

Thalassaemia AUSTRALIA

Unifying support and genetics

Thalassaemia Australia Summer 2014 Volume 6 Issue 17

Quarterly

May 8 2014 – International Thalassaemia Day Message

Theme: 'Economic Recession: Observe – Join Forces – Safeguard Health!'

Dear members of the Thalassaemia International Federation, we are delighted to present you this years' theme for the 8th of May activities which is:

Theme: 'Economic Recession: Observe – Join Forces – Safeguard Health!'

This year's theme highlights the need to support policy decisions that safeguard health and reduce inequalities in the health field, and that protect the countries affected by the financial and economic crisis. The global financial crisis has already had wide-reaching social, economic, and political impact, but some of the most devastating consequences affect the health care field.

TIF's mission is to ensure equal access to quality health care for all patients, so that they receive appropriate treatment, free of charge or reimbursed by the government, and in concurrence with the guidelines and standards of international experts. In addition, TIF's efforts are directed towards creating, developing, and implementing effective national prevention programmes, to reduce the affected births of children with thalassaemia, saving resources for the national public health care.

Website: www.thalassaemia.org.cy

Contents

In loving memory of Maria Kastoras	3
Research:	
• Interview: A/Prof Rachel Codd	4
• Update on the national Haemoglobinopathy Registry project	5
Community Education & Advocacy	
TAAGM Meeting Report	6
General Practitioner Conference Exhibition – Melbourne	7
Noticeboard	9
News from NSW	
• Letter from the Centre Coordinator	10
• Thalassaemia Gala Dinner Information	11
• Committee Dates	11
Patient Story:	
The Three Musketeers	12
TIF Conference Report	
• By Nancy Lucich	14
• By Spiros Bombos	17
• By Joanne Shaw and Mary Tassigiannakis	18
Bits & Pieces	19
Kids Stuff	20

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TIF 2013 - World Congress Abu Dhabi

Thalassaemia Australia Inc.

Committee of Management 2014

Executive

President – Spiro Bombos
Vice-President – Mary Triantafyllou
Secretary – Mary Konstantopoulos
Treasurer – Sotirios Katakouzinis

General Committee Members

Dr. Jim Vadolas
Bessy Mougos
Julie Christopher-Costa & Billy Costa
Helen Kosmarikas
Julie Dascoli

Committee meeting dates for 2014

Committee of Management meetings begin at 7.30pm and are held at the Thalassaemia Centre, 333 Waverley Road, Mt Waverley 3149 on the **3rd Tuesday in every month**

18 March	22 July	18 November
15 April	19 August	16 December
20 May	16 September	
17 June	21 October	

We currently have two vacant positions on the Committee, if you would like to join us, please contact Spiro Bombos – President on 9888 2211 or email 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 or Thalassaemia Society of NSW at coordinator@thalnsw.org.au to update your records!



Thalassaemia Australia Inc. acknowledges the support of the Victorian Government.

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#makeitcountformaria

Thalassaemia Australia's #makeitcountformaria campaign began on the 1st of March 2014 and will conclude on May 8, International Thalassaemia Day.

Our aim is to celebrate the life of Maria Kastoras, and continue her great work as a passionate advocate for thalassaemia and blood donation by:

- 1: Encouraging others to find out more about Thalassaemia and Sickle Cell: www.thalassaemia.org.au
- 2: Donating blood or asking a friend to donate blood in your place and register your details on the Australian Red Cross Blood Service website: www.donateblood.com.au – Club Red, Thalassaemia Australia #makeitcountformaria
- 3: Like our Facebook Page
- 4: Show your support for the campaign by adding a photo to our Facebook page with the hashtag #makeitcountformaria
- 5: Make a donation to Thalassaemia Australia to support a travel scholarship in Maria's honour to send young patients to international thalassaemia and sickle cell conferences/meetings.



www.thalassaemia.org.au



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

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.



In loving memory of Maria Kastoras



On December 25th 2013, Thalassaemia Australia lost a dear friend, work colleague and community educator Maria Kastoras.

As many of you are aware Maria was an integral part of Thalassaemia Australia for many years, just some of her roles included Committee Member, President, Thalassaemia International Federation board member, Committee Member of the Australian Thalassaemia Association, Office co-ordinator and of course Community educator. In these roles she also participated on numerous consumer health boards both at Monash Health and within the wider consumer health/genetic community. On a local level Maria attended of regular meetings with the medical therapy unit team and was often called upon to assist new patients and families at the unit – a role that she loved dearly.

On an international level, Maria presented at a number of the TIF Conferences, sharing her experiences and the work of Australian thalassaemia community. Some of her greatest work however was carried out in quiet conversations with young patients from around the world, encouraging them to embrace their condition, become informed and look forward to a brighter future. She also loved and cherished the many international thalassaemia professionals, patients, families and friends she met along the way - her laughter and smile will be forever etched in their hearts.

As our community educator, Maria spoke to thousands of secondary school students', during her time at TA helping them to understand genetic blood conditions such as thalassaemia – not only as shown in a text book, but what it was like to live with the condition, including all the highs and the lows. Maria gave of herself freely, passionately and with a great sense of humour encouraging students at all times to be screened and become regular blood donors. Here is a note passed onto us recently from one of the schools that Maria visited:

'What an amazing woman she was and what a hard act to follow by anyone. She came out to our school twice last year and won the hearts and minds of my Yr 10 students in an instant'.

Finding the right words to explain the loss of Maria to you, and the wider community is extremely difficult during this time, as there are so many people that were touched by Maria's presence and words do not seem to be enough to acknowledge the full scale of her great work and the impact she and on so any people's lives and for that we apologise. On behalf of Thalassaemia Australia Committee and Management and Staff we again send our heartfelt condolences to Maria's son Theodore and parents Mr & Mrs Marinakis – to know Maria was to love her, and she will be forever in our hearts.



RESEARCH

Interview: A/Prof Rachel Codd



My research into iron overload: an update

I am an academic in the School of Medical Sciences at The University of Sydney, where I lead a research team that focuses upon designing new drugs for conditions associated with irregular metal concentrations. My research expertise in chemistry covers an understanding of what types of molecules have a preference for binding particular types of metals, which is important for designing new and improved agents for chelation therapy. Iron overload, which occurs as a result of the frequent blood transfusions needed to manage the anaemia caused by β -Thalassaemia Major, requires life-long chelation therapy. It is important that excess iron is removed from the body, since humans do not have a mechanism to remove excess iron, and its accumulation can damage organs, including the heart, liver and pancreas, which can lead to serious morbidity in later life.

At present, there are three compounds in clinical use for treating iron overload: desferrioxamine mesylate (Desferal), deferiprone (Ferriprox®), and deferasirox (Exjade®). I am most interested in the first of these compounds – Desferal – since of the three compounds, it has the highest affinity towards iron(III). A picture of Desferal bound to iron(III) (in yellow) is shown below. Desferal was discovered in the 1950s as a compound produced by a soil bacterium for the purpose of leaching iron from its surrounds and returning the iron to the cell as a necessary step for survival. Iron is essential for all life, including bacteria, plants and humans – the tricky part is that its concentration must be tightly controlled for good health. The discovery of Desferal was a great moment in science, since it was quickly realized that this compound, which was shown to be relatively non-toxic, could significantly improve health outcomes for people with transfusion-dependent blood disorders. Desferal was rushed into the clinic in the 1960s and proved to be a seminal agent for the clinical management of iron overload from β -Thalassaemia. The drawback of Desferal is its mode of administration, since it must be infused

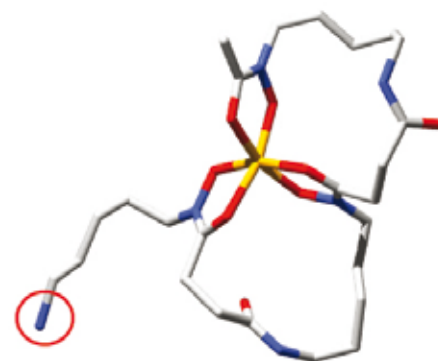
slowly under the skin for 50-70 hours per week. This can be difficult to tolerate – particularly for children and young adults. I didn't know anyone with β -Thalassaemia when I began my research, which prompted me to seek out information from Thalassaemia Australia in Melbourne, where I saw first-hand the Desferal pump; and subsequently met with Nancy and other members from Thalassaemia Society of NSW for ongoing advice about the patient experience. My major goal is to modify the properties of Desferal in a way that does not reduce its affinity towards iron, but: (i) improves its performance in removing more difficult-to-access iron stored inside cells; and (ii) increases the time the drug remains active in the body (plasma residence time). This would in turn: (i) reduce the amount of drug needed, which is important in the context of treating a chronic disease; and (ii) reduce infusion times, to make administration more tolerable. Improved Desferal could assist patients who are intolerant of deferiprone or deferasirox and those on Desferal-based combination therapies. My group has prepared about 15 new variants of Desferal with modifications that have improved the ability of the compound to get inside cells for iron removal. We have modified the molecule in the region circled in red on the picture, which does not compromise its iron binding efficiency. In the latest modification, we have added a small chemical motif to Desferal which has been designed to improve plasma residence time. Later this year, we hope to test the effectiveness of these drugs in more realistic models of β -Thalassaemia.

