Thalassaemia AUSTRALIA

Unifying support and genetics

Thalassaemia Australia Autumn 2011 Volume 3 Issue 9 Quarterly

Welcome

to our Autumn newsletter! In this edition you will see that we have been actively involved in many programs and practices on a local, national and international level that represent the different areas of our ongoing strategic plan. During this time, Thalassaemia Australia and the Thalassaemia Society of New South Wales have also held a number of social functions and honoured significant members of our community and recognised the importance of May 8 International Thalassaemia Week during this time.

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Nepal opens its first transfusion clinic • A tribute to Libby Reid • Thalassaemia Day celebrations

Thalassaemia Australia Inc.

Committee of Management 2011

Mr. Sotirios Katakouzinos – President
Mrs. Maria Triantafillou – Vice President
Mr. George Ambatzidis – Treasurer
Ms. Mary Konstantopoulos – Secretary
Ms. Lien Sam
Mr. John Wilson
Dr. Jim Vadolas
Mrs. Bessy Mougos
Mr. Diva Duvaroren

Committee meeting dates for 2011

All meetings held at: Thalassaemia Centre, 333 Waverley Road, Mt Waverley 3149
7.30pm start

All welcome!

Tuesday 21 June
Tuesday 19 July
Tuesday 16 August
Tuesday 20 September
Tuesday 18 October (proposed AGM)
Tuesday 15 November
Tuesday 13 December (Christmas Dinner)

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Noticeboard

Ensuring access to affordable Medicines in Australia

Thalassaemia Australia and Thalassaemia Society of NSW are currently supporting the Consumer Health Forum's (CHF) campaign against a recent Cabinet decision to defer approval of the listing of several medicines on the Pharmaceutical Benefits Scheme (PBS), despite the Pharmaceutical Benefits Advisory Committee (PBAC) recommending their inclusion, based on their relative clinical and cost-effectiveness and a demonstrated need by Australian consumers.

Through the CHF on-line survey, Thalassaemia Australia and Thalassaemia Society of NSW have raised the concerns of our consumers/members, in respect to patients' right to access medicines when needed and at a fair and reasonable cost.

We therefore insist that Government should reinstate its own independent body to determine which medicines are value for money, cost effective and should be made available to patients through the Pharmaceutical Benefits Scheme rather than allowing Cabinet to make these decisions.

This is of particular importance to our consumers, as one of the drugs that is soon to be considered for PBS listing is Boceprevir a new drug developed by Merck for the treatment of hepatitis C. Trials have shown that treatment with a combination of Boceprevir, ribavirin and pegylated interferon gives a much higher chance of successful treatment in people with hepatitis C genotype 1.

For further information and lend your support, please go to www.chf.org.au and www.hepcvic.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

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.

NOVARTIS

New Thalassaemia Minor Brochure

Thalassaemia Australia has just released a new brochure specifically for those people recently diagnosed as a carrier of Beta Thalassaemia Minor, in response to a number of enquiries received at the Thalassaemia Australia office.

You can get a copy of the brochure from Thalassaemia Australia, or download one from our website: www.thalassaemia.org.au . This brochure was produced in conjunction with Monash Medical Centre – Medical Therapy Unit and is proudly supported by the Lord Mayor's Charitable Foundation.

TA and MTU Pharmacy Survey – Update

Further discussions with pharmacy have taken place regarding the issues outlined in the above mentioned survey, and our issues have been noted. MTU staff and pharmacy are currently working towards a solution and we will notify you all of any changes in the near future.

VITS Language Link

Emergency Auslan interpreting service available now!

SLC VIC and VITS LanguageLink collaborate to provide an Afterhours Emergency Auslan Interpreting Service

If a Deaf person is in an emergency situation i.e. at a hospital; Police station or in an afterhours court; VITS will provide a Professional Level 3 Auslan interpreter. This service operates from 6pm to 8am Monday to Friday and all day Saturday, Sunday and Public Holidays.

This is not a free service; charges apply for this Emergency Service. THIS SERVICE IS FOR EMERGENCIES ONLY.

Should an emergency arise, please contact:
VITS – V: 9280 1955 or SLC VIC – V: 9473 1117/8

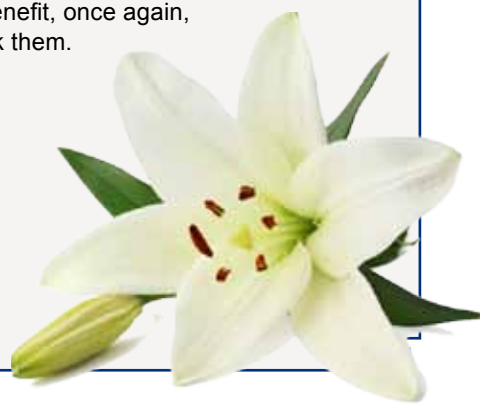
For more information on this arrangement, please contact VITS or SLC.

Memorial Board at Medical Therapy Unit

On 4 April, 2011 Thalassaemia Australia and Medical Therapy Unit team held a small gathering to acknowledge those patients that have passed away over the years.

A Memorial board has been erected in their honour and their families were asked to join us on the occasion.

Many of those listed on the honours board and their families have made significant contributions to the Unit and the thalassaemia community from which we all benefit, once again, we thank them.



An interview with Dr Rachel Codd, School of Medical Sciences, University of Sydney

How did you become aware of β-Thalassemia?

