

Thalassaemia AUSTRALIA

Unifying support and genetics

Thalassaemia Australia Spring 2010 Volume 2 Issue 7

Quarterly



Welcome! With the start of a new season upon us, we celebrate in this edition of the contributions from our interstate and international partners, with news updates for all members of the thalassaemia community to read and be inspired by. As a response to some of the queries received at the TA office, we have enclosed with your newsletter a copy of the Australian Government 'A guide to Centrelink Concession Cards' for your reference.

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Make every drop of blood count for Thalassaemia Australia

As you know, we are keen supporters of the Australian Red Cross Blood Service (ARCBS) and the great work they do. In order to support them further, and to receive some well deserved recognition for our personally referred blood donors, we draw your attention to the following information regarding the updated ARCBS Club Red program and how you and your friends can be a part of this exciting program.

Club Red is now run through the ARCBS website www.donateblood.com.au/clubred

All donors that donate on behalf of Thalassaemia Australia need to visit this web site and register their details. This will then add any donations made by that individual to the overall Thalassaemia Australia tally for 2010.

To do this members need to follow the following steps;

- Visit www.donateblood.com.au/clubred
- Click **Join a Club Red group online**
- Complete the registration form
- and most importantly in the 'Organisation or Group' field enter **Thalassaemia Australia**

Once completed all donations made by that donor will be automatically counted towards the groups total for 2010.



Members from the Thalassaemia Society of NSW and donors throughout the rest of Australia are also encouraged to book under the 'Thalassaemia Australia' name, so that we can obtain an Australian-wide perspective of our efforts and watch our tally GROW!

Thalassaemia Australia Inc.



Committee of Management 2010

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

Committee meeting dates for 2010

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

All welcome!

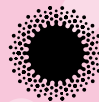
Tuesday 14 September 2010
Tuesday 19 October 2010

Thursday 21 October 2010 – TA AGM

Tuesday 16 November 2010
Tuesday 14 December 2010

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Noticeboard



the women's
the royal women's hospital

Women's Health Information Centre (WHIC) at the Women's

Free, confidential, state-wide health service. We offer information, individualised support and referral options on a wide range of women's health issues.

Telephone, walk-in or email

Our experienced women's health nurses and midwives are available by telephone or email; or come into our centre for one-on-one support and advice.

Information also available in a range of languages other than English. Interpreters available.

Telephone

Health Information Line **(03) 8345 3045**

Regional/Rural Callers **1800 442 007**

Library Line **(03) 8345 3035**

Email whic@thewomens.org.au

Website www.thewomens.org.au

What we offer

- Information on any women's health issue in English and other community languages.
- Help with using the internet on our public access computers to search for health information.
- Pregnancy testing and screening for Chlamydia
- Access to our specialist library to browse or borrow a book or DVD.

How to find us

The WHIC is in the front foyer of the Royal Women's Hospital, to the left of the main entrance.

Open 9.00am to 5.00pm
Monday to Friday.

The Royal Women's Hospital is on the corner of Flemington Road and Grattan Street in Parkville.

Postal address

Women's Health Information Centre
The Royal Women's Hospital
Locked Bag 300
Parkville Vic 3052

Stock No 300760 D09-116 October 2009

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.



Donating blood in the suburbs of Melbourne

Thalassaemia Australia has continued its role in thanking blood donors with visits to the Melbourne Metropolitan Blood Collection Sites of Australian Red Cross Blood Service (ARCBS) throughout the winter months.

These thank you visits give TA staff and work-experience students the opportunity to liaise with ARCBS staff, volunteers and members of the general public to tell them a little about their 'thalassaemia' story and encourage further donations.

This year, TA is also giving formal educational presentations to ARCBS staff at the mobile units to increase their understanding of living with thalassaemia and the importance of each blood donation to our community.

According to the ARCBS, in Australia we need over 26,000 blood donations every week, so it is vital that we all do our bit for them.

If you know of any workplace, school or business that is interested in donating blood, please contact ARCBS on 131 495. Please let us know too, so that we can be there to hold a few hands!

In June, after some insightful discussions with TA staff, Andrew Saunders, Senior Business Manager, Medical Division – Sigma Pharmaceuticals Ltd (inc. Orphan Australia & Sigma Medical), decided to donate blood at the Dandenong Mobile Unit and we made sure we were there to support his great efforts. It is always encouraging to see our corporate sponsors personally contributing to our cause with this very precious gift. Thank you Andrew!

Thalassaemia Australia Inc.

Annual General Meeting and Specialist Panel

21 October, 2010
6.30pm for a 7.00pm start

Murdoch Childrens Research Institute
Royal Children's Hospital
10th Floor
Flemington Road, Parkville

Thank you to our supporters

Thalassaemia Australia would like to sincerely thank the following organisations and individuals for their kind donations to support the work of Thalassaemia Australia.