My relationship with Thalassaemia Society of NSW

I have attended several meetings of Thalassaemia Australia in Melbourne, and Thalassaemia Society of NSW at the King George V Hospital and AGMs at the Burwood RSL. These meetings are helpful to me to have the chance to chat with patients and to catch up with Nancy, and to also meet other scientists and clinicians with interests in β -Thalassaemia. Through these meetings, I have met Dr Jim Vadolas and Dr Vasili Berdoukas. Dr

Jim Vadolas approaches β -Thalassaemia from an 'upstream' genetics perspective, rather than my approach, which is a more 'downstream' therapeutics perspective. It is undoubtedly the case that research from each of these different angles will be necessary to progress the understanding and treatment of β -Thalassaemia – Jim and I hope to consolidate our approaches to collaborate in the future. One other fantastic outcome of getting to know Nancy was having her give a lecture on β -Thalassaemia to my University class. This was intended to give these students studying medicinal chemistry a sense of purpose to their studies – you could have heard a pin drop during Nancy's talk! Her presentation was inspiring and would have led to a new group of dedicated medicinal chemists and to a new group of 130 student blood donors!

I look forward to my ongoing relationship with Thalassaemia Society of NSW and to providing further research updates as the project progresses.



Desferal bound to iron (yellow)

Update on the national Haemoglobinopathy Registry project

by Ri Scarborough, Haemoglobinopathy Registry Project Officer, Monash University



By now, many of you have already heard about the national Haemoglobinopathy Registry project, being launched by the Transfusion Outcomes Research Collaborative based at Monash University with our hospital partners. A/Prof Erica Wood, a haematologist and transfusion medicine specialist, who also works at Monash Medical Centre, is leading the project at Monash University, with the support of a national steering committee of haemoglobinopathy experts. The steering

committee is chaired by Prof Joy Ho from Royal Prince Alfred in Sydney, whom many of you will know. Even more of you will know Dr Jim Vadolas from the Murdoch Institute at the Royal Children's Hospital, who has also recently joined the project steering committee. We look forward to Jim's input.

We also wish to convey our sadness on the passing of Maria Kastoras, who had been an enthusiastic supporter of the Haemoglobinopathy Registry project, from the first time Erica and I spoke with her about it, in early 2013. We deeply regret that Maria did not live to see the benefits that the project will bring to the entire Australian haemoglobinopathy community that she cared so much about.

Ten major hospitals have signed up for Stage 1 of the project, including Monash Medical Centre (other hospitals will be added later):

If you are receiving care at any of these hospitals, over the coming months, you will be invited to participate in the

Haemoglobinopathy Registry and will receive a brochure about it. With your agreement, we'll be collecting information such as when you were diagnosed, what your exact diagnosis is, any complications you have had, and what medications and transfusions you receive. In Stage 2 of the project, we will ask your doctors for some additional information, such as results of scans or echocardiograms.

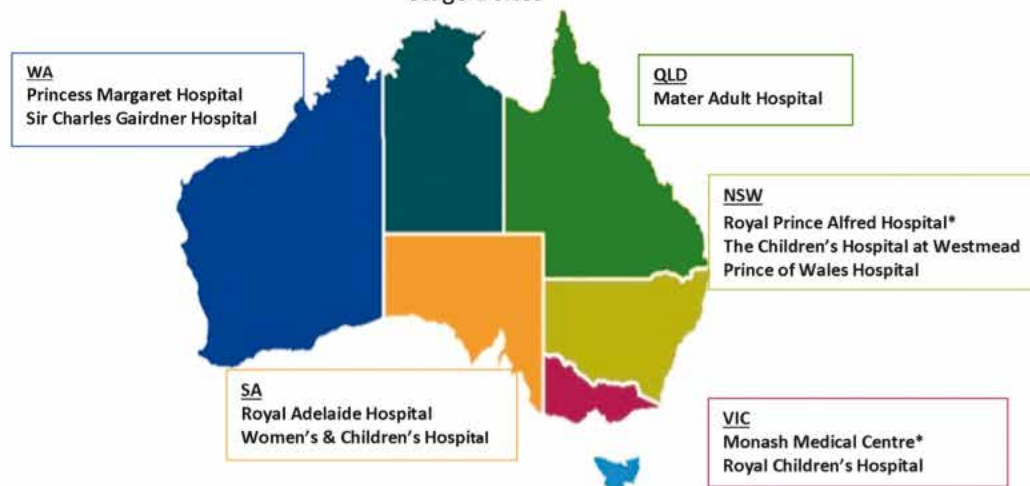
We had hoped to be able to begin collecting patient data from our pilot sites, Monash Medical Centre and Royal Prince Alfred Hospital, before Christmas last year, but due to some unforeseen delays, this is now likely to begin in March.

Your participation in the registry is voluntary and if you decide to participate now you can still opt off at any time. All personal and medical information is kept strictly confidential. We do hope that you will allow us to learn from your story.

If you have any questions about the project, please email me on hbr@monash.edu

Haemoglobinopathy Registry

Stage 1 sites



COMMUNITY EDUCATION AND ADVOCACY

Thalassaemia AGM Report 2013

Monash Medical Centre – Lecture Theatre 2, 26 November 2013.

Our Annual General Meeting (AGM) began with a welcoming address from Thalassaemia Australia (TA) President, Spiro Bombos. Spiro noted the achievements of TA over the 2012-2013 period and thanked the staff and committee for their continuous support during this time.

Spiro then welcomed our guest speakers for the evening, Ms Ri Scarborough from the Transfusion Research Unit Department of Epidemiology & Preventive Medicine School of Public Health and Preventive Medicine Monash University, Dr. Jim Vadolas from the Cell and Gene Therapy Unit at the Murdoch Childrens Research Institute and members of the Medical Therapy Unit team: Professor Bowden, Ms Joanne Shaw, Ms Mary Tassi and Ms Fiona Cunningham.

Ri Scarborough gave introduction to the Haemoglobinopathy Registry as well as an update on its progress to date – please see her detailed report in this edition of the newsletter. Ri noted that a great deal of consideration has gone into maintaining patient privacy throughout this whole process.

Dr Jim Vadolas updated us on the latest on cell and gene therapy from around the world being used to treat Thalassaemia. He noted that he is collaborating with a research unit in NSW that are working on clinical trials for patients in Australia.

The MTU team were invited to take part in a Question and Answer session and covered the following areas:

How is the unit coping with the increase in numbers of patients at MTU?

The MTU staff are working with Monash Health Senior Management to bring about the best outcomes for patients. Any change to operation hours will be done in consultation with the patient group.

Monash Children's Hospital – will our young patient group be treated there?

There are currently discussions being held at the hospital about this. It is planned that the Monash Children's Hospital Staff will be

contacting the paediatric patient families to discuss their views and ideas about this matter. It is helpful however to keep in mind some of the well known benefits of a 'whole of life' such as offered currently by the MTU. Such a service usually makes for a smoother transition from paediatric to adult services and information shared by adult patients to younger patients and their families has been shown to provide invaluable support and reassurance.

What is pre-screening for thalassaemia?

Carrier screening for haemoglobinopathies (including alpha and beta thalassaemia major and sickle cell disease) involves some simple blood tests (done on one sample of blood).

- The first of these, an FBE, looks at a number of blood indices, including MCV (size of red blood cells), MCH (how much haemoglobin in each red blood cell), and haemoglobin. If the MCV and/or MCH are lower than the normal range, this may be an indication that the person is a carrier of thalassaemia and further testing is needed. MCV and MCH can also be low because someone is iron deficient, so it is important to work out if that is the cause first, wherever possible. DNA testing will not proceed without iron studies unless the person is pregnant.
- The next test is haemoglobin electrophoresis (HPLC). This looks at the types and amounts of the different types of haemoglobin that are present. If this is normal, and someone has low MCV/MCH they may be a carrier of alpha thalassaemia. HPLC will identify carriers of beta thalassaemia as they have higher than normal levels of haemoglobin A2. HPLC will also detect carriers of sickle cell disease and other variants who may have normal MCV and MCH unless they are also carriers of alpha thalassaemia.
- DNA studies are usually only done if someone is suspected of being a carrier after the above testing and iron deficiency is ruled out as the only cause.
- Carrier screening is best done before pregnancy. However, this does not always occur. All pregnant women in Victoria

now have a haemoglobinopathy screen involving the above tests if they have not had one before. Partner testing is recommended if the woman is identified as possibly being a carrier, and is essential to assess the risk for a couple having a baby with a severe form of thalassaemia or sickle cell disease.

- Carriers who want to know more about what this means, or couples who are both carriers of a haemoglobinopathy can be referred for genetic counselling to assess their risk of having a baby with a severe haemoglobinopathy and to discuss options.

Diet and thalassaemia.

A well balanced diet is recommended for all thalassaemia patients. Unless individuals have special needs.

Supplements and thalassaemia.

