



Thalassaemia Symposium

Sunday 6th August 2006 Brisbane

Coinciding with the 11th International Congress of Human Genetics also held in the Brisbane Convention Centre – Novartis kindly sponsored this Symposium covering topics including genetic research on Thalassaemia, prenatal diagnosis, population screening, treatment protocols and their efficiency, adherence and monitoring, and quality of life measures.

An outstanding collection of speakers presented their work and provided an informative overview on the advances in the scientific world of Thalassaemia, and the screening programs used.

Sr. Libby Reid, the Nurse Unit Manager of the state-wide Medical Therapy Unit, Thalassaemia Services at Monarsh Medical Centre in Melbourne captivated the audience of physicians, scientists and Thalassaemia community present with her vast experiences and techniques in facilitating compliance by individualizing care plans, continued care, partnership in care with the patients and advocating patient peer support.

An essay was heard written by a 16yr old boy, giving insight to his emotional needs as a patient, and the individualistic approach Sr. Reid used to provide the ideal support for him as he persisted with iron chelating and other treatment.

Parents traveled from all over Australia, New Zealand and Thailand to meet other parents, as well as representatives from pharmaceutical, diagnostic imaging, and research companies. Physicians and speakers were available after their presentations to answer questions from patients and their families.

8th May, International Thalassaemia Day at the Australian Red Cross Blood Service

On 8th May 2007, members of the Thalassaemia Society of NSW (ThalNSW) spent the better part of the day at the Red Cross Blood Service, Clarence Street, Sydney, promoting awareness of Thalassaemia, while personally thanking the many blood donors present for their generous gift of life for others.

Danny Stagnitta, the Marketing Team Leader for the Australian Red Cross Mobile Blood Service (pictured), stopped by for a quick introduction.



Maria Aravantinos, the President of ThalNSW, was overwhelmed by the commitment and enthusiasm shown by the many donors present that day, most of who regularly donate blood.

Left to right: Jane Lampitsi, Danny Stagnitta & Maria Aravantinos

upcoming events

- **Lunch for a Cause:**
RPA Thalassaemia Unit Revamp - Sunday 29th July 1.00pm at the **Cyprus Community of NSW** Stanmore
For tickets contact Maria or Dina (02) 98962749 or 0406754437, or E:Coordinator@thalnsw.org.au
- **See our new website at:**
www.thalnsw.org.au Support Services, Updates and Events

donations in memoriam

- **Phoebe Moustakas**
- **Sam Moustakas**
- **Giuseppe Franzoni**
- **Mary Lampitsi**

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- **Philanthropy at All Saints Grammar School** Belmore
- **"Shrek the Third" Movie Night** at Greater Union Burwood Westfield
- **Introducing the Thalassaemia Society of NSW Executive Committee 2006 / 07**

Text and photos should be supplied on disk or by e-mail to: coordinator@thalnsw.org.au
Story ideas and photos are welcomed.
Please call Jane Lampitsi on 02 9550 4844 regarding any newsworthy event you would like included in our publication.

It takes someone special to give blood

To become a blood donor visit www.donateblood.com.au or call 13 14 95

Message from the Thalassaemia Centre of NSW Coordinator

The Thalassaemia Society of NSW, (ThalNSW), now in its 29th year since its inception, is the chief fund raising body supporting the comprehensive Thalassaemia services at Sydney Children's Hospital, Randwick, Prince of Wales Hospital, Randwick, the Children's Hospital at Westmead, Westmead Hospital for Adults and the Royal Prince Alfred Hospital, Camperdown. It has also been instrumental in negotiating the optimal provision of service to the patients at these hospitals.

During that time the Society has witnessed a steady progress in the advancement of the treatment of Thalassaemia Major and other haemoglopathies including Sickle Cell Anaemia and Blackfan Diamond Disorder.

Research has played a crucial role in these changes, and ThalNSW has played an essential role in the support of research.

Studies of oral chelators have resulted in two oral chelators; Deferasirox (Exjade) and Deferiprone (Ferriprox) which are now available in Australia.

Desferal (Desferrioxamine) (by slow infusion 8-10 hrs nightly) is still being used by many patients,

though compliance by the older patients continues to be a concern.

Thalassaemia is one of the most common inherited genetic disorders worldwide. Anyone now living in Australia, regardless of his or her racial background is potentially at risk of inheriting Thalassaemia.

As reported in TIF Magazine, the official newsletter of the Thalassaemia International Federation (August 2006) the **“World Health Organisation (WHO) declares Thalassaemia a public health priority.”**

The Thalassaemia International Federation (TIF), was established in 1987 to improve awareness of thalassaemia and quality of life for thalasseemics. TIF is a Non Governmental Organization, in official relations with WHO since 1995.



