Australian Thalassaemia Nurses Workshop

Thalassaemia Australia and Thalassaemia Society of New South Wales held a Thalassaemia Nurses Meeting/Workshop on 8 October, 2011 – at Southern Health, Melbourne.

Before this meeting took place TA, Thal NSW, Libby and MTU staff met to discuss the proposed content of the nurse’s workshop. The invited nurses were also invited to propose topics of interest.

The meeting was attended by 18 nurses from around Australia, including Jo Shaw from Medical Therapy Unit. Guest speakers included: Assoc. Prof. Don Bowden, Libby Reid, Mary TassiGiannakis-MTU Social Worker and Jo Shaw – Nurse Unit Manager – MTU and was supported by Novartis Oncology and Aspen.

Holding the meeting at Southern Health Clayton also enabled the nurses to visit the specialised Thalassaemia Services of Victoria, Medical Therapy Unit.

The information presented by guest speakers was targeted appropriately to the nurses in their role as carers of thalassaemia patients and touched on subjects relating to changing demographics, clinical care and psycho-social issues. Where possible, and with the extensive experience of our panel of guest speakers, we were able to provide many examples to illustrate the treatment and care of both patients and their families.

A special mention and thanks must go Libby Reid, who gave freely of her time to meet with these nurses and highlight the changes that have occurred in thalassaemia treatment in Australia over the last 30 years.

The meeting also provided the nurses with an opportunity to exchange ideas and look at different ways of improving clinical services and care.

As a result of this meeting an Australian nurses’ network was established among the participants to enable further communication, education and exchange of their ideas.

(Cont. on page 2)
Nurses Workshop (Cont. from page 1)

Some of the topics covered included:
- Cannulation
- Introducing new staff to patients
- Chelation – compliance and assisting families
- Administration/Treatment centres
- Co-ordinating specialist services
- Care-planning

The feedback from the nurses at the workshop was very positive, many requesting another opportunity to meet again in the near future.

‘...the topics (of the Nurses Meeting) were diverse and gave an in depth overview of the complexities of this patient population…’

‘...the key speakers gave us an insight into the broad history (of thalassaemia) and a multidisciplinary perspective…’

‘...a great networking experience for thalassaemia nurses…’

‘...thank you for such an amazing, well planned day!...’

From the perspective of Thalassaemia Australia and Thalassaemia Society of NSW the meeting was a great success, as we have enabled the nurses to collaborate together and share their knowledge to further assist our patients throughout Australia.

Fortunately, we can now confirm that there will be another meeting organised for the nurses in 2012!

On behalf of Thalassaemia Australia/Thalassaemia Society of NSW we would again like to thank our guest speakers, in particular Jo Shaw for chairing our meeting and our sponsors Novartis Oncology and Aspen for their assistance.

More information on the Nurses workshop can be found on page 10 in Nancy’s Letter from the co-ordinator.

Post Graduate Certificate in Transfusion Practice – Information for Nurses

- http://www.mccp.unimelb.edu.au/courses/award-courses/graduate-certificate/graduate_certificate_in_transfusion_practice

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.
Resources for Families from Siblings Australia

A new DVD, Stronger Siblings, developed by Siblings Australia and presented by Andrew Daddo, was launched in Adelaide on 3 November, 2011.

This DVD will assist parents, and those who work with families, to understand the experience of brothers and sisters of a child with disability and how to support them. Parents and siblings share their stories and, together with professionals, explore a number of issues. It is an ideal resource for organisations to use with groups of parents, especially given the DVD includes notes to facilitate further discussion.

An order form for the DVD is available at http://www.siblingsaustralia.org.au/ps_resources.asp. Please contact Kate Strohm, Siblings Australia, Director for further information by email at kate@siblingsaustralia.org.au

HAPPY BIRTHDAY

JOHN KOSMAS

A long time supporter of TA (TSV) and past committee member, has recently turned 80. We send him our congratulations and best wishes for this special occasion.

