

Thalassaemia AUSTRALIA

Unifying support and genetics



Thalassaemia Australia Winter/Spring 2013 Volume 5 Issue 16

Quarterly

TORC Annual Seminar 2013 – Thalassaemia and sickle cell disease:

Update on clinical management, new research and emerging therapies

On 20 September 2013, Thalassaemia Australia and Thalassaemia Society of NSW were privileged to be invited to attend and to be a part of the Annual TORC meeting on thalassaemia and sickle cell disease, held at the Alfred Hospital.

This was the first seminar to support the introduction of the national haemoglobinopathy registry. Prior to this seminar, members of TORC steering committee, met with both Thalassaemia Society of NSW and Thalassaemia Australia to discuss the proposed registry, its requirements and how it will assist our patients and members.

The seminar was attended by medical specialists, registrars and nurses from a range of disciplines, laboratory scientists, and government, patient, Blood Service and industry representatives from around Australia.

A wide range of topics covered the care and treatment of Thalassaemia and sickle cell patients and their families in Australia from some of the issues faced with initial testing, the complexities of blood transfusion and iron overload, as well as health complications and caring for patients into old age. An introduction and update on the progress of the Haemoglobinopathy Registry was also given.

From Thalassaemia Society of NSW and TA's perspective, we were extremely grateful for the opportunity to participate in this seminar, and promote the services of our organisations to a wider group of professionals and patients.

Other than our recent Nurses Meetings, there have been few opportunities to promote thalassaemia and sickle cell disease in Australia with such a wide range of health professionals. This seminar also highlighted the need for our organisations to provide more information on sickle cell disease and other Haemoglobinopathies, in light of our increasingly diverse population and the recent increase in the number of patients that are being treated for these conditions in our treatment centres Australia-wide.

'As the Coordinator of the Thalassaemia Centre of NSW it was overwhelming to also see the turnout of participants and also speakers from NSW, and very encouraging to know that we are all working in collaboration to support the health and well-being of our special group of patients.'

– Nancy Lucich

Thalassaemia Australia and Thalassaemia Society of NSW would like to thank the TORC steering committee for arranging this informative and inspiring event, and putting thalassaemia and other haemoglobinopathies back on the map. We look forward to keeping you up to date with the progress the Haemoglobinopathy registry in due course.

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See page 8 for more details about
the Haemoglobinopathy Registry.

Thalassaemia Australia Inc.

Committee of Management 2013

Executive

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

General Committee Members

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

Committee meeting dates for 2013

Committee of Management meetings begin at 7.30pm and are held at the Thalassaemia Centre, 333 Waverley Road, Mt Waverley 3149

15 October
19 November
17 December

All welcome!

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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Thalassaemia Australia Inc. ANNUAL GENERAL MEETING

Questions and Answers, 2013

Do you have any questions that YOU would like to ask Prof. Don Bowden, Joanne Shaw and members of the Medical Therapy Unit in an Open Forum regarding general information about your care and treatment, hospital procedures or anything else? Then, please join us at our upcoming AGM for your opportunity. Dr. Jim Vadolas will also update on the latest research into thalassaemia and cell and gene therapies.

Light refreshments provided.

When: Tuesday 26 November, 2013, 6.30pm for a 7pm start

Where: Monash Medical Centre – Clayton
246 Clayton Road, Clayton VIC 3168

Venue: Lecture Theatre 2

Parking: Nearby street parking or the carpark within the hospital grounds. (please note normal parking charges apply)

RSVP: Friday 20 November, 2013

Ph: 9888 2211

Email: info@thalassaemia.org.au

Please check our website and Facebook for more information on our guest speakers, confirmation to be advised.

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.



National Disability Insurance Scheme and Genetic conditions

TA as members of the Chronic Illness Alliance we were invited to attend an information forum on the National Disability Insurance Scheme and genetic conditions in July this year by presenter: Dr Jane Tracey – Centre of Developmental Disability Health Victoria – Monash University.

The National Disability Insurance Scheme (NDIS) is now referred to as Disability Care – and was rebranded to align with Medicare. It is now active and an online website can be found at www.disabilitycareaustralia.gov.au.

It was noted that although the scheme has begun, there are still gaps in the program to be filled.

With the number of carers passing away, there is a recognised need to rely more heavily on the community to support people with a disability.

Many factors can affect the support a person may receive with a disability: how you got, what support system you currently have in place, what the diagnosis was, who advocates on your behalf and the area that you live in.

The core principle behind this scheme is that all Australians with permanent and significant disability:

- Receive the reasonable and necessary support they need to achieve their individual goals and aspirations in their particular circumstances.
- Have choice and control over their lives
- Have opportunities and support to participate in the social and economic life of the community.

