

Thalassaemia

A U S T R A L I A

Unifying support and genetics

Thalassaemia Australia Summer 2013 Volume 5 Issue 14

Quarterly

TA AGM 2012

Thalassaemia Australia held their Annual General Meeting on Tuesday 16 October, 2012 the evening was a very relaxed one with guest speakers from the ARCBS and our very own researcher, Dr. Jim Vadolas.

The evening was well attended with people coming in from as far as Sydney, as well as some very familiar faces from years gone by. Sotirios Katakouzinis opened the evening by welcoming everybody and introducing our guest speakers. We heard from Kylie McCaw who spoke about the journey of blood collection from donor to recipient. It was interesting to see how the blood gets processed and how much work actually goes into making sure our recipients receive fresh, clean, safe blood.

We would like to take this opportunity to thank ALL the staff at the ARCBS Processing Unit for taking such care to ensure the safe arrival of our blood for each transfusion our recipients receive – it is truly the best gift.

Our second guest speaker was Dr. Jim Vadolas who gave us a brief update on his wonderful work at the Murdoch Childrens Research Institute. He also noted how important it is to support this research and to hopefully be the first in the field

to make a change in so many lives with thalassaemia.

After going through the important business of the AGM and having brief refreshment, we came back in to hear from special guest, Lisa Malaxos from Sydney. Lisa held a fundraising event and managed to raise \$10,000 which was donated to Dr. Jim Vadolas and his team MCRI. This caught many by surprise especially Dr. Vadolas.

Towards the end of the night we introduced the new committee of management for 2013 to our guests. We welcome them all and wish them good luck for the year ahead. Our outgoing President, Sotirios Katakouzinis spoke of how the Society had changed over the years and how good it was to see some new families joining the committee and giving it a fresh approach.

We also heard from a past committee member who spoke of the years on the committee before our generation took

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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

19 March	16 July	19 November
16 April	20 August	17 December
21 May	17 September	
18 June	15 October	

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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TA AGM 2012 (Cont. from page 1)

over including the struggles, the achievements and the journey they all took as a united front to make a difference to the patients, families and carers. She also noted that it is important to make sure that we do not let that legacy go.

Our new President, Spiros Bombos then had the opportunity to speak about his vision of the society in 2013 and beyond. We wish Spiro and his committee all the best for the coming year.

Finally, we would like to thank firstly the ARCBS Processing Unit for allowing us to hold our AGM in your wonderful building. A special mention also goes to Nancy Lucich from Thalassaemia Society New South Wales for coming down to assist me in the on the day and supporting TA throughout the year.

We again thank Lisa for her wonderful surprise and also wish her good luck in her fundraising in 2013. And

a finally a big thank you to Spiro Bombos for organising catering, our two Mary's from the TA committee for making the arrangements at the venue on our behalf.



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>



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.



President's Report

Dear members, families and friends,

My name is Spiro Bombos and I am the newly elected President of Thalassaemia Australia Inc. Firstly let me tell you a little about myself. I am married with two beautiful boys, Jared and Jasper. I run my own IT business, supporting small to large business with their IT needs.

Our life changed in July 2010 when our eldest son become extremely sick and was admitted to Monash Medical Centre. Jared was nearly two when we were advised that Jared was dealing with more than pneumonia. That week my wife and I were introduced to the world red blood disorders. We were informed that the results of his blood work revealed that he had Sickle Cell Beta Thalassaemia. Hence our journey into the unknown began, from meetings with the Medical Therapy Unit to becoming members of Thalassaemia Australia (TA). We were baptized in fire, from trying to comprehend the condition, understand the treatment, medical jargon, medications, medical tests, whilst endeavouring to abridge all this information into our life.

I can say it has been a steep learning curve, dissecting all this information and understanding the impact of this condition on Jared physically and emotionally. How this new information would impact on our family, the changes to our lifestyle and to the importance of effective parenting. That's not to say, that explaining this to the extended family and friends has not been remotely easy when we were struggling to come to terms with the condition ourselves. Dealing with your own emotions is difficult enough, let alone anticipating others reactions.

We like to call Jared's condition a "hybrid" although he presents more like a sickle patient his treatment is much similar thalassaemia patients. As we have come to realise that there are few patients with this particular disorder in Australia, and trying to find information on line was equally challenging, let alone explaining it to others.

This is where TA came into play with us, they welcomed us all with open arms, made themselves available to answer our questions and explain processes and procedures. We even had a home visit were over lots of cups of coffee, we grilled the TA representative, asking a range of questions. Not only were they generous of their time but they also shared their own story to us. This meeting left

us with a sense of relief, greater knowledge and an overall increased understanding on how to tackle our concerns and issues.