Medicine Reminder

The start of a New Year is a good opportunity to clear out your medicines cabinet.

Any medicines that you no longer need or are past their expiry date are not only cluttering up your home, they can also be dangerous. Unwanted medicines should always be disposed of safely by taking them to your local pharmacist.

Community Education Program 2011/2012

The 2011 community education program for TA finished on a high, with back to back secondary school presentations being held throughout the Melbourne metropolitan area and regional Victoria.

In fact, it was a very busy time for the office with the Nurses Meeting being organised and held at the same time as well as our regular attendance at meetings with our partner organisations and the conclusion of the Community Based Placement Program.

We also attended the Health Consumer Advocacy workshop in Sydney.

Our AGM was held on 22 November in Coburg. Thank you to all our members, guest speakers and MTU staff for making the effort to attend. We welcome our new Committee members and look forward to an exciting 2012.

We also have some new resources available on the TA website to be downloaded or collected from our office. These ‘So you think you have BETA thalassaemia’ brochures have now been translated into 8 different languages including: Cantonese, Italian, Arabic, Greek, Tamil, Sinhalese, Vietnamese and Mandarin. These brochures were funded by the Lord Mayors Charitable Foundation. If you know of anyone that may be interested in receiving a copy, please call the office.

Christmas Party/Picnic

Sadly, our Christmas party/picnic was cancelled due to the wild weather predicted for that day, however did manage to alter Santa’s delivery run to go via MTU to leave our patients (under 12 years old) with a small gift. We are hoping to reschedule the picnic in early 2012, so please keep an eye on the noticeboard at the Medical Therapy Unit for further details.

New family function

Thalassaemia Australia would like to extend an invitation to all new families to get together and share their experiences in a fun/welcoming environment such as a play centre or restaurant. Although a date has not been finalised at this stage, please contact TA with your expression of interest.

Office

As TA only has two part-time staff, occasionally the office is unattended when we are out at meetings and presentations.

If you call the TA office and no one answers your call immediately, please leave your contact details so that we can get back to you promptly. Alternatively, you might like to send us an email at info@thalassaemia.org.au.

Please note: If you require medical assistance, please call the Medical Therapy Unit on 9594 2756 or 000.

Community Presentations

If you know of a community organisation or school that you would like TA to visit and spread the word about Thalassaemia, please do not hesitate to contact our office!
Thalassaemia Australia’s 2011 Annual General Meeting report

Thalassaemia Australia’s (TA) Annual General Meeting (AGM) this year was held at Moreland City Council in Coburg on 22 November, 2011.

At this AGM we invited a number of guest speakers and representatives from State and Federal agencies to present to our members and provide with additional information that may be relevant to their needs. These agencies/representatives included Bronwyn Halfpenny MP, Local Member for Thomastown, Carers Victoria, Victorian Spleen Registry and Centrelink.

Two of these representatives were able to stay for the duration of the meeting and address the queries that were put forward. Although there was not an opportunity for these agencies to present extensively to our members, it is always important to remind families/members/patients of the services available to them.

On behalf of the TA Committee of Management we would like to thank all the agencies for assisting us with our AGM and their continued support.

Our guest speakers: Resident Fellow Sant-Rayn Pasricha (MTU), Dr Jim Vadolas – Cell and Gene Therapy (MCRI) and Nicole Cousens – PhD Scholar, Bruce Lefroy Centre for Genetic Health Research (MCRI), ensured that those present received up to date information on thalassaemia, clinical management, treatment. Novel therapies and recent advances in thalassaemia research in Australia and around the world were also discussed. Nicole Cousens spoke of her research project that focused on carrier couples and their experience of screening for thalassaemia.

In addition, Lani De Silva, our student from the Community Based Placement Program – Monash University spoke to us enthusiastically about what she had learnt during her time with TA and how the Community Based Placement Program has assisted second year medical students to develop a greater understanding of the community health sector in Melbourne.