At the age of 65 Disability Care will stop. The new system is based on a 'lifetime of cost/care' and how to maximize a person's economic and community participation.

Level of Function – and not diagnosis is the key to understanding this new system. The new system will be rolled out from 2016 to 2019, but some areas have already begun to use the system.

Ideally there will be more creative options and resources to assist people with a disability and the system has changed from a welfare based system to more of a business model of care (retail market). For those that are under the age of 65 they will be eligible for support from Disability Care or Aged care, if they require residential care.

Once over the age of 65 a person then is covered by Aged care. It is essential that people with a disability register before the age of 65 to ensure their eligibility.

In terms of thalassaemia, most of the health costs to patients will come under the 'Health' banner and not Disability Care. The health system – will cover what is reasonable and necessary. However, it is a case by case proposition and some individuals will be covered.

Disability Care has been set up to compliment the current health services and it is expected that GP's will require a great deal of assistance with the assessment of disability.

Further information and eligibility criteria can be obtained from the Disability Care Australia website or telephone 1800 800 110.

www.disabilitycareaustralia.gov.au



UPDATE



**13th International
Conference on Thalassemia
and Hemoglobinopathies**

**15th TIF International
Conference for Parents
and Patients**

**20 – 23 October 2013 –
Abu Dhabi, UAE**

The TIF World Congress is coming soon and a contingent from the Australian thalassaemia and sickle cell community will be in attendance at this international event.

We can tell you that we also have some guest speakers amongst us, with Nancy Lucich and Maria Kastoras participating in the Parent's and Patients forum, and Dr. Jim Vadolas in the Scientific Program.

Thalassaemia Australia and the Thalassaemia Society of NSW will be holding a combined stand in the Global Thalassaemia Societies Village.

For further information, please go to www.tif2013.org.

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)

COMMUNITY EDUCATION AND ADVOCACY



CHRONIC ILLNESS ALLIANCE

Many of you may know that Thalassaemia Australia (TA) is a member of the Chronic Illness Alliance.

In recent times, there have been a number of submissions that have been put forward to government on behalf of those people with a chronic illness, their families and carers, these have included:

- Person centred health care – Policy statement for the 2013 election
- Carpark survey for Melbourne Public Hospitals

By spreading the word, and asking our members to participate in surveys, we are able to make a contribution to these policies by having our voices heard.

Please let us know at the TA office if you would like to be a part of this process and to add your thoughts and ideas to the issues that affect you and your care on a day to day basis.

TA Community Education

Thalassaemia Australia's (TA) community education program has continued since our last newsletter with presentations to the following schools and groups:

- William Ruthen Secondary College – Preston
- Preston Girls Secondary College
- Monash University Second Year Medical Students
- Monash Health – Transfusion Nurses Workshop
- Kiwanis
- Caulfield Grammar School
- Parade College
- Mentone Girls Grammar College
- Maribyrnong College
- Rowville Secondary College
- August Whittlesea Secondary College

TA staff attended the Health Consumer Advocacy meeting in Sydney and met with REM systems regarding pumps. Preparations are also currently on the way for our input into the upcoming Thalassaemia International World Congress in Abu Dhabi as well as the Melbourne General Practitioner Conference and Exhibition in November.

TA will be holding three workshops and will have an education stand throughout the exhibition.

Over the last few months, we have been spending some time down at the medical therapy unit, meeting and supporting some of our new patients and families. We have also been answering numerous enquiries from our members and members from the community regarding thalassaemia, sickle cell anaemia, and treatment centres both here and overseas.

Sadly this month, we have said goodbye to our Community Based Placement students for 2013. Again, we have been fortunate to have students that have made the most of their experience with us, and have learnt the value of community health organisations for patients and medical professionals. We wish them well with their studies and look forward to hearing from them at our AGM in late November.



MEDICAL THERAPY NOTICE TO PATIENTS – BLOOD COLLECTION SERVICES

Southern Health

246 Clayton Road
Clayton, Victoria 3168
Australia

Postal address:
Locked Bag 29
Clayton South, Victoria 3169
Australia

tel 03 9594 6606
fax 03 9594 6111

16th September 2013

Dear Patient

As you are aware RDNS changed the service model and is no longer collecting blood specimens (crossmatch, FBE, U&Es, LFTs, Se ferritin) for the Medical Therapy Unit.

The Medical Therapy Unit staff had advised patients to attend any Melbourne Pathology or Dorevitch collection centre free of charge. These private companies are not earning any money for the collection from Medicare and so have been collecting bloods for free.

The Medical Therapy Unit staff has had contact from Dorevitch collection centre management on Monday 16th September and Dorevitch will now charge a fee for collection invoiced to the patient. This fee will be \$20.00 + GST.