With this new experience, my wife voiced that she wanted to become a TA committee member. Her theory being that we can represent our son during his journey, be his voice and advocate on his behalf until he becomes an adult. With that decision made, over the next couple of months we both somehow morphed into joint committee members, when one of us could not attend a meeting the other went on their behalf. Over time we become engrossed participates, representing the next generations of patients.

As I believe, things happen for a reason I found myself accepting the new challenge of the TA President. As this is all new to me, I saw my role to be bring diversity into the TA committee. That is, Members representing the different generations and cultures, the scientific community, patients and Mum's and Dad's all participating in their capacity.

I would like to welcome all the newly elected members of TA and thank them for their commitment. During the year, we will endeavour to make more enhancements in the way we do things: from enhancing the TA website to be more interactive, to increasing our engagement in social media via Facebook and Twitter. This is for the overall goal of increasing awareness and patient support.

We plan on hosting and participating in several social functions throughout the year. The first is a sponsored function being the Mates on a Mission Blood Drive on the 27 February and a Mates on a Mission Annual Charity Gala Night to be held at River's Edge Events on Thursday 18 April 2013 to raise funds for medical equipment for the MTU. With many more events to come throughout the year, like the successful TA Kids Christmas party. I encourage you to contact us with any suggestions for possible functions, thalassaemia presentations and topics of interest regarding the treatment and care of your condition, so that we can address these throughout the year.

Finally, I am looking forward to this New Year and I am honoured to be able to have this opportunity.

Sincerely
Spiro Bombos



An update from Nepal

A number of years ago, seven in fact, we placed an article in our newsletter telling you about the wonderful work a lady called Wendy Pinker from England.

Wendy helped establish a transfusion clinic for thalassaemic patients in Nepal through a large variety of fundraising events. It has been some time since we have given you an update on this great work and also wanted to acknowledge the support offered by some of our own readers/members that have given donations to their cause.

We understand that patients are now receiving regular blood transfusions, but iron chelation is still very expensive and difficult for some of the Nepalese patients to obtain. However, with the help of the contributions from Australia and overseas, some of the most needy patients now have access to iron chelation.

Wendy notes:

'Oh my word how the children had changed in the year I have been away in the UK so many of them were hardly recognisable! All grown up and in so much better health I couldn't stop looking at each and every one of them..... there were new faces too lots of them! Somehow the word of our incredible clinic had spread far and wide. Today was not normally a day our clinic opened but just for us many had travelled up to 14 hours on along the mountainous roads of the Kathmandu Valley just to come and say THANK YOU :))) I couldn't believe my eyes.... such joy I can't explain...with all the excitement I had forgotten that we now had two treatment rooms!

Anyone that would like to help out people in Nepal, please contact the TA office and we will put you in contact with TA Committee member Julie Dascoli, who deals with Nepal directly.

The 3rd Pan-European Conference on Haemoglobinopathies and Rare Anaemia

24-26 October 2012, Grand Resort Hotel – Limassol, Cyprus

By Helen Kosmarikas, Parent and Thalassaemia Australia Inc. Committee Member 2012/2013

Knowledge is our power – Unity is our strength

This was the mission (motto) statement of the conference.

Its Aim: Bringing people together from cross many countries, joining together to share knowledge and educate.

Purpose: That this conference is about understanding the current role of Thalassaemia in the various medical fields, the socio economics of the condition and the key importance of education.

In conference afterglow, let me reflect on an experience that has made a mark on my life. I cannot say it was easy to leave the family behind, possibly one of the hardest things I have ever done. As the event drew near, it was getting harder and harder to breathe. Then the more I questioned whether this was the right decision for me and the family.

After all the kisses, hugs and farewells were made, I stepped onto the plane with my heart in my hands. I was equally exited for the road ahead wondering what the next couple of days would reveal, and apprehensive as I was going to this conference alone. The people I would meet and the stories that would be shared, their insights and ultimately the knowledge to be gained. All this activity in my head, I was getting nervous. Going to a country I have never been before, attending a conference about conditions that has completely re-prioritised our existence.

I went to the Grand Resort Hotel, the venue for the conference, to complete my

registrations. I was handed my delegate pass – it read patient/parent. It dawned on me, what my presence represented, not just a parent of a child who has this condition, but for all the parents at home with their children with these conditions. I made a promise to myself, to meet as many people I could, talk to as many people time would allow, absorb as much of this my head and heart could take.