Emmaus College \$50.00

AHEPA Chapter Athena No. 2. \$1,000

Victorian University Secondary College
\$50.00

D. Nickolakopoulos \$20.00

St. Alloysius College \$50.00

Community education and advocacy: On the road again... education update



Thalassaemia Australia's (TA) community education/advocacy program has continued throughout the winter months and has seen us travelling far and wide, with trips to our rural Victoria such as Rochester and Kyabram.

We have visited a number of metropolitan secondary schools including St. John's Regional College, Nazareth College, Kew Secondary College and Werribee Secondary College. Being invited to these schools gives us the opportunity to pass on our valuable message about genetics and thalassaemia.

TA staff attended the following workshops and meetings:

- TA/MTU Meeting
- Victorian Multicultural Community Consultation
- Consumer Health Forum
- Victorian Multicultural – Culturally and Linguistically Diverse workshop
- CIA Special Interest Group – Healthwise workshop/meeting
- Better Health Channel – Thank you celebration

TA is currently working consistently with the Community Based Placement Students from Monash University and the Master of Genetics Counselling Community Program. At this stage, students have met with staff at Medical Therapy Unit; gone with TA staff to Donor Thank You Sessions at ARCBS mobile units throughout Melbourne and accompanied staff at school presentations.

Participating in these meetings/excursions enables the students to obtain a well-rounded understanding of the services provided by TA. The students have additionally been working on their individual projects for TA. Furthermore, students from Caulfield Grammar School and Avila College have also been participating in community service with our organisation.

For those members/carers that are based in Victoria, please see the article on the next page for details about the Victorian Government's new Carer's Card that was launched in July 2010. This card offers eligible carer's considerable discounts on goods and services.





It's time Carers were recognised for all the work they do

When the Victorian Government Carer Card launches in 2010, all eligible unpaid primary carers will enjoy a wide range of discounts, incentives, specials and deals created especially for carers.

The Victorian Government is very pleased to introduce the Victorian Carer Card program. The Carer Card is a new initiative that has been created to recognise the invaluable social and economic contribution of carers.

The Carer Card is your ticket to a whole range of fantastic products, goods and services, and experiences. It's just one way that Victoria is showing Carers that we care.

Carers will enjoy discounts on food and drink, travel and entertainment, automotive supplies, garden supplies, homewares, clothing, recreation and more.

Carers will also be able to enjoy free public transport every Sunday with a free Sunday Pass, plus two return off-peak travel vouchers for travel anywhere within Victoria.

Cardholders can also enjoy discounted entries to many State Government venues such as zoos, museums and various festivals.

To be eligible to receive a Carer Card you will need to be a resident of Victoria and an unpaid primary carer of a person with a disability, a severe or chronic medical condition, a mental

illness or someone who is frail aged or in need of palliative care.

Foster and kinship carers are also eligible to apply for a Carer Card.

The Victorian Government Carer Card program has been created to provide more recognition, support and understanding of carers.

For more information about this program call 1800 901 958 or visit www.carercard.vic.gov.au to download an application form.



In brief

Using the car park at Southern Health For Medical Therapy Unit patients

Patients attending the Medical Therapy Unit are reminded that they are able to get a Discount Car Park Pass from Medical Therapy Unit Staff which will reduce the car park fee to \$6.00 for the day.

Unfortunately, due to Southern Health Policy, patients attending outpatient clinics are not entitled to the discount above, and standard car park charges will apply.

Thalassaemia Australia/Medical Therapy Unit Pharmacy Survey/Questionnaire

Recently, you may have assisted the Medical Therapy Unit and Thalassaemia Australia to complete a questionnaire on your experiences with pharmacy at Southern Health.

The information from this survey currently in the process of being analysed and collated and will be submitted to the hospital shortly for discussion. Both the Medical Therapy Unit and Thalassaemia Australia would like to thank all participants for their input into the survey to date.

Self management tools

Working With Your Liver's Clock Benefits Hepatitis C

While most of us check the time throughout the day to stay on schedule, few realise that the liver also has a timed agenda. By heeding your liver's innate clock, those with Hepatitis C can help relieve some of the extra burden on this multitasking organ.

By Nicole Cutler, L.Ac.

While most of us check the time throughout the day to stay on schedule, few realise that the liver also has a timed agenda. By heeding your liver's innate clock, those with Hepatitis C can help relieve some of the extra burden on this multitasking organ.

Chronic Hepatitis C is a worldwide problem infecting the livers of an estimated four million people in the U.S. alone. Until a guaranteed cure is devised for Hepatitis C, those with the virus must make every effort to support their liver's health by relieving it of unnecessary tasks. While there are a variety of strategies employed to support liver health, one that is often overlooked is working with the liver's schedule.

In charge of a long list of life-sustaining functions, the liver is an extremely busy organ. A few of its crucial duties, include:

- Producing bile, which helps carry away waste and breaks down fats in the small intestine during digestion.
- Producing certain proteins for blood plasma.
- Making cholesterol and special proteins to help carry fats through the body.
- Converting excess glucose into glycogen for storage.
- Converting poisonous ammonia to urea (urea is an end product of protein metabolism and is excreted in the urine).
- Clearing the blood of drugs and other poisonous substances.
- Resisting infections by producing immune factors and removing bacteria from the bloodstream.