I have a background in chemistry with a long-standing interest in the roles played by iron (and other metals) in biology.

With my recent move to medical sciences at the University of Sydney, I became more aware of β-thalassemia and began to look into treatments for iron overload. Sometimes it can be really helpful to consider a problem with 'fresh eyes', since this can often lead to new ideas.

I found it difficult to imagine what it must be like to manage iron chelation therapy every day. My visit to Thalassemia Australia in September this year – and to Thalassemia NSW in November – where I was able to talk with patients, has been really helpful for me and given me much more insight into the day-to-day reality of living with a hemoglobin disorder. I think it is important for medical researchers to occasionally leave aside their test tubes and beakers and remind themselves that the real issue is with real people!

Could you explain to Thalassemia Australia what you have done?

I came up with the idea to modify Desferal in a way that didn't affect its job of mopping up iron, but in a way that might improve other properties, such as the rate of clearance from the body. Desferal is a good drug in many ways and is non toxic. What I wanted to do was to 'value add' to Desferal, rather than to make a completely new type of drug from scratch.

I began by selecting a compound that was similar to drugs that are used to treat flu – this class of compound, known as an adamantyl group, is non toxic, is well tolerated, and can be taken as a pill. I thought that if I 'tied' together an adamantyl group with Desferal then some of the good properties of the adamantyl group might be transferred to the newly linked adamantyl-Desferal compound. The unique chemical structure of Desferal enabled us to proceed with this strategy.

What do the results look like?

My research team and I are very excited by the early results shown by the new adamantyl-Desferal compounds. Laboratory tests have shown that the new compounds remain just as able to bind iron, compared to Desferal; and, although Desferal is non toxic, the new compounds are about 10-times less toxic than Desferal.

What is particularly exciting is that the new compounds have shown the potential to get inside cells, collect the iron inside the cell, and exit the cell with the iron securely bound by the new compound. Since the new compounds showed such promise in laboratory tests, we moved quickly to see how well one of the new compounds was tolerated by animals. These studies showed that the new compound was well tolerated by mice and was non toxic.

What is the next step and how do you see the future?

The next step is to test whether the adamantyl-Desferal compound effectively removes excess iron in a mouse model of β-thalassemia; and whether the compound can be given by mouth. These types of experiments are very expensive and we are currently looking for financial assistance to enable us to continue the work and to ultimately progress these compounds into clinical trials.

My team and I are very excited by the new adamantyl-Desferal compounds and hope that one day there may be a new, effective and non toxic iron overload drug available for people with β-thalassemia, sickle cell disease, myelodysplastic syndromes, Diamond-Blackfan syndrome and other hemoglobin disorders.

I look forward to a continuing relationship with Thalassemia Australia and Thalassemia NSW and to be able to talk with patients to keep me on track.

For further information, please contact Rachel by email: rachel.codd@sydney.edu.au or phone: (02) 9351 6738.

Self management tools

MEDICINES LIST

IMPORTANT THINGS TO KNOW ABOUT YOUR MEDICINES

To help you get the best results from your medicines, there are important questions you can ask your doctor, pharmacist or health professional including:

Why do I need to take this medicine?
How should my medicine work?
When will my medicine start to work?
How should I take my medicine? With water or food?
When should I take my medicine and for how long?
Do I need to avoid any other medicines, foods or drinks when I am taking this medicine?
What should I do if I miss a dose?
Do I need regular check ups or tests while taking the medicine?
What are the side effects of taking this medicine?
What should I do if a side effect occurs?
How should I store my medicine?

Write down any other questions you may have:

.....

.....

USING YOUR MEDICINES LIST

To get the most from your Medicines List:

Keep it up to date by crossing out any medicines you are no longer using and adding new medicines as you start using them.

Take it with you each time you visit the doctor, pharmacist or health professional, or if you go into hospital.

Keep it with you at all times in case of emergency.

Allergies or previous problems with medicines:

.....

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Emergency contact details:

.....

.....

.....

GET INFORMATION ABOUT YOUR MEDICINES OVER THE PHONE

NPS works with *healthdirect Australia* to provide consumers with information on:
- prescription medicines
- over the counter medicines
- herbal and natural (complementary) medicines

1300 633 424
1300 MEDICINE

Calls to Medicines Line will be answered by a *healthdirect Australia* registered nurse.
Note this is not an emergency service and does not replace advice from your doctor or pharmacist.

Call **1300 MEDICINE** (1300 633 424) from anywhere in Australia for the cost of a local call (excluding mobiles). Service is available Monday to Friday 9am-5pm EST except NSW public holidays.

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KEEP YOUR MEDICINES LIST UP TO DATE

List ALL medicines currently used, including: prescription medicines, over-the-counter medicines, herbal and natural medicines. Medicines come in many forms, including: tablets, liquids, inhalers, drops, patches, creams, suppositories and injections.

MY NAME: ..... **DATE TO HAVE ALL MY MEDICINES REVIEWED:** .....

Name of medicine Active ingredient or brand name	Strength	What is the medicine for?	How much do I use and when?	Special instructions or comments	Date Started	When to stop or review
EXAMPLE: Paracetamol	500mg tablets	Pain from arthritis	2 tablets every 6 hours	THIS LINE IS AN EXAMPLE ONLY. Doctor recommends taking regularly, rather than as needed for pain.	18.09.02	18.12.03

Members of the Nepal Thalassaemia Society outside the new clinic. Children present Wendy Pinker with flowers.