Vitamins should be obtained where possible from natural foods. Supplements may be required for some patients if recommended by their doctor.

Succession plan for Prof Bowden and understanding the different staff roles within the unit.

Don is not planning to retire at the moment, however succession planning has commenced.

The formal part of the AGM then took place and the 2014 Thalassaemia Australia Committee was elected and are as follows:

- Spiro Bombos – President
- Maria Triantafillou – Vice President
- Sotirios Katakouzinis – Treasurer
- Mary Konstantopolous – Secretary
- Dr Jim Vadolas
- Bessy Mougos
- Helen Kosmarikas
- Julie Costa
- Billy Costa
- Julie Dascoli

There are two positions currently available on the TA committee, if you are interested in becoming a member of it, please contact the office or President Spiro Bombos.

General Practitioner Conference Exhibition – Melbourne

17 to 19 November 2013, Attended by: Sarah Burton & Maria Kastoras. Workshops presented by: Prof Don Bowden & Fiona Cunningham

Last year the Thalassaemia Society of NSW took part in the General Practitioner Conference Exhibition in Sydney, this year (2013) it was Thalassaemia Australia's turn to take part in the three day Melbourne event.

We manned an information booth full of our resources and answered any queries that that GP's had, as well as giving them our latest resource the 'Haemoglobinopathy Carrier Screening Recommendations' by Thalassaemia Services Victoria, which was very well received. Many GP's and Practice Nurses took copies for themselves and for other members of their practice. Questions from the GP's and Practice Nurses included screening, refugee health, genetic counseling, thalassaemia and pregnancy, translated reference materials, other information on other haemoglobinopathies in Australia. GP's showed particular interest in the current prevalence rates and changes/innovation in clinical management of thalassaemia and sickle cell anaemia around Australia.

The three workshops held by TA were directly targeted at General Practitioners (GP's) with the professional assistance of

the Medical Therapy Unit staff Prof Don Bowden and Genetic counsellor, Fiona Cunningham to give them an update on diagnosis, treatment and screening for haemoglobinopathies in Australia. We have since received our report from the organising committee and it was found that the presentations were very informative and relevant to all the GP's practices.

These events are also a great networking opportunity for staff at TA to meet with other stakeholders throughout the conference. Some of the information we have obtained from our talks with other stakeholders has resulted in their information or products being passed on to and adopted by the medical therapy unit to further assist our patient group. These networking experiences also help us to increase our profile within the medical/allied health community.

In summary, being able to meet with GP's face to face, add them to our database, answer their queries and provide them with new resources to assist them on a day to day basis, is what makes being part of these conferences worthwhile.



Note: Please see a copy of the latest 'Haemoglobinopathy Carrier Screening Recommendations' on the following page. Please contact the TA office on 9888 2211 if you would like a copy or download it from our website.

NOTICEBOARD

Cross Match and Blood Collection

Since Royal District Nursing Service have ceased their blood collection service we have had numerous problems with outside pathology providers.

Monash Health has a zero tolerance for errors policy and this is to ensure we provide you with the safest transfusion possible. We understand the frustrations some of you are experiencing, with having to have you or your child re-bled. We know that this causes huge inconveniences and trauma. We hear your frustrations and we are currently looking for a workable solution to this problem.

Please don't hesitate to contact us if you wish to discuss this further. In the meantime, we suggest that if you have had problems with your pathology provider in the past, that you ask the nursing staff for a sample form and tube that has been filled out correctly, to take with you to ensure the pathology collector is fully aware of all of the labelling requirements.

Private Pathology Accounts

If you have been sent an invoice by your private pathology provider, you can either pay the bill and take it to Medicare for reimbursement or alternatively, take the bill directly to Medicare.

Thalassaemia Australia Inc. is on Facebook



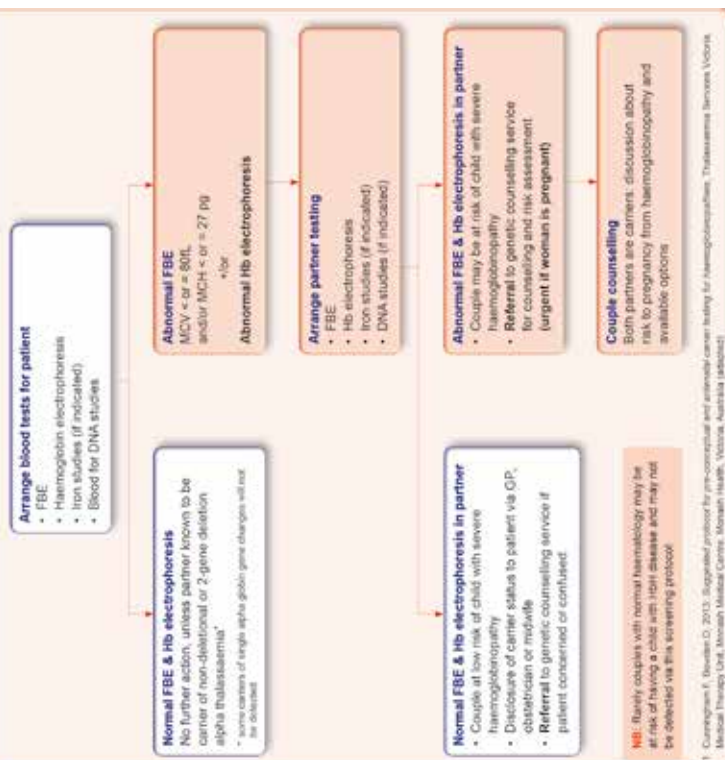
Like us to receive updates regarding our community awareness program and access links to important websites.

www.facebook.com/pages/Thalassaemia-Australia-Inc/198157430216491

This flow chart was developed to assist with the identification of carriers of haemoglobinopathies for the purpose of genetic counselling, treatment and management (if required).

Suggested protocol for pre-conceptual or antenatal carrier detection for haemoglobinopathies¹

Due to migration patterns and the multi-ethnic origin of many individuals, we now recommend screening all women once for haemoglobinopathies, preferably prior to pregnancy, or as early in pregnancy as possible.



1. Cunningham F, Beutler O. 2013. Suggested protocol for pre-conceptual and antenatal carrier testing for haemoglobinopathies. Thalassaemia Services, Victoria. Medical Therapy Unit, Monash Medical Centre, Monash Health, Victoria, Australia (adapted).

For more detailed information on haemoglobinopathies either:

1. Refer to website: www.rnrc.gov.au/your-health/genetics/health-practitioners/genetics-family-medicine-australian-handbook-general-prac-and-click-on-Haemoglobinopathies
2. For hard copy of the information pack call Thalassaemia Australia Inc. Ph: (03) 9594 2211 Email: info@thalassaemia.org.au
3. For general clinical and counselling advice call either:

Thalassaemia Services Victoria, Medical Therapy Unit,
Monash Medical Centre, Clayton
Royal Women's Hospital Thalassaemia Clinic
Mercy Hospital for Women Genetics Dept.

Ph: (03) 9594 2697 Fax: (03) 9594 6648
Ph: (03) 8345 2160 Fax: (03) 8345 2179
Ph: (03) 8458 4250 Fax: (03) 8458 4254

This information is provided by Thalassaemia Australia Inc. and the Medical Therapy Unit, Monash Health
This fact sheet was last updated October, 2013

Haemoglobinopathy Carrier Screening Recommendations Thalassaemia Services Victoria

Thalassaemia Services Victoria, based at Monash Health, Monash Medical Centre, Clayton Campus, provides an integrated service, which includes both clinical and diagnostic services. It is a treatment clinic caring for patients with haemoglobinopathies and related blood disorders throughout their lives.

The following services are available at the Thalassaemia Services Victoria:

CLINICAL MANAGEMENT of all haemoglobinopathies, including transfusion services

INFORMATION about haemoglobinopathies for:

- medical professionals
- patients
- public

DIAGNOSTIC SERVICES

- Diagnosis of haemoglobinopathies
- Carrier testing
- Partner testing
- Prenatal diagnosis and cord blood testing
- On-site DNA laboratory
- Telephone advice to doctors regarding patient's results and further testing

GENETIC COUNSELLING

- Education and counselling for patients and family following haemoglobinopathy diagnosis
- Assessment of risk of severe disease in offspring of couples who are carriers of haemoglobinopathies
- Counselling re decision making in pregnancy and discussion of prenatal options
- Arranging prenatal testing

Thalassaemia Services is staffed by Dr Don Bowden (Head Thalassaemia Services, Victoria), Joanne Shaw (Thalassaemia Services Coordinator) and Genetic Counselling Services.