Not surprisingly, the liver can't accomplish all of its amazing feats simultaneously. All of the body's organs, including the liver, have periodic cycles where different functions are emphasised at different times. The liver is no different, with a cycle completing every 24 hours.

The Liver Cycle

Although scientists are just beginning to recognise the phases of the liver's cycle, the following appear to describe the hepatic clock:

- The liver synthesizes complex chemicals and processes toxins the most when the production of bile is lowest.
- Along the same lines, chemical synthesis and toxin processing is lowest while the liver's production of bile is highest.
- Because bile is needed for food processing, the liver makes a greater proportion during the day - and less at night.
- Bile production is assumed to be at its highest at 9am and lowest at 9pm.
- After 9pm, the liver switches to its other primary functions, synthesizing chemicals and processing accumulated toxins.

- The cycle begins shifting around 3am, when the liver slows chemical synthesis and readies itself for bile production.
- The liver cycle shifts again around 3pm, when chemical synthesis begins to increase and bile production decreases.

Thus, the liver is most prepared to aid digestion with its synthesis of bile between 9am and 9pm. This is important information for those with chronic Hepatitis C who want to work with - and not against their liver.

Practical application of the Liver Clock

Although our busy lifestyles often dictate when we eat and when we sleep, those with Hepatitis C could benefit from scheduling necessities around their liver's needs. Since bile production is down late at night, eating a big meal past 9pm puts an additional strain on the liver. Thus, experts advise eating the last meal of the day long before the nine o'clock hour.

In addition, the liver's schedule of producing chemicals and detoxification (crucial for liver health) is best accomplished without additional demands. For this reason, most experts suggest retiring for the night close to 9pm whenever possible. Although this seems extremely early for many adults, those who try it report achieving a deeper and more restful sleep.

The liver's clock may not mesh with a modern, busy schedule. However, eating early and going to bed early cooperates with your liver's natural rhythm. By taking small steps to conform to your liver's cycle, those with Hepatitis C can remove the extra challenge that multitasking can place on their liver.

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This article was reprinted with permission of Hepatitis Central, July 6, 2010

Consumer Health Forum media release

Health consumers get a say in local health services - at last!

Australia's health system will benefit greatly from the real engagement of health consumers in health service decision-making, the Executive Director of the Consumers Health Forum, Carol Bennett said today.

She was speaking following an announcement by the Health Minister, Nicola Roxon, in Canberra today to support community based health consumer engagement in health service planning and decision making.

"A new era of consumer-driven health care is on the horizon with the decision to fund a national network of trained and accredited consumer health representatives actively engaged in Local Hospital Networks, Medicare Locals, other community based health services and state and national health policy forums," Ms Bennett said.

"Rather than decisions being taken on behalf of consumers by well meaning health service providers, health bureaucrats and elected representatives, we now have an opportunity for the real engagement of health consumers: the people who use and pay for Australia's health system. This is something that is long overdue in Australia and can only bring benefits to our community. We are finally moving beyond the rhetoric of putting patients first and creating the opportunity for real health reform through genuine health consumer engagement.

"Health problems and health policy and implementation are all becoming increasingly complex and there is no single repository of wisdom. Having a trained and accredited network of health consumers providing advice and experience will produce many benefits to our community including:

- Better informed policy and evaluation of health strategies
- Improved implementation processes
- Improved health and services that better meet the needs of communities.
- Smoother relationships between service providers and consumers.

"At a political and policy level, greater and more effective consumer engagement helps policy makers identify which health services work well and where; and has the added benefit of increasing public confidence in the decision making and policy processes," Ms Bennett said.

Health consumers expect that all political parties will see the benefits of consumer engagement in community health decision making processes and will support this common sense proposal.

CHF is the national peak body representing consumer health organisations and individual health advocates around Australia. www.chf.org.au



Medicines Line - update

Medicines Line gives people access to advice and information about all kinds of medicines. It is a valuable resource for people with chronic illnesses.

Medicines Line will continue to operate Monday to Friday, 9am to 5pm AEST. Under the new model:

- Medicines related calls are answered by a healthdirect Australia registered nurse in the first instance and triaged on the basis of need and clear protocols
- Complex calls which fall outside the scope of national nursing standards will be referred to either the caller's doctor, community pharmacist, another health professional or transferred to NPS
- NPS will operate an in-house pharmacist service. This service will only be available from Monday - Friday, 9am to 5pm.

This new model aims to offer consumers greater access to information about their medicines, and the NPS in-house service aims to ensure that consumers will continue to have access to a service that can answer more complex questions. Importantly, it will also allow NPS to capture data about medicines issues to better inform its quality use of medicines programs.

Please note that, as part of the new arrangements, the Medicines Line number has now changed. The new number is 1300 633 424 (1300 MEDICINE).