Some inspirational reading...

Some time ago we were introduced to the great work of Wendy Pinker in Nepal. With the support of many of her friends from the UK, she has achieved great things for the International Thalassaemia Community.

Reproduced with thanks from the UKTS

I am writing with the most wonderful and exciting news… the long awaited and desperately needed BLOOD TRANSFUSION CLINIC IN KATHMANDU, NEPAL is now OPEN!! Three years ago my dear friend Durga Pathak (Nepal) and I had a dream…it was what seemed like an impossible dream but never the less a dream that we would pursue until it came true.

We wanted to open a blood transfusion clinic for the very sick thalassaemic children of Nepal. As many of you will already know a thalassaemic child has to have a blood transfusion once every two weeks just to survive… Until now it has been a painful and arduous procedure for each and every child and their family.

In Nepal, blood transfusions are not widely available meaning that most have to travel to Kathmandu just to receive a treatment. There are no trains in Nepal and the roads are long, slow and very mountainous… many patients travel over 12hrs by bus every 2 weeks. Others who are more fortunate have been able to afford the costs of relocating nearer to the capital.

On arrival in Kathmandu the patient and parent check in to Kanthi Children's Hospital in Lazimpat. Kanthi Hospital, like most in Nepal is under equipped, under financed and unimaginably dirty. The stench that hits you on entering the hospital is one that will stay with you forever. The child is admitted to the ward and then the parent has to travel across the capital to the Red Cross Blood Bank to collect a packet of blood.

In the searing heat of the monsoon period, often the blood is off by the time the parent returns to the hospital and the whole process has to start again. It is a long and heart wrenching procedure. Nobody should have to struggle so to help a sick child receive such simple treatment.

After a two-year stay in Nepal I returned to the UK to start my mission. Durga, The Nepal Thalassaemia Society and I had drawn up a financial plan to get our little clinic off the ground. Just £14,000 would be enough to set it up and run it for 2 years offering totally free treatment for every child.

It was much to my amazement that many people already knew of my plan and shortly after my arrival 2 incredible ladies contacted me. Sue Woolston and Ann Brodin. They said that they had heard of my dream and that they were going to help me – I couldn't believe my ears! There was no turning back now. Without them it may never have got off the ground.

Before long garden parties, casino nights and dinner dances were being arranged. Local people came to my home with offerings of personal donations and my very dear friends Alison and Justine Perkins had donations made to my clinic instead of receiving wedding presents!

Later that year I was to meet a wonderful lady called Maureen Donnison who went with 12 of her friends to visit my family in Nepal and were so touched by what they saw they decided to help too. After collecting sponsorship for their treks in the Himalayas and arranging a very successful ABBA night back home in the UK they were able to donate just the amount we needed to secure the £14,000 target… mission accomplished! Now all we had to do was start phase 2.

In December 2009 I returned to Nepal to meet with Durga and the Nepal Thalassaemia Society (NTS) members.

They had no idea that we now had the funds needed to open the clinic and then I told them they were totally shocked and

elated. I will never forget the looks on their faces.

The NTS committee is made up totally of members who have thalassaemic children meaning that everybody is working for the good of their own family. They are an active and enthusiastic team. They now had one of the biggest challenges ahead – to find a suitable building (very close to the Red Cross Blood Bank), furnish and equip it, find a nurse, a doctor and set up the new NTS offices!

After 12 months in the UK while my son had surgery I returned to Nepal at the beginning of February 2011, more than 6 months after the long awaited opening of our life saving Blood Transfusion Clinic. I finally got to see the fruits of all of our work and… it was far and beyond what I ever could have dreamed of.

Early on the morning of 6 February my husband Rishi, son Tall and I got into a taxi and made our way across Kathmandu near to the Red Cross Blood Bank.

We didn't really know where we were going and it was hard to make out where we were with all the dust in the polluted air. The taxi dropped us in the area we were heading to and we walked aimlessly, not really knowing where to look…Then from the corner of my eye I saw it!!!!… In big red letters… "Nepal Thalassaemia Blood Transfusion Clinic".

Goose bumps shot over my body from head to toe. There it was as real as life… my dream… in a little dusty old side street in the heart of the capital of Nepal… Oh my word… whoever in a million years would have thought this would happen!

I opened the gate to find everybody waiting – society members, parents, nurses and most important of all – the children.

It was amazing… a moment in my life I will never ever forget. I was greeted with flowers and dozens of smiles. We went into the building and had a tour around.

First the meeting room, a very simple, clean spacious room with lots of chairs to be used for meetings, resting and private consultations. Then the examination room, again very simple, a room used by the doctor if a child gets sick whilst having a transfusion.

Then the office! Well, it was so grand I think the whole country could be run from there! There was even a computer and printer, all lovingly covered with cloths to protect them from the dust. Then the moment of truth – the transfusion room. Wow, what a wonderful surprise it was. It was the most beautiful, brightly coloured, clean, bright, airy, cosy room you could imagine – I was moved to tears instantly.

We all sat (about 40 of us) and talked about how things were going and how life had changed so much since last the time we all met. The parents talked of how their lives have been made so much easier and the children told stories of how they look forward to coming to Kathmandu for their fortnightly transfusions!!!! It was like a fairy tale.