Penny Jones from the Spleen Registry also gave us a quick update on the services that are offered at their organisation and encouraged patients to contact their office if they had any queries regarding their spleen.

Overall, our speakers managed to cover a wide range of topics, if you would like any further information on these subjects, please call our office on 9888 2211.

The formal part of the evening concluded with the President’s, Treasurers’ and Staff report highlighting aspects of the 2010-2011 financial year.

Please call the TA office or visit www.thalassaemia.org.au for your copy of the 2010-2011 Annual Report.

The 2011-2012 Committee of Management was elected and is as follows:

**Executive**
- Sotirios Katakouzinos – President
- Maria Triantafillou – Vice President
- George Ambatzidis – Treasurer
- Mary Konstantopolous – Secretary

**General Committee Members**
- Dr Jim Vadolas
- Bessy Mougos
- Betty Koutanas
- Helen Kosmariakas/Spiros Bambos
- Julie/Billy Costa

On behalf of Thalassaemia Australia, we would like to say a special thank you to our outgoing committee members, Diva Duvaroren, Lien Sam and John Wilson for their assistance and efforts over the last year or so and we wish them well with their future endeavours.

We would also like to thank the rest of the 2010/2011 committee of management and staff for their time and efforts over the last year and we look forward to an exciting and successful 2012.
When do I have to disclose my hepatitis C status?

You need to disclose your hepatitis C status if:

1. you want to join the Australian Defence Force/secret services, or if you are a current member of these services
2. you are a health care worker who performs exposure prone procedures (EPP)
3. you would like to be a blood donor: people with hepatitis C, or who have had hepatitis C, are excluded from donating blood
4. you are applying for health and/or life insurance
5. You belong to a martial arts federation/competition where the ‘blood rule’ is not applied.

Completing a form which asks about hepatitis C

For dental/medical treatment

There may be health/medical reasons for why it might be a good idea to disclose your hepatitis C status, (e.g. poor oral health due to low saliva production, or a damaged liver unable to process medications), however, from a legal standpoint, you are under no obligation to disclose this information.

Bodily fluids and blood are always treated as infectious by health workers who are legally required to follow standard infection control guidelines that protect both you and them from possible infection.

For employment

An employer seeking information about your health must explain why your personal health information is being collected and the intended use of the information.

A GP or medical practitioner appointed by your employer should carry out pre-employment medicals. These results are confidential between you and the medical practitioner.

The Equal Opportunity, Privacy and Health Records Acts cover pre-employment medical test results.

A medical assessment requested by your employer or prospective employer, may only measure your fitness to perform the essential tasks of a job. You are entitled to ask for information about what those requirements are.

You are also entitled to a copy of the information provided to your employer by the medical practitioner. If you do not consent to the provision of information to the employer, the medical practitioner cannot provide any information to the employer.

If an employer asks you about your hepatitis C status, unless you are in one of the five categories described above, you are under no legal obligation to disclose your hepatitis C status.

If you do not fall within one of these five categories who are obliged to disclose their hepatitis C status, it is then up to your employer to demonstrate that in the circumstances of your particular case, it was reasonable to require you to disclose your hepatitis C status.

In particular circumstances, there may be ramifications for you and/or your employer in relation to WorkCover and insurance issues, if you have not disclosed your hepatitis C status.

If you have any queries around your personal circumstances, you can contact the Hep C Infoline on 1800 703 003 for further advice.

Background to the advice on disclosing

- Hepatitis C is a blood borne virus. Transmission of the virus can only occur when infected blood enters the bloodstream of another person.

- Under the Government’s Occupational Health and Safety guidelines, all bodily fluids and blood are regarded as infectious at all times.

- ‘Standard Infection Control Procedures’ have been developed to protect the health of both worker and client from infection from blood and bodily fluids. Health care workers treat anyone as if their blood and/or bodily fluids are infectious (including their own).

- All work practices, including any protective practices, should be non-discriminatory.

- All workplaces should protect the privacy and confidentiality of all people.
Employers have a legal responsibility to take reasonable steps to maintain a safe working environment in the workplace for employees and the general public.