The opening ceremony began, I was eager to experience this, to see and to feel it. There were loads of people waiting to enter the halls, and you could see a lot of these people were regular attendees as they were familiarities with their greetings. I began reading peoples passes, there were diverse groups, medical, scientific, officials, Sheik, patients and parents.

As I entered this conference the next day with brand new eyes, I saw this collection of people all eager to get started, others to present and others to listen. I can tell you, sitting in the halls and progressing through the schedule; I felt a sense or reassurance.

Reassurance in knowing that this conference means something to people: “the Quest, a forum to everyone, for exchanging of knowledge and experience” to create a greater understanding for all. I felt the reassurance in knowing conferences like this exist, that there are passionate people putting these events together to assist all those touched by these conditions. That there are doctors dedicated to the various conditions, some more specialised. Scientists furthering their research, seeking cures, no matter how Sci-Fi some of them sounded. There were also philanthropists and various Thalassaemia Societies members making putting forward their socio-economic issues affecting their patients. This was all brought together to further the cause and that they are prepared to look outside the box to understand, to further the education and treatments of these conditions, as

well as finding innovation and leverage of knowledge for now and the future.

It warmed my heart to be present, to witness all this activity. It provided me with hope that we are progressing through to better times with these conditions and that the key issues are shifting towards a better quality of life for our patients.

We are not naïve to not know that these professionals are in pursuit of furthering their personal career goals or to acknowledge that these people are forging their status in the industry. On the flip side of this, who are we to complain if the end results transpire into positive future outcomes for the treatment of thalassaemia and conditions alike. Advancements in this area of understanding and treating these conditions are not only for the now, but way into the future.

Day 2 of the patient/parent conference was filled with mostly medical associated conditions to thalassaemia. There were a few sessions that piqued my interest; firstly it was a patient's recount of her life with thalassaemia, from the early days to the current. Focusing on how she has overcome obstacles and turn them into triumphs in her life. How she now dedicates her time to the Cyprian thalassaemia society and is now giving back.

That other controversial topic was “Are rare anaemia's a disability?” This issue had many talking during the coffee break, quite a few voiced that they did not believe that this topic should be session as they did not want to steer these conditions down the disability path.

The presentation was delivered and much to everyone's surprise it was answered in a satisfactory manner. That the conditions themselves were not a disability, rather a disability only comes into play if a patient has serious complications to other associated medical issues.

The highlight for me was the session on “Challenges and personal relationships” present by Photis Eliade (patient). This was delivered from a personal perspective, were Photis shared his personal account of all the important relationships throughout his life: from his parents, siblings, spouse and children. His presentation style was informative, engaging with added humour. He captivated the audience and reinforced the message that the condition should not affect any relationship, that relationships are what you make them to be.

I personally would of have appreciated more of these types of sessions throughout the patient /parent conference. I found that these sessions could have been longer, allowing time to explore different relationships, such as parent – child, sibling. Delving into the psychology of the patient during the different stages of life, from infant, early childhood, teenage, early adulthood etc. would have also been of interest. As well as focusing on physical and emotional wellness, with positive tips and recommendations for managing there conditions.

One important factor that I did note was Thalassaemia Australia's presence at this conference and its position within the international thalassaemia community. Many knew and recognised our society, from people within Thalassaemia International Federation, from the scientific community or members from other societies. It was pleasing that people know of us, especially as we are quite removed from the European community and we made the effort to represent ourselves at this event. They recognised the work we do for our region, the staff and their contributions and to patients and the thalassaemia community. It made introductions efficient and conversations effective. One particular conversation I had with an important member of TIF stood out for me as they mentioned that they keep up to date with what Thalassaemia

Australia is doing by viewing our website. That social media was the new tool in reaching patients and educating people about the condition.

I met many people from other nations representing their respective societies. I heard many of stories, stories that made me feel like running out of the room screaming, others that left me speechless. I heard stories of how the European crisis is affecting the cost of treatments that some countries charge for the treatment of blood. That in one country they do not undertake the cross match process, hence high accounts of reactions to the blood that is provided. The doctors treating patients do not have adequate knowledge in understanding the conditions. The distance some travel to receive their treatments. As these stories continued, it confirmed my appreciation of our health system in Australia.

One common theme, which was present within conversations with other Thalassaemia Societies, was the membership levels compared to number of patients. That many societies have low membership levels and have difficulties retaining their members. That many patients were either becoming complacent as treatments have advanced or, that they are expectant that others will participate in the charity/fundraiser activity, rather than themselves personally. That participation in organised fundraising or social events were low and that most committees were struggling to raise funds in this current economic environment.