Consumers who call the former Medicines Line number will hear a recorded voice message advising them the number has changed. They will then need to hang up and call the new number.

Adverse Medicine Events Line will not be affected by these changes and its number remains the same (1300 134 237).

This information was provided to us by the Consumer Health Forum and Chronic Illness Alliance, with thanks.

International news

Thalassaemia International Federation



Unity is our strength – knowledge is our power

Thalassaemia International Federation (TIF) is a non-profit, non-governmental patient-driven organisation founded in 1986 and working in official relations with the Non-Communicable Diseases/Human Genetics Department of the WHO since 1996. Our close collaboration with WHO recently resulted in the adoption of resolutions EB118.R1 on thalassaemia and WHA59.20 on sickle cell anaemia, and we are now working towards the worldwide implementation of these resolutions.

In addition we collaborate with other relevant departments of the WHO, the European Commission, national, European and international patients' organisations, pharmaceutical industries and agencies, as well as other health-related bodies with an interest in haemoglobinopathies, blood safety and public health in general.

TIF is an umbrella organisation involving 98 national, European and international thalassaemia and other disease orientated associations, medical and research centres, health professionals in the field, industries and other interested organisations and individuals participating from over 60 countries of the world. TIF represents hundreds of thousands of patients with thalassaemia worldwide. TIF focuses its attention and resources on supporting these patients throughout the world with one objective: to improve survival and the quality of life of every affected patient.

To date, TIF has organised 65 delegation visits in 60 countries worldwide and 44 local, national, regional and international educational events (conferences, workshops and seminars). Some 18,000 health professionals, patients and parents from over 60 countries have participated in these events.

TIF's internationally recognised educational programme spreads information and awareness about thalassaemia and its prevention, management and cure to patients, parents, health professionals and the community. The Federation organises several conferences and workshops each year at local, national and international levels.

In recent years, through the networks it established, it began to organize regional conferences (the "1st Pan-European Workshop on Thalassaemia & Haemoglobinopathies" in Lisbon, Portugal).

The 1st Pan-Middle East Conference on Haemoglobinopathies took place in Damascus in May 2009, and the 2nd Pan-European Conference on Haemoglobinopathies in Berlin in March 2010. TIF is in the process of moving to the creation of a third network (ASIAN) and the organization of the Pan Asian Conference in the next couple of years. Countries outside the main World Health Organization Regional divisions will be invited to participate in

the Global network of collaborators. The main objectives of the network of activities at the Regional level are to discuss problems and concerns that are common to each region, but also share experience and successes of a Region, extending them over to other regions.

TIF publishes an extensive range of educational materials, including a quarterly magazine. To date, TIF has published 11 books and numerous leaflets, which have so far been translated into up to 20 different languages. TIF publications are distributed worldwide, free of charge to its members and at nominal cost to other interested individuals and organisations, and can all be viewed, read and downloaded from our website (<http://www.thalassaemia.org.cy/>).

One of the main challenges for TIF is to "bridge the gap" that exists between industrialised and developing countries – to extend the knowledge, experience and expertise gained in those countries where effective control programmes were first developed, to other affected countries across the world. TIF works closely with national health authorities and patients' associations towards achieving effective prevention of new affected births and towards improving the life of existing affected children with thalassaemia.

Another educational initiative of TIF's educational programme is the unique e-learning course. This was supported by TIF and materialized as a project jointly with one of the world's most prestigious universities – the University College London (UCL).

The objective of the course is to offer physicians and medical students especially from developing countries the opportunity to develop specialist skills for the effective control – including the prevention and holistic management – of haemoglobinopathies, thus helping to further the mission of TIF to improve the medical care and quality of life of thalassaemia patients across the world. The course was formally launched in April 2009.

Its electronic format provides the best opportunity for interested health professionals to study and acquire a world recognized postgraduate degree at their home without interrupting their professional and family life.



The 12th International Conference on Thalassaemia and Hemoglobinopathies and the 14th TIF International Conference for Patients and Parents

TIF's largest and longest-established international event for medical professionals, scientists, patients and parents is the biannual International Conferences on Thalassaemia & Haemoglobinopathies, organised jointly with the TIF International Thalassaemia Patients/Parents' Conference, which attracts hundreds of delegates from all corners of the world.

TIF has had impressive results over the years with regards to the impact these conferences have had on awareness and education of both health professionals, patients and parents.

The upcoming 12th International Conference on Thalassaemia and Hemoglobinopathies and the 14th TIF International Conference for Patients and Parents, will take place next year 2011 in Antalya, Turkey.

This event, combining two simultaneous conferences, aims to provide the latest scientific and medical updates to both health professionals and patients and their families and to support the exchange of knowledge and experiences.

Above all and very importantly, these conferences serve as great opportunity to built up new and strengthening existing relations

and collaborations. By working together, patients and experts, individuals and organizations, can all achieve their common aim: the best possible quality of care for every patient with thalassaemia wherever in the world he or she may live.