Previously a transfusion would take all day and possibly the next day. Now the patient's carer just makes one simple phone call to the clinic the day before they are able to come to Kathmandu and Paras (our secretary) calls the blood bank and the blood is prepared for that particular child.

The blood is then collected later that day and stored ready for use the next day. The next day the patient arrives and after a few checks the transfusion begins… and thanks to our wonderful nurse there are no tears to seen or cries to be heard and it's all over in 4 hours. And to top it all, it's totally free of charge.

Cartoons, movies and Nepali music are played all day. It is like a holiday for many of the children who don't have the privilege of a TV or electricity in their own homes. The children have all become friends and it's like a big family all with the same illness. The parents sit and talk and compare stories, worries and concerns.

Amazingly, two of the older children now walk alone to the clinic so their parents are after many years of being tied now free. It really is a miracle to see.

This little clinic has truly changed the lives of each and every child and parent we support and it's all down to YOU… each and every one of you who has made even a single pound in donations or has bought my jewellery or helped at one of our many fund raising events – you are the ones who have made this possible.

Every single penny has come from the UK and it has come from one of you. It has cost just £13,500 to open and run the clinic for 2 years and… we almost have enough for another year!!!! I can't thank you enough for all of your support and I dream that we can continue to raise the funds for the years ahead.

Every penny you donate goes direct to the clinic fund and not a single penny goes for administration because I do it all myself. I thank you for your continued support from the bottom of my heart.

My next mission is to try to raise the funds for all the children to have the next stage of their treatment. Chelation treatment is the removal of excess iron caused by having blood transfusions on a regular basis.

It is essential for the prolonged life of a thalassaemic. At the moment only 10% of our children are receiving this treatment and all are by donation. It costs just £30 per month or £360 per year.

I would like to thank all those who have already sponsored a child for these costs… your love and support has given a new lease of life to an otherwise very sick child.

Thank you with all my heart x

If anyone would like to know more about our clinic or make a donation please call Wendy Pinker on 07836 572 062 or email pinkyland_2000@yahoo.co.uk

Special Note: The oldest thalassaemic in the UK is about 60 years old… the oldest known thalassaemic in Nepal is Paras, he is 23. We want to change these statistics and make a more wonderful world for all the thalassaemia children of Nepal.

You can't change the world… But you can make a difference in your own space.

If any of our members or readers would like to assist Wendy and the clinic in Nepal in anyway, please contact Thalassaemia Australia on 9888 2211 and register your interest.

Community education and advocacy:

TIF Conference – Antalya, Turkey 2011

The 12th International Conference on Thalassaemia and Haemoglobinopathies and the 14th TIF International Conference for Patients and Parents was held between 11-14 May 2011 in Antalya, Turkey.

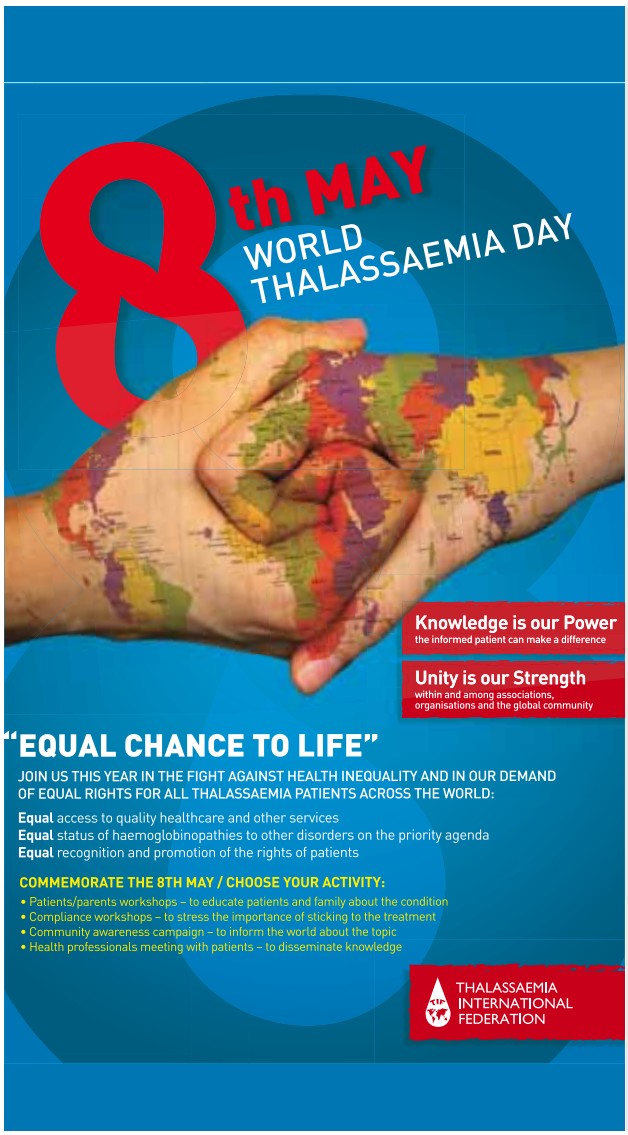
Representatives from Thalassaemia Australia including Maria Kastoras, Sarah Burton and Vice President, Mary Triantafillou were in attendance, along with Maria Aravantinos from the Thalassaemia Society of New South Wales and Teresa Alvaro from the Thalassaemia Association of Western Australia.

