



Thalassaemia

A U S T R A L I A

Unifying support and genetics

Thalassaemia Australia Autumn 2013 Volume 5 Issue 15

Quarterly



Thalassaemia Research at the Murdoch Childrens Research Institute

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Murdoch Childrens Research Institute (MCRI) located in Melbourne, is Australia's largest child health research institute. As a national, independent and non-profit organisation, Murdoch Childrens is leading the way in child health research.

The MCRI attracts excellent clinicians, scientists and academics from all over the world to create a dynamic environment where medical problems can be investigated. A team of over 1500 researchers focuses on combating emerging conditions affecting child health like allergy, diabetes and obesity, as well as finding answers to unsolved problems like cancer and genetic conditions.

I joined the MCRI in 1999 and with a series of awards and grants allowed my vision in thalassaemia to become an integral part of my scientific career. Current therapies for thalassaemia depend on restoring the body's ability to produce haemoglobin,

which would end the need for regular blood transfusions and prevent subsequent complications. Although improved blood transfusion and iron chelation therapy have resulted in a brighter outlook for thalassaemia patients, this is not the case for the tens of thousands of patients born worldwide each year that do not have access to blood or chelation therapy.

My thalassaemia research is driven by key priorities, which include the development of safer and more effective therapies for patients. One approach involves gene therapy – introducing healthy copies of genes into patients' blood stem cells. This therapy has proven harder to implement than previously thought. Safer and

(Cont. page 2)



Thalassaemia Australia Inc.

Committee of Management 2013

Executive

President – Spiro Bombos
Vice-President – Mary Triantafyllou
Secretary – Mary Konstantopoulos
Treasurer – Sotirios Katakouzinou

General Committee Members

Dr. Jim Vadolas
Bessy Mougos
Julie Christopher-Costa & Billy Costa
George Ambatzidis
Helen Kosmarikas
Amin Hasmat
Julie Dascoli

Committee meeting dates for 2013

Committee of Management meetings begin at 7.30pm and are held at the Thalassaemia Centre, 333 Waverley Road, Mt Waverley 3149

16 July	15 October
20 August	19 November
17 September	17 December

All welcome!

Dear Members and Readers, if you would like to receive your newsletter via email, rather than in the mail, please contact Thalassaemia Australia at: info@thalassaemia.org.au or Thalassaemia Society of NSW at coordinator@thalsnw.org.au to update your records!



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Thalassaemia Research

(Cont. from page 1)

more efficient ways of delivering replacement genes directly to patient stem cells are required. Research is also needed to keep the introduced gene intact and retain its normal function. We are aware of the current limitations of this technology and are committed to addressing these issues.

Throughout my career, I've seen an enormous benefit working along with national and international experts to solve the challenges at hand. Every day I see evidence of our collaborative efforts making a difference. Much of what we have achieved is via the support and development of students as well junior researchers in their scientific careers. Currently, my lab is hosting 2 PhD students, Ms Panjaree Siwaponanan and Ms Tiwaporn Nualkaew from the Thalassaemia Research Centre, Bangkok, Thailand. This is part of an ongoing collaboration with Prof Suthat Fucharoen and Dr Saovaros Svasti. We have also enrolled Ms Betty Kao from New Zealand. She is into her second year of her PhD and more recently, Mr Mark Roosjen, from Van Hall Larenstein, University of Applied Sciences, the Netherlands completed his internship. In my experience, international exchange is fundamental to the development of global networks

for research training with the aim of improving thalassaemia research and development of better therapies for the future. What we have achieved as a research group would not have been possible without the kind financial and personal support I've received over the past few years. Ultimately, fostering the environment that promotes scientific excellence when adequately funded drives discovery and innovation. I've been very fortunate to receive philanthropic support from Thalassaemia Australia and Thalassaemia Society of NSW, including organisations and interested individuals such as the Greek Conference, which allowed my group to gain the resources and capabilities to develop our thalassaemia research program. With your ongoing help, we can be certain that our pursuit will continue and gain in strength.

