Communicate information to your healthcare provider during clinic visits – be a partner in your care



Available on the App Store

## Thalassaemia Australia Inc. is on Facebook

Like us to receive updates regarding our community awareness program and access links to important websites.



[www.facebook.com/pages/Thalassaemia-Australia-Inc/198157430216491](http://www.facebook.com/pages/Thalassaemia-Australia-Inc/198157430216491)



## Why become a member of Thalassaemia?

Your support in becoming a member is very vital to us for many reasons:

- Raising funds for urgent medical equipment such as slow infusion pumps.
- For world class Medical Research Projects such as Stem Cells, Gene Therapy, Foetal Haemoglobin, Bone Marrow Transplants, Iron Chelators etc.
- To promote greater awareness and education in the wider community through publications, newsletters and materials for health professionals (i.e. GP's, Nurses), community groups (CALD-Culturally and Linguistically Diverse Communities), secondary and tertiary institutions.
- Keeps you informed of important events, or issues relevant to patients, parents and health professionals.
- The greater the membership base, the greater our voice is with the State/Federal Government in understanding the health issues and the need for greater Government assistance.
- To continue our valuable Community Education programs in Secondary Schools, Hospitals, GP clinics, etc.



**Thalassaemia Australia Memberships include the above and the following:**

- Other Medical services such as a Play Therapist for our younger patients.
- Equipment for our Medical Therapy Unit such as chairs, vein finder, blood refrigerator, etc.
- Assists in the day to day operations of Thalassaemia Australia and maintaining a strong profile in the general community.

**Memberships are currently divided into categories:**

Life	\$200	Non-profit organization	\$20
Annual	\$20	Private Sector/Corporate	\$30

Thalassaemia Australia  
Phone: 03 9888 2211 Email: [info@thalassaemia.org.au](mailto:info@thalassaemia.org.au)



**Thalassaemia Society of NSW**

**Thalassaemia NSW memberships include the above and the following:**

- Other Medical services such as a MRI T2\* for our patients.
- Equipment for our Main Treating Centres such as chairs, vein finder, TV's, etc.
- Assists in the day to day operations of The Thalassaemia Society of NSW and maintaining a strong profile in the general community.

**NSW membership annual fee is \$20**

Thalassaemia Society of NSW  
Phone: 02 9550: 4844 Email: [coordinator@thalnsw.org.au](mailto:coordinator@thalnsw.org.au)







## Committee of Management 2015

<b>President</b>	Rosa Dimitrakas
<b>Vice President</b>	Maria Chate
<b>Treasurer</b>	Lela Dallas
<b>Secretary</b>	Marianne Dimitrakas
<b>Assistant Secretary/ Treasurer</b>	Stella Stilianou
<b>Communications Officer</b>	Haroula Volvoizidis

### Executive Members

Nicholas Kotrotsos  
Glenda Hughes  
Tracey El Bayeh  
Martha Gerolemou

## Committee meeting dates 2015

The committee meetings begin at 7pm sharp every 3rd Wednesday of each month and are held at Level 7, King George V Building, Missenden Road, Camperdown NSW 2050.

19 August 2015  
16 September 2015  
21 October 2015  
18 November 2015  
16 December 2015

**NOTE: AGM is on Wednesday 23 September at Burwood RSL Club.**  
Invitations will be sent out soon.

## Coordinators note...

*Hi everyone, I hope this newsletter finds you all well and keeping nice and warm.*

As you may have noticed Thalassaemia Australia have undergone staff changes since the last newsletter. On behalf of the Thalassaemia Society of NSW and myself we would like to thank Helen and Jim for their joint work, ideas and collaboration while they were both in the role with TA and we wish them all the very best of luck in their next ventures.

We have had a busy first half of the year with many of our events and functions covered in this edition of the newsletter. Along with what you see we continue to be active amongst the community with taking part in multicultural festivals around Sydney when we get the opportunity. Recently the Society took part in the Middle Eastern Night Markets which are held in Hurstville. This was a fantastic opportunity to be able to reach out to the Middle Eastern community and make them aware that Thalassaemia is also prominent and growing amongst their community.

The Society once again supported the Kids picnic, which was organised together with the Children's Hospital Network, inviting our young patients and their families along to enjoy a picnic away from the hospital setting, to meet, mingle and share stories with other families who are all feeling the same. The day was again a success with the children having a great time playing and dancing with one another as the

parents got to enjoy some time to chat. The highlight of the day was when the children were surprised by the special guest... I believe Sponge Bob square pants was a hit!!!

As we enter the second half of the year we prepare to hold an information session alongside our AGM, so please look out for this up and coming night, along with preparing to exhibit at the Haematology Societies of Australia and New Zealand Nurses conference which will be held in Adelaide at the end of the year. This will be a great opportunity to network with nursing staff who come in contact with our patients. More on these two projects in our next newsletter.

Until next time I wish you all the best in health and warmth during the cold months ahead.

Please remember that we love to hear from you with feedback and suggestions or if you would like to contribute a relevant article in our next newsletter please also come forward.

Ciao for now,

**Nancy Lucich – Coordinator  
Thalassaemia Centre of NSW**



## "The Forgotten Ones" Event at Customs House

Congratulations to Rare Voices Australia and Alexandrena for a great night and for working on such an amazing project together to highlight the importance of not forgetting the siblings of children who are affected by a rare condition.

Alexandrena being a sufferer of a genetic condition herself realised that siblings, somewhere along the way, become forgotten...

"There was always a lot of support for myself and my parents through these hard times, however the challenges and concerns my siblings had were often overshadowed and forgotten amongst the chaos. This concern got me thinking about other families in similar situations and I decided I could use my photography to shed light on this particular aspect of the rare disease community."