The conference program was divided into two main areas: a scientific and parent-patient forum based on the theme – "Haemoglobin disorders in the next decade" Thalassaemias and Sickle Cell Disease, featuring latest scientific and medical research. This conference also provided an opportunity for parents and patients to meet and discuss all areas of their condition in a welcoming environment. Expert panels of specialists were made available to all, to answer any questions.

As in Singapore 2008, Thalassaemia Australia participated in the Parents and Patients Forum in both the round table discussions, and as a guest speaker presenting on the many personal challenges faced by a thalassaemia patient.

From an organisational perspective, TA also continued to build new and existing relations with similar patient support agencies, individuals, specialists and experts from the international community.

The knowledge we have obtained from the experience in Antalya 2011 will be detailed in a separate report, and distributed to all of our members, readers and stakeholders shortly.



8 May – World Thalassaemia Day – "Equal Chance to Life"

World Thalassaemia Day 2011 deals with health inequality as experienced by all of you – the thalassaemia patients and their families.

Patients are the victims of inequality in more ways than other people. Patients struggle each day to overcome the obstacles for quality healthcare and good quality of life, to which they have every right as patients and human beings.

Building on last year's theme, *Knowledge is Power*, this year we take a step further and declare for all to hear that thalassaemia patients deserve an equal chance to happiness and life.

This year we fight for unity, knowledge and equality. This year we encourage thalassaemia patients worldwide to fight for their basic human rights and their rights as patients, for their voice to be heard, and their struggle to be acknowledged by their governments.

2011 must be a year of positive changes, of empowerment and gaining new ground for every patient with thalassaemia across the world. We demand on behalf of all thalassaemia patients:

- **Equal** access to quality healthcare and other services
- **Equal** status of haemoglobinopathies to other disorders on the priority agenda
- **Equal** recognition and promotion of the rights of patients

Adopt and embrace this year's theme. Let us work together to fight against health inequality experienced by thalassaemia patients all around the world.

Mr Panos Englezos
President of the Thalassaemia International Federation

Health and Medical Research Funding in Australia

Recently in the media there have been some disturbing reports that the federal government would cut up to $400 million over three years from the National Health and Medical Research Council budget. In response to this, Thalassaemia Australia on behalf of its members joined Research Australia's petition in support of funding for medical research. See the following:

Just prior to Tuesday's budget, Research Australia advised government that 14,500 Australians had joined our petition in support of funding for medical research.

In the Budget, the government announced funding for the NHMRC will increase from $715 million to $746 million in 2011-2012.

By adding your voice, you have helped secure much needed research funding! Find out more from our "Budget at a Glance" on www.researchaustralia.org

Kind regards,
Rebecca James
Chief Executive – Research Australia

Thank you for supporting our Petition!

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rebecca.james@researchaustralia.org
W: www.researchaustralia.org

Libby's Farewell

It was with great pleasure and a touch of sadness that Thalassaemia Australia held a function in honour of Nurse Unit Manager – Libby Reid's retirement from nursing and the Medical Therapy Unit at the Athenian Tavern in Box Hill on 20 March, 2011.

With over 120 guests in attendance including Libby's family, patients, parents and work colleagues we all enjoyed a great day of festivities, to celebrate and send Libby into a happy retirement.

A number of gifts were given to Libby, representing members of our group, both young and old, parents and mentors, and a short presentation highlighted Libby's many achievements.

TA would like to thank everyone for their contribution in making the day a success and giving Libby a celebration she well and truly deserved.

My Dear Friends,

I can't believe that it is now two months since we celebrated together my retirement at Athenia Tavern. As I wrote to Sotirios at the time, I was overwhelmed by the 'amazing' tribute paid to me on Saturday 20th March. To be surrounded by so many of you that I have known over many years – was wonderful. It was lovely to see so many beautiful families – all happy and enjoying themselves – a very meaningful finale for me.

Thank you all for your generous gifts, flowers, your lovely cards – often with a little advice for me on my retirement – much appreciated. I think of you all often and I do miss being part of your lives and always enjoy hearing your news.

I was particularly thrilled to have Dr. Rae Matthews present for my Special Day – it was she who introduced me in the early days of my career with Thalassaemia. It was a time of enormous change as she implemented all the new approaches to lifesaving management and attitudes to Thalassaemia.

My journey in my career continued with Prof Don Bowden, with whom I have worked for more than 20 years – He has given me amazing opportunities to participate in and innovate management. He was always encouraging and supportive.

We have certainly been very privileged to have had such wonderful physicians to be head of unit. Prof as you know is held in very high esteem by his colleagues and receives queries for advice from all over Australia and Internationally. Thank you Prof for everything you have done for me over the years.

It was lovely to have Rhonda and Sooi with us – we have shared so much over the years, and I really appreciated their support. The Speech Makers: Sotirios, Josie, Nick, Eugie and James – Thank you all for your gracious comments – well done!

I was thrilled to receive the magnificent gold watch – I wear it with great pride – and reflect on a lifetime of memories. Thank you for all your confidence in my management and the very tangible appreciation.

Last but not least, to Sarah and Maria what amazing event organizers – Thank you for all your hard work, thank you for inviting my children and grand-children to share my special day.

To you all, my love, keep up the good work, be very proud of your achievements.