Employees have a corresponding duty to take reasonable care for their own safety, the safety of others and to cooperate with their employer in relation to workplace health and safety.

Note: Not all workplaces or service providers may have a good understanding of the law and their responsibilities with regard to blood borne viruses, or of policies and procedures that take these into account. Even so, it is not the responsibility of the person with hepatitis C to disclose their status, regardless of the employer’s understanding about their responsibility.

Annotation
1 Exposure Prone Procedures involve surgery performed in body cavities, with sharp instruments where there is not always a clear line of sight between the eyes of the health worker and their hands. This applies to surgeons/dentists and any health care workers intimately involved in the surgical procedure.

2 The blood rule in sports means that a player who is bleeding is excluded from playing until the bleeding has stopped and the wound is covered up. The exclusion is required because of the bleeding, not because the player may have hepatitis C. All players are treated the same way, therefore no disclosure is needed because of a player’s hepatitis C status.

About the Author:
Piergiorgio has been working at Hepatitis Victoria for almost 11 years. Pier duties have changed over this time and he is now the advocacy and communications educator. Pier’s main roles are to increase the profile of viral hepatitis in the community, lessen the burden of stigma and discrimination, and advocate for people living with viral hepatitis, both at the structural and individual levels.

Source: Good liver, March 2011 edition Hepatitis Victoria, with thanks.
6th December 2011

Dear

As you are aware the Medical Therapy Unit has had some staffing changes this year.

Subhag Droom has retired and Nicole Hall has been appointed the role of Associate Nurse Unit Manager.

Cecilia Sze has taken long service leave for 10 months and Shan Sun is replacing Cecilia. Shan has an extensive experience in the Emergency Department, Coronary Care Unit, Cardiothoracics and Day Infusion Centre.

Alana O’Brein has joined the Medical Therapy Unit as a registered nurse she has considerable general medicine and specialist experience. She is also undertaking a Masters of Nursing.

Terri Dunstan has been appointed as a registered nurse in the Medical Therapy Unit. She was previously employed by the Australia Red Cross Blood Service. Terri has substantial experience in apheresis, blood products and management.

We have worked hard this year in training Southern Health nurse bank staff to ensure we have experienced staff to cover annual leave and sick leave.

Fiona Cunningham has commenced as the Medical Therapy Unit Genetics Counsellor. Fiona has an extensive background in genetics and teaching. Please contact the Medical Therapy Unit staff if you wish to make an appointment regarding Genetic Counselling.

Professor Don Bowden will be taking long service leave from February to August 2012. Dr Sant-Rayn Pasricha will be acting Head of Department.

The nursing and medical staff ask that all patients attending the Medical Therapy Unit for treatment arrive before 9.30am as this helps with unit operations. Thank you.

If you have any further questions or queries please contact the Medical Therapy Unit staff on 9594 2756.

Regards

Medical Therapy Unit Staff

Joanne Shaw  
Thalassaemia Service Coordinator  
Southern Health

Professor Don Bowden  
Director of Thalassaemia Services  
Southern Health
2012 Committee of Management

President/Chairperson – Martha Gerolemou
Vice President – Marianne Dimitrakas
Treasurer – Lela Dallas
Secretary – Open Position, if you are interested please contact coordinator@thalnsw.org.au
Assistant Secretary/Assistant Treasurer – Theodora Michalopoulos
Executive Member – Glenda Hughes
Executive Member – Nicholas Kotrotsos
Executive Member – MD Faisal
Executive Member – Rosa Dimitrakas

2012 Committee meeting dates

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 February
Wednesday 7 March
Wednesday 4 April
Wednesday 2 May
Wednesday 6 June
Wednesday 4 July
Wednesday 1 August
Wednesday 5 September
Wednesday 3 October
Wednesday 7 November
Wednesday 5 December

Research grant of $60,000

The Thalassaemia Society of NSW recently gave a $60,000 research grant to the Murdoch Childrens Research Institute to support their research into Thalassaemia.