If patients attending Dorevitch wish to continue having the blood collection at a Dorevitch Centre an invoice for service will be sent in the mail (usually within 1-2 weeks).

Patients can attend Austin Hospital and Northern Hospital free of charge and currently there is no charge for Melbourne Pathology (this may change in the future).

Please do **not** attend for collection of blood specimens on **Fridays**. Due to lack of couriers the blood specimens do not reach Monash Medical Centre, Clayton, over the weekend. Blood samples older than 48hrs are not viable and give inaccurate results.

Please contact the Medical Therapy Unit staff on 9594 2756 if you have any questions.

Regards

Medical Therapy Unit Staff



Southern Health

ABN 82 142 080 338

Dandenong Hospital
Kingsdon Centre
Cranbourne Integrated
Care Centre

Monash Medical Centre - Clayton
Monash Medical Centre - Moorabbin
Casey Hospital
www.southernhealth.org.au

Community Health
Services across the
South East

SELF MANAGEMENT TOOLS

Medical Tests What do you need to know?

Why do I need a medical test?

Medical tests are used for various reasons, including:

- to screen for a common problem, or risk factor, in someone without any symptoms (e.g. cholesterol test)
- to help diagnose a problem or rule out possible causes (e.g. a chest X-ray for someone with chest pain)
- to monitor a health condition or the effects of treatment (e.g. blood glucose testing for people with diabetes).

Take an active role in your health decisions by discussing your medical tests with your health professional.

Useful questions to ask

It's important to understand your medical test options and what each test involves.

The following questions may help you to discuss your options with your health professional, and help you find out more about a test. In some cases the benefit of a test is not clear cut, and you may want to discuss the 'pros and cons' with your doctor.

Are there options?

- What will happen if I don't have the test?
- Is there an alternative test?

Why has the test been requested?

- Will the test guide or change my treatment?
- What could the test results show?
- How soon do I need to have the test?

With any medical test, procedure or treatment it's always a good idea to find out all your options. Sometimes 'watchful waiting' may be a valid option.

Asking about the possible consequences if you do – or don't – have the test is important, especially if this could affect your decision.

What are the potential risks and benefits?

- What are the possible positive outcomes?
- What are the possible negative outcomes?
- How reliable are the results likely to be?

Positive outcomes include accurate diagnosis of your condition, to help guide your treatment. A test may also help prevent problems by detecting risk factors (e.g. high cholesterol). Negative outcomes include the risk of complications associated with performing a test, as well as anxiety and concern about having the test and its results. Tests do not always provide a definite answer, which can lead to more testing or an uncertain conclusion.

What does the test involve?

- How long will the test take?
- How do I prepare for the test?

How much will the test cost?

- Is the cost covered by Medicare, my concession card or private health insurance?

When can I expect to get the results?

- When should I see my doctor again?
- What is the next step?
- Will further tests be likely?

Find out what the test involves and any special instructions (e.g. fasting, or not driving afterwards). Ask if you will have to pay any out-of-pocket costs. Also ask what the next step will be, and who you'll need to talk to about the results. Request a copy of the test results to keep at home. Discuss your options with your health professional.

Weigh up your options

Whether to have a test at all, and the choice of test for you, will depend on your individual situation. This includes your personal and family medical history, the reason for the test and its potential risks

and benefits, as well as your preferences. Remember that medical tests may not give definite answers about your health condition. A test is usually just one part of the picture – your doctor may need other pieces of information to diagnose and treat your condition.

Example: Same test – different recommendations

Regular mammogram screening is recommended for older women (50–69 years of age), but not for young women (below 40 years). Breast cancer is uncommon in younger women, and the test is less reliable with younger breast tissue. So there could be more false alarms (false positives) as a result of testing – where changes found on a mammogram lead to further tests, but do not turn out to be cancer. Different testing recommendations apply to women of any age who have symptoms or are at high risk (for example, because of their family history). Every woman should talk to their doctor about their individual needs.

Be familiar with your test history

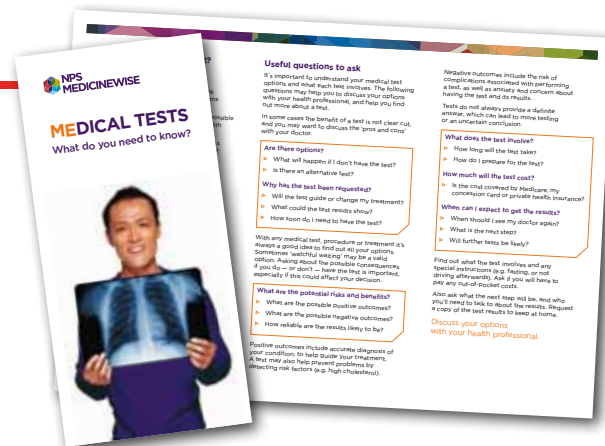
Your health professional may ask about your medical history including any previous tests and results. These may help your doctor understand your current situation, and could reduce the need for further tests. It is important to keep your test results (including the images or scans) in a safe and accessible place.