Importantly, most of our research is published in scientific journals and presented at national and international meetings. This year I'll be attending the 13th International Conference on Thalassaemia and Haemoglobinopathies at the end of October in Abu Dhabi. I'll be presenting our recent work specifically focusing on the reactivation of foetal haemoglobin synthesis. I look forward to seeing you there!

Thalassaemia Australia Inc. is on Facebook

Like us to receive updates regarding our community awareness program and access links to important websites.
<http://www.facebook.com/pages/Thalassaemia-Australia-Inc/198157430216491>



Thalassaemia Australia Inc. acknowledges the support of the Victorian Government.

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.

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All content presented in this newsletter has been independently prepared by Thalassaemia Australia.



Haemoglobin Registry Monash University

By: Ri Scarborough, Project Officer, Haemoglobinopathy Registry, Monash University

In the last few decades, huge advances have been made in the diagnosis and care of haemoglobinopathies (thalassaemia and sickle cell disease), but surprisingly little information is available about Australians currently living with these disorders.

There are lots of very important basic questions that doctors do not have the answers to, such as:

- How many Australians have a haemoglobinopathy?
- What kind of treatment/s are they receiving?
- What complications do they have from the disease, and from the treatment for the disease?
- What are the long-term outcomes for these people?
- How do patient outcomes in Australia compare to outcomes in other countries?

Monash University's Transfusion Research Unit is establishing a national database of patients with a haemoglobinopathy, called the Haemoglobinopathy Registry, to help answer these questions, and form

a framework for more detailed research in the future, which will benefit current and future generations of Australians with these diseases. We hope to have the registry up and running in the second half of 2013 and will continue to collect information for at least 5 years.

The Haemoglobinopathy Registry is very pleased to have the support of Thalassaemia Australia and Thalassaemia International Federation.

Patients at participating hospitals around Australia will be asked by their treating doctor to participate in the registry. This would normally happen during an outpatient appointment or a hospital admission, and with the patient's permission, the doctor enters their details into the secure database. After the initial information has been gathered from

each patient, the doctor will be asked to update the database every 6-12 months, or whenever there is a significant event for that patient, so researchers can see what is happening with patient groups over time. Privacy and security of patient information is treated with the highest priority, and only the treating medical team and the researchers at Monash will have access to identifiable information. Patients can withdraw from the registry at any time.

Every patient who agrees to participate in the registry will form a piece of a large jigsaw puzzle, and the more pieces of the puzzle we can include, the clearer and more helpful the final picture will be. So we hope that you, too, will support this important research, and say YES! when your doctor asks you to be part of the registry.

Blood Balance Fundraiser

Hi my name is Nick and I'm the creator of "Blood Balance". I have been involved within the thalassaemia Community for many years, one could say I had a very strong attachment within the inner circles.

Now days I simply want to give back what I once had – support and hope for a better future. Let me ask everyone can dreams come true. I would say yes that they can and if you are to ask me why. Actually my dream came true when I was cured of Thalassaemia Major.

If you ask me how my dream came true. It came through my sister who shared my vision and not only gave me her bone-marrow but also the strength to accomplish my dream. So I say yes dreams do come true. Now I want to share another dream I have. My dream is that Thalassaemia is cured for everyone not compromised but actually non-existent.

Three years ago I met Dr Jim Vadolas from Murdoch children's Research Institute. Who is a well-recognised researcher within the Thalassaemia world both locally and internationally. On 3 November 2012 "Blood Balance" organised an event called ride the loop, were 40 cyclists rode around the lake in Canberra to raise awareness of thalassaemia and as a result \$1580 was donated then on 25 May 2013 we held a "Taverna Night" fundraiser.

The night booked out quickly and raised \$5800 giving a total of \$7380. Dr Vadolas attended the event and spoke about the research he is doing. where the money raised for this event were donated to.

A special thank you needs to go to Patty Giorgio who helped me organise the events and to all the sponsors who made the event possible:

Driveday.com, Giorgio's Hair & Beauty, StraightLine Ski and Scuba, Caphs Manuka, Exquisite Jeweller's, All Books For Less, DJ KRAZY Kon, Napoleon Makeup, Adora Chocolates, Hoyts, Rebel Sport, Beutopia, Holli Grove, Coffee Club, Elite Meats, Schwazkopf Professional, Diamond Design Jewellery, Bobby's Barbers, DJ Stavros, 16yo Strato and his band, OStratos Taverna.