The clinic is open:

1. For clinical treatment (transfusion) services:
Tuesday to Friday, from 7am to 4.30pm, and Saturday from 7am to 2.30pm;
 2. For clinical appointments:
Tuesdays 1.30pm to 4pm; Wednesdays 1.30pm to 4.30pm;
Coordinator Joanne Shaw Ph: (03) 9594 2756
 3. Urgent appointments will be available outside of these hours by arrangement with Dr Bowden or Coordinator Joanne Shaw Ph: (03) 9594 2756
 4. Patients can also be seen at short notice, if required.
- Copies of test results and a referral letter from the patient's doctor (GP) should be addressed to Dr. Bowden and can be faxed to (03) 9594 6648
 - Patient details are also needed to arrange an appropriate appointment

Thalassaemia Services Victoria - Monash Health
246 Clayton Road, Clayton VIC 3168 Ph: +61 9594 2756

Thankyou

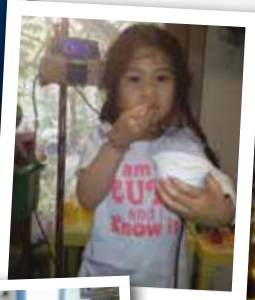
We would like to take this opportunity to send out a huge Thankyou to

Mr Craig McGrath, from LynxIT, for his generous donation of 6 portable DVD players, headphone sets and numerous DVD's. They have been a huge hit with both the kids and adults. Now the children can watch a movie of their choice, alongside their friend or sibling who can watch a different movie simultaneously. This has certainly made the unit a little 'quieter' for the adults and gives 'Mums and Dads' a little bit of quiet time or a chance to have a chat with others.



Our special thanks to the owners of the **Gloss and Gossip Warehouse in Moorabbin**, who assisted Santa's little helper with the gifts for the young patients at the Medical Therapy Unit.

We would also like to thank **'Bon Appetite Australia Ice-creams'** for their generous donation of the ice-cream freezer which is full of delicious ice-creams for our patients and their families. The ice-creams have been extremely popular especially with the recent run of heat waves. This company have already re-filled the freezer due to popular demand. If you have been lucky enough to enjoy one of the delicious ice-creams then you can show your gratitude by 'liking' them on their Facebook page which is: Bottega del Gelato.





Letter from the Centre Coordinator

Hello everyone and welcome back to the start of another busy year. I hope you all had a break of some sort over the festive season and spent some quality time with your family and loved ones.

As some of you may be aware the Thalassaemia Community in Australia and around the world received some very sad news of the passing of our very special Maria Kastoras. Maria's passed away suddenly on Christmas Night and left us all in shock and disbelief, many patients, family and friends from all around Australia came together to support the family, farewell Maria and pay tribute to what a beautiful full of life person she was.

Our deepest sympathy and condolences go out to Maria's son Theodore whom has grown up to be an amazing, loving and respectful young man. Theodore, you make us all proud I can only imagine how proud your guardian angels and parents would be looking down on you forever.

To Maria's parents, we are truly sorry for the loss of your special daughter however we would like you to know that her time on earth was truly inspirational, Maria touched many people's hearts and made a BIG difference and impact on the Thalassaemia community around the world.

To the staff and members at Thalassaemia Australia, we feel the loss and sadness with you of a valued loved and respected work colleague and friend, Maria will never be replaced however her hard work and legacy must live on. Meetings, conferences and events that Sarah, Maria and I attended on a yearly basis will be very different now, however we have amazing memories of the times we spent together working hard to make a difference at something that we all were so passionate about. As Sarah from Thalassaemia Australia has said, "Maria has now moved on to become our Christmas Angel".

So after a sad start to the year, we have managed to hit the ground running and work on many projects for an exciting new year!

Sarah from TA joined me last week in a presentation to Aspen Pharmaceuticals, it is always nice to have the opportunity to share your life experience growing up and living with Thalassaemia. The presentation was very well received with many positive comments coming back to me after.

"It is always nice to have a patient come in and explain their story, it helps to know how the medications work and help people".

"Having a patient come in and speak makes it real, very inspirational well done".

After the presentation I made the most of Sarah being in town and booked us solidly for the next day and a half with meetings. We met with many important people regarding advice, ideas and information sharing on our Nurses meeting which take place in May down in Melbourne.

Now that I have mentioned the Month of May let me tell you we have lots planned this year to celebrate international Thalassaemia day – Month!

Come and say hello to us at Westmead Children's Hospital at our community awareness stand on the 7th, 8th or 9th of May. If you are lucky enough you may even come in on the right day and meet Billy Blood Drop....

We will then celebrate in style on Saturday 10th May at our very special Gala dinner. Please see detail further along in the newsletter and help us to spread the word to family and friends so we can ensure that everyone gets tickets for this special night.

Moving right along we will be down in Melbourne weekend of the 17th-18th May as the Thalassaemia Society of NSW and Thalassaemia Australia join forces

and take part in the Haemochromatosis Conference to hold a Thalassaemia Nurses meeting.

For other events please see our save the date section and pencil in your diary so you don't miss out.

Also please make a note of our Committee Meeting dates for 2014 and remember that you are always welcome to attend. We love seeing new faces and having fresh input and ideas.

I would like to say a special thank you to Arthur Bazikas for his patient story for our newsletter as well as gorgeous photo of the three musketeers. We love hearing patient's stories of their experiences growing up in the Thalassaemia world. Please become courageous like Arthur and contact me with your patient story to share in one of our newsletter this year! Again, "it makes it real".

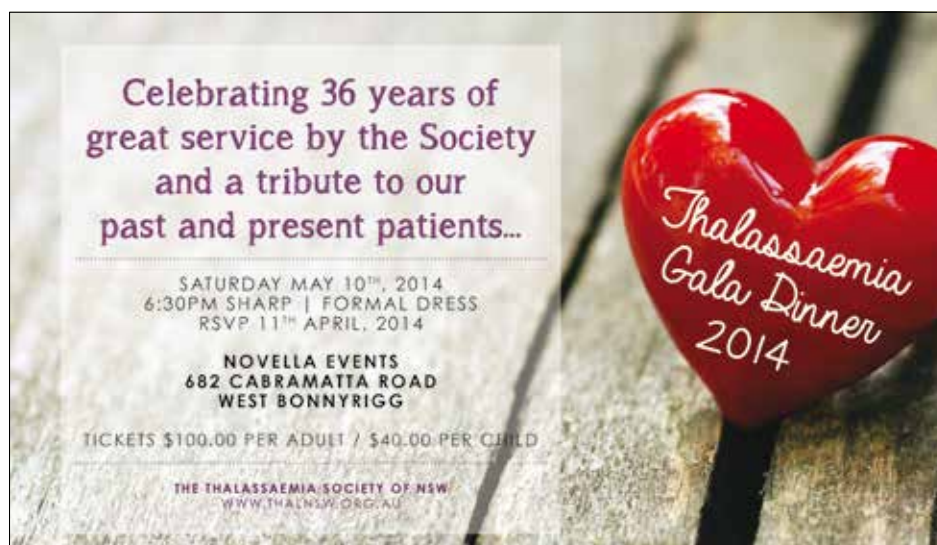
As promised in our last newsletter you will find my article on my experience of my very first time attending a TIF Conference. As I mention in the article, if anyone would like further in more elaborate information on anything in my article please contact me.

On this note I will leave you to continue reading our newsletter and hope you enjoy what you see and read.

Please remember if ever you would like to contribute or suggest articles for our newsletters please do not hesitate to contact me. coordinator@thalnsw.org.au

Until next time.

Nancy Lucich
Centre Coordinator



Ticket includes: 5 course dinner and unlimited beer, wine and soft drink.

2014 Committee of Management

President – Rosa Dimitrakas
Vice President – Nicholas Kotrotsos
Treasurer – Lela Dallas
Secretary – Marianne Dimitrakas
Assistant Secretary / Treasurer – Stella Stillianou
Communications Officer – Position Vacant

Executive Members:

Maria Chate
Glenda Hughes
Haroula Volvozidis
Theodora Michalopoulos

2014 Committee meeting dates

Committee of Management meetings are held monthly at the Thalassaemia Centre, please call the office for further details. All Welcome.

Wednesday 19 March
Wednesday 16 April
Wednesday 15 May
Wednesday 18 June
Wednesday 16 July
Wednesday 20 August
Wednesday 17 September
Wednesday 15 October
Wednesday 19 November
Wednesday 17 December

All meetings take place in the board room on Level 7, King George V Building, Missenden Rd, Camperdown 2050 NSW.

If you would like to attend please notify the coordinator@thalnsw.org.au so you can be added to the introductions of the Agenda.



**Find us on Facebook
Thalassaemia NSW!**

CareFlight

MAGIC MANIA at the Hellenic Club of Canberra

3rd July 2014 FREE TICKETS

Dear Sir / Madam,

It is with great pleasure to announce that we have booked The Hellenic Club Woden again this year for Magic Mania on Thursday 3rd July 2014 at 11am. Of course, this is a FREE show for the members of your organisation and the show is as for the youngest and oldest of us. We would like to see a record number in attendance this year and as I am sure you know, the more the merrier. Could you please pencil this date in your calendar so that all your members can enjoy the great event. We will be in touch later in the year to find out how many tickets you may require for which show time.