Find out more about medical tests

Visit the NPS MedicineWise website www.nps.org.au/tests for:

- reliable information on medical tests
- practical tips for getting more involved in your health decisions
- where to find more information about a specific test.

Reproduced from the NPS MedicineWise brochure titled 'Medical Tests: What do you need to know?' (pictured above).



Identifying Iron Overload with MRI — CLINICAL TRIAL

Do you know how much excess iron due to blood transfusions you have in your body? Iron is good for your health, but too much iron may cause problems.

An Australian study is assessing the amount of excess iron in liver and heart with MRI, in patients with anaemia who require chronic transfusions. Patients enrolled in this study will have an MRI performed to measure both liver and cardiac iron levels.

The results of this study will provide a better understanding of the impact of excess iron on these organs. Please note that eligibility criteria apply, so only some patients may be able to participate. If you want to know more about your iron levels or about this study, please speak to your doctor.

Participating sites -

- Royal Prince Alfred Hospital, Sydney (Prof. Joy Ho)
- Monash Medical Centre, Melbourne (Prof. Don Bowden)
- Royal Adelaide Hospital, Adelaide (Dr. Devendra Hiwase)
- Royal Perth Hospital, Perth (Dr. Paul Cannell)
- Royal North Shore Hospital, Sydney (Dr. William Stevenson)
- Flinders Medical Centre, Adelaide (Dr. David Ross)
- Mater Adult Hospital, Brisbane (Dr. Raymond Banh)

Study: TIMES study – ICL670AAU05

An epidemiological study to assess the prevalence of iron overload using MRI in patients with transfusional siderosis.
www.clinicaltrials.gov NCT01736540



In loving memory of Bill Tsaptsalis

who was born on the 24 January, 1969. Bill lived a very fruitful and truly enjoyable life. He was known to be very blunt and straightforward, along with being a practical joker and having a dry sense of humour. Bill had formerly been a proud committee member of Thalassaemia Australia, his fondest memory of which was "The Lorne Camp". He would have blood transfusions every third Wednesday with his "Wednesday Crew". Bill was surrounded by his loved ones and friends right up until his death on the 31 July, 2013.

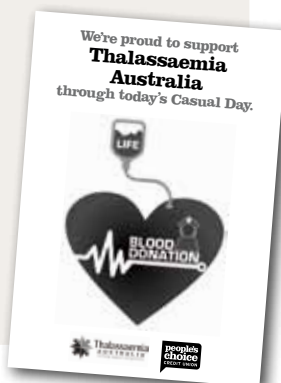
Our condolences to Bill's partner Angelina and extended family and friends.



People's Choice Fundraising

Recently, the staff and management of the People's Choice Credit Union held a Positive Impact Day and raised \$960 for Thalassaemia Australia.

We thank them for their generosity and support.



Why do we need an Australian Haemoglobinopathy Registry?

- Australia has a significant number of people with haemoglobinopathies and a unique mix of cases, which is changing as migration patterns change, but we don't know exactly how many people are affected, how severely they are affected, or how their health is changing over time.
- Different centres currently manage patients with the same disease in slightly different ways, and we don't know which strategies work best.
- People with haemoglobinopathies are living much longer than in the past, but little is known about their long-term complications and outcomes.

The registry will tell us all of these things. It will also:

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

The Registry is the first step in a major project to ensure that all Australians with a haemoglobinopathy continue to receive the best possible care.

Why is Monash University's Transfusion Research Unit involved?

- The Transfusion Research Unit (TRU) is part of Monash University's Department of Epidemiology and Preventive Medicine. Australia's leading institution for clinical research, and has the required infrastructure and expertise in public health, epidemiology, biostatistics and management of large databases of confidential information.



A girl who has sickle cell disease, and her mother, posing for a photo for the registry. Photo courtesy of Thalassaemia Australia.



A group of people, including children and adults, sitting around a table, looking at a large puzzle that represents the haemoglobinopathy registry. Photo courtesy of Thalassaemia Australia.

www.med.monash.edu



A group of people, including children and adults, sitting around a table, looking at a large puzzle that represents the haemoglobinopathy registry. Photo courtesy of Thalassaemia Australia.

Australian Red Cross BLOOD SERVICE

What are haemoglobinopathies?

- Inherited conditions, caused by changes in the genes that code for parts of the haemoglobin molecule of red blood cells, which carries oxygen in the blood.
- Haemoglobinopathy genes are common in people whose ancestors came from South East Asia, China, the Pacific, Africa, the Middle East, the Indian subcontinent and Southern Europe.
- People with a single altered gene usually have no symptoms and might not be aware that they carry the altered gene - problems generally only occur when a person inherits two altered copies of a gene.