Community Education and Advocacy

For Thalassaemia Australia, it has been a busy few months with being out and about within the community raising awareness about thalassaemia and other haemoglobinopathies. We have been doing the rounds and presenting to various schools within Melbourne and we would like to take this opportunity to thank those schools for inviting us to come out and present to their students.

Our school program is designed to tie in nicely with the secondary school curriculum within science/biology Year 10 – Year 12. According to the feedback we have received the students find our presentation very informative and also very inspirational.

It is our aim to encourage the students to think about becoming blood donors, IF they had not thought about it before, also to be screened for genetic conditions such as thalassaemia. During the recent months, we have presented to the following schools/organisations: -

- Flinders College
- Nazareth College
- Antonnine College
- Strathmore Secondary College
- Strathcoma Secondary College
- Lyndale Secondary College
- Sacre Ceour College
- Mentone Girls Grammar
- Sacred Heart College – Geelong
- Southern Health – Transfusion
- Nurses Workshop
- Country Woman's Association

TA also celebrated Rare Disease Day – on February 28th and with Genetic

Support Network of Victoria, a great meeting was had by all with the launch of new support group for Primary Ciliary Dyskinesia (PCD).

You may be aware that we currently have two students with us once again from Monash University, please see their article.

Monash University Community Based Placement students and Thalassaemia Australia

Hi, we are Dustin and Sukarnan, 2nd year medical students at Monash University and currently we are fortunate enough to have our community based placement at Thalassaemia Australia, which gives us the opportunity to understand the importance of health promotion alongside the roles of a doctor in treatment of Thalassaemia.

At first, we both had very little experience and knowledge in Thalassaemia, and this program, thus far, has given us a greater understanding of this genetic blood disorder in terms of the impact it has on the patient and also on the community.

We have learnt that this organisation promotes health and gives awareness to the community about this blood disorder as it is not commonly known as other health conditions such as diabetes or cardiovascular disease.

The program also helps people who have already been diagnose, in terms of giving support networks, information and services available to them that they might not be aware of.

Our experience thus far with Thalassaemia Australia have shown the diverse network that this organisation is involved in, from the different support and information in medical therapy units at Monash Medical Centre, working with the Murdoch Childrens Research institute to find a cure for Thalassaemia, as well as educating the younger generations in high schools to give a greater understanding of this blood disorder in the wider community.

We hope to learn as much as we can while on this placement, and look forward to keeping you up to date with our experiences in the near future.

General Practice Exhibition and Conference (GPCE) – Melbourne 2013

In November 2013 Thalassaemia Australia will be taking part in the General Practice Exhibition Conference being held in Melbourne.

This will be our opportunity to liaise directly with GP's and Practices Nurses and update them on thalassaemia and

other haemoglobinopathies in both the exhibition and workshops.

Advocacy: National Disability Insurance Scheme and genetic conditions forum – 23 July 2013

The CIA will be holding an information session at a city venue on the impact of the NDIS on people with genetic conditions and chronic illness.

Come along and hear how the NDIS might impact on your service delivery and together we can formulate strategies to meet the

demands of this new era. Dr Jane Tracey – The Centre for Developmental Disability Health School of Primary Health Care at Monash University will present her views.

Visit www.chronicillness.org.au for more details.

In the Media

Over the last few months thalassaemia has received some much needed publicity in the media. Here is a copy and links to just some of the articles that have featured members of our community.

Thalassaemia Australia also made its YouTube debut courtesy of Mates on a Mission http://www.youtube.com/watch?feature=player_detailpage&v=YZN1KmCyuZk – The Publican Group Melbourne and Perth Blood Donor Drive, which recruited 96 new blood donors – a great response.

LAYLA Costa, 4, knows the Royal Children's Hospital far too well.