My conference really began during a break on the Friday schedule, when I sat down in an adjoining room and a powerful discussion with another parent. This parent sat down with me and allowed me to ask her many probing questions, a parent who listened to me, to my concerns, fears and joys. She was parent who was open and shared her stories and experience throughout the years of raising her

daughter with a genetic blood condition. She was also a parent who generously gave her time and energy to befriend me and be my guide though this conference experience.

During a many conversations, we covered many of topics, from varied treatments available, medications and other related side effects/issues. We talked about raising a child with these conditions, how it alters relationships, how it effects siblings, how it feels to be the parent/s, effective parenting tools. One topic merged to another, conversations flowed, tea and coffees were ordered, introductions were made and more stories were told.

In moments of solace, there were tears shed. For that reason, a few others of my own, I stood on the edge of conversations but in the comfort of my room I would let the tears flow freely. I cannot thank her enough for graciously providing me her time and heart. For opening up and taking me under her wing, for introducing me to the greater family (Conference family of patients and parents). For the stories shared and stories created, for the friendships shared and friendships created.

The most important information I can bring back to deliver, is that Australia has a world class medical service provider. Our patients have quality care, in treatments received, quality of blood and medications. That we have very high standards in care and treatment of these genetic blood disorders in comparison to other countries. That the Medical Therapy Units a centre of excellence and by all of us having patience and working together we can make it a stronger service focused centre. That information and education is the power for the future.

This was all positively overwhelming experience. I am privileged to be elected to go and grateful to have had the opportunity to attend.



TIF 2012 Conference Report by Dr Jim Vadolas

Murdoch Childrens Research Institute

The 3rd Pan-European Conference on Haemoglobinopathies and Rare Anaemias was held in Lymassol, Cyprus on 24-26 October 2012. This meeting was organized by the Thalassaemia International Federation (TIF).

For twenty-five years now, TIF has put a tremendous amount of effort at improving the quality of prevention and care of thalassaemia patients. One of the main challenges for TIF has been to bridge the gap that exists between developed and developing countries and it has achieved this by organizing such annual meetings.

TIF's conferences are indeed very special, as they contain an ideal balance between the education of doctors, nurses, patients and their families. TIF has done a fantastic job over the past 25 years, functioning all over the world and should be congratulated for its success as no other academic institute, government or international organization has done so much for thalassaemia.

The conference ran over three days and was divided into a scientific program and a patients' and parents' program. I mostly attended the scientific sessions. There were several interesting presentations by internationally recognized authorities covering in detail, the current state of art in the prevention and clinical management of haemoglobin disorders, as well as the latest research data on gene therapy and other innovative therapies.

More specifically, there were presentations on iron metabolism in thalassaemia and rare anaemia including iron monitoring and treatment. There were presentations on the pathophysiology of cardiovascular disease and the significance of liver iron overload, monitoring and management. Over recent years we have seen a significantly improvement in our ability to control iron levels. But in the future we will see iron load management will require an iron load map of the body for targeting chelation therapy and other medical treatments according to which organ is adversely affected.

Other areas of interest included endocrinology related issues such as diabetes and fertility in thalassaemia. In addition, bone disease represents a prominent cause of morbidity in patients.

Adequate hormonal replacement, effective iron chelation, improvement of haemoglobin levels, calcium and vitamin D administration, physical activity, and not smoking are the main measures for the management of the disorder.

The meeting also highlighted education and training for rare anaemias by the European Network for Rare Congenital Anaemias (ENERCA) <http://www.enerca.org>. ENERCA was established back in 2002 and is funded by the European Commission to set up expert centers and set up networking opportunities for health professionals, patients and stakeholders interested in rare anaemias.

ENERCA has established a list of core laboratory tests that are used in the diagnosis of rare and congenital anaemias. For example, hereditary spherocytosis (HS) is the most common congenital red cell membrane defect in Caucasians, with an estimated prevalence ranging from 1:2000 to 1:5000. Other conditions such as Glucose-6-phosphate dehydrogenase (G6PD) deficiency is the most common erythrocyte enzyme defect. In some populations, more than 20 percent of people may be affected by this enzyme deficiency. There are many more rare anaemias which are slowly begin micro-mapped across Europe.

There were also a number of presentations highlighting the next generation molecular therapeutics for β -thalassaemia and sickle cell anaemia patients.

Over recent years we have seen a tremendous amount of information generated about the degree of clinical variability. For example, in HbE/beta thalassemia the degree of clinical variability depends on the severity of the β -thalassaemia allele, but many other genetic factors are involved. More recently, several genes including HBS1L-MYB and BCL11A have been identified to modulate foetal haemoglobin (HbF) production alleviating the clinical phenotype.