Best wishes always, love Libby

A tribute to *Libby*

Over the years, retiring Nurse Unit Manager Libby Reid has been many things, to many people and is well recognised for her professionalism, grace and wisdom in her work with thalassaemia, sickle cell and other haemoglobinopathies. Please enjoy the following snap shot of Libby's professional life, as was submitted by Thalassaemia Australia for Libby Reid's nomination for the HESTA 2010 Nurse of the Year Awards.

Sister Libby Reid's position with the Medical Therapy Unit, Southern Health, involves the clinical management of more than 160 patients with Thalassaemia, Sickle Cell Disease and related haemoglobinopathies in collaboration with the Unit Consultant, Professor Don Bowden, as well as the management of specialist nurses and tuition of postgraduate and undergraduate nurses.

Libby is a registered general nurse and midwife, and a member of the Australian Confederation of Paediatric and Child Health Nurses. She has extensive clinical experience in paediatric nursing, including Unit manager at the Queen Victoria Hospital, neonatal, casualty, burns and midwifery units at Royal Children's Hospital in Melbourne.

Libby continually offers treatment advice, psycho/social support, grief and loss counselling, individualised treatment plans, and peer support for a medically complex group of people. Libby performs this role with ease and determination that has improved the level of care and outcomes for patients.

In 2006 significant changes in the treatment of thalassaemia took place with the introduction of oral iron chelation. Libby successfully introduced and integrated this new treatment regime to all patients in the unit. Libby is currently coordinating the ICL 670 clinical and has briefed nurses and treating doctors from around Australia at the Transfusion Nurses' Advisory Board Meeting.

The medical therapy unit is unique in that it provides a 'whole of life' service whereby Libby Reid has played an active part for all our patients.

Libby has been involved in the lives of many patients and their families for many years. She is always willing to assist others in their understanding of these blood conditions and speak on the importance of adherence to life-saving medical treatment at local and international conferences.

For many of her patients, Libby is considered 'a part of their family'. Her kindness, compassion and understanding, and her personal yet professional approach has resulted in Libby being invited to many weddings, birthdays and other celebrations.

Libby gives freely of her own time, and acknowledges her part in her patient's and their families' lives.

From Thalassaemia Australia's perspective, Libby Reid reflects the aims of our organisation, to support and medically treat our patients to the best of her ability, ensuring improving outcomes for patients; to raise the awareness of blood conditions throughout Australia and the world; to advocate on behalf of patients and to support those within this unique community.

We have no hesitation at all in recommending Libby Reid for the Hesta Nurse of the Year for 2010.

Committee of Management 2011

Martha Gerolemou – President
Marianne Dimitrakas – Vice President
Rosa Dimitrakas – Chairperson
Maria Aravantinos – Treasurer
Theodora Michalopoulos – Assistant Treasurer
Penny Volvozidis – Secretary
MD Faisal – Assistant Secretary
Maria Santos – Press Secretary

Committee Members
Lela Dallas
Nicholas Kotrotsos
Jimmy Vrontzos
Glenda Hughes
Aris Volvozidis

Committee meeting dates for 2011

All meetings held at: Thalassaemia Centre, Level 7, King George V Building Missenden Road, Camperdown 2050. Meetings start at 7pm.

All welcome to attend and join!

Wednesday 1 June
Wednesday 6 July
Wednesday 3 August
Wednesday 7 September
Wednesday 5 October
Wednesday 2 November
Wednesday 7 December

Visit...

www.bloodbuddies.com.au

An informative new website that answers questions regarding blood and blood products and covers donating blood.

Letter from the Centre Coordinator

I hope that you are all trying to stay warm in this cold start to winter – I know I had to get my winter woollies out early this year!!

I am excited to share with you all our celebrations and information stands went well through the month of May to celebrate International Thalassaemia Day!

On May 6 the Thalassaemia Society of NSW held an event to celebrate International Thalassaemia Day and raise awareness about the genetic disorder. The theme was "Equal Chance to Life". The night saw 50 people come together to celebrate at Vivo Cafe' in George Street, Sydney.

A big thank you to Angela and Con from Vivo who provided a fantastic venue for our celebration along with great food, lots to drink and a live jazz band to enjoy!

We had two wonderful guest speakers – Clare Harris from Sydney IVF and Joe Patkes from Australian Red Cross Blood Service.

Thank you to the following sponsors for your support and donation for the nights lucky door prizes: Seafood @ Hornsby, Clairy Fakinos and Family, Zena Thomas & Lela Dallas.

A special thank you also to sponsors Sydney IVF and MBE Business Service Centres for your support and donations towards the event.

The night was fantastic! Lots of fun had by all who attended and we endeavour to do the same again next year to celebrate.

I have been busy raising awareness on Thalassaemia and the importance of blood donation to many organisations and schools throughout Sydney and I wish to thank the Australian Red Cross Blood Service for giving me this opportunity.

The Society and I have also been busy with several community awareness stands, the interest and response we receive when we are out there is amazing, it is great to be out spreading the work and educating the public.

I will continue to present and educate about something I am so passionate about so I hope to see you out there at some stage! Remember to contact me with any suggestions or presentation requests.

Stay warm and healthy!

Nancy Lucich
Centre Coordinator

Greek Festival 26 and 27 March 2011

The weather couldn't keep the crowds away, people came from near and far to be a part of the Greek Festival and be proud of our heritage.