The cell and gene therapy research group is committed to finding better treatments for Thalassaemia, to help alleviate the suffering of patients and improve their quality of life.

Their current therapeutic strategies for Thalassaemia include the restoration of the body’s ability to produce haemoglobin, which would end the need for regular blood transfusion and prevent subsequent complications.

The groups recent achievements include the identification and evaluation of a new class of drugs that can reactivate the production of haemoglobin.

With further funding support the group hope to begin clinical trials in the near future.

The funding given will be used to support the appointment of PhD students to continue current research projects.
Letter from the Centre Coordinator

Hello everyone and welcome to another year, I hope you all had a magical festive season with family and friends and I hope this year brings good things to all. For me 2012 is a new chapter in life as my little boy Nicholas will start School, I am very proud, sad and excited all at the same time......fun times ahead!!

I am looking forward to another great year at the centre, informing and educating about Thalassaemia as well as being there for all new and existing patients and their families, please remember we are here for you so come forward with any questions, comments or concerns.

Late 2011 saw a new achievement on a national level: Our very first Thalassaemia Nurses Meeting/Workshop was held in October 2011 at Monash Medical Centre – Melbourne, organised by Thalassaemia Australia and Thalassaemia Society of NSW. This was very well attended and enjoyed by nurses throughout Australia.

My very special role on the day saw me leaving home in the wee hours of the morning to catch an early flight and escort nursing staff from NSW to Melbourne. At Melbourne Airport, I met round up the nursing staff from other states before marking my role, and seeing that everyone got on the bus to Monash Medical Centre.

I did the same in reverse later on that afternoon once the Workshop was over. The trip there was nice in that I had the pleasure of introducing staff to one another and was able to let them know a little about what was install for the day......within me I hoped that the day would run smooth and be enjoyed by all!

The trip home was a blast, loads of fun, laughs talking and sharing. The nurses had formed a nice bond with one another and there was loads of positive feedback about the day. I am confident in saying that there were positive outcomes reached at the Workshop and the nurses walked away with a refreshed knowledge of Thalassaemia and a new nurses network to participate in.

We wish to thank all the nurses who gave of their time on a weekend to attend this meeting, and it was overwhelming to see how many of you have an interest and passion for our patients. Again we thank the Pharma companies who supported this event and look forward to an exciting meeting in 2012.

The end of 2011 saw an interesting information session for our patients, family friends – “Emerging Data in and Thalassaemia”. The evening saw 60 attendees and two very special guest speakers, Dr Vasilis Berdoukas & Dr Jim Vadolas. I have had nothing but positive feedback from the night and patients giving thanks for organising such and informative session. Thank you to our guest speakers for giving of their time, and we look forward to updates from you in 2012.

In 2012 the Thalassaemia Centre of NSW will continue to hold community awareness stands in the foyer of our main treating hospitals, please be sure to look out for us and say hello if you are in the hospital on that day, we always like to see our members and familiar faces when out educating the community.

We will continue to work together with The Australian Red Cross Blood Service in creating awareness of the importance of blood donation to keep our patients alive as well as giving thanks to existing and long term donors.

Please see the following “Gift of Life” article used for presentations. The Australian Red Cross Blood Service are often looking for recipients who are interested in sharing their story to existing and new potential donors so if you are interested and happy to share your story please contact me.

Other events install for 2012 include:

• May 8th Celebrations for International Thalassaemia Day (awareness & celebration, details to follow)
• Patient & family camp (date to be advised)

I look forward to another fun filled year!

Nancy Lucich
Centre Coordinator

“The Gift of Life”
A thank you to Blood Donors

Blood donors became my lifeline at the early age of 3. I was showing signs of anaemia, I became pale, did not sleep well, lost my appetite and was failing to grow and thrive like a normal healthy little girl. At this point after many trips to the doctors I was diagnosed with a genetic blood disorder called Thalassaemia.