A genetic condition means the Port Melbourne girl needs life-saving blood transfusions every three weeks and medication to control her iron levels.

But while the treatments can make her "a bit grumpy", nothing can stop Layla from enjoying life.

Our photographer took this picture of Layla just minutes after her latest transfusion on Wednesday.

On Sunday, she joined the Run For the Kids, which supports the annual Good Friday Appeal.

Family friend and Citylink employee Adrian Ciarrocchi, who ran with Layla and her family in the 5.5km event, said Layla was an inspiration.

"I saw her do it last year and thought 'if she can do it, I can,'" Mr Ciarrocchi said. "She's so full of life, boisterous and vocal most days you would never know she has this condition."

Almost 300 employees from Citylink, which is based in South Melbourne, joined the Run for the Kids.

Thalassaemia Major affects the red blood cells, stopping them from transporting oxygen.

Layla's mum Julie Costa wants to raise awareness about the disorder, which has a one-in-four chance of being passed on if both parents are carriers.

Parents-to-be can find out their risk by having a blood test. She also wants to give back to the Royal Children's Hospital.

The appeal raised nearly \$16 million last year.

Donations: Good Friday Appeal

Leader Community ePaper

Hotel BBQ to support young boy

STAFF and patrons of a Melbourne hotel have banded together to support an employee's young son as he battles two inherited blood diseases.

People met at The Wharf Hotel in the CBD last week for a barbeque, awareness and fundraising event for Jared Bombas, whose father Spiro works at the hotel.

The four-year-old relies on blood transfusions to combat the effects of thalassaemia and sickle cell anaemia and 59 people pledged to give blood at the event.

His mother Helen Kosmarikas said she was "overwhelmed" by the support.

"He was diagnosed two years ago and it's been a baptism of fire trying to understand all the medical lingo and what treatment he needs to have," she said.

The Wharf Hotel is owned by The Publican Group Australia and director Steve Garcia said the company was moved to help.

They founded a local Mates on a Mission and will hold events for local causes a few times a year.

Do you need some inspiration?

We would like to congratulate Gabriel Theophanous – President of the United Kingdom Thalassaemia Society (UKTS).

We would like to congratulate Gabriel Theophanous – President of the United Kingdom Thalassaemia Society (UKTS). Gabriel ran in the London Marathon on the 21st April, 2013 to raise money and awareness for his charity (UKTS) He was running in memory of two dear friends Costa Kountourou and Andreas Paul.

Well done Gabriel on a magnificent effort, we hope you reached your goal in raising funds. If anybody would like to support Gabriel please go to <http://www.justgiving.com/Gabs77>.

Young Brandon Michael member of the UKTS is also planning on a crazy jump out of a plane all in the name of thalassaemia. Brandon has decided to take the plunge with his friend Lewis to jump out of a plane to raise funds and awareness for thalassaemia as Brandon's father and sister are both thalassaemia major patients. The skydive will be taking place on the 10th July, 2013 – oh we failed to mention that Brandon is from the UK so all the money will be going to United Kingdom Thalassaemia Society into research for ALL Thalassaemia patients worldwide.

So if you would like to support Brandon and Lewis please go to <http://www.justgiving.com/KTSskydive>



Check out Belinda skiing!

Self Management Tools: Hepatitis C – The Basics

By Louisa Walsh, Take Control Program Coordinator Hepatitis Victoria

Hepatitis C is a blood borne virus. It is transmitted when the blood of an infected person enters the blood stream of a non-infected person. While hepatitis C is not a new virus, it was not identified and able to be tested for until 1990.

People with thalassaemia, and other conditions requiring treatment with blood products, were at risk of contracting hepatitis C before donated blood was able to be tested. Anyone who received blood products before 1990 and hasn't been tested for hepatitis C should consider having a test. Similarly anyone who has been involved in practices which can result in blood sharing – such as injecting drug use or getting tattoos or piercings in an unsterile environment – should also consider having a test for hepatitis C.



