



newsletter

ISSUE 02, 2008

The Thalassaemia Society of NSW presents \$20,000 for research at 30th Anniversary dinner dance

30 years ago, a group of doctors, parents, siblings and older patients with thalassaemia major and sickle cell anaemia met at the Royal Alexandra Hospital for Children at Camperdown, and formed what was to become the Thalassaemia Society of NSW (Incorporated in 1979).

These parents, friends and professionals came together to provide support for each other and to find ways of improving patient care by raising funds to purchase medical equipment, furniture for patient comfort, and to research new therapies.

From those early days, much advancement has been made in the treatment of thalassaemia, sickle cell anaemia, blackfan diamond and other related blood disorders.

The Society's ultimate goal has long been to find a cure, while giving hope and inspiration to those living with thalassaemia and other haemoglobinopathies.

To celebrate three decades of the Society's achievements, a Masquerade Charity Dinner Dance was held at the Grand Roxy on Saturday 30th August 2008.

During an evening of fun, frivolity and surprises the President of the Society, Maria Aravantinos, presented a cheque for \$20,000 to a delighted Dr Jim Vadolas from the Murdoch Children's Research Institute.

Dr Vadolas, Group Leader, Cell and Gene Therapy Group, MCRI, spoke of thalassaemia being a global health problem and that to find a cure required commitment and compassion. He stated that "he was very grateful to the Thalassaemia Society of NSW for their ongoing support towards the MCRI's thalassaemia research", and asked everyone to be generous not only on that night, but also throughout the year, in a true spirit of community solidarity.

Proceeds from the evening will also be used for the Society's patient support services.



Proudly supporting thalassaemia research at the



Thalassaemia Society of NSW gratefully acknowledges long time sponsor and supporter



upcoming events

- International Thalassaemia Day 8th May 2009
- See our website at: www.thalnsw.org.au News for future events

donations in memoriam

We gratefully acknowledge donations received in memory of:

- Michael Kyriakou
- Severino Scarfo
- Mary Lampitsi

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Happy New Year

May 2009 be filled with

Health, Peace and Happiness

Story ideas and photos are welcomed. Please e-mail Jane Lampitsi at coordinator@thalnsw.org.au or phone (02) 9550 444 regarding any newsworthy item or photos you would like included in our publication.

Weekend Camp at Vision Valley

30th November to Sunday 2nd December 2008 as reported by *Ginetta Diblasi*



Excitement was in the air as most guests arrived Friday afternoon, ready for a weekend of fun and games with little sleep expected.

Being Halloween, the evening began with the resident friendly witch, Maria Sk handing out lollie bags to the children while entertaining us with her groovy dance moves to the beat of "Thriller". She had us all laughing.

Friendships were rekindled with one of our Thal patients from Melbourne, Maria, and her 14yr old son Theodore attending the camp. Theodore tried so hard to out beat me in scare tactics and silly antics!! What a sweet young boy. We were also honored with the presence of our dear friend and past Thalassaemia Social Worker, Chris Hardy, who sang a love ballet on sing star with me.

Helen and Martha sang wonderful duos together with the assistance of Nancy and Marianne, our very talented backup dancers and vocals. In competition was handsome young Mohamed, a 13 yr old sickle cell patient. Surely the next top Video Hits star!!!! He also played a tough game of Connect 4, beating the adult players!!!!

Rummikub was a favourite game among the girls; with many strategies used to out beat each other.

Meanwhile, the older women, (our wonderful mums) were in one corner of the table competing with each other with their very serious card games, very nearly outlasting the youth in staying up power.

With food there was no beginning and no end. Breakfast began at 8am but junk

food was still being consumed until 3.30am from the previous evening. Oops, breakfast in 4 ½ hours!! We had to stop the munchies to make room for bacon, eggs, hash browns, toast and a selection of 3 – 4 cereals once again. Maria S, Yvonne & Jane arrived at 7.30 am Saturday morning to join us for the fabulous breakfast!!

During the weekend, Chef Ramsay had no chance as the lovely Dina gave us all a Greek style cooking lesson by teaching us the delicate process of making almond, Sesame Seed and Honey Snaps. They were very sweet, very delicious and we even had doggy bags to take home. May I say the cooking demonstration was carefully monitored by OH&S food standard's (by me), ensuring utensils and equipment were clean at all times.

On Saturday, some of the youthful patients enjoyed themselves on the very daring waterslide. You ask why daring? With Theodore coming down like a roaring thunder it was MOVE OUT OF THE WAY or BE BOWLED UNDER!! Oops, poor Martha was way too slow trying ever so hard so stand up and move out, but without her knowledge, Johnny slid down knocking her backwards. Down she goes! Quick get up! Here comes the roaring thunder (Theodore). Oops, too late... This time poor Johnny & Martha were both bowled over. Carol, one of our daring mums, took the challenge to join in the fun on the slide.