The Coordinator, Thalassaemia Centre of NSW is responsible for the coordination of medical, nursing and allied health support services to all those affected by Thalassaemia Major, Sickle Cell Anaemia, Blackfan Diamond

Disorder and other haemoglobinopathies.

The coordinator's objective is the development and coordination of the health education programmes, while providing support to the Thalassaemia Society of NSW's Executive Committee.

ThalNSW provides funding for education, purchase of life saving equipment, research, as well as support for patients and carers of patients with Thalassaemia Major and other blood related disorders, and their families.

The Thalassaemia Centre of NSW's contact details are:

P: (02) 9550-4844

F: (02) 9519 3516

The coordinator can be reached on M: 0400 116 393, and

E: coordinator@thalnsw.org.au

See our new Website at:

www.thalnsw.org.au

A handwritten signature in black ink, which appears to read "Jane Rampitsoi". The signature is written in a cursive style.

**Thalassaemia Centre of NSW
Coordinator**

The Thalassaemia Society of NSW gratefully acknowledges the support of the Sydney South West Area Health Service for funding the position of Coordinator, Thalassaemia Centre of NSW

The Sounds of Silence.....interrupted

Vision Valley Retreat – 3rd to 5th November 2006

On Friday 3rd November 2006, Stringy Bark Lodge located at Vision Valley, was a haven of serenity no more, at least for the ensuing weekend.

Patients, families and friends had arrived for 2 days and nights of frivolous fun and fabulous activities including archery, and swimming for the brave.

The rain did not deter the incredibly fit who chose to enjoy their grueling run through the surrounding National Park.

For those who sought a more mind challenging pastime, the children were happy to oblige with their creative “Scooby” classes. For others who preferred a more competitive activity, the game of Rumikub was in full swing.

The weekend was a marvelous opportunity for all who had attended to enjoy good food and fabulous company, with the opportunity to spend this time being as active or as relaxed as one preferred.

It was a wonderful time spent catching up with friends and creating new friendships.

The Thalassaemia Society of NSW sponsored all patients (those with Thalassaemia Major, Sickle Cell Anaemia & other related blood disorders) who attended this fabulous retreat.

When a dream becomes reality

Arthur's dream has always been to become a teacher. In 2003 at the age of 42 Arthur made a start by completing a bachelor of Adult Education, which gave him the opportunity to teach part-time at Tafe in 2005.

Arthur didn't stop there. He



Left to right: Helen, Arthur, Nora & Dimitris Bozikas

commenced immediate post graduate studies specialising in Management, and in September 2006 he graduated with a Master of Management.

Arthur's dream came true due to the love and support from his family.

Arthur, we wish you to be always happy; that you continue to succeed in your goals, and to enjoy your family and your lives together.

We are very proud of you.



Jimmy, Helen, Arthur and Pamela

*(Story sent in by
Dimitris and Nora Bozikas)*

Thank you.....

Dinner Dance

The ThalNSW is very grateful for the tireless efforts of executive committee member Mrs. Maria Solomou, who was the driving force behind the organisation of the Dinner Dance held early last year at the Marana Auditorium at Hurstville Civic Centre. Special thanks to Perry from Pelopithas Catering who partly sponsored this function which raised \$13,815.

Philanthropy at All Saints Grammar School, Belmore

Early in April of this year the Coordinator, Thalassaemia Centre of NSW, was asked to speak to the year 12 students at All Saints Grammar School, Belmore on the topic of Thalassaemia, along with the aims and objectives of the Thalassaemia Society of NSW.

Most of the students were unaware of this genetic blood disorder, and many interesting questions and scenarios were covered.

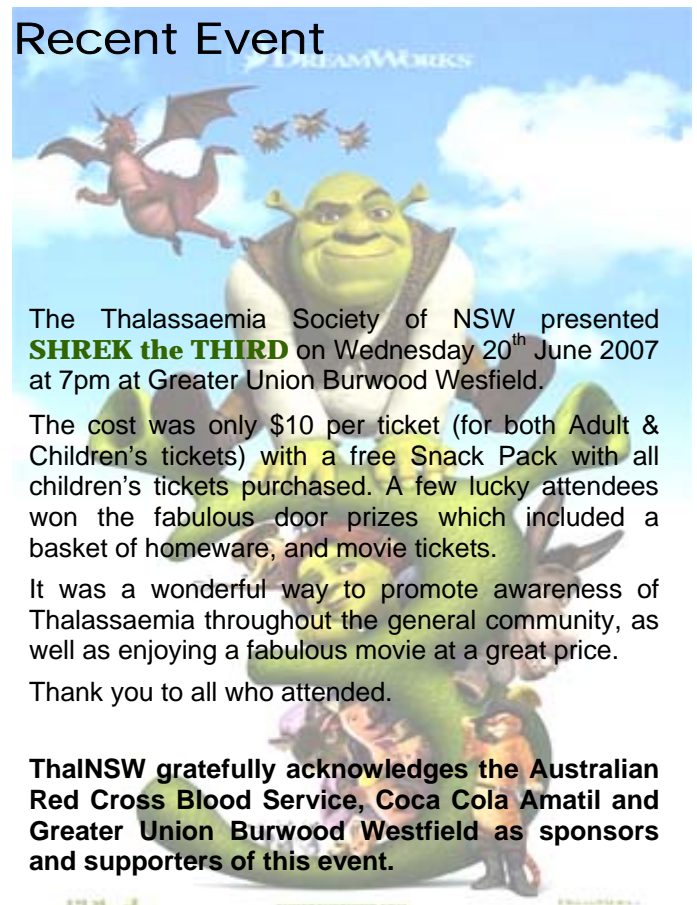
The need to donate blood was also discussed with the students as only 3% of the population regularly donates blood, and yet it is estimated that one in every three people will require the services of blood donations sometime in their lifetime. For Thalassaemia patients, regular blood transfusions are their lifeline.