Hepatitis C is only transmitted if the blood of an infected person enters the blood stream of a non-infected person. It is not transmitted through casual contact such as hugging, kissing or sharing food, cups or cutlery. Hepatitis C is also not sexually transmitted – it is not transmitted through semen or vaginal fluids, and monogamous couples, where one partner has hepatitis C and the other doesn't, do not need to change their sexual practices to avoid transmission. If one or both partners has HIV there may be an increased risk of sexual transmission, and you should contact either Hepatitis Victoria or Living Positive Victoria for advice on safer sexual practices.

Hepatitis C causes liver disease as the virus replicates in the liver and causes the death of liver cells. Because of the liver's amazing ability for repair and regeneration it usually takes many years of living with the virus before there is significant liver damage. Liver function tests can also remain within normal limits for many years. Often people with hepatitis C don't experience symptoms, or just experience non-specific symptoms such as headaches, muscles aches,

fatigue or problems with concentration and memory. The lack of symptoms, experiencing non-specific symptoms, and normal liver function tests, means that people with hepatitis C can go undiagnosed for many years, or be misdiagnosed with chronic fatigue or a similar condition.

The test for hepatitis C is a simple blood test that can be done by any GP or liver clinic. Testing for hepatitis C consists of 2 tests – an antibody test and a PCR test. The antibody test is a screening test to see if a person has been exposed to the virus in the past. The PCR test is a diagnostic test that is confirmation that the virus is still in the body. A positive PCR test means that a person has hepatitis C.

There has been treatment for hepatitis C since the mid 1990s, and while successful treatment does result in a cure of the hepatitis C, it does not work for everyone and can have many side effects. The good news is that we are currently moving into an exciting era for people with hepatitis C because treatments are rapidly advancing. Two new drugs for the treatment of one of the hardest to treat genotypes (strains) have been approved for use, and this is just the start of the expected treatment advancements over the next few years which will result in more effective treatments with fewer side effects. If you have hepatitis C it is a good time to get a referral to a liver clinic from your GP to discuss treatment options.

Pyjama Fun

Congratulations to the owners, staff and children at Bamboo Early Learning Centre for holding a Pyjama Day fundraising initiative to raise funds for Thalassaemia Australia to support the children's section of the Medical Therapy Unit.

We thank them for their donation and the beautiful photo.

People with hepatitis C sometimes experience discrimination because of their hepatitis C status. This can either be because of misinformation about how the virus is transmitted or can be due to assumptions made about how the virus was contracted. Either way, discrimination based on health status is illegal and there are ways to challenge discriminatory decisions or complain if you feel you have been treated unfairly. It's also important to remember that there are only very few situations in which you have to disclose your hepatitis C status. You are not legally obliged to disclose your status to health professionals, schools, workplaces (unless you work for the Defence Force or are a dentist or a surgeon), family, friends or sexual partners – even if asked. If you have questions about disclosure or discrimination, contact Hepatitis Victoria.

Hepatitis Victoria has a range of services for people with hepatitis C and we are here to help. We have a freecall Hepatitis Infoline (1800 703 003 or info@hepvic.org.au), a monthly support group, provide information sessions and training, and hold regular events such as our Love Your Liver lunch for World Hepatitis Day. We are a membership based organisation, and membership is free for people with hepatitis B or hepatitis C. Please feel free to contact us if you have any questions about hepatitis C or would like to know more about our services.



NOTICEBOARD

Thalassaemia International World Congress 2013 – Abu Dhabi

Please note the Thalassaemia International World Congress 2013 is now open for registration, this is a fabulous opportunity to learn more about thalassaemia, meet members of the international thalassaemia community and share your experiences.

Go to: <http://www.tif2013.org/> for the Scientific/Patient and Parent Program

Further details:

13th International Conference on Thalassaemia & Hemoglobinopathies, 15th TIF International Conference for Parents & Patients, 20th – 23rd October 2013 – Abu Dhabi – UAE

Congratulations



TA would like to extend its congratulations to Committee Member, George Ambatzidis and his partner Areti on the safe arrival of Konstantina Areti Ambatzidis born 19th January, 2013.