Regards, Jenny Goodman

**Please note: This is an Announcement ONLY,
Your Ticket invite to follow closer to event.**

MAGIC MANIA Phone. 02 9699 3925 Fax. 02 9699 1280 E. jennyg@magicmania.com.au

Save the date

- | | |
|-------------------|--|
| 7-9 May | Community Awareness Stand Westmead Children's Hospital |
| 10 May | Gala Dinner at Novella Events – see notice. If you would like to contribute in the way of donations to support this event, please contact our centre coordinator: coordinator@thalnsw.org.au |
| 31 May | Children's Family Picnic |
| 26 October | Norton Street Italian Festa Come visit us at our stand |

PATIENT STORY

The Three Musketeers

By Arthur Bozikas.



53 years ago, just after I was born at Crown Street Women's Hospital in Sydney, I was diagnosed with a rare genetic blood disorder called beta thalassaemia major.

The disorder meant that my body wasn't able to produce functioning red blood cells on its own, so I needed blood transfusions every few months in order to help me live. With developing medical practices, I now receive monthly transfusions of two-to-three units of blood, and have done since my late teens. Prior to this period, things were most unregulated, but what this also means for sufferers of beta thalassaemia is that our existence is completely dependent on the generosity of people's blood donations.

The ratio for being born with beta Thalassaemia from both parents carrying the gene, are 1 in 4, and with 4 boys in the family I happen to be that one. Following my diagnosis I was taken to Camperdown Children's Hospital, where I received ongoing treatment. Although the hospital closed in 1995, it was a wondrous and exciting place, right up until our relocation to Royal Prince Alfred (RPA) Hospital in the late 1980s. With regular hospital visits being part of my life, Camperdown became my stomping ground.

I can recall the time, when I was 12, when I'd received the wonderful news that I would be meeting new 'thal patients', the same age as me, at my next 'blood day'. This made me even more eager and excited than usual; although I enjoyed spending time with my mum and dad on my blood days, I couldn't wait to meet other kids, especially kids who would understand me and my situation.

By then, the hospital had become a very familiar place to me. I'd been treated well by all the hospital staff and all the wonderful nurses, and I would be very fortunate to come across a few good doctors. (It didn't happen very often, but the horrible ones

that I would occasionally come across I would soon send on their merry way with a death stare or two!)

On that next blood day, I tried to get there early that morning with my mum, but as we arrived at the place I called 'my domain of pleasure and pain' I was horrified to see that the four new thal patients were already there, IV drips already up and their blood already running, full-steam ahead, in my domain, without me! They looked as though they'd been coming here for years! They had already had rearranged my domain by removing the hospital beds and adding armchairs to fit them all in. I felt that, even though it was an old operating theatre room fitted out with a couple of beds, it was my place, not theirs.

I was flabbergasted and angry. But I didn't show it and kept my cool. My mum thought it was great and quickly encouraged me to introduce myself to everyone. Brother and sister couple, Mary and George, sat opposite where we stood. Sevarino sat next to Peter, who was sitting on the left hand side of my room. I'll never forget the first time I met Peter. He had one of the biggest, smart-ass grins I ever saw in my life. I also noticed that, strangely, they were all alone – their parents weren't with them. Why were they all alone?

There was an empty armchair for me, in between them all, but not one for my mum. I thought, 'how rude!', and was overwhelmed with a rush of conflicting emotions – joy and distress. So I asked my mum to leave me alone for the day and to come back later in the afternoon.

Overjoyed at my 'confidence', my mum (embarrassingly!) kissed me on the cheek and left to do some shopping at the local shopping centre. As I quietly sat in the vacant armchair, I felt the stares cutting through me from the other kids. "Do you always come here with your mother?"

asked Peter, that smart-ass grin breaking through my thoughts. I couldn't believe I was in unfamiliar territory and I suddenly found myself out of my comfort zone in my very own surroundings. Things had changed for me. It felt very strange.

Before I had a chance to reply, I heard a familiar, deep authoritative voice calling my name. I knew Sister Sue Shaw's voice as well as I knew my mum's. She had been my guardian angel, looking after me as far back as I could remember – and the feeling that I did not want to share her with these people rushed over me like a wave. This was going to take some adjustment on my part.

It was after lunch when Peter (having exhausted the supply of conversation with everyone else, as well as challenging everyone to a game of chess, and mostly losing) asked me what I knew about beta thalassaemia, and shared some information of his own.

We all were on our last bottle of blood, and Sister Shaw had been quite competent in handling all of us at the same time. I was beginning to settle in and almost enjoy the experience. And it was then that Peter announced first to me, in front of everyone, that a beta thal sufferer's life expectancy is only to their early twenties! All of a sudden, a chorus of "shut up!" came from everyone. Thankfully, he did. The coordinated exclamation seemed to bring a sense of unity, despite my being shattered at what Peter had said. My heart was racing and I was overcome with mixed emotions, and found hard to breathe. I slowly composed myself by gathering my thoughts, and my safety mechanism kicked in. And I was curious to know more. I said to him, "I haven't got an illness...I just need blood, like all you do."

After a few minutes of stunned silence, everyone carried on as normal with an assortment of conversations, and nothing was said of it again. Mary, the elder of her

and George, was four years my senior. Sevarino was three years older than me, and Peter was two. They all made it clear that I really was too young to join in with any conversation. Anyway, having been confronted by my life expectancy for the first time, I now preferred to sit and observe everyone, and hope that they wouldn't notice that I was worried in at all.

It wasn't long after that when mum came back, balancing bags in both hands, looking very pleased with herself seeing me among my new Thal mates. But I was now so frustrated. I needed my questions answered, and I tried to get her attention without all the others noticing, but to no avail. I had to wait until we were alone.

It was when I was about to have my IV removed from my arm, watching the last lot of blood leave the bottle and slither all the way down into the tube, I quickly said, "Mum, what's beta thalassaemia? Am I going to die before I get too old? And, why hadn't you told me this?"

With the doctor and Sister Shaw removing my IV, she didn't have time to reply. Last to leave, I was now glad that this day was finally over. As we left the hospital, I remember being very determined not to bring the beta thalassaemia subject up ever again. Not because my mum didn't know how to answer me I guess, but I think it was more so, that I didn't want her to. I concealed it really well from my mum soon after, and she was absorbed with being happy that I found new friends my age to recall my outburst.

All the way home in the car I filled her in about what I thought of Peter and that stupid grin of his. I thought Mary and George were great and Sevarino was a little too mature for me to get on with, but he was okay. Arriving home from the long drive back, I recall mum asking me why was I talking about Peter the most if I liked him the least?

Each visit after that got better, and by the time Mary passed away two years later, the thought of what Peter said about our mortality brought reality to us all very abruptly. It was too close for comfort and we were at a delicate age, and it cemented that we really did have a very short 'shelf-life'. Mary had been the first person to extend her arms to me and welcome me into the group. She'd protected and cared for me when I'd needed it most in the beginning. Even though I only had a few years with

her, before she left, I remember her as an awesome friend, in this first dark period of my life.

With Severino always keeping to himself and sometimes setting his own scheduled visits, the bond that Peter, George and I developed was grand. Our coordinated efforts of scheduling every blood day together gave us a reputation, and we became known by all the hospital staff as 'The Three Musketeers'. The nickname stuck right up until our relocation to RPA.

I recall in our late teens, and with our mortality always in the back of our minds, a 'magic' new drug called Desferal (desferrioxamine) became available to help rid the body of excess iron by excreting it via the urine. The valuable blood that was keeping us all alive was also slowly killing us with iron overload, saturating our bodies with iron from the blood, leading to organ failure for many patients in their early twenties. Both George and Peter were now in their early twenties and were quickly put on it and, when I turned twenty-one, I was finally introduced to it, hoping for the best.

Children with beta thalassaemia are these days introduced to Desferal at the early age of four-to-six, and live a relatively normal life. So when we were told in our early twenties that the damage had already been done, but it would be in our best interest to commence treatment, we did so without any hesitations. I must be honest, I did become complacent with my treatment, and in my early thirties I was told that if I didn't commence routinely using Desferal again, that the doctors would insert a portacath into my chest and intravenously run Desferal twenty-four hours a day!

I had stopped using it because I somehow got it into my head back then that it would be any day that I would die. I wasn't listening to the doctors, and it was my wife who made it clear that she could perhaps get hit by a bus anytime and she could go first, because no one knows when their time is up. Helen and I were married for about five years at that stage, and with two children under five, she quickly snapped me out of it. She has remained my light in my darkness.

She changed my whole outlook. I was forty-two when I first went to university. It wasn't long after that I achieved a lifelong ambition of being a part-time TAFE teacher, after twenty years of working in middle management. I was then thrilled to have the

opportunity of taking a position of casual academic tutoring and lecturing at the same university I attended. Not long after that, our question of mortality was brought to the fore once again, when another of our Thal family passed away in late November 2007 – our close and dear friend, Sevarino.

With the three of us now in our fifties all living very busy lives with families of our own, I finally feel less concerned about my mortality, as a result of lastly living life without worrying about things I can't control. Strangely enough, I'm actually feeling 'fortunate' to experience now 'old-age-related' ailments!

I have been happily married to Helen since 1985. We have raised our two children, who are now in their mid twenties and I'm now leading a disability (not-for-profit) organisation in a full-time role as the CEO.