For this reason the potential reactivation or increased production of HbF by drugs has been investigated as the next generation molecular therapeutics for β -haemoglobinopathy patients.

We are now at the stage where with the knowledge of the genomic background of the patient, a more personalized treatment could be envisaged in the near future and this is a particularly exciting prospect. As we have seen on numerous occasions not all patients receiving therapy will respond to the same degree. In the future, knowing the patient's genome will help to implement the appropriate therapeutic intervention.

During the last scientific session the latest research data on gene therapy was presented. Gene therapy, based on transplantation of genetically corrected blood stem cell taken from the patient holds great promise for the treat β -thalassaemia and sickle cell anaemia patients. The dream has now finally become a reality. One patient has remained transfusion independent five years following gene therapy treatment.

Over the next two years we will see many more gene therapy clinical trial conducted at several centers throughout the world and hopefully we will see this state of art technology provide better control and improved therapeutic outcomes for many more patients.

If you would like to find out more information about the TIF Conference, please visit <http://www.pagepressjournals.org/index.php/thal/article/view/thal.2012.s2>

Finally, I would like to thank Thalassaemia Australia their generous financial support to attend the 3rd Pan-European Conference on Haemoglobinopathies and Rare Anaemias.

The next International meeting will be held in Abu Dhabi, UAE 20 – 23 October 2013. For more information about this meeting please visit <http://www.tif2013.org>.



Thalassaemia International Federation World Congress

The 13th International Conference on Thalassaemia and Haemoglobinopathies, and the 15th TIF International Conference for Parents and Patients in Abu Dhabi from October 20-23, 2013 has been announced.

Congress Chairperson Her Highness Sheikhha Sheikh Bit Saif Al-Nahyan and TIF President Mr. Panos Englezos have invited patient and parent organisations, health care professionals and medical specialists, academics and researchers and policy makers to attend the Thalassaemia International World Congress.

This conference will focus on equal access and treatment for all patients locally and globally. Both the scientific and patients' programs can be viewed at www.tif2013.org and registrations for the conference can be made online.



See our Facebook page for regular updates.

Our future doctors need you!

In the Patient Teaching Associate (PTA) program, volunteer patients meet a small group of students and their tutor in a GP clinic setting.

The students share the role of the doctor in a consultation in which the patient is asked about their medical story and undergoes a physical examination related to their condition. Students, patient and tutor all contribute to a discussion to clarify the key points and also to provide the students feedback on how the session went.

The program is managed by the Eastern Health Clinical School, part of the Monash University Medical School located at Eastern Health. Medical students having their clinical training at Eastern Health participate in this new program to learn more about patient-centred care and peoples' experience of living with a chronic condition.

No special skills are required, just a willingness to give some time a couple of times a year, and to share your personal story. The sessions are for teaching, your information is treated with confidentiality and no treatment or medical advice is offered. We do however offer parking or taxi vouchers, afternoon tea and the opportunity to work with the doctors of tomorrow.

If you are interested in more information, please go to our website at <http://www.med.monash.edu.au/ehcs/msp/index.html> and click on Patient Teaching Associates, or call the PTA Coordinator on 03 9091 8821 or email pta.ehcs@monash.edu



NOTICEBOARD

Change of name

The **Victorian Spleen Registry** has changed its name! It is now the Victorian Spleen Service. To register your details go to: www.spleen.org.au Telephone: 9076 3828

Reminder

Medical Therapy Unit

Patients are reminded to check the noticeboard on arrival at the Medical Therapy Unit for changes to operating hours, particularly during public holiday periods and treatment protocols. Please make sure that you are up to date.

Cross Match at Southern Health Dandenong

Please note Southern Health in Dandenong is now open on Sunday mornings for cross-match. The Pathology Rooms are located on the lower level of the Dandenong Hospital, please check at information desk for further details.

In loving memory of
Andrew Costa

who passed away on
Thursday 28 February, 2013.

*Our deepest sympathy
to his family, and
may his memory
be eternal.*



2012 Trees of Hope initiative

The nine charities participating in Penrith Panthers' 2012 Trees of Hope initiative need your help for the chance to score a share of \$12,000.

The annual campaign, which is supported by Lion, was launched on Tuesday when representatives from each organisation gathered in the club foyer to decorate their Christmas trees. The trees will be on display until January 3, and Panthers members, staff and directors will be able to vote for their favourite.



The winner of the members vote will receive \$8000, and \$2000 will go to each of the directors and staff categories. Each charity will also receive a \$500 donation.

Young researchers from the Nepean Medical Research Foundation turned up in lab coats and balloon hats to decorate their tree with medical equipment, Christmas ornaments and pictures.