New Resources

The Thalassaemia International Federation has released an animated Youtube version of their book titled: 'All about thalassaemia' by written Dr Androulla Eleftheriou. This is a popular resource for both adults and children that would like to gain a new understanding of thalassaemia and its treatment.

<http://www.youtube.com/watch?v=xEFIG0G2HtY>



The difference YOU can make
As a regular recipient of donated blood, you may not realise the difference YOU can make!

The Australian Red Cross Blood Service regularly shares the stories of blood recipients with donors – whether they are existing donors, or prospective donors.

It could be at a group or school presentation, in a newsletter, in the media through print or television, or simply by sharing written letters of thanks. These stories inspire people who are considering blood donation and will often influence their decision to make an appointment to donate. It can be the push they need to realise that they too could know and love someone who needs this life-saving gift at some point in their lives.

But these stories also help remind those already donating about the amazing gift they are giving – that they are saving the lives of people touched by the need for blood; a way of thanking them for their incredible generosity.

These stories are invaluable and if you're interested in sharing yours we'd love to hear from you.

There are many ways in which to share your story as mentioned earlier and if you are keen to help inspire potential blood donors and thank those who already give then please let Sarah and Maria at Thalassaemia Australia know and they can keep your details on hand for when the next call for blood comes.

National Blood Donor Week 2013

Every year the Australian Red Cross Blood Service takes the time to honour its milestone donors with an awards ceremony held during the National Blood Donor Week.

This year's Milestone Donor Awards will see the Blood Service honour more than 1,500 donors in Victoria across three ceremonies being held at the Melbourne Town Hall on Sunday 14 July and Saturday 20 July.

For these events the Blood Service would like to invite individual recipients, and their family members, who may wish to attend and say thank you to these milestone donors, some of which have made more than 500 donations.

Should you wish to volunteer your time and help out at this event as a speaker, usher, or just mingle with the crowd saying thank you to these wonderful donors, please contact Maria and Sarah at Thalassaemia Australia to advise them that you wish to attend.

Thalassaemia International Federation Message:

The Thalassaemia International Federation (TIF) theme for 2013 was "The right for quality health care of every patient with thalassaemia, major and beyond."

Dear friends,

under such economic global austerities, it is our responsibility and duty as patients organisations, while continuing the fight for adequately managing β thalassaemia major, to focus on improving the health and lives of our friends with these other forms of haemoglobin disorders. Unless we, ourselves, become

knowledgeable and true ambassadors of these advances, these conditions will continue to remain under-recognised and under-estimated.

In light of this message we note that Thalassaemia Australia is determined to widen its banner to allow for greater representation of other Haemoglobinopathies under its umbrella.



Sydney – Vivo Café Celebrations

Again another great night celebrating International Thalassaemia Day at Vivo Cafe in Sydney with society members, patient's sponsors, health professionals, family and friends. It is priceless to be able to mark such an important day with special people coming together to raise awareness about Thalassaemia.



We were able to remember past patients, praise current patients on how well they are doing, as well as encouraging them to stay positive and aim high in all aspects of their life.

It was also a great opportunity to be able to stop and give thanks to the health professionals that treat our patients, and give them the best possible medical advice, and to our sponsors and supporters who continue to

support and give us the ability to do what we do best, that is inform, support and research. A great night and we would love to see you all and more next year and don't forget to put the date in your diary!

Melbourne – Thalassaemia Australia

International Thalassaemia day 2013 celebration for Thalassaemia Australia turned into a week of festivities.

We began by reflecting on those living with or touched by Thalassaemia, both in the past and present. We welcomed the opportunity to recognise and formally thank those people in our local, national and international Thalassaemia community: medical professionals, nurses, researchers, carers, families and blood donors for their ongoing care, support and strength.

throughout Melbourne TA staff gave thanks to the blood donors on behalf of our recipients during this special week. The blood donor centres included: Southbank, Rowville, Templestowe, Caulfield and our local centre, Mount Waverley. Whilst visiting these centres we give the blood donors a small token of our appreciation, and fact sheets on Thalassaemia and other Haemoglobinopathies to raise awareness of the condition and for them to take home to their families. For some of these blood donors, this is the first time that they have

ever met a blood recipient and even heard about Thalassaemia! TA staff always cherish these visits, as we are able to hear the blood donors stories, as to why they donate blood, and the length of time they have been donating blood for – we are always constantly amazed. During this year's visit we met a number of 30 year donors, first-time donors from Caulfield Grammar School and some wonderful ARCBS staff.