Another of the sporting challenges of the weekend was Archery. Arrow's were flying everywhere hitting the ground and the trees; however some did manage to

hit a bull's eye!! It was lots of fun for everyone.

Table tennis was no match for Chris Lianis who seemed to show everyone his skills and talents, even though part of the game was played with DVD covers.

The weekend was filled with lots of fun, friendship, food and games. There was something for everyone, both young and older.

Angelique (9), Vittoria (8) and Sarah (9) enjoyed it all; the sing star, the games played, little sleeps and lots of fun. Sweet little Nicholas, only 2yrs old and with so much energy, sang and laughed all weekend until the very late hours of the night.

The weekend ended with the group quietly relaxing and reminiscing past Society events while seeing how much we have all changed. Mmmmm.... thank goodness the blonde streak mop hairdo is out.

So for next time please don't miss out, come along, join us and experience the connection we all had. Everyone is welcome.

Ginetta Diblasi
Thalassaemia Patient

A special thank you to Saras Domingo, Clinical Nurse Specialist from the Children's Hospital at Westmead, who joined us for a few hours Saturday, even though she was flying overseas Monday morning.

The Thalassaemia Society of NSW sponsored all NSW patients to attend the Vision Valley weekend camp as part of its ongoing commitment to patient and family support



Xmas Picnic 2008
Fabulous fun for all



**For patients,
families and friends**

Thank you

Leo Club Oatley held a fundraiser



Sausage Sizzle and from the proceeds, **donated \$800** (in April 2008) to the Thalassaemia Society of NSW for the purchase of a flat screen TV for patients undergoing regular transfusions in a treatment centre. Thank you so much. Your support is very much appreciated.

International Thalassaemia Day
8th May 2008. Thank you to the following



volunteers who manned the thalassaemia information stand at Westfield Burwood during May 2008 on 2 separate occasions: (L-R) Maria Aravantinos, Rosa Dimitrakas, Marianne Dimitrakas and MD Faisal. (Tracey El-Bayeh, Yvonne Phokos and Jane Lampitsi not in photo).

AON Charitable Foundation, in recognition of service of their employee Mirsina Houvdas, donated \$500 to her favourite charity on her behalf. Thank you.

All Saints Grammar School invited Jane Lampitsi to speak to the Year 11 & 12 students at their Philotimo Day about thalassaemia and the work of the Society. Thank you students for your kind donation of \$450.

An Information afternoon was held on Sunday 21st September 2008 preceding the Society's AGM.

Thank you **Dr Rob Lindeman** from POWH for taking precious time away from your family to not only speak to the many interested patients, family members and friends who attended, but to also make yourself available for questions afterwards.

30th Anniversary Masquerade Charity Dinner Dance
30th August 2008

The Grand Roxy, Brighton-Le-Sands was the perfect venue for the Masquerade Charity Dinner Dance which celebrated the 30th Anniversary of the Thalassaemia Society of NSW.

The Society wishes to express its heartfelt thanks to **Bill Mougious** who generously sponsored part of the cost of the venue for this event.

A very special thank you to **Chris Skiladellis, Master of Ceremonies** for the evening, and sincere thanks to **Tom Panos, Real Estate Auctioneer** who very generously donated his fabulous skills for the evening, and to our **delightful violinist, Ms Chantel Benbow**.

Thank you to all who attended and gave generously to this very worthwhile cause. A special mention to the **Philoptochos and Friends Rookwood** for their generous donation of \$450.

Christmas Picnic at the Beach
Sunday 30th November 2008. Over 100 patients, family members and friends attended the fun-filled Christmas Picnic held on Sunday 30th November 2008 at Dolls Point.

Much work behind the scenes is required for an event to be successful.

Thank you to our young chefs **Nick Aravantinos** and **John** (Martha Gerolemou's brother) who ensured that the sausages and onions were cooked to perfection, as well as transporting food, drinks, the BBQ and other necessities to and from the venue.

Belmore Continental Bakery, Blooms the Chemist Padstow, CSA Designer Kitchen's & Detail Joinery, DFG Pty Ltd, Hawkins Butchery & Quality Foods, Hellenic Bakery & Cakes, Maria Solomou and Rydges Bankstown are also gratefully acknowledged as sponsors and supporters of this event.

Christmas Gift Bags
206 gift bags were distributed in December 2008 to all our transfusion dependent patients undergoing treatment in hospital for the month preceding Christmas.