President Brad Turnbull said the initiative was a great way to raise awareness of the foundation. "We are participating to lift our profile in the community because we are a local Penrith-based organisation," Mr Turnbull said. "Christmas is a time of hope, so it is very fitting for our medical research foundation to participate."

Nancy Lucich, from Ingleburn, helped decorate the Nepean Blood Donor Centre's tree with logos and photos of

survivors. Mrs Lucich, who has the blood disorder thalassemia, said Trees of Hope was a great way to encourage people to give blood at Christmas.

"I need blood transfusions every three to four weeks for the rest of my life, and without blood donors I would not survive," she said. "Donating blood is the best gift you can give."

The List

- Nepean Blood Donor Centre
- Penrith Community Kitchen
- Thorndale Foundation
- Nepean Neonatal Intensive Care Unit Parents Support
- Nepean Medical Research Foundation
- Women in League
- Panthers on the Prowl
- Wesley Mission
- Cancer Council Relay For Life

BBQ at Bunnings Warehouse Greenacre

After a lot of organising and preparation Saturday 2 February had arrived not looking so bright and sunny.

I woke up at 5.45am dressed and ready for a big day looking out the window the weather reminded me of the times we had our Shark Island picnics, how in the mornings it was always so miserable and I was thinking I hope we are undercover because everything and everyone will get wet.

With the van packed, my dad and I left to go and collect the yummy soft rolls from The Italian Bakery in Burwood Plaza, the rolls in the van we were off to Bunning Greenacre to meet up with the rest of the committee to start preparing for the day.

By 8am we had arrived at Bunnings Warehouse Greenacre to my surprise and relief we were in the undercover parking. After unpacking it was all systems go. Our cooks John Tsirigotis and George Houssos fired up the BBQ and started cooking the sausages and onions. John's mum Helen, sister Betty and cousin Joanne cut up the rolls and with Martha, Rosa and Theodora preparing the sausage and onions ready to be made up in the rolls, Lela was ready for the first sale of the day at 9am – just in time for the rain to

stop and the sun to come out. There was no stopping us. We had a production line going and I provided drinks and raised awareness on Thalassaemia and what the Society is all about. By 4pm we had sold our last roll in a sausage and the grand total of the day was \$977.00 we were all happy with what we achieved on the day.

I would like to say a big thank you to those who supported and volunteered on the day of this event:

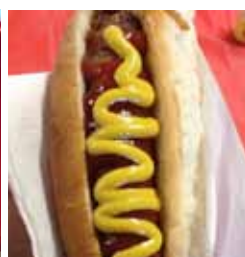
- Debbie and the staff of Bunning Warehouse Greenacre
- Alexandra Rigas for donating the bottles of water



- DFG Produce for donating the onions
- Luigi from The Italian Bakery in Burwood Plaza for the yummy rolls
- Mick's Meats at Padstow for the delicious sausages
- Mrs Helen Tsirigotis
- Betty and Con Psihoyios
- Joanne Blaslov
- John Dimitrakas

Finally I would like to thank the committee members of the Thalassaemia Society of NSW for their help and great day.

Marianne Dimitrakas
Communication Officer
Thalassaemia Society of NSW



TA Christmas Picnic

It was with great pleasure that we were able to gather together: staff, committee, families and friends, for a BBQ lunch and enjoy each other's company at Bundoora Park on December 9 2012 for the Thalassaemia Australia Christmas Picnic.

The children had a great time together, playing games, chasing treasure, having their face painted and of course having a visit from Santa – their smiles were priceless!

We would like take this opportunity to thank Costco for their generous donation, our very own Santa, Julie Christopher-Costa and Sandy for the wonderful face painting and all the other volunteers that helped in the food preparation and catering. All in all, a great day was had by all.



Our fast and furious!

On 7 October, 2012 a small group of big hearted, competitive souls gathered together, complete with their own cheer squad to take on the Go Kart circuit at Le Mans Go Kart Hire in Dandenong for a thalassaemia fundraiser. All drivers were competing to take home the inaugural Thalassaemia Australia Cup.

As you can see by the photos, a great time was had by all and the winner was: Sam Shaw from Leftbank Melbourne. All funds raised in this event will go towards the development of the Thalassaemia Australia website. Special thanks to all those that participated, cheered and organised this fun and entertaining fundraiser!



Blood Balance ride / special feature

Cured, but Nicholas won't stop fight for others

FOR the first 25 years of his life, Nicholas Kotrotsos endured regular blood transfusions and extreme lethargy due to a genetic disorder called beta thalassaemia major. But the illness was cured when Nicholas' sister donated her bone marrow so that he could have a transplant.