On May 8th, International Thalassaemia day was also celebrated with the patients and staff at MTU, with morning tea for all!

Publicity / Social Media – International Thalassaemia Day

This year we were able to secure some publicity in local media and through the ARCBS.

Our Facebook page had its best week yet, with a high level of interest in our articles from thalassaemia communities around the world.

It was great to see a new Thalassaemia support group has been formed in Afghanistan called the Meena Welfare Association, the very first of its kind. We wish them every success!

TIF also released a fantastic new video for International Thalassaemia Day that you may find interesting: <http://www.youtube.com/watch?v=AtNldifZock>





2013 Committee of Management

President – Martha Gerolemou
Vice President – George Houssos
Treasurer – Lela Dallas
Secretary – Theodora Michalopoulos
Assistant Secretary / Treasurer – Stella Stilianou
Communications Officer – Marianne Dimitrakas

Executive Members:

John Tsirigotis Faisal MD
Maria Chate Lisa Malaxos
Nicholas Kotrotsos Glenda Hughes

2013 Committee meeting dates

Committee of Management meetings are held monthly at the Thalassaemia Centre, please call the office for further details. All Welcome.

Wednesday 17 July
Wednesday 21 August
Wednesday 18 September
Wednesday 16 October
Wednesday 20 November
Wednesday 18 December



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NSW!



Letter from the Centre Co-ordinator

Hello everyone, I hope this newsletter finds you all well and trying to keep warm...

I honestly cannot believe that we are in the 6th month of 2013, can someone please slow this year down. I feel like I am running against time it's crazy. My work life has been hectic and my home life, well let's just say Michael and I have just completed building our new home and are doing the big move on the long weekend, by the time you will read this newsletter I will be all moved in and in desperate need of a holiday!

Anyways getting onto business... the centre and the Society have been busy, we are keeping at it with presentations and community awareness stands. You will read articles in the newsletter on other things we have been busy with like the Greek Festival, International Thalassaemia Day and the GPCE. As you will notice we have all been kept busy! I would like to say a big thank you to all who attended and celebrated with us for International Thalassaemia Day again it was a great night.

The GPCE this year was again a success and I would like to extend thanks to the committee members who helped me in the lead up getting ready for the Conference as well as a big thank you to Thalassaemia Australia for allowing Sarah Burton to fly into Sydney to help with the set up as well as the running of the conference on they Friday. It was a great experience working and sharing ideas with Sarah and I look forward in doing the same for Thalassaemia Australia when they do the GPCE in Melbourne in November... (lucky it is not in winter!)

Two weeks ago I attended a Fundraiser Taverna night held in Canberra organised by an Executive Committee Member Nicholas Kotrotsos. Nicholas worked hard in the lead up to this event getting approx 120 people on the night, I would like to congratulate Nicholas on his efforts and on a fun filled evening with great food, great company and great music with some great and not so great dancing...Nicholas raised funds

for The Murdoch Children's Research Institute to go towards research into Thalassaemia.

On the note of fundraisers' there is also another up and coming fundraiser in Sydney organised for the second year running by Lisa Malaxos. Lisa is a parent of a 4yr old Thalassaemia Major Patient, Lisa has organised a fundraiser dinner on the 3rd of August. For further information regarding the event and to purchase tickets please refer to the Thalassaemia Society of NSW facebook page or you can contact Lisa directly on 0404 070 912. I wish Lisa all the best with the preparations to her event and look forward to another great night.

I will leave you all to enjoy the rest of the newsletter. Please remember if you have any feedback or questions regarding anything you have read in the newsletter please do not hesitate to contact me on 9550 4844 or email; coordinator@thalnsw.org.au



The Greek Festival

The Greek Festival this year was a phenomenal event with thousands and thousands of people, young and old flocking into Darling Harbour to attend a well organised festival.