For the first time in our history of international conferences, this event will present experts patients as key speakers in the faculty. Patients and parents from all over the world will have the opportunity to interact between them and between health professionals of all relevant expertise.

The audience in these sessions is strongly encouraged to participate expressing questions and concerns, but also sharing experiences with others.

For more information, visit www.tif2011.org

Thalassaemia is a chronic disease that can be effectively managed. With the right treatment, patients with thalassaemia can live a full and happy life, have careers and families of their own, and achieve their individual aspirations. This is the vision of the Thalassaemia International Federation, which can only be realized with the close support and collaboration of our members.





Diary dates

19 September 2010

2010 Blackmores
Sydney Running
Festival

Support team **Blood
Pumping Run!!**

See page 13 for
more details.

29 September 2010

Thalassaemia Society
of NSW AGM and
Information Session
See page 15.

12-14 November 2010

Patient Family & Friends
Camp

Letter from the Centre Coordinator

Hello everyone,

I hope this newsletter finds you all well. Thank you to everyone who emailed or called me with positive feedback regarding the new format of our newsletter. I am happy to know that you are all enjoying the variety of extra information.

*"I like that there's sections for
what is happening in each state."*

Over the month of July Australian Red Cross Blood Service had a number of events and celebrations not only to keep encouraging the importance of blood donation but also to thank and give recognition to the ongoing milestone donors.

I was very lucky to be invited as a guest speaker at the Sydney Metro National Blood Donor Week celebration which was held on the 17th July at NSW Parliament House.

I had the pleasure of thanking and sharing my personal story with 400 very generous Australians who donate regularly and also met with Glenn Wheeler (radio presenter for 2GB), who MC'd the event. Later on that evening Glenn carried out a short on-air interview with me, recapping the importance of ongoing blood donation for Thalassaemia Patients.



The following week Glenn and one of my dear friends Sandra, made a pledge to donate together. This was a fantastic morning which gave me the opportunity to stand beside both of them as they gave blood and then be able to thank other blood donors who were present on the day.



I will be visiting mobile blood vans over the next few months to also create awareness and thank donors on behalf of all Thalassaemia Patients.

As you will also notice in our newsletter we have the Blackmores Sydney Running Festival on the 19th September which a few Thalassaemia Society members, patients and nursing staff are taking part to raise money for a great cause! I hope to "run" into many of you on the day.

The Thalassaemia Society of NSW will be holding their AGM and Information afternoon in September and, an invitation will go out to all our email contacts and mailing list database. Until next time, thank you

Nancy Lucich
Centre Coordinator





Sydney Running Festival fundraiser

Patients, family, friends and Nursing Staff are taking part in the 2010 Blackmores Sydney Running Festival under team name **Blood Pumping Run 2010** to raise money for a great cause!

All funds raised will go to Thalassaemia Society of NSW, and every contribution made to my Fundraising Page will get us one step closer to reaching our team target of \$5,000.

Please visit <http://www.gofundraise.com.au/thalnsnw> and support us in the race!

All donations made through this site are electronically wired to Thalassaemia Society of NSW and an automatic receipt will be emailed to you immediately. Thank you for your support and for helping to make a difference!



SYDNEY RUNNING FESTIVAL
Official Sponsor
Sunday Telegraph
19 September 2010

The run that's fun for everyone!

Take part in one of four exciting events

B your best BLACKMORES HALF MARATHON	B your best BLACKMORES SYDNEY MARATHON	Sunday Telegraph body+soul BRIDGE RUN	Sunday Telegraph FAMILY FUN RUN
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For more information and to enter on-line visit - www.sydneyrunningfestival.org.au



Fundraising and events

Thalassaemia Society of NSW

Annual Dinner Dance

On Saturday, 26 May 2010, The Thalassaemia Society of NSW held their Annual Dinner Dance at the Mytelinian House in Canterbury.

The night was a great success with 250 supporters attending the event. Some of our special guests on the night included, the Parish of Saint Paraskevi, Blacktown and St Nectarios, Burwood.

The Sydney Folk Dancers of NSW performed a series of dances which set the mood for a great atmosphere.

The Society raised approximately \$25,000.00 on the night. Thank you to all our sponsors and supporters for their ongoing generosity to our cause. We hope to see you at our next function!!!

The impact of Iron Chelation on the quality of life - A patient's story

At five years old when starting school should have been the most exciting time, the beginning of my education, for me and my parents, it was time to learn all about making up Desferal infusion and inserting a needle. There was no monster under my bed; it was sitting in my bed making all sorts of noises.

It was just the beginning of many more years of arguments, begging and rebellion. What kid wants to learn how to inject themselves and wear a needle all night, five nights a week? What parent wants to inject their child and argue; or give in when they know that this is the only way their child could survive?

It hurts, you can't get comfortable, you've got a pump which pushes the medication through the syringe strapped to your side and as the medication is injected under the skin it becomes extremely itchy. All things you learn to live with as the years roll into decades.