If I could only go back to those 'The Three Musketeers' days and take all the heartache away of that scared little boy, by telling him that all he needed to do was to just focus on living one day at a time and slowly chip away at the most important goals he had, and not discard them.

These days, it's inspiring to see all the many young Thals I've been fortunate to come across over the years. Some have even achieved prominent positions such as police officers and bank staff, and even become parents, and the stories I come across of their triumphs and tribulations are really encouraging. I admire them all because they don't have the 'stunned deer in the headlights' stare that I once shown at a time of uncertainty and trepidation.

It wasn't until I read Josephine Bila's all inspiring article titled: Why It Pays To Be Vulnerable, in the Thalassaemia Australia Summer 2013 Volume 5 Issue 14 newsletter, that really encouraged me to reflect on my life. It was then that I decided to put an article together of my own, so I can be of the same mind as Josephine and finally have peace with my Thal.

Josephine reminds me of a quote by Oprah Winfrey: "The more you praise and celebrate your life, the more there is in life to celebrate".

TIF CONFERENCE 2013

Report by Nancy Lucich

– Co-ordinator, Thalassaemia Society of NSW



Being given the opportunity and granted sponsorship to attend the 15th TIF International Conference for Patients & Parents 20th – 23rd October 2013 was a great honour and it fulfilled my expectations in every way. Following I would like to give you an overview of this great experience and share with you my highlights of wonderful faces I came in contact with, along with the fantastic key note speakers that stood out to me.

Day 1 entailed registration and meeting the patients from Canada, the UK and NY as well as coming face to face with the TIF Board Members whom I have communicated with time after time over email. It was great to be able to put faces to the names. After being blown away by the overall size and richness of the Abu Dhabi National Exhibition Centre I was overwhelmed to see streams of patients and health professionals from all over the world come together for something so important to me. That afternoon we attended the opening address, as did all who registered for the conference, this was the first time we all came together as a group, I sat and looked around and very quickly started to notice and make note of faces that I would like to meet and get to know over the course of the four days.

We received a warm welcome from Panos Englezos, President of TIF and then were informed of the Milestones and current initiatives of TIF by Dr. Androulla Eleftheriou, Executive Director of TIF. Following the welcome was a keynote session with keynote speakers;

Dr David Weatherall, from the United Kingdom “The Global Status of Haemoglobin Disorders”, was stating that it is currently estimated that over 400,000 babies are born each year with these conditions, particularly the Sickle Cell disorders and Thalassaemia. The talk attempted to assess the global health burden brought about by these conditions and their impact on the foreseeable future. He noted that it is vital that the international health agencies are made aware of these problems and low income countries in particular must be given the opportunity to develop national programs for their prevention by prenatal diagnosis and better management.

Ivan Ivanov, Thalassaemics’ Organisation

in Bulgaria spoke on “Ensuring Quality of Life-the patient’s perspective”. Ivan presented on health related quality of life and suggested that a quality of life questionnaire would increase the number of studies aimed at therapy optimisation and there lead to achieving a good quality of life level in these patients. There is currently way to assess this health related quality of life. It was proposed that a general questionnaire for examining the quality of life should be comprehensive and should include physical, psychological and social dimensions. He noted that, quality of life is directly related to the self-assessment. According to the social psychologists, the sources of happiness can be personality traits such as high self-esteem and internal control, as well as the opportunity for education, work, social participation and satisfactory rest.

Dr Cappellini from Italy spoke on the “Milestones in the History of Haemoglobin Research,” was highlighting a patients’ timeline from first diagnosis of Thalassaemia to modern medications throughout history. From here on and, throughout the 4 days Dr Cappellini stood out in my mind to be inspirational, dedicated and worldly.

After some light refreshments we then attended the Sultan Bin Khalifa International Award Ceremony, these awards were to recognise the hard work and dedication of individuals who contribute towards research and ongoing treatment for Thalassaemia Patients around the world. A very prestige and high-end ceremony, men and women from the UAE were dressed in traditional clothing, and were a great introduction into their culture. It was like attending the Logies, paparazzi galore!

Day 2 was the official first day of the running of the conference. We set up the Thalassaemia Australia / Thalassaemia Society of NSW Information stand at the Global Village. The Global Village was a new initiative introduced to the TIF Conference, where societies from around the world were asked to participate. We were all given a designated area with little stands to set up and display the work, information and support services we provide in our home countries. The stand was to be manned by the representatives from each society. This gave conference attendees the opportunity

to be informed and network amongst like organisations, forming new networks and exchanging ideas and information. I found this to be very worthwhile and successful and I was once again overwhelmed by the opportunity that we had been given to come face to face with other organisations, who like us work hard to achieve the best for their peers and patients. Many contact details were exchanged and both working and personal friendships and relationships were formed.

On this particular day we were also informed by conference organisers that two very special guests would visit our stand, we were given instructions as to what time to be at the stand ready to receive these visitors, along with how and where to stand. This was all very exciting and the anticipation around the Global Village was evident. Soon our first guest arrived and it was His Highness Sheikh Zayed Bin Sultan Bin Khalifa Al Nahyan who is the Chairman of Humanitarian and Scientific Foundation and Chairman of Board of Trustees – and presenter of the Sultan Bin Khalifa International Thalassaemia Award. May I tell you that I found him very attractive and I was left pretty much speechless at the fact that we had a Prince from the UAE was standing before us and was truly interested in the work we were doing for our patients back in Australia. He was genuinely interested in the picture Maria and I painted of what we do for our patients in Australia as well as the prevalence of Thalassaemia. When I said that we are at the end of the day “like one big family!” he turned to me with a beautiful big smile and said, “Yes, you are right, we are all one big family”.

Later on the same afternoon we received our second special guest, Her Highness Sheikhha Sheikhha Bint Seif Al Nahyan Chair Person Emirates Thalassaemia Society and the Mother of the Prince we had just met. Again pure beauty stood before us, with a genuine interest and passion for Thalassaemia Patients from around the world. She stood and took in all that was said to her from all Societies. Although the time with both the special guests was brief it was still an honour and a once in a lifetime experience and that we will be forever grateful for. Her Highness also announced that the partnership between “His Highness Sheikh Sultan Bin Khalifa Al Nahyan

Humanitarian and Scientific Foundation" and "Thalassaemia International Federation" had gained new momentum, following the launch of the Regional Collaborating office of Thalassaemia International Federation, in Abu Dhabi, earlier in 2013.

The rest of the day rolled on with meeting many more inspiring people, some of whom stood out to me were:

Samira Elyamani – The President of the Association of Moroccan Thalassaemia Organisation. Samira's son is 20 years old with Thalassaemia Major; he had a massive battle from an early age. Samira is thankful to health professionals in Genova Italy who were able to get on top of treatment for her son and turned his life around. She still fears for him however his improvement is positive. Samira then introduced me to a 27 year old young lady who is the oldest living Moroccan patient. She found that in order to get optimum treatment and to look after her health she needed to move to Italy. Unfortunately for many many patients in Morocco this is not an option. Sadly, medications are extremely expensive in Morocco and patients are not living past their 20's.

I also had the pleasure of meeting important members from the Maldivian Thalassaemia Society whom were in the stand next door to ours. These patients made a lasting impression on me with the work, activities and projects that they carry out for their patients – they are truly inspirational. In the Maldives they have 700 patients who are being treated for Thalassaemia on the mainland Male. I had the pleasure of meeting two beautiful adults one with Thalassaemia and the other with Sickle Cell Anaemia, both whom had become parents, which is a massive achievement in the Thalassaemia Community in the Maldives. The prevalence of Thalassaemia in the Maldives is 18%. This is the highest in the world, this means that 1 in every 30 marriages is between 2 carriers and every 1 in 120 live births is a child born as a Thalassaemic.

Some of the other patients I met on this particular day were from the UAE, Saudi Arabia, Iran and Nepal. Each with a story to tell and a recount of what living with Thalassaemia is like back at home for them. It became clearly evident to me that we as patients back in Australia are very fortunate to have an excellent health system and such a high level of care – for this we should all be very grateful.

Patients from all parts of the world were interested to learn of the treatment costs back home in Australia. There was lots of interest in knowing if they can travel to Australia and have treatment while they are visiting.

Later on this evening we attended the Novartis sponsored talk on Non Transfusion Dependent Thals. A very interesting panel discussion covering Thalassaemia Intermediate and Thalassaemia Minor. Dr Androulla Eleftheriou, Prof. Mara Domenica Cappellini, Prof. Ali Taher, Ass. Prof. Vip Viprakasit, Durhane Wong-Rieger, Mr Thomas Troadec (Photographer), Michaele (patient from Italy)

This session was all about highlighting the importance of raising the awareness of Thal Intermediate and Thal Minor, screening for it and treating these patients so they don't have to keep living with symptoms and basically being told that there is nothing that can be done for them. In Milan, a photo campaign containing interviews with a few of these patients and spread of beautiful real life photos has been made. These photos will be used to launch awareness of Non Transfusion Dependent Thalassaemia on a variety of social media and media sites. It has not yet been decided when or exactly where however it is in the near future and we will receive notification so we can also promote it accordingly. It would be fantastic if we could do such a campaign here in Australia or perhaps have the approval to use the photos and stories.