People with haemoglobinopathies make insufficient and/or abnormal haemoglobin (e.g. thalassaemia and sickle cell disease), which can cause a wide variety of problems. They may have very high health care requirements throughout their lives, including needing many blood transfusions, and experience serious complications of the disease and of its treatment.

The Australian Haemoglobinopathy Registry is a national database for collecting medical information from patients with thalassaemia and sickle cell disease, over many years.

MONASH University

Thank You'

Cell and Gene Therapy Group event by Murdoch Childrens Research Institute

On 31 July, 2013 the Cell and Gene Therapy Group at the Murdoch Childrens Research Institute held thank you evening for people that have given to thalassaemia research headed by Dr Jim Vadolas.

On the evening the Cell and Gene Therapy team were available to host tours and showcase the new facilities and give people a behind-the-scenes look at the research laboratories at the Murdoch Childrens Research Institute.

Guests including some very lucky children were also treated to some great entertainment from a harpist, magician Anthony Demasi whilst MC John Orcsik steered presentations from the Murdoch's new Director, Professor Kathryn North AM, Dr. Jim Vadolas and parent/TA committee member, Julie Christopher-Costa.

Over a number of years many people have made significant contributions to thalassaemia research and the following people/groups were acknowledged for their support.

- Eugenia Mitrakis
- Blood Balance
- Thalassaemia Society of New South Wales
- Thalassaemia Australia Inc.
- Lisa Malaxos

We also like to thank the following VIP's for attending the event, and taking the time to learn about the new advances in thalassaemia research and lend their support.

- Ms Bronwyn Halfpenny MP – Member for Thomastown
- Ms Maria Vamvakinou MP – Member for Caldwell.



Spiro's Mates On A Mission

Back in February this year, friends of TA President, Spiro Bombos, the Publican Group Directors Steve Garcia and John Ahern hosted a blood drive at The Wharf Hotel.

59 people pledged to donate blood, and the newly established Melbourne Chapter of Mates on a Mission proposed holding a Gala Ball to raise awareness of inherited red blood cell diseases and fundraise for the Medical Therapy Unit. The unit where the thalassaemia and sickle cell patients in Melbourne receive their blood transfusions.

Fast forward to 1 August this year, where the Mates on a Mission Gala Ball at Rivers Edge, Melbourne was held, the evening was a great success, with over 200 people in attendance. Friends and suppliers of the Publican Group donated their time and

products to the event to ensure that it was a fundraising success for two things: a vein finder and a play therapist for the young patients at the Medical Therapy Unit.

The MC for the evening was Tim Ross, and between juggling entertainers, guest speakers and artists – he did a great job. Helen Kosmarikas shared her personal journey, with Jared and his trip to MTU for blood, whilst Wayne Carey the guest of honour for the night was a true professional and generous with his time.

One lovely initiative of the night was an 'adopt-a-bear' program, where guests

purchased a bear to be given to the children at MTU, to help make their experience at hospital a little nicer, as you can see by the photos included in this article, they have been very much appreciated!

The evening raised \$55,000, but more importantly those present learnt more about inherited red blood disorders.

On behalf of Thalassaemia Australia and the Medical Therapy Unit, we would personally like to thank Steve Ahern, John Garcia and Kylie Moncur and their staff for their efforts in bringing this fabulous night together.

Thank You' to our special community

by Helen Kosmarikas and Spiro Bombos

It takes a community to raise a child. Our community includes a few extra faces, doctors, nurses, medical technicians, researchers, blood donors and also those people who give so generously of their time and money to assist our son Jared.

One member of this community is Jared's friend Paula, with whom he has a beautiful relationship.

Paula is a play therapist, but to us she is more an angel. She accompanies Jared through most of his treatment sessions, which sessions can be a frightening experience for a child. She utilises her powers of distraction, redirection and empowerment to make each session a little bit easier and a little bit more fun. Her skills also benefit the parents and the nurses present, by creating a more comfortable and relaxed environment, where anxiety levels are reduced significantly.

Funds raised by your generosity tonight, and through this event, will make it possible for Paula and other play therapists to be available to help all the children of the Medical Therapy Unit. This will ease the experience for the children and also remove some of the emotion and anxiety the parents feel when bringing their child in for treatment.

Another benefit flowing from the funds raised through this event will be the procurement of a Vein Finder. This will create a positive impact to the cannulation process by making it easier to locate viable veins. Effective veins become more elusive the more treatments one has. So having this machine in the unit will lower the number of attempts that need to be made to find an effective vein. None of us and perhaps this is even more so with little children, enjoy being a human pin cushion.