No one seems to understand, brothers, sisters, parents, other family, friends and peers don't really know. No one that is, except for other patients with Thalassaemia and Sickle Cell disease.

Over the years the bond developed with other patients grows stronger, only they are able to convince you to comply, and through their experiences you learn to cope with all the issues that impact your life because of iron chelation therapy.

As I grew older the issues of having to chelate became a little more complicated than just the pain at the needle site and sleep disturbance, but as an adolescent when all my friends were beginning to dress up and go out at night, I would be self conscious of the unsightly lumps and bruises on my arms, legs and tummy and refused to wear tight clothing. I also had to choose the evening I went out and plan what nights I would wear the pump.

On top of all of this I had my parents constantly questioning me, when I chose not to wear my pump, I had to justify the reason I wouldn't and see the guilt in their face when

an argument broke out, worse still when they let me get away with it.

When L1 or otherwise known as Deferiprone came out as a trial I jumped at the chance to give up the pump.

When the trial was over it was back to the pump, well by that stage I had become accustomed to sleeping without it and the leisure of late nights, I had a social life to maintain.

To most it won't make sense that these things take priority. Well they don't, and when you see what iron overload can do to your body, how it affects the heart, liver, pancreas; as it has affected so many of my friends and the pain in their parents eyes as they advise you to look after yourself, you know what the priority should be, you understand how important it is to chelate but oh, how easy it is to stray.

I've done my best to lead a 'normal' life. Finished school, continued my education and am now a successful medical clinician and still at times cheat when it comes to wearing my pump. I educate others on the importance of wearing the pump and still I am not always the most compliant.

Fitting in school, university, work and a social life, meanwhile taking care of your health is a challenge but such is the cycle of life or my life at least. In order to maintain a quality of life I know I must sustain good health and to do that I must comply.

A message to all patients who find it hard, you are not alone. To all those who helped me, thank you. To all the friends we've lost along the way, we miss you!

Anonymous



Patient Support

Patient's Transition

We all know that coping with Thalassaemia can be a difficult challenge and asking for and taking support is not always easy.

This entails a great deal of effort and stress; some emotions you may experience include anxiety, fear, anger, depression, worries and apprehension.

For this reason the counsellor and the Coordinator of the Thalassaemia Centre NSW have put together a transition pack for all the younger patients transferring from the Children's hospitals to the adult's hospitals in NSW.

We meet with the patients for their first treatment appointment at the adult's hospital to introduce them to their new environment, the medical staff and the hospital facilities.

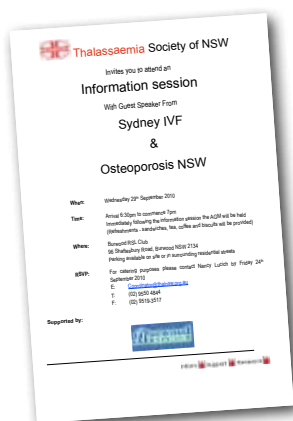
To this effect we hope that the transition procedures put in place will continue to ease the new move to the young patients.

**Thalassaemia Counsellor
Amy Elzahaby**



Notice of 2010 Annual General Meeting and information session

Wednesday 29 September 2010 at 6.30pm for 7pm start
Burwood RSL Club, 96 Shaftesbury Road, Burwood NSW 2134



All financial members of the Thalassaemia Society are invited to attend and participate in the meeting.

At the conclusion of the AGM, all are invited to attend the Information Evening. We will be having two guest speakers – a Scientist from Sydney IVF on PGD and an educator from Osteoporosis NSW.

For catering purposes please RSVP as per the instructions on the Information session flyer enclosed.

All financial members of the Thalassaemia Society of NSW Inc. are eligible to stand for election to the Executive Committee.

If you are unable to attend the AGM but wish to nominate for a position you may use a 'Nomination' form (enclosed). Verbal nominations will also be taken during the election process at the AGM.

If you are unable to attend but would like to direct your vote to another member of the society you may do so by filling in an 'Appointment of Proxy' form (enclosed).

'Nomination' and 'Appointment of Proxy' forms may be brought to the AGM or sent in advance, by Friday 24 September 2010, via fax to (02) 9519 3517 or by post to:

The AGM will include the following:

- Chairperson's / President's report
- Treasurer's report
- Adoption of the audited 'Annual report including financial report for the year ending 30th June 2010'*
- Appointment of Auditor
- Election of Officers to the Committee for the next 12 months

The following Committee positions will be elected:

- | | |
|---------------------------------|-----------------------|
| • Chairperson | • President |
| • Vice-President | • Secretary |
| • Assistant Secretary | • Press Secretary |
| • Treasurer | • Assistant Treasurer |
| • 7 x General Executive Members | |

AGM 2010

Thalassaemia Society of NSW
PO Box M120 CAMPERDOWN NSW 2050

* The audited 'Annual report including financial report for the year ending 30th June 2010' will be made available at the AGM. It can also be viewed prior to the AGM on the Society's website www.thalns.org.au or at the 'Thalassaemia Centre of NSW' at Level 7, King George V Building, Missenden Road, Camperdown.