This day concluded with a magical experience of dining at the Prince's Palace in Abu Dhabi on the Royal Island. The invitation was extended by the Princes to all conference attendees, after her royal visit earlier on in the day. We were all picked up and transported to and from the Palace for a beautiful dinner and we were all treated like prince and princesses. This experience was needless to say amazing and again a once in a lifetime experience, we did actually feel like one big happy family celebrating, and enjoying the time with one another away from the conference.

Day 3, involved manning the stand and networking, however I did manage to attend a few sessions:

Hypogonadism: from the Diagnosis to Treatment – Vincenzo De Sanctis, explained that in Thalassaemia some hormones are not produced therefore some thalassaemia patients do not develop or go through

puberty. Hormone treatment is however available and offered to patients. Common ages for treatment to commence are girls 15 years and boys 13 years. Treating professionals will keep a close eye on the hormone levels of these young patients and as the hormone levels drop they will then commence hormone treatment before it gets too late and puberty stops all together.

Infections in Thalassaemia - Christina Stepanidou presented the risks of Thalassaemia patients contracting various infections and the importance of prompt treatment with antibiotics.

Emergency Management in Thalassaemia – John Porter, John went through the very descriptive Emergency Booklet published by TIF. This booklet goes through the ins and outs and the dos and don'ts for an emergency department when a Thalassaemia patient presents. As we are all away Emergency is a very busy place and as we would like to think that every emergency and every staff member knows all about Thalassaemia, however the reality is that this is in no way possible. The key thing to remember is for all patients and parents need to be as well informed about their condition as they possibly can. So educate yourself so that if, and when the situation arises you are able to somewhat take control and inform the medical staff if they are unsure. We must remember that something minor to a non Thalassaemia sufferer may be something significant to a patient with Thalassaemia and may in fact compromise a Thalassaemia patient. These booklets are a great information source for the health professionals as well as patients and parents and they can be downloaded from the TIF website.

On this day to tie in with the Emergency Management I was invited to give a small presentation on "a patient's experience and perspective in the emergency room." My presentation was based on one major admission I encountered with the Emergency Department for the first time as a very sick 21 year old. I explained my symptoms and how unwell I was feeling and also my feelings, emotions, fears and how it all unfolded for me. My learning experiences and what I took away with me from this admission. I was very fortunate in this instance that although I did present very unwell and did get progressively worse, I was able to make a full recovery. At the time, I was lucky that the staff in the emergency department was aware of Thalassaemia and with me further educating them and

TIF CONFERENCE 2013

Report by Nancy Lucich – continued

prompting them I received the treatment that I needed at the time and the right medical team were called to my bedside.

Communication to Patients and Families – Josephine Bila

Josephine is a patient from New York, and she took us on a journey from when she was a young girl having treatment for her Thalassaemia and discussed her fears, sadness and mixed emotions she felt and how this prevented her from living life to the fullest. Josephine lived with these fears and emotions for many years until one day a young child turned Josephine's fears around and made her realise not to be afraid, that she would be okay and most importantly that there were worse off people out there in this big world.

Josephine is now the owner and a wellness consultant at Josephine Bila Inc. Josephine provides one on one group coaching services to those seeking emotional wellness or stress management. Josephine at the end of her presentation received a well deserved standing ovation. She is an inspiration to many and it is great to see patients just like Josephine turning their experiences into positive energy and create such positive outcomes not only for herself but others too.

Day 4, this was the last and final day of the conference, while walking into the conference hall this morning I told myself to be strong and brave as I say good-bye today to many beautiful people I have met over the past few days, this was however easier said than done. Needless to say, I was an emotional wreck all day!

Today we also attended the Patients/Parents Associations Open Forum Part 1 and later in the afternoon Part 2 where we got to sit and be educated by various patient organisations from around the world. The following organisations gave a presentation of their organisation, the work they carry out, their achievements and goals for the up and coming years....

1. Greek Thalassaemia Federation (Greece)
2. Thalassaemia Australia Inc (Australia) presented by our very special Maria Kastoras

3. Chronic Care Centre (Lebanon)
4. Charity Foundation for Special Diseases (Iran)
5. Maldivian Thalassaemia Society (Maldives)
6. Thalassaemia Association of Argentina (Argentina)
7. Thalassaemia Association in Niniva (Iraq)
8. Egyptian Thalassaemia Association (Egypt)
9. The Society of Inherited and Severe Blood Disorders (Trinidad and Tobago)
10. Lab One Foundation of Thalassaemia (Bangladesh)
11. Blood Patients Protection Council (India)

The day concluded with the TIF Constitutional Meeting which both Maria and I attended followed by the TIF General Assembly Meeting.

To conclude I would like to say that in no way was I prepared as a patient or as the Coordinator of the Thalassaemia Society of NSW for the ride of joy and emotion that this conference was to bring to me. It has given me such a scope of knowledge as to what goes on in all other parts of the world for patients with Thalassaemia.

I have walked away from this conference with experiences and stories that I will forever hold close to my heart. It has changed my outlook on life and I am happy to share more information with anyone who is interested in any part or aspect, so please just contact me.

I would like to thank each and every person who made this experience come to life for me and who shared in this amazing experience with me..... We have made memories that will live forever!

My wish is for every Thalassaemia/Sickle Cell anaemia patient to one day experience what I just did!

Thank you!
Nancy Lucich

Thalassaemia Society of NSW and Thalassaemia Australia - acknowledge and thank Novartis Oncology for their unrestricted educational grant used to assist staff and committee members to attend this conference.



My Experience

Report by Spiros Bombos – President, Thalassaemia Australia

WOW! I cannot adequately express how this experience opened my world.

I would like to keep this report simple and provide you with a quick overview.

Most of the people from the Australian contingent (Melbourne and Sydney) arrived in Abu Dhabi early Saturday morning, a day ahead the official opening Sunday evening,

So here I am in Abu Dhabi, tired as hell from jet lag and from being sick on the flight. It is 6.30am and I am walking out of the airport and it hits me just how really hot this place is ... and apparently its winter!

Arriving at the hotel, I am amazed at the plushness of the amenities, and wonder how many stars this hotel has. As I check in and get orientated, I realise that the conference centre adjoins the hotel and everything here seems to be on a grand scale.

Once I had freshened up, I sought to meet up with our other committee members whom have all arrived at the venue at different times. It Saturday night and most of the other contingents from other countries have arrived and are settling in for dinner.

I sat down for dinner with Maria Kastoras, Nancy Lucich, Maria Avarantinos, Helen Matsis, Rosa and the rest of the Australian patient /parent contingent. Soon enough we are joined by other patient / parent groups from around the world.

More people started arriving as the night went on and I am being introduced to all these people, and the girls are starting to explain who is who. I am thinking to myself, most of these people are patients that most of them have funded themselves to get here, the fact that they want to be part of this conference - WOW.

The night quickly evolves into an amazing night of introductions and reconnections. At this stage I would have loved to have stayed on, but I have succumb to my tiredness and I just needed to get to bed.

Sunday morning I'm eating breakfast by myself and I start looking around the restaurant and start recognising some of the patients from last night. Luckily most are staying in the same hotel, and it dawns on me just how many people must be attending these conferences and that's not including the scientific representatives!

As the remaining Aussie crew were coming down to join me for breakfast, more introductions were made and I met representatives from the USA, Canada and the UK. Everyone began to mingle and before I knew it I am chatting to Andy and Gabs from the UK (President of the UKTS) and he effortlessly opens up to me. Granted at this point I think, I don't know this man from a bar of soap, but here he is connecting with me and outlining his experiences with Thal, both personally and professionally.

Later, we all migrate to the upstairs pool and lounge areas and our conversations organically continue. I start to realise that this is a real extended world family, which gets patients and parents together once a year and their relationships continue from where they left off a year ago.

Sunday evening, we head to registration and the opening address.

So here I am amongst all the following: Patients/ Parents, Medical Community, various international committee members and dignitaries' that have gathered in one area for the collective share of knowledge.

At Monday's breakfast I begin to analyse the itinerary/conference programme for the day and mark out all the sessions I want to attend.

Thalassaemia Australia & Thalassaemia Society of NSW has set up an Information Stall at the Global Village, where they could show people how Australians care for and treat people with the different blood disorder/conditions. The Global Village contained many stalls from across the world and it was an amazing opportunity to visit the other stalls and learn how other countries deal and treat the conditions.

We all took turns manning the stall and it was by far the most surreal experience for me. They had been setup a section of the conference centre with stalls for all of the organisations around the world to represent them at the conference.

I left the ladies shortly after my arrival as I wanted to go and hear some presentations. I was recommended by Andy from the UK to go and listen to two doctors from the UK: one presenting on haematology and the other on the heart.

Whilst in the main patients/ parents presentation room, there were also American doctors presenting of various wellness topics, such as stress, depression, and better health and self motivation etc.

As I cannot sit down in one spot for too long and I wanted to get back to the stall and to see if everything was okay, and absorb the buzz around the global village.