The Thalassaemia Society of NSW held an awareness stall to educate the community in Thalassaemia. Our stall was filled with brochures, fact sheets and friendly Committee members who gave up their weekend to spread the word. We also distributed Red and White ribbons to members of the community, who wore these proudly to support Thalassaemia.

It was overwhelming the amount of interested people that came to visit the Thalassaemia Society of NSW awareness stall and we thank them for attending.

A huge thank you goes to Dimi Lafazanos – the Greek Festival Manager – who assisted us along the way. A big thank you to the Greek Festival organising committee for providing the stall for us to carry out our education in the community. We hope to be part of all the future events.

I was proud to be the President of the Thalassaemia Society of NSW and part of such a great community campaign. Keep up the great work and spread the word to give people with Thalassaemia an "Equal chance to LIFE".

Australian Red Cross Blood Service Type for Donors and Patients

A useful chart from the Australian Red Cross Blood Service Blood Type for Donors and Patients, showing who can donate and receive blood from each other.

Donor's Blood Type

Patient's Blood Type	O-	O+	B-	B+	A-	A+	AB-	AB+
AB+	✓	✓	✓	✓	✓	✓	✓	✓
AB-	✓		✓		✓		✓	
A+	✓	✓			✓	✓		
A-	✓				✓			
B+	✓	✓	✓	✓				
B-	✓		✓					
O+	✓	✓						
O-	✓							

Home blood collection service

for Prince of Wales Hospital Patients

SEALS Pathology is now running a home collection service for patients of Prince of Wales Hospital. This will eliminate patients having to go into pathology for their pre transfusion blood tests/ cross match.

The service covers areas as far North as Bondi, far South as Cronulla and western suburbs of Menai, Peakhurst, Bexley and Tempe.

To find out if your area is in the boundary of the service call the Hotline number below, or speak to your transfusion nurse next time you are in for your treatment.

If you are in the service area and would like to arrange for home collection please call the hotline.

Bookings Hotline: 1300 788 944

Preferably please give 48 hours notice.

Giving you peace of mind for a healthy baby

Sydney IVF is pleased to announce their support of the 'PGD Assistance Program'. The Program has been created by generous donations to provide financial assistance to families in the community who would otherwise be unable to afford Preimplantation Genetic Diagnosis (PGD).

PGD is an advanced screening technique that can determine whether an embryo has a genetic condition, common examples include cystic fibrosis, Huntington disease or muscular dystrophy.

Tests for over 160 different genetic conditions have been developed to date. More tests are being developed as required. PGD is most commonly used by couples who are aware of the possibility that their children risk inheriting a serious genetic condition.

The PGD Assistance Program provides qualifying couples access to Sydney IVF's PGD services – either at no out-of-pocket cost for PGD treatment expenses, or for a co-contribution, depending on their financial circumstances.

Both levels of assistance provide PGD treatment for two cycles and two additional cycles to use any tested but frozen, stored embryos within 12 months – or longer, for further pregnancies if a baby has resulted.

Couples can be considered for the PGD Assistance Program by submitting a completed application form providing information about their income, expenses and medical history, along with a supporting letter from their healthcare professional familiar with their genetic condition.

A selection committee assesses each application based on a set of eligibility criteria. This committee is independent and comprised of members of the genetic field and the broader community. The selection committee meets throughout the year with closing dates available on this site.

The PGD Assistance Program helps support families in our community whose lives are affected by a genetic disease and the associated financial hardship to have the opportunity to consider PGD treatment in their quest to have a healthy baby.

For more information on how to apply, visit www.pgdassistance.com or call 02 8484 7600.

Fibroscan Technology:

To aid in assessment of Patients with Viral Hepatitis

The Royal Prince Alfred Hospital (RPA) and Concord Repatriation General Hospital both now have considerable experience in Fibroscan (Transient Elastography).

Fibroscan is a fast, non-invasive, painless procedure used to assess liver fibrosis in patients with chronic hepatitis C or B. Given the high prevalence of hepatitis C and B the hepatologists believe it will be beneficial to offer more people with viral hepatitis the opportunity to undergo this assessment.

A Fibroscan result can assist clinicians and patients make treatment decisions. There are now excellent treatments for hep B and C. Effective antiviral treatment can prevent severe complications of viral hepatitis including liver failure and hepatocellular carcinoma (HCC).

If you are interested in having this test you need to get a referral from your doctor and with one of the doctors listed below and make an appointment.

RPAH Liver Clinic Bookings:
Phone: 95157268
Geoff McCaughan, David Koorey, Simone Strasser, Nick Shackel, David Bowen, Gok Paven, Paul Haber

Concord Hospital Liver Clinic Bookings:
Phone: 9767 5570
Alice Lee, Meng Ngu, Gordon Park, Sarah Walker, Nemes Sandanayake

If you have a genetic disorder in your family and are thinking of having children, you're invited to hear about PGD

If you or your partner have a genetic disorder yourselves or know of a genetic disorder in your family, and you want to have children, you may be interested in hearing about Preimplantation Genetic Diagnosis or PGD.

PGD is the process of screening embryos for genetic disorders. Once screened, healthy embryos can be implanted with the aim of producing a healthy pregnancy and baby.

Because PGD involves genetic screening of the embryo, at Day 5 or 6 of development, it is done as part of an IVF cycle. While IVF is usually used to help couples with fertility problems, it is also used with PGD to help people with genetic disorders in their family to have healthy children.