Thalassaemia Society of New South Wales Committee

What is Osteoporosis and what are the risk factors?

Osteoporosis is a disease in which the bones become fragile and brittle. They fracture more easily than normal bone. Even a minor bump or fall can cause a serious fracture. Half of all women and one-third of men over 60 in Australia will have a fracture due to osteoporosis.

Osteoporosis and fractures are major causes of injury, long-term disability and even death in older Australians. One fifth of people who suffer a hip fracture will die within six months. Of those who don't die, 50 per cent will be unable to walk without help or stay in their own homes. Some may even need full-time nursing care.

Osteoporosis is often called a silent disease, as there are usually no signs or symptoms until someone has a fracture. Any bone can be affected but the most common are bones in the hip, spine, wrist, ribs, pelvis and upper arm.

What causes osteoporosis?

The health of your bones depends on:

- your genes (60-80%)
- the level of hormones in your body. In women this hormone is oestrogen; in men it's the hormone testosterone.
- how physically active you are
- what you eat

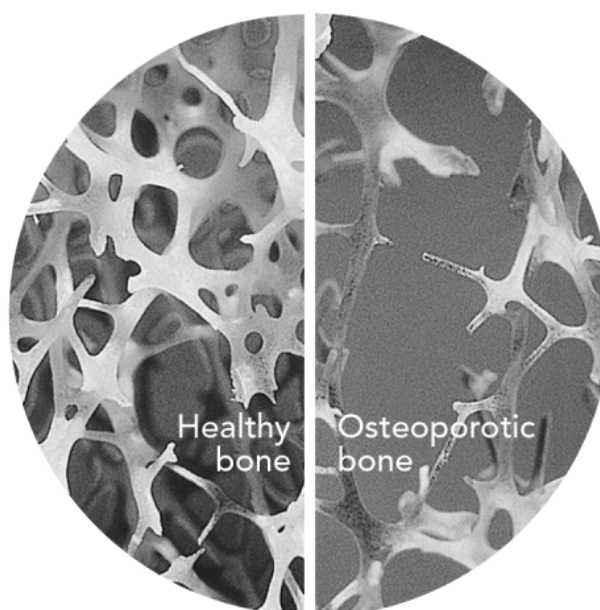
These things affect how well bones form in early adulthood when your bones are at their strongest. After the 30s, it's important to maintain bone strength and prevent bone loss.

Menopause and osteoporosis

Menopause means the time around a woman's last period. Most Australian women reach menopause between the ages of 45-55, but it can happen earlier.

From about the age of 45 years, women may begin to lose bone at the rate of about 1-2% per year. This is because women's bodies usually make less oestrogen at this age.

After menopause, oestrogen levels keep decreasing, and this speeds up bone loss to about 2-4% per year, especially in the



first 5-10 years after menopause. This stage of bone loss caused by menopause may last up to 15-20 years. All women lose bone at menopause. The amount varies, but some can lose as much as 30% of their bone during those years. If you have an early menopause for some reason, you will begin to lose bone at an earlier age. You should ask your doctor about preventing osteoporosis.

Men and osteoporosis

The male hormone, testosterone, does not decrease suddenly like oestrogen does in women during menopause. Instead, testosterone gradually decreases from about 50 years of age in men. However, men's bone density tends to stay the same until they are much older. But after 75 years of age, both men and women lose more bone, especially in the hip. This is part of the ageing process.

Osteoporosis Australia

Website:

www.osteoporosis.org.au/

Excerpts from the fact sheets *What is Osteoporosis? What are the Risk Factors for Osteoporosis? and What is a bone density test?*

Reprinted in this newsletter with thanks.

Risk factors for osteoporosis

Risk factors for osteoporosis and fractures caused by osteoporosis are similar in women and men. They include some things that you can change, and some that you can't.

Risk factors you can change

You have a higher risk of having a fracture due to osteoporosis if you:

- Do little or no physical activity
- Are a smoker
- Have a high alcohol intake
- Have low body weight
- Have low calcium intake
- Frequently fall

Risk factors you can't change

You have a higher risk of having a fracture due to osteoporosis if you:

- Have a parent or grandparent who has osteoporosis or who has had a fracture caused by osteoporosis.
- Are female



- Are Caucasian or Asian
- Have a small body build
- Had delayed puberty or early onset of menopause
- Had anorexia which caused loss of periods
- Have already had a fracture caused by osteoporosis
- Are over 60 years of age
- Have rheumatoid arthritis, chronic liver disease or kidney failure
- Have a history of over-active thyroid or parathyroid glands, or have been treated with thyroid hormones
- Are a male with low levels of testosterone
- Have had long-term drug treatment with corticosteroids (such as prednisone)

Preventing osteoporosis – reduce your risk

Preventing osteoporosis is important. Although there are treatments for osteoporosis, there is no cure.