As I was heading over, I could see that patients, parents and medical staff were reconnecting with each other, and other nations representatives were visiting the other country/medical stalls to see what others were presenting.

The next day, I went back to our stall at the Global Village, and before I knew it I had spent three amazing hours there. This where I met a cross section of people from across the world, in affect it was bigger than the night before. It was an enlightening experience to share my son's journey and listening to others journey's with Sickle/Thal.

On that Monday we were all honoured by the presence of the Prince and Princess of Abu Dhabi who visited our stand, and later the evening we were gracefully invited to attend a dinner at the Grand Palace. Interesting note: All the men had to leave the conference area for the Princess to attend. You should also note that both Maria Kastoras and Nancy Lucich did Australia proud when they met the Prince and Princess.

Unlike Andy from the UK he proceeded to ask the Prince which football (soccer) team he follows!

This is a brief summary from my eyes, as the conference continued more bonds/connections where formed, knowledge was shared and gained at each and every stage of the day.

From meeting people at the Global Village, during break times at the conference area, dinners and just lounging around the pool after the conference.

For any patient, parent, medical staff or family member who hasn't been to one of these conferences I can try and tell you what an amazing experience these conferences are but I don't believe I would do it justice. All I can say is I can hardly recommend enough for you to attend one Conference. Various Thalassaemia Australia committee members, and my wife have attended these conferences and I could never comprehend the stories they shared with me until I participated in one myself.

So go with open heart and mind, and you will enjoy and appreciate the wonders that these conferences have to offer.

TIF CONFERENCE 2013



Report by Joanne Shaw, MTU Nurse Unit Manager and Mary Tassigiannakis, MTU Social Worker.

Dear Readers,

Our participation in the 13th International Conference on Thalassaemia and Haemoglobinopathies and the 15th Thalassaemia International Federation Conference for Patients and Parents in Abu Dhabi in October of 2013 was very rewarding and professionally interesting and informative. There were 1300 participants, from over 50 countries, across 5 continents who attended the conference. Parallel scientific and patient, parents and family sessions were open for attendance. Presenters for the sessions included more than 60 internationally renowned experts, patients and family members.

It was, of course, impossible to attend all the sessions that we would have liked to and so we tried to cover, between the two of us, those we felt most relevant to our patient group here in Melbourne, Australia. It was pleasing to have a number of our own patients and families attend the conference and we are sure that they too benefited from the experience.

We attended sessions from both the Scientific and the Patient/Parent Conferences and found an overwhelming atmosphere for the exchange and sharing of information very intense and moving. The scientific sessions particularly focused on the global status of haemoglobinopathies. Statistical reports indicated an increasing international number of haemoglobinopathy patients and there is estimated to be over 400,000 babies born each year. There has been a particular increase in Sick Cell Anaemia births over the past 5 years.

One of the overriding themes in the Patient/Parents Conference was the issue of patients' 'Quality of Life', especially as treatment has improved and patients are living well into their middle-aged years and beyond and participating in all aspects of life (where of course there is reasonable treatment available).

Empowering patients to be more involved in their care and to take on more responsibility for their treatment was also seen as a way of helping patients develop improved self-management skills and increase adherence to treatment. This was a clear message by many presenters.

A number of studies presented indicated a very strong correlation between a patient's adherence to their treatment and the social/psychological/emotional support they receive while learning how to manage and live with their chronic condition.

Some treatment centres have developed and adopted the use of a Quality of Life questionnaire to gather information and assess patients' perception of their wellbeing and how they cope with their chronic condition assisting in better patient centred interventions.

Some statistics that were presented by Mr Ahmet Varoglu, a patient from Cyprus, in his paper stated that: 80% of Thalassaemia Major patients may manifest psychological symptoms including depression, anxiety and somatization (Mahdi et al 2009) and in another comparative study on adolescents, found that adolescents with Thalassaemia presented with high rates of depression, phobias, obsessions and generalized anxiety relative to their peers (Evangelini et al 2010).

As important however are other factors that also play a very significant role for patients' assessment of their quality of life. These are such things as: quality and safety of treatment, availability of and safe chelation therapy, healthcare professional support with clear, honest communication, access to allied health workers such as psychologists, social workers and dieticians and an overall collaboration and multidisciplinary approach to the patient's care (home, healthcare, school and community) from the point of diagnosis and beyond and particularly at every significant life-stage.

Having attended quite a number of presentations in the Patient/Parents Conference, the sincerity and professional manner in which these papers were delivered was impressive. Patients were very willing to share their very personal journey and the difficulties they have encountered along the way with the many challenges they have faced with their treatment and particularly with their chelation therapy. Many spoke about the invaluable support they have received from family and friends and the damage that can be done to a patient's sense of self-worth and acceptance of their illness if this support is not available or forthcoming and a level of secrecy is maintained about the illness to others.

In our discussions with many other conference participants it became quite clear that the model of care we have in the Medical Therapy Unit at Monash Medical Centre where we provide a whole of life service, is quite envied by many other overseas centres.

We also had the opportunity, on returning to Dubai after the conference ended, to visit the Latifa Hospital, which also provides a whole of life service for Thalassaemia patients. Dr Khawla M Belhoul, whose presentation we had attended was very helpful in showing us the facilities of the Dubai Thalassaemia Centre and agreed with us about the benefits of treating patients together providing them with the opportunity of sharing and teaching one another their coping strategies.

One of the other very interesting aspects of the Conference, apparently organised for the first time, was the Thalassaemia Societies Pavilion/Patients' Village. Each booth was manned by volunteers/patients/families/staff representing the many countries participating in the conference.

Moving around and speaking to many of the participants it became clear how there is still a very big need around the world for increased awareness of Thalassaemia, better quality treatment and psycho-social support for patients and families. Funding for pre-natal diagnosis and treatment, especially in developing countries where there are still large numbers of children with Thalassaemia being born, remains a critical issue.

The enthusiasm and eagerness by many of these groups to embrace information about how treatment is delivered in Units such as ours in Melbourne and whether they could receive any support for their centres was a moving experience but often quite confronting.

We were pleased to have had the opportunity to attend an overseas Thalassaemia conference and to have been able to meet other health professionals from around the world to share our experiences.

It was encouraging to see that the issues our patients face and the intervention and support we offer are not dissimilar and are being recognised more and more on the international stage as an imperative component of patient centred care.

Global Village thank you letter

29/10/2013

Emirates Thalassemia Society wrote:

Dear Friends,

On behalf of Emirates Thalassemia Society & United Arab Emirates, we thank you immensely for joining us at the TIF World Congress and specially being a part of the Global Pavilion for Thalassemia Societies.

This new concept was introduced to unite societies from all around the world so we can develop a long term relationship & sustain efficient communications, share experiences, know each other's working tools, & specially to make great friends.

With your enthusiasm, love and appreciation we have achieved even more than what we had expected. Your efforts, preparations and time spent on the Global Pavilion are invaluable & will always be remembered.

It is mandatory to mention that you had been an integral part of the Global Pavilion for Thalassemia Societies. We also would like to mention that the Global Pavilion was the biggest highlight of the entire conference and was the most successful area visited by many guests and VIPs.

We commend you for making this concept come into life. A big note of thanks and congratulations for making our Global Pavilion a big success.

We wouldn't have done it without you!

We look forward to organize many such events in the future to unite all our friends from the Thalassemia fraternity under one roof.

Thank you!

Best Regards

Abdul Baset Mohd Merdas
Vice Chair Person
Emirates Thalassemia Society

BITS & PIECES

*Update: Thalaset now
been rebranded Neria*

These are available for purchase online using through the Home Support Network option www.homesupportnetwork.com.au

For enquiries please contact Emma Brady 03 9918 5328 who will also set up a user name and password for you.



New Ambulance Victoria mobile application available now!

Would you know what to do in a medical emergency? The Ambulance Victoria mobile application is a fun and interactive way to learn how you can help save lives.

The various features on the application will assist you in learning how to:

- Identify and manage a medical emergency
- Call 000 (Triple Zero)
- Recognise cardiac arrest and perform CPR through 4 Steps for Life Plus
- Assist ambulance paramedics in an emergency
- Party safely



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Travellers Aid offers trained volunteer medical companions to meet people at the train (Southern Cross or Flinders St), bus, tram or taxi and help them negotiate the city to and from medical appointments (all hospitals, specialists and dental clinics).

The volunteer companion is free- the person just covers their own fares. To book 48 hours' notice is required: Free call- 1300 700 399 or email scs@travellersaid.org.au



Make your own Banana Chips!

Preparation time: 5 mins
Cooking time: 15 mins

Ingredients:

- Bananas

Method:

1. Peel and slice banana thinly..
2. Bake in a hot oven (250°) for 15 to 20 minutes or until crisp.

Yum!

Hi Kids!

Pop in the kitchen and try out our new yummy recipe!

Super quick and easy to make!

Banana chips will be your little ones favourite snack in no time!



Q: Why do bananas wear suntan lotion?

A: Because they peel!

Q: What kind of a key opens a banana?

A: A Monkey!

Q: Why are bananas never lonely?

A: Because they hang around in bunches.

Colour me in!