A big "thank you" to **Greater Union Burwood** for their very generous donation of **discounted movie vouchers, McDonalds Café Camperdown** for the donation of **VIP vouchers**, and **Woolworths Strathfield** for their generous donation of a **gift voucher** used to purchase "munchies" for inclusion in the gift bags.

The Christmas Gift Bag is an initiative of the NSW Thalassaemia Centre, **generously supported by the Thalassaemia Society of NSW.**

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.

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

The Thalassaemia Society of NSW is proudly supported by



Greater Union Burwood



as well as our sponsors and supporters for 2008 (listed alphabetically)

Adora Handmade Chocolates
All Saints Grammar School
Avery Dennison
Arthur's Pizza Paddington
AON Charitable Foundation
Atlantis Seafood Restaurant
Belmore Continental Bakery
Blooms the Chemist Padstow
Breville
Bridgeclimb Sydney
Captain Cook Cruises
CEVA Logistics
Chantel Benbow - Violinist
Chris Skiladellis
Colleen from Nutrimitics
Crosby Textor Research Strategies
Results Pty Ltd

CSA Designer Kitchens & Joinery
Cyprian Community Club Stanmore
DFG Pty Ltd
Dawn Fraser
Diethnes Greek Restaurant
Ensemble Theatre
Father John & Prespytera Penny Gryllis
GMV Cleaning Services
Greater Union Broadway
Greater Union Hornsby
Greater Union Bondi Junction
George Miller - Oscar winning Director
Halime El-Afshal
Hawkins Butchery & Quality Goods
Hellenic Bakery and Cakes
Hellenic Club Canberra
Hoys

Imax Theatre
K & A Jewellery
Karen Janssen
Kitsa Mihalopoulos
Lipsian Brotherhood
Maria Solomou
MacoPharma
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Nia Makris
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Otter Press
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Penrith Powerhouse Dick Smith Elect
Philoptochos and Friends Rookwood

Purezone DFO Homebush Bay
Random House
Rydges Bankstown
Strathfield Auto Electrical
Studio 275 Art Framing Gallery
Seafood @ Hornsby
Sunbeam
The Grand Roxy
Tim Campbell
Tom Panos- Auctioneer
Web Sessions
Wests Ashfield Leagues Club
Woolworths Strathfield
Zoological Parks Board of NSW

Introducing ThalNSW's Executive Committee for 2008/09

The Thalassaemia Society of NSW's AGM was held on Sunday 21st August 2008 with the following members being duly elected to the Executive Committee.

- | | |
|--------------------------------------|--|
| Chairperson: Martha Gerolemou | Press Secretary: Theodora Michalopoulos |
| President: Maria Aravantinos | Vice President: George Houssos |
| Secretary: Courtney Houssos | Asst. Secretary: Marianne Dimitrakas |
| Treasurer: Yvonne Phokos | Asst. Treasurer: Rosa Dimitrakas |

and the Executive Committee members, (listed alphabetically):

Kelly Abrakasa, Ginetta Diblasi, Halime El-Afshal, MD Faisal, Nancy Lucich, Christine Mihos and Maria Solomou

BE THE TYPE TO HELP
SAVE LIVES THIS
FESTIVE SEASON



This relies on blood type O for her monthly transfusions, however donations of all blood types are needed this festive season.

Do something special. Give blood.
Call 13 14 95 or visit donateblood.com.au



Raffle Sellers Promotion



Thank you to all our Raffle Book Sellers who assisted in making our Major Raffle 2008 the success that it was.

To show our appreciation for their fabulous efforts, for every 50 raffle books sold (\$500 raised), the following have been awarded a Greater Union complimentary movie voucher, and for every additional 25 raffle books sold (\$250 raised), 1 discount movie voucher has been awarded.

Complimentary Movie Vouchers kindly donated by Jane Lampitsi In Memory of Mary Lampitsi, and Discount Movie Vouchers donated by Greater Union Burwood.

- | | |
|---------------------|--|
| Maria Solomou | 4 complimentary movie vouchers |
| Dina Aravantinos | 2 complimentary & 1 discount movie voucher |
| Maria Matsas | 2 complimentary movie vouchers |
| Kitsa Mihalopoulos | 2 complimentary movie vouchers |
| Nia Makris | 1 complimentary & 1 discount movie voucher |
| Amal Chemuel | 1 complimentary movie voucher |
| Marianne Dimitrakas | 1 complimentary movie voucher |
| Niki Lampitsi | 1 discount movie voucher |

Support the work of the Thalassaemia Society of NSW

Become a member 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 _____

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:..../...../.....

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