You can reduce your risk of developing osteoporosis and having a fracture by:

- Having a balanced diet rich in calcium and vitamin D. For most people, three serves of dairy foods daily will provide enough calcium
- Vitamin D to help the body absorb calcium (see fact sheet on vitamin D for more information). Vitamin D is in small amounts in foods such as dairy products fortified with vitamin D, egg yolks, saltwater fish and margarine. The best source of vitamin D is from safe sunlight exposure.
- Weight-bearing, high impact and strengthening exercises (such as walking, tennis, dancing and weight training)
- Having a bone density test, if appropriate
- Asking your doctor if you need medication
- Asking your doctor if any medicines you take may be causing bone loss
- Not smoking
- Drinking less alcohol

What is a bone density test?

The medical name for this test is Dual-energy X-ray Absorptiometry (DXA). However, it is commonly known as a bone density test.

It is a short, painless scan that measures the density (strength) of your bones, usually at the hip and spine. The result from this test is called a T-score.

Your GP will assess your risk factors for osteoporosis which include your age, medical history and lifestyle factors before referring you for a test.

Bone density tests are available at most large hospitals, many private radiology centres and at nuclear medicine practices. Some specialists also offer this service.

There is a medicare rebate for a bone density test (DXA scan) if you:

- have been previously diagnosed with osteoporosis;
- have had one or more fractures due to osteoporosis;
- are 70 years or over;
- are taking cortico-steroids or have Cushing's syndrome;
- are under 45 years and have not had a menstrual cycle for 6 months (excludes pregnancy), or are male and have low testosterone;
- have rheumatoid arthritis, chronic kidney or liver disease, overactive thyroid or parathyroid, or coeliac disease.

NOTE: You may see advertisements for other types of bone tests in chemists and shopping centres called Heel Ultrasounds. Heel Ultrasound is not the

recommended standard test to measure your bone strength and predict your risk of fracture.

What does the test tell me?

A bone density test will give you a T-score. The result will be in the range of normal; osteopenia (low bone density); or osteoporosis.

If the test shows normal

You have normal bone density. Exercise, adequate calcium intake and vitamin D are all important factors for maintaining healthy bones.

If the test shows osteopenia (low bone density)

Your doctor may recommend lifestyle changes to reduce risk factors that can affect bone health. See list of risk factors on opposite page. Your doctor will also recommend a follow up test in 1-2 years to monitor your bone density.

If the test shows osteoporosis

This means your bone density is low and at risk of fracture. Your doctor will probably recommend that you start treatment to stop further bone loss and prevent fractures. Lifestyle changes will also be recommended. A follow-up test is commonly conducted in one year to monitor your bone density and the effectiveness of the treatment.

Osteoporosis Treatments

If you are diagnosed with osteoporosis there are effective treatments available that help to prevent fractures, slow bone loss and in some cases build bone.



BONE DENSITY TESTING

Diagnosing Osteoporosis

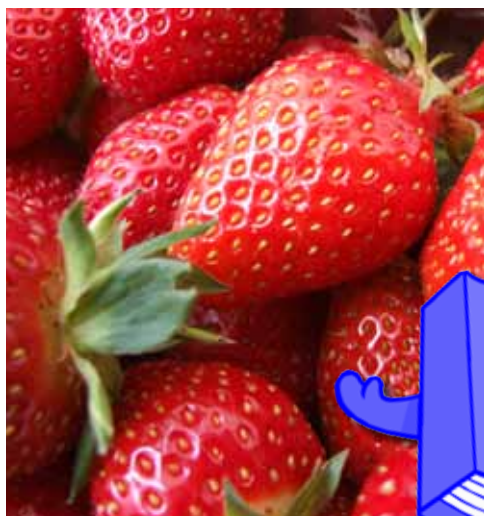
HOW STRONG ARE YOUR BONES?

National tollfree number

1800 242 141

www.osteoporosis.org.au

The Australian Government has provided funding to support this project.



Spring time



Marshmallow Fruit kebabs

Preparation time: 15 minutes
Assembly time: 20 minutes
Makes: 18

Ingredients

- 2 medium bananas (300g)
- 1 tbs lemon juice
- 1/2 cup (25g) desiccated coconut, toasted
- 1 punnet (250g) strawberries, washed, hulled, halved
- 3 kiwifruit, peeled, sliced
- 18 pink marshmallows (85g)
- 18 Paddle Pop sticks

Method

1. Peel bananas and cut into 2cm slices. Toss gently in lemon juice and coat lightly in coconut.
2. Thread Paddle Pop sticks with fruit and marshmallows.

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

Enjoy!

Hi Kids!

Spring is a great time to have fun and get creative! Why not try out our recipe for yummy fruit kebabs?!

Q: Where do cows go on holiday?
A: Moo York!

Q: What season is it when you are on a trampoline?
A. Spring-time!

Q: What dog loves to take bubble baths?
A: A Sham-poodle!

Colour me in!