We are blessed to have a son like Jared, for it has provided us with the opportunity to observe just how kind one person can be to another. But many kind people are required if the dreams of children such as Jared are to come true.

His 30 blood donors to date, and the thousands more who will be required throughout his life. The many generous people who have devoted their time, skills and money to create an event this. The people who dig deep and provide our life

saving unit with valuable funds. To all of these very, very special people we extend our deepest appreciation and gratitude. While words cannot convey adequately the depth of this gratitude, please know that every one of you is in our prayers.

Finally, a very big "thank you" to all the lovely people at "Mates on a Mission" for taking the time to listen to our stories and getting behind us to support our cause. Your involvement has made a huge impact on us personally, on the Thalassaemia Australia and, most importantly, on the patients who are the beneficiaries of all your kindness – our children. We are completely blown away by all you all have done, from the Blood Drive to this spectacular event.

We use these examples of your kindness as valuable lessons for Jared, to enable him to learn that people are kind, that miracles do occur and that the aim of life is giving to those who need your help.

Thank you.

What is play therapy?

A Play Therapist's aim is to work towards the emotional wellbeing and comfort of all ages of children from infants to adolescents, whilst in hospital.

Our main focus is on procedural pain and trauma. We provide children and adolescents with assistance for medical and nursing procedures such as 'needles', cannulas suturing or stitching of wounds, plastering of broken bones etc.

Play Therapists do this by 'teaching or explaining' to parents and patients what will happen during the procedure and then devising ways to make the process as 'comfortable and fear free' as possible.

Play Therapists use a range of techniques of which some might include:

- Medical Therapy (explaining and teaching)

- Physical Positioning
- Distraction Techniques
- Relaxation Methods
- Pain Relief Medications
- Advice to Parents
- Help for siblings and other family members

We then attend the procedure and assist the patient throughout again with the objective of making the process as pain free and comfortable as possible.

We also provide distraction materials to assist with emotional wellbeing such as books, toys and art materials. (subject to funding)



We offer parents and family members support and advice and hope that our presence reassures children and families.





Letter from the Centre Coordinator

Hello everyone and welcome to this nice warm weather. I hope this newsletter finds you all well and getting stuck into some spring cleaning.

Since the last newsletter the Thalassaemia Centre of NSW has been busy with our ongoing awareness presentation programme and attending workshops and meetings as well as doing our Annual Report for Sydney Local Health District (SLHD), our funding body (see some of the results below).

Over the months of June – July I was invited to present to the Greek Orthodox Community, this has seen me travel to four different locations in Sydney to meet four different groups of around 30-50 people.

Although these groups are made up of older community members the presentation was very well received and information was taken away from each attendee to pass on to their children or grandchildren to inform them about Thalassaemia and the work of the Society.

I thank the Greek Orthodox Community for the opportunity to speak to them and beautiful welcome I received each time.

Recently, I was invited to give a "Patient perspective" talk at the Clinical Review meeting for AIMS NSW Branch in North Ryde.

Attendees were overwhelmed by my talk and come up to me at the end of the meeting to thank me. It made it clear to me that it is very enlightening for health professionals whether they be nurses, doctors, scientists or lab workers to come face to face with patients. It makes it real and gives them a better understanding of the condition that they may be working with.

In early July this year, I attended the Health Consumer Advocacy Workshop with Sarah and Maria from TA.

This year the workshop was held at the Vibe Hotel in North Sydney over the weekend, again another great team building networking two days with a fun social dinner at the beautiful Luna Park

on the Saturday night. It was fantastic to catch up with existing and familiar consumer representatives and to meet and welcome new comers to the group.

Topics discussed during this meeting were issues that we could all relate to and ones that were important to the individual organisations.

The varied agenda addressed topics including fundraising, risk management, Health Technology Assessment (HTA)/Pharmaceutical Benefits Scheme (PBS) processes for small patient populations, and identifying common agendas for health consumer organisations.

Annual Report

As a result of our in depth Annual Report to SLHD I can share with you that there has been a rise of 2,675 tests conducted for the Thalassaemia trait in NSW from 2011/12 to 2012/13.

These tests relate to the investigations charged to Medicare. It is good to see that testing is on the rise, this is a confirmation that awareness is working amongst the community. The number and type of health promotion/education activities and estimate of numbers reached over the 12 months were; 13 information/presentation sessions, number of participants 975 in total and 6 Community awareness stands at hospital stands reaching out to approximately 420 people.

Advocacy and Support

In terms of advocacy and support offered by the Society, in the last 12 months the Thalassaemia Society of NSW has distributed 11 syringe driver pumps to Thalassaemia, Sickle Cell or related haemoglobinopathy patients around NSW. Each and every pump issued was received with gratitude and appreciation. This is fantastic work from the Thalassaemia Society of NSW and

only with the support and donations we receive can we continue to support patients in this manner, so thank you to all who have given their support.