Nicholas had been told that his chances of finding a compatible donor were a million to one and, after his entire family was tested, it was found that his sister was 100 per cent compatible.

"I was blessed with the opportunity to undergo such an intense therapy and... this meant that no longer did I need to have

regular blood transfusion and I no longer have to worry about my iron levels going up due to the transfusions," Nicholas says.

Although the transplant was a success, it wasn't without risks.

"I had a friend who had a bone-marrow transplant and he passed away, which was a big shock to me.

"I am now living an easier life. Many call it a normal life," he says.

Now that Nicholas is cured, he's on a mission to raise awareness and ultimately help find a cure for thalassaemia.

"Nowadays I simply want to give back what I once had - support and hope for a better future," he says.

It was with this in mind that he came up with the idea for a Ride the Loop charity event called Blood Balance.

The ride took place on Saturday, November 3, with about 40 participants with the purpose of raising awareness.

Nicholas hopes that if more people know about thalassaemia, they will help donate to important research and help find a cure.

He's supporting the work of the Murdoch Children's Research Institute in developing of new ways to treat blood disorder conditions.

"The money raised will be going to Murdoch Children's Research Institute headed by Dr Jim Vlodas, he is a well-recognised researcher within the thalassaemia world, both locally and internationally," Nicholas says.

Nicholas is passionate about finding a cure for thalassaemia for all.



Nicholas Kotrotsos... "Life with thalassaemia is regular blood transfusions, I used to wear a pump to bed to medicate overnight."



Creator of Blood Balance, Nicholas Kotrotsos, with co-founder Patty Giorgio and other participants in the Blood Balance ride... he hopes that if more people know about thalassaemia, they will help donate to important research and help find a cure.

"I'm cured from thalassaemia and I no longer have the condition, but my genetics still have thalassaemia, so going on in life, if I chose to have children, I may pass that on," he says.

"Life with thalassaemia is regular blood transfusions, I used to wear a pump to bed to medicate overnight.

"I used to wear a needle under my skin. When I'd have a blood transfusion my body would get loaded up with iron and then I had to get rid of that... it was just a horrible way to be.

"I didn't play sport in school and later on as I grew up, my friends would go out

clubbing and I'd stay at home."

For more information or to donate go to www.thalassaemia.org.au

To find out more about Blood Balance go to www.facebook.com/BloodBalance

"thank you,"

to all participants and supporters of the 'Ride the Loop' event that was held on the 3rd November at Lake Burley Griffin.

You have assisted in raising awareness and funds for vital research. All money raised will go straight to the Murdoch Children's Research Institute.

For more information, head to www.mcri.edu.au/research/themes/gd/cell-and-gene-therapy or to donate to this worthy cause, please contact Maria from Thalassaemia Australia on (03) 9888 2211 or visit www.thalassaemia.org.au



Personal stories: Why it pays to be vulnerable

Thirty six years ago, I was diagnosed with a rare genetic blood disorder called beta thalassemia major. By Josephine Bila

My body can't produce functioning red blood cells on its own, so I receive transfusions every few weeks to survive. I have been doing this since the age of three. What this means is, my existence is completely dependent on other people's generosity. If people ceased donating blood, I would die.

Oddly enough, this isn't what makes me feel vulnerable. What makes me feel vulnerable are the instances when I open up to friends about having a strange blood disorder that they've never heard of before, or when a romantic partner requests that I accompany him on a month long vacation, to which I must regrettably explain that my dependence on medical treatment makes this very difficult, if not impossible to accomplish.

I also feel vulnerable when I have to tell my boss that I'm leaving work early to get hooked up to an IV for five hours. Above all, I feel vulnerable when I publicly admit that I am not what I perceive everyone else to be: normal, healthy, free.

What's ironic is that the more I stand in my truth and the more I allow myself to be

vulnerable and honest about who I am, the more normal, healthy and free I become. What I discovered is that normalcy, health and freedom are not qualities of the body. They are qualities of the mind. If you do not believe yourself to be normal, healthy or free... then, well, you're not. I would not have known this had I not allowed myself to open up to others about my hospital experiences.

There were many years when I thought I was better off bottling up my emotions about having thalassemia. I lived my entire young adult life in chains. Not only was I chained to my doctor, my hospital, the blood bank, and my illness, but I was also chained to ideas of being different, less than, odd, unhealthy, sick, unlovable, unworthy, and unhappy.

Then I hit rock bottom. I could no longer stand the sad little me that I perceived myself to be, so I started to tell people the things I once considered "dark secrets." For those who knew me well, my "dark secrets" uncovered a hidden dimension of my being that they sensed existed, but couldn't quite point out.