Thalassaemia is one of the most common genetic disorders in the world, however my parents like many people had no idea what it was, let alone that they were carriers of this affected gene.

Both my parents being carriers and had a 1 in 4 risk of having a child with the full blown disorder and yes, I am the lucky one out of two children in my family to be born with Thalassaemia.

Basically for me it means that my body destroys red blood cells almost as soon as they are produced and my bone marrow cannot produce a sufficient number to replace them leaving me with a very low haemoglobin and quite anaemic. Red blood cells make up almost 45% of the body’s total blood volume and play a very important part to carry oxygen around the body and to your organs.

Therefore every 3-4 weeks of my life I require a blood transfusion of at least three units of blood, this means that 40 people need to donate their blood every year to keep me alive.

Blood donors know that their blood will help someone who has been in an accident, having an operation or save a life, this is all very special but for me and my friends who suffer from Thalassaemia you are giving us the gift of life!

You keep me alive every month, you give me the opportunity to live, work, be a wife and a great mother and I can’t thank you enough and encourage you to continue giving that gift!

Thank you!
New Treatment Centre –

Exciting news from 2011 for those of you who may not have heard!!

The Thalassaemia Society of NSW has today welcomed Premier Kristina Keneally's announcement of $31.5 million to build a new Blood Disorder Centre at Prince of Wales Hospital. This Centre will provide world class treatment for life long sufferers of Thalassaemia, and other blood disorder diseases.

"This is a great initiative and one that we have been campaigning for, for a long time," Mrs Nancy Lucich, Co-ordinator of the Thalassaemia Centre said today. "These types of facilities exist overseas and in other States and now NSW has one too."

“This is a great relief for Thalassaemia patients across NSW who rely on life saving treatment to ensure they live normal, healthy lives.

“This new Centre is a big step in ensuring that we get a world class, one-stop treatment facility, where we can receive the attention of specialised doctors while we get treatment. I want to thank everyone who made this possible. For a long time we have been trying to get this Blood Disorder Centre up and running.”

“With good quality treatment, sufferers of Thalassaemia are able to lead normal lives. Professor Linderman stated. "For many patients the Prince of Wales has been a second home to them. It gives us great joy to see this Centre becoming a reality that will reduce the hassles of travel and treatment.”

“This state of the art Comprehensive Cancer and Blood Disorder Centre will bring together clinical and support services to help patients through their treatment. The centre will also enhance operational efficiency and provide a one stop shop for patients – reducing travel time between vital services.”

Survey – Thalassaemia Society of NSW

The Thalassaemia Society of NSW would like to say thank you to those patients or parents of patients who took the time out to complete the survey that the Society had developed.

The surveys were developed for the Society to get feedback and ideas on what the patients would like to see the Society work towards & the level of involvement that patients would like from the Society.

Members of the Society will be getting together to compile feedback from these surveys and to form some constructive outcomes.

We look forward to more involvement from our Patient and Parent group.

If you are interested in filling in a survey and did not receive one please contact the Centre Coordinator on 9550 4844 or email coordinator@thalnsw.org.au and one will be sent to you.
RECIPE
After School Delight

Ingredients
• 1 cup fruit (mango, pineapple, banana, watermelon, rockmelon, berries)
• 1 cup juice (apple, orange or pineapple)

Alternatively:
• 1 cup of fruit (as above)
• Additional extras: 1 cup of milk, 3 tablespoons of icecream or a small tub of yoghurt

Method:
1. Place fruit into blender and pour in 1/2 of the juice/milk
2. Add remaining ingredients
3. Blend until smooth. Add a little more juice if required.

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

Hi Kids!

It’s back to school time so have some fun colouring in this great picture and why not try our delicious & healthy fruit smoothy!

Q: Why did the jellybean go to school?
A: To become a smartie!

Q: What did the calculator say to the other calculator?
A: “You can count on me!”

Q: Why did the clock go to the principal’s office?
A: For ticking too much!

Enjoy!