And with this, Alexandrena put her amazing skill and passion into action and exhibited some amazing photos of siblings who she was put in contact with through Rare Voices Australia.

One of our very own beautiful families took part in this special project. Thank you Zac – Zac has a brother who suffers from Sickle Cell Anaemia.

"The hardest thing about having Sickle Cell Anaemia is the pain that you would go through and all the hospital visits. Also my brother has lots of needles and never cries. My brother is like a normal big brother. He pokes and prods me. He annoys me and sometimes we have fights. I don't think of Christian as someone with a sickness. He is my big brother". – Zac



## 2015 GPCE – General Practitioners Conference and Exhibition

Again the Thalassaemia Society of New South Wales took part in the GPCE in Sydney which was held over 3 very long days in Homebush.

135 Delegates visited the stand and received information and chatted to our representatives. The Delegates' information was scanned and now the society is able to compile its own database to continue to feed information to the relevant GPs.

As this is the 3rd GPCE that the society has taken part in, it is interesting to see, over the years, familiar faces of GPs returning to our stand and giving positive feedback that it is good to see the society active in the community giving information about treatment and services.

The fact that more and more GPs are becoming familiar with who we are and what we do is wonderful as they can be hard to get through to and make contact with on a day to day basis as they are so busy.



## DONATIONS

### Donation from the Thalassaemia Society of NSW

The Haematology and Oncology Day Centre at Prince of Wales were extremely happy to receive their new Patient Monitoring Equipment, which was proudly donated by the Thalassaemia Society of NSW.

The staff at the unit greatly appreciate the support, well done Society!!







## Raspberry Blackberry Smoothie

### Ingredients

- 1 small banana
- 1/2 cup fresh blackberries
- 1 cup fresh raspberries
- 6 oz vanilla yoghurt
- 1 tablespoon honey
- 4 ice cubes

### Method

1. Place banana, blackberries, raspberries, yoghurt, honey and ice cubes into a blender
2. Blend until smooth

*Tip: add some wheat germ to add extra zinc to your diet*

Recipe and picture from <http://allrecipes.com/recipe/raspberry-blackberry-smoothie/>  
Tip from [www.rodalsonorganiclife.com/food/zinc-rich-foods](http://www.rodalsonorganiclife.com/food/zinc-rich-foods)



## The Role of Zinc



Zinc has important biological functions which are still not fully understood. Among other roles, it is important for the growth of children, sexual maturation of adolescents, a strong immune defence system and healthy skin.

Several studies have shown that people with thalassaemia tend to have low levels of zinc in the blood, probably because they excrete more zinc in the urine. This is partly because iron chelators (such as Desferal and Deferiprone) not only bind iron but also some zinc and excrete it in the urine. So what can we do to help maximise the amount of zinc we get from our food and prevent us to get a deficiency? Unlike iron, zinc is not stored in our body. We are therefore dependent on a regular supply of zinc from our daily diet to provide our requirements.

In this article, I will highlight the main sources of zinc in our diet and explain how to get the most out of the zinc in our food. Zinc supplements bought across the counter but it is not safe to use them unless recommended your doctor or dietician. Taking zinc supplements above our requirements can interact with other nutrients such as copper and can also be bad for the immune system.

The main nutritional sources of zinc are animal foods (meat and dairy products) and wholemeal cereals. These will be discussed below.

### 1. Animal foods:

Beef, pork, chicken and fish contain large amounts of zinc. Zinc is present in the lean part of meat and not the fatty part. Therefore, choose lean cuts of meat and skinless chicken, especially if you need to watch your calorie intake. As red meat is also high in iron, it may be better to choose chicken or fish instead. Dairy products (milk, cheese, yoghurt) and eggs also contain a lot of zinc. Milk and milk products are very important in thalassaemia for a variety of reasons; they inhibit the absorption of iron, they can help to prevent osteoporosis, are important for growing children and are also useful sources of zinc. I cannot stress it often enough how important it is to take plenty of milk every day, either as a drink or as part of your meal recipes. Choose low-fat cheese, yoghurt and skimmed or semi-skimmed milk if you are watching your weight.

### 2. Cereals:

Zinc is present in the outer part of the grain of most cereals. Therefore, unrefined varieties of wheat, maize and rice are good sources of zinc, while refined cereals are poor sources. Try to switch to wholemeal bread for sandwiches and use brown rice and wholemeal flour and pasta in cooking.

Cereals contain a substance called phytic acid which inhibits the absorption of zinc from food. What is interesting is that the animal food sources described above (meat, chicken, fish, milk, eggs) can prevent this. It is therefore beneficial to include some chicken, fish or milk with the unrefined cereals. Examples are chicken, tuna or cheese sandwiches and wholemeal bread, chicken curry with brown rice, wholemeal spaghetti with grated cheese, chicken or cheese pies made with wholemeal flour. I am sure you can add your own examples to this list! Taking your meal with a glass of milk or a cup of milky tea will give you an extra star!

### 3. Food preparation:

The way we prepare our food can also affect the amount of zinc we get from our diet. Like many other nutrients, zinc can leach into cooking water during food preparation. It is better to avoid using too much water when boiling and to try steaming instead. When cooking chicken or fish, we can use the juices after roasting, frying or boiling to cook sauces which can complement the meal. In this way, any zinc leaching into the cooking media will still be included in the meal. A few weeks ago, I was watching one of the TV chefs preparing a pasta meal and much to my surprise he added the water from boiling the pasta into the sauce! Apparently, it is supposed to make it more creamy! Certainly from the zinc point of view, it is not such a bad idea!

Information courtesy of UKTS:  
<http://ukts.org/living-with-thalassaemia/thal-life/diet-exercise.html>