ThalNSW would like to express their appreciation to Ms Antonia Kolotouros, the Year 11/12 coordinator of All Saints Grammar School for her kind invitation, and to the Year 12 Students of the school for their very generous donation of \$220 which they raised and donated to the Society as part of their school Philanthropic Program.

Greek Night

The Thalassaemia Society of NSW sincerely thanks Mrs Koula Sakellaris, who for the second consecutive year, organized a Greek Night at Red Martins, Sydney where the proceeds from the entrance tickets, an amazing \$2,850 was donated to ThalNSW.

Recent Event



The Thalassaemia Society of NSW presented **SHREK the THIRD** on Wednesday 20th June 2007 at 7pm at Greater Union Burwood Westfield.

The cost was only \$10 per ticket (for both Adult & Children's tickets) with a free Snack Pack with all children's tickets purchased. A few lucky attendees won the fabulous door prizes which included a basket of homeware, and movie tickets.

It was a wonderful way to promote awareness of Thalassaemia throughout the general community, as well as enjoying a fabulous movie at a great price.

Thank you to all who attended.

ThalNSW gratefully acknowledges the Australian Red Cross Blood Service, Coca Cola Amatil and Greater Union Burwood Westfield as sponsors and supporters of this event.

Introducing the Thalassaemia Society of NSW's Executive Committee for 2006/07

The Thalassaemia Society of NSW's AGM was held on Sunday 23rd Sep 2006 with the following members being duly elected to the Executive Committee

- | | | | |
|-------------------|--------------------|-------------------------|---------------------|
| Chairman: | Theo Matsas | Press Secretary: | Maria Skarparis |
| President: | Maria Aravantinos | Vice President: | John Alaveras |
| Secretary: | Helen Matsas | Asst. Secretary: | Marianne Dimitrakas |
| Treasurer: | Carol Fotheringham | Asst. Treasurer: | Rosa Dimitrakas |

and the Executive Committee members, (in alphabetical order):

David Bradshaw, George Houssos, Rita Ioakimidis, Courtney Roche, and Maria Solomou

Australia needs you four times a year!

The gap between the number of blood donors and the number of Australians who need blood is set to widen, unless Australians step up their efforts as blood donors.



Call 13 14 95 for an appointment.

Support the work of the Thalassaemia Society of NSW

Our Membership fees for the 2006/07 financial year are now due. All new members are welcome to join.

- Yes..I would like to become a **Financial Member (\$20)**
- Yes..I would like to become a **Lifetime Member (\$200)**
- Yes..I would like to become a **Lifetime Family Member (\$400)**
- Yes I would like to **donate \$**_____ Donations of \$2. and over are tax deductible

Title _____ Given Name _____ Surname _____

Address _____ State _____ Postcode _____

Phone (H) _____ (W) _____ Mobile _____ Email _____

- My cheque/money order is enclosed Please charge my credit card: Name on card _____
- MasterCard Visa Expiry Date: ____/____

Credit Card Number:

Cardholder's signature: _____ Date:...../...../.....

Information & Privacy Policy

The Thalassaemia Society of NSW will use your information for the purpose of data processing, receipting of donations and to keep you informed of our programs and services.

If you wish to remain anonymous please tick this box (By remaining anonymous a Tax Receipt cannot be issued).

PLEASE COMPLETE THE FOLLOWING AND RETURN IT TO: **THE THALASSAEMIA CENTRE OF NSW**
PO Box M120 Camperdown 2050

To unsubscribe from this newsletter, or if you would prefer to receive the newsletter by email, please contact ThalNSW on 02 9550 4844. or send an email to Jane Lampitsi at coordinator@thalnsw.org.au

The Thalassaemia Centre of NSW

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