Sydney IVF is the most successful PGD clinic in the world, offering testing for over 170 chromosome and genetic conditions, with the ability to develop new tests as required. We were the first clinic worldwide to introduce PGD successfully for Day 5 embryos.

To find out more about IVF and PGD and how they may be able to help you have a healthy baby, come along to our free information evening.

You can hear about PGD from top medical professionals, then enjoy some light refreshments and talk through any questions you have.

The evening is at 7pm, July 19th at Rydges Parramatta, 116 James Ruse Drive, Rosehill 2142. Register now at sydneyivf.com/events or call 02 9229 6439 for more information. Places are limited so register or call today.

SYDNEY IVF
no better chance, no greater care

Month of May International Thalassaemia Day Celebrations...

The month of May was full of celebrations with a Cocktail Party at Cafe Vivo, George Street Sydney and raising the profile of Thalassaemia with community awareness stands at the Royal Prince Alfred Hospital, Westmead Private Hospital and Prince of Wales Hospital, Sydney.

World Rare Disease Day Event

Recently a cocktail party hosted by Velo Cardio Facial Syndrome Foundation of NSW, was held to bring organisations and community groups of rare diseases together to raise awareness, form networks and share stories amongst each other whilst celebrating the theme of "Rare But Equal".

This was a great night, Tim Maddren from Hi 5 was the MC for the event. Tim was fantastic, a great supporter and he was very proud to be part of the event.

Guest speakers on the night were Yvonne Zurynski from the Australian Paediatric Surveillance Unit and Laurie Taylor from AGSA.

The night was a success as stories and experiences were exchanged, connections aand friendships were made.

Thank you to Maria Kamper and Velo Cardio Facial Syndrome Foundation for organising a great night and also for the mention in the speech!

Hot Banana Chocolate Drink

Makes: 4

Ingredients

- 1 litre full fat or skim milk
- 2 large ripe bananas
- 50g plain chocolate
- Marshmellows

Method

1. Put the milk and chocolate in a large saucepan and slowly bring to the boil melting the chocolate.
2. Remove from the heat.
3. Peel and chop the bananas into small slices.
4. Add the banana to the chocolate milk. Blend thoroughly using a hand held electric blender.
5. Pour into 4 mugs. Add Marshmellows.
6. Serve when cool enough to drink.

Please note: when in the kitchen, children should always be supervised by an adult.

Hi Kids!

Have fun with our dot-to-dot and stay warm and cosy this Autumn and Winter with our yummy hot banana chocolate drink recipe!

Q: Why are bananas never lonely?

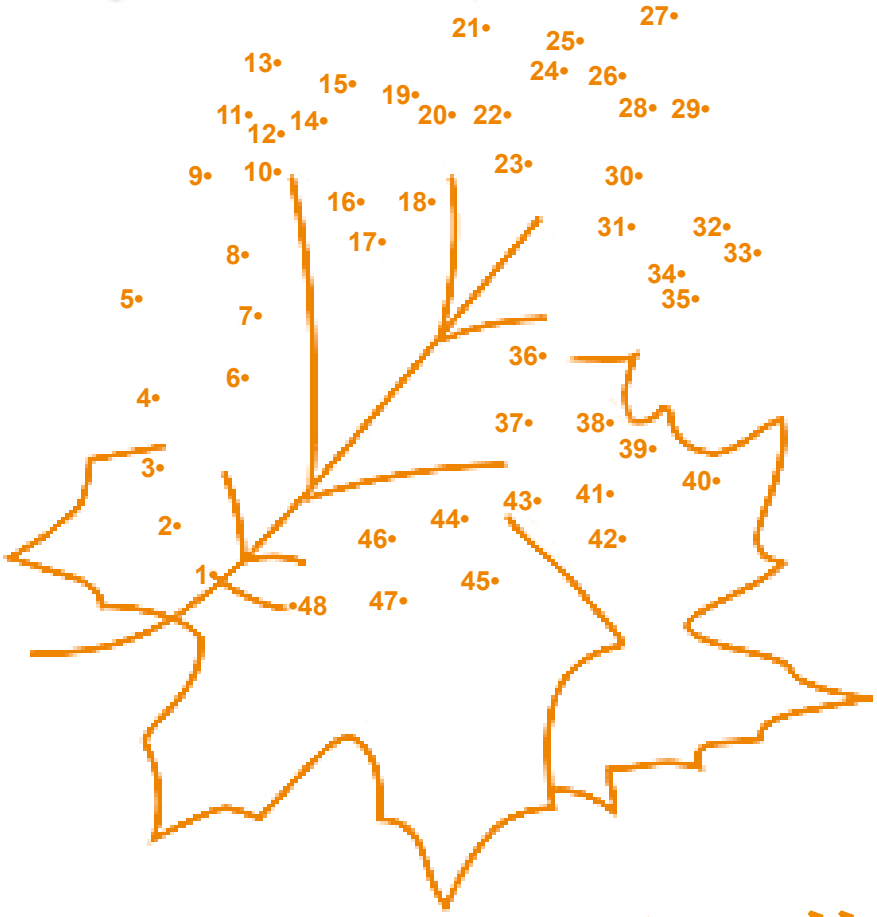
A: Because they hang around in bunches!

Q: Why did the banana go to the doctor?

A. Because it wasn't peeling well!

Q: Why did the computer sneeze?

A: It had a virus!



DOT-TO-DOT FUN!!