The crowds were the biggest I have ever seen them. I was lucky enough to duck out when their headline act Mihalis Xatzigiannis was on stage. It was amazing to witness the sea of people, young and old singing and enjoying the event – making us proud to be Greek.

Again we must thank the Greek festival of Sydney for once again welcoming us with open arms. A special mention goes to Dimi Lafazanos and the Greek Festival committee for all their help. Without their fantastic organisational skills, the day would not be as successful as it was.

You all do a fantastic job. You out did yourselves this year.

We had an abundance of people stopping to grab a pamphlet and have a chat with our committee members and educate themselves more on Thalassaemia.

In terms of awareness, we reached out to approximately 50% more people than we did last year which is a fantastic effort.

The Thalassaemia Society has been attending the Greek Festival for many years but this year we were overwhelmed with the

interest of the community. The hard work we put into our charity work as a committee is rewarding when we can reassure a Thalassaemia carrier about family planning and providing them and other interested parties with more information about this very common blood disorder. AWARENESS is the way to go!

It was a great effort from our committee members to come down and volunteer their weekend to educate our community. THANK YOU SYDNEY and see you again in 2014.



Rare Disease Day 28th February 2013

A Transition Information evening was held at Westmead Children's Hospital, covering all aspects of transition for the patients moving from the Children's Hospital into the Adults hospital and adult "World".

Adolescent patients were educated on the basics of Thalassaemia and the treatment they need to comply with in order to be able to lead a normal life. They also heard from two adult patients from Royal Prince Alfred Hospital who told their stories of growing up with Thalassaemia, transitioning into the adult world, how they managed study, work, getting married and becoming parents. The take home message was that it can all happen if you look after yourself, manage your treatment and make it a part of your life! The sky is the limit for many of our patients.

This was a very informative evening put together by Adrienne Woods, Haematology Clinical Nurse Co-ordinator at Westmead Children's Hospital and we take this opportunity to thank her for a great night.

General Practice Conference Exhibition (GPCE) 2013

For the second year running the Thalassaemia Society of NSW exhibited at the GPCE Sydney held in Homebush, at the Dome.

Again it was a successful event as our staff and committee members were able to meet face to face with over 150 GP's from all around Australia, and educate them on the services we provide not only to patients and family members, but also to GP's and Health Professionals.

We were able to raise some much needed awareness on Thalassaemia and how patients are now treated in today's world. It is particularly good for those GP's who

don't often come across patients with Thalassaemia and educate them on the condition. The response from the GP's, Practice Nurses and Students was very positive, many taking the time to interact with us and take away information packs. This year's exhibition enabled us continue to build on our GP database adding approx 70 new GP's to it from last year's one.

It was also nice to see familiar faces from last year's exhibition and receive some positive feedback towards the Thalassaemia Society for exhibiting again. Thank you! At the end of a long three days we were grateful to be able to provide this much needed information to GP's. We thank Novartis Oncology for supporting us with this project.

RECIPE Tropical Pizza Fingers

Preparation time: 10 mins
Cooking time: 15 mins
Serves: 16

Ingredients:

- 6 cubes tasty cheese
- 2 slices leg ham off the bone
- 6 cherry tomatoes
- 100g fresh pineapple, peeled and cut into 6 chunks

Method:

1. Preheat oven to 180°C.
2. Stand the french stick cut side up on a paper-lined baking tray.
3. Spread tomato pasta sauce on bread halves.
4. Top with ingredients, sprinkling the cheese last.
5. Bake in oven for 15 mins or until heated through. Cut each pizza into 4 fingers.

Variation

Substitute a foccacia slab, split horizontally, for the french stick. English muffins may be used as the base.

Enjoy!



Hi Kids!

Pop in the kitchen and try out our new yummy recipe!



Q: What did the snowman say to the customer

A: Have an ice day!

Q: What do you call a cow that eats your grass?

A: A lawn moo-er.

Q: Why do fish live in salt water?

A: Because pepper makes them sneeze!

Colour me in!

