



newsletter

ISSUE 01 WINTER 09

International Thalassaemia Day

May 8th has been designated by the World Health Organisation as International Thalassaemia Day.

We take this opportunity to recognise and thank all who have, and will continue, to give hope and inspiration to our friends living with thalassaemia, while remembering those we have lost.

YEAR OF THE BLOOD DONOR 2009

The Australian Red Cross Blood Service has launched a major recruitment drive in 2009 Year of the Blood Donor to recruit more than 100,000 blood donors to meet the anticipated doubling of demand within the next 10 years.

A key part of the drive is the Year of the Blood Donor Travelling Exhibition which opened on 15th March 2009 for a Family Day at Customs House, Circular Quay. The four-day exhibition included a free and easy finger-prick blood typing service and highlighted the special relationship between blood donors and recipients.

Australian Red Cross Blood Service Operations Manager (NSW/ACT), Garry Wolfe said lack of awareness of blood type and its importance in medical treatment is a major barrier to blood donations in Australia.

“Blood types may be vast numbers of people you are giving someone second chance at life.

“We know that blood type, and the individual’s blood recipient, motivates regular donors.

As well as blood typing, the unique relationship and recipients through a stories.



different, but they link together. By giving blood else just like you a

increased awareness of relationship between an donation and the people to become

the exhibition highlights between blood donors series of personal

“We need all types of blood. Every drop is valuable. And we need more blood donors.”

Mr MD Faisal, an Executive Committee Member of the Thalassaemia Society of NSW was invited to attend as a blood donor recipient representing his lovely young daughter who has thalassaemia major and who requires monthly blood transfusions to survive and thrive.

Mr Faisal was delighted to be able to personally thank blood donors who generously donate blood, giving the ‘gift of life’ to his child.

The **Thalassaemia** Society of NSW supports The **YEAR OF THE BLOOD DONOR 2009**

Do something special. Give blood.

Call **13 14 95** or visit donateblood.com.au



upcoming events

- POWH Focus Group 20th Aug
- AGM 27th September 2009
- See www.thalnsw.org.au News for future events

donations in memoriam

We gratefully acknowledge donations received in memory of:

- Mr Ugo Buracchi

in this issue

- International Thalassaemia Day
- Year of the Blood Donor
- Information Evening Update
- A Celebration of Life – Peter is ‘fabulous at 50’
- Taverna Night May 8th
- Thank You
- POWH Focus Group
- Support the work of the Society

Thalassaemia Society of NSW Inc. gratefully acknowledges long time sponsor and supporter



Story ideas and photos are welcomed. Please e-mail coordinator@thalnsw.org.au or phone (02) 9550 4844 regarding any newsworthy item or photos you would like included in our publication.

past events

Information Evening Update 26 February 2009

Over 80 patients, carers and clinicians attended the Information Evening held on Thursday 26th February 2009 at Burwood RSL Club.

Guest speakers Dr Rob Lindeman from the Prince of Wales Hospital spoke of the "T2 Star (MRI), and Dr Vasili Berdoukas OAM, spoke on "How do we tailor iron chelation today".

The Thalassaemia Society of NSW would like to express its gratitude to our dedicated speakers Dr Lindeman and Dr Berdoukas for once again giving of their time for the benefit of our members, as well as Burwood RSL Club for kindly supporting this event.



(Pictured: Speaker Dr Rob Lindeman and attendees)

A Celebration of Life..... Peter is 'fabulous at 50' as reported by Jane Lampitsi

It was a special evening for Peter Karamihalidis, his lovely wife Amanda, and children Michael and Ally who were joined by the family's many friends and family to celebrate Peter's 50th birthday.

Enjoying the nights festivities was Sister Sue Shaw (pictured below left with her husband Rolfe), who had devotedly cared for Peter and other thalassaemia major patients at the Royal Alexandra Hospital for Children at Camperdown for a period of ten years.

That evening, Peter spoke of enduring friendships spanning over 40 years, and told many anecdotes resulting from his journey with the treatment of his blood disorder.

This milestone was especially significant for Peter, and it was a privilege to be invited to share this '**celebration of a lifetime of good friendship**'.



(Pictured L to R) Peter, Amanda and their children Ally & Michael)

Celebrating a lifetime of friendship spanning three generations



Taverna Night Friday 8th May as reported by Martha Gerolemou

A sold out event weeks before the function, was the key to the success of the evening. A great time was had by all with some sore legs from all the dancing that took place.

The Society wishes to apologise to our supporters who were not able to obtain tickets due to the sell out event.

Please see www.thalnsw.org.au for the next Taverna Night which we will endeavour to hold in the near future.



Seafood for the evening kindly donated by Seafood@Hornsby

Thank you

A big "Thank You" to the Year 11 students at All Saints Grammar School for inviting Jane Lampitsi, Coordinator of the NSW Thalassaemia Centre to their school on Tuesday 7th April 2009, and allowing her the opportunity to inform them about the Centre and the role the Thalassaemia Society of NSW plays in the community.

The Society is also very appreciative of the student's generous donation of \$250. as their vital programs are supported through the proceeds of the Society's fundraising events and the generosity of their donors.

A Social Afternoon was held on Sunday 26th May 2009 at the home of Jane Lampitsi.

A small group of mothers, patients and friends enjoyed a complimentary afternoon tea which included rum balls and other delicacies prepared by Christine Mihos.

Ms Carlien Smithuis from Learning Ladder kindly donated \$81. from the sales of the fabulous books on display, while additional donations on the day totalled \$365.

Thank You Members!

A big "thank you" to our members who have applied for, or renewed their membership for 2008/09.

Maintaining a healthy membership gives us strength when advocating for thalassaemia, sickle cell anaemia, blackfan diamond and other haemoglobinopathies

When
Thursday 20th August 2009
From 6 – 7.30pm

Where
10 West Tea Room

Would you like to share your experiences of services at Prince of Wales Hospital?
Your feedback will help us to help you

Any queries please contact Emily Allen – Thalassaemia/Transfusion CNC on 02 9382 4982 or Emily.Allen@scs.health.nsw.gov.au

POWH Patient Focus Group

for thalassaemia & sickle cell patients at Prince of Wales Hospital

The Thalassaemia Society of NSW gratefully acknowledges NSW Health / SSWAHS for funding the NSW Thalassaemia Centre and the position of Coordinator

Proudly supporting thalassaemia research at the



**BE THE TYPE
TO HELP SAVE A LIFE**



Tina, blood type B, relies on donations for her monthly transfusions.

Support the work of the **Thalassaemia** Society of NSW

Become a member and / or make a donation

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

Title _____ Given Name _____ Surname _____

For Family Membership, please name other family members: _____

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 If you wish to remain anonymous please tick this box

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