Research

Please note that although the Society continues to support research projects into finding a cure for Thalassaemia, it also supports new advances in treatment and promoting the continued wellbeing of existing patients, as well as providing equipment and support for our treatment centres.

If you would like a copy of our Annual Report, please contact the thalassaemia centre.

Lastly, I would like to tell you all that I am very excited to have received sponsorship to attend the 15th Thalassaemia International Conference for patients and parents this year in Abu Dhabi from Novartis Oncology and the Thalassaemia International Federation. The conference takes place on the 20-23 October 2013.

I have also been lucky enough to have been invited to present at the patients and parent session on day 3 of the conference. My talk is about 'A Patient's Experience and Perspective in the Emergency Room'.

I look forward to attending the conference to meet patients and health professionals from all around the world and will endeavour to come back full of information, stories and experiences to share with you all on my return.

Enjoy reading the newsletter and please come to me with any feedback or questions you may have.

Until next time.

Nancy Lucich
Centre Coordinator



2013 Thalassaemia Society of NSW committee of management

Thalassaemia Society of NSW Information Session and AGM

It was great to see many patients, parents and members come along to support the Society once again at our AGM.

Thank you to the guest speakers Dr Jim Vadolas who gave an update on the research he and his team are currently undertaking.

Dr Vasili Berdoukas for giving updates on Thalassaemia and chelation around the world and Natalie Maier with the exciting news and update on the new treatment centre that is being built at the Prince of Wales Hospital, for all haematology and oncology patients, estimated to be completed in 2016. Natalie also was able to unveil and reveal the name of the new centre, being 'The Bright Alliance'. In the future, our patients can refer that they are being treated at the Bright! A very new, modern and state of the art centre.

Following the information session the Society carried on they there AGM and the election of the new Executive Committee.

I would like to congratulate the new Committee for 2013-14 and wish them all the best of luck as they move forward with projects, fundraising and awareness.

I would also like to take this opportunity to thank the Committee of 2012-13 and commend them on all their hard work!

A note to Prince of Wales Patients...

We are currently trying to extend the service provided in the outpatient clinic at Prince of Wales Hospital (POWH) for a seven day period (currently Monday – Saturday).

In order to achieve funding and support from the Hospital for increased accessibility, the Haematology department needs to provide evidence that this service is needed and that there will be sufficient utilisation. This will require an increase in the efficiency of the department to allow for greater numbers of haematology patients to be treated, without increasing staff numbers.

If patients are attending late it results in an overlap of appointments, and creates an inefficient system. Therefore strict adherence to allocated appointment times is essential for the unit to function to its capacity. I ask that you might take this into consideration and ensure that appointment times are adhered to, as a Sunday service would be of great benefit to many Thalassaemia patients.

Kind regards

Kristen Brown
CNC

AN ARTICLE FROM THE COUNSELLOR



What is depression?

According to the National Institute of Mental Health, major depressive disorder is characterized by a combination of symptoms that interfere with a person's ability to work, sleep, study, eat, and enjoy once-pleasurable activities.

Sadness or downswings in mood are normal reactions to life's struggles, setbacks, and disappointments.

Many people use the word "depression" to explain these kinds of feelings, but depression is much more than just sadness. Some people describe depression as 'living in a black hole' or having a feeling of impending doom. However, some depressed people don't feel sad at all – they may feel lifeless, empty, and apathetic.

Whatever the symptoms, depression is different from normal sadness in that it engulfs your day-to-day life, interfering with your ability to work, study, eat, sleep, and have a normal life. The feelings of helplessness, hopelessness, and worthlessness are intense and unrelenting, with little, if any, relief.

Are you depressed?

If you identify with several of the following signs and symptoms, and they persist for more than 6 months, you may be suffering from depression.

- Not sleeping or sleeping too much
- Not concentrating or finding previously easy tasks have become difficult
- Feeling of hopeless and helpless
- Excessive fatigue
- Reacting aggressively and having constant negative thoughts
- Lost your appetite or you can't stop eating
- Irritable, short-tempered, aggressive and angry

- Consuming more alcohol than normal or engaging in other reckless behavior
- Have thoughts that life is not worth living
- Becoming over sensitive
- Becoming anti-social

The faces of depression

Depression often looks different in men and women, and in young people and older adults. An awareness of these differences helps ensure that the problem is recognized and treated.

Depression in men

Depression is a loaded word in our culture. Many associate it, however wrongly, with a sign of weakness and excessive

emotion. This is especially true with men. Depressed men are less likely than women to acknowledge feelings of hopelessness. Instead, they tend to complain about fatigue, irritability, sleep problems, and loss of interest in work and hobbies.

Other signs and symptoms of depression in men include anger, aggression, violence, reckless behavior, and substance abuse. Even though depression rates for women are twice as high as those in men, men are a higher suicide risk, especially older men.

Depression in women

Rates of depression in women are twice as high as they are in men. This is due in part to hormonal factors, particularly when it comes to premenstrual syndrome (PMS), premenstrual dysphoric disorder (PMDD), postpartum depression, and perimenopausal depression.

As for signs and symptoms, women are more likely than men to experience pronounced feelings of guilt, sleep excessively, overeat, and gain weight. Women are also more likely to suffer from seasonal affective disorder.

Depression in teens

While some depressed teens appear sad, others do not. In fact, irritability – rather than depression – is frequently the predominant symptom in depressed adolescents and teens. A depressed teenager may be hostile, grumpy, or easily lose his or her temper. Unexplained aches and pains are also common symptoms of depression in young people.

Left untreated, teen depression can lead to problems at home and school, drug abuse, violence or suicide. But, on the positive side, with help, teenage depression is highly treatable.

Depression in older adults

The difficult changes that many older adults face – such as bereavement, loss of independence, and health problems – can lead to depression, especially in those without a strong support system. However, depression is not a normal part of aging.

Older adults tend to complain more about the physical rather than the emotional signs and symptoms of depression, and so the problem often goes unrecognized.

Depression in older adults is associated with poor health, a high mortality rate, and an increased risk of suicide, so diagnosis and treatment are extremely important.

Types of depression

There are a few types of depression which have unique symptoms, causes, and effects. Knowing the type of depression can help manage the symptoms more effectively.

Major depression

According to DSM IV, major depression is sometimes called major depressive disorder, clinical depression, unipolar depression or simply depression.

It involves low mood and/or loss of interest and pleasure in usual activities, as well as other symptoms such as feeling tired all the time, sick and run down, headaches and muscle pains, sleeping problems, loss or change of appetite, significant weight loss or gain. Symptoms also include feeling overwhelmed, guilty, irritable, frustrated, lacking confidence, unhappy, indecisive, disappointed and sad.

The symptoms are experienced most days and last for at least two weeks. The symptoms interfere with all areas of a person's life, including work and social relationships. Depression can be described as mild, moderate or severe.

Dysthymia (recurrent, mild depression)

Dysthymia is a type of chronic "low-grade" depression. More days than not, you feel mildly or moderately depressed, although you may have brief periods of normal mood.

The symptoms of dysthymia are not as strong as the symptoms of major depression, but they last a long time (at least two years).

These chronic symptoms make it very difficult to live life to the fullest or to remember better times. Some people also experience major depressive episodes on top of dysthymia, a condition known as "double depression."

Amy Elzahaby
Counsellor for the
Thalassaemia Centre NSW



2013-2014 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 Volvoizidis
Theodora Michalopoulos

2013 Committee meeting dates

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

Wednesday 9 October
Wednesday 20 November
Wednesday 18 December



Find us on Facebook
Thalassaemia NSW!



Tiny Teddy cars recipe

Preparation time: 20 mins
Cooking time: 2 mins

Ingredients:

- 100g milk chocolate, melted
- 1 bag Milky Way bars (you will need 24)
- 1 box Tiny Teddy biscuits, honey flavour
- 1 bag Smarties (340g)

Method:

1. Set out a tray or serving plate for the Teddies.
2. Sort the Smarties into colours and cut 12 Smarties in half with a sharp knife to use for steering wheels (keep in mind steering wheel colours need to match with wheel colours).
3. Remove the wrappers from the Milky Way bars.
4. Cut 24 Tiny Teddies in half at the belly button using a sharp knife.
5. Place the melted chocolate into a resealable bag and snip a tiny corner off. Squeeze out a few drops of chocolate to glue 4 Smarties 'wheels' on each car then place on the serving tray.
6. Place a few drops of chocolate on the top of each 'car' and sit the Teddy's on. Place a drop of chocolate on the 'car' in the front of each Teddy and glue on steering wheels.

Notes: These are super-cute! You can just plate them up and serve them as a special treat or use them to top cupcakes or birthday cakes.

This recipe was created by Jennifer Cheung for Kidspot, Australia's best recipe finder.

Enjoy!

Hi Kids!

Pop in the kitchen and try out our new yummy recipe! Get these Tiny Teddies on the grid for your next birthday party and you will be super popular with the little ones. Serve them on their own or use them as cars on racetrack birthday cake!



Q: What did the alien say to the garden?

A: Take me to your weeder.

Q: What season is it when you are on a trampoline?

A: Spring time!

Q: What kind of car does Mickey Mouse's wife drive?

A: A minnie van!

Colour me in!