People intuitively felt that I was hiding something from them, but they had no idea what it was. When I finally shared my story with them, they reacted as if they were relieved and thankful to know; as if I had handed them the missing piece of a puzzle.

This is when I discovered that true relationships can never be fully materialized until you are completely honest about who you are. This is not to say that you are a medical condition or whatever your dark secret is. This just means that your dark secret, which is only dark because it has not seen the light of day, has shaped your reality (i.e., perspective) and to deny that part of yourself is to deny a large part of your existence. As I opened up to others, I allowed myself to feel raw, uncomfortable and exposed. Each time I revealed to

someone that I need blood transfusions to survive, I felt that piece of armor, the one I created by hating my need for transfusions, fall to the ground.

When I told my boss that I have a genetic illness that requires medical treatment every few weeks, I was scared, but then felt that piece of armor, the one I created by hating the illness I had no choice but be born with, fall to the ground.

Then, when I finally went public with my blog josephinebila.com and exposed an uninhibited version of my story to the world, I felt completely released.

Vulnerability has given me freedom from myself. Of course, I do still get pangs of self-conscious grief every now and then. I've had about 30 years of resistance to allowing myself to feel vulnerable, so there is still some residue to break through. Fortunately, the more I allow myself to feel vulnerable, the more authentic and fearless become.

What I want you to know is this: when you air out your dark secrets, you expose them to light. This allows them to vanish. The sooner and more frequently you expose them, the faster they disappear. For your own sake, move into vulnerability now and stop being your own worst enemy. Just allow yourself to be authentically you, because only then will you truly become normal... healthy... free.

Josephine Bila, M.S.W., is a storyteller who helps people who suffer from chronic illness overcome their physical and emotional blocks to wellness. She creates one new blog or vlog post every Wednesday. Psychology, nutrition through raw foods, and personal experience drive her work and lead others to transformation. Josephine also provides FDA Advisory Committees with expert patient advice on chronic illness. Join Josephine's newsletter (<http://eepurl.com/oEZE1>) to receive weekly inspiration and raw food recipes.



New cancer and advanced treatment centre for Prince of Wales Hospital

The Minister for Health and Minister for Medical Research, Jillian Skinner, and the Member for Coogee, Bruce Notley-Smith, today broke ground for the construction of a new \$76 million facility that will deliver modern facilities and provide treatment and post-care to cancer patients.

Construction will now commence on the Nelune Comprehensive Cancer Centre and the Australian Advanced Treatment Centre at Prince of Wales Hospital.

Named in honour of Nelune Rajapakse, the Nelune Comprehensive Cancer Centre will provide a patient-focused approach to the treatment of patients with cancer and blood disorders in one centralised location.

The Australian Advanced Treatment Centre will be the first purpose-built early phase clinical trial facility in NSW, which will provide the opportunity for stand out medical treatment and cures-of-tomorrow to be tested.

"The NSW Government has contributed \$47 million towards the development of this project and this significant investment is a reflection of our commitment to improving the lives of those affected by cancer and in progressing medical research in NSW. The Centre will provide an integrated patient-centred approach to the treatment of patients with cancer and haematological disorders," she said.

The new Centre will bring ambulatory, outpatient and radiotherapy services currently spread across eight sites on

the Randwick Hospitals Campus into one centralised main building.

"The Centre provides services to over 1500 new patients per year and up to 5000 inpatient cancer treatments, and is responsible for delivery of radiation oncology treatment to patients across the hospital campus and provides regional services to cancer patients from Tamworth, Bathurst and Canberra," Mrs Skinner said.

"Additionally, the Centre offers a major teaching role in the training of oncologists, radiation therapists, physicists and nurses throughout NSW, and is the site of clinical trials research."

Minister Skinner said the Advanced Treatment Centre will promote NSW as a premier location for clinical trials and provide an opportunity for stand-out medical treatments to be adequately tested, meaning more patients will be able to access state-of-the-art medications for all diseases, including cancer.

Mr Notley-Smith said this new specialised facility was another major improvement for cancer patients and a huge coup for medical research throughout South Eastern Sydney.

"This significant investment is a reflection of our commitment to improving the lives of those affected by cancer and in progressing medical research in NSW," he said. "The project will be carried out in two stages and involves the construction of four new radiotherapy bunkers, transfer of linear accelerators from the existing facility and demolition of the current Radiation Oncology building at Prince of Wales Hospital."

The Prince of Wales Hospital Foundation has contributed \$10.7 million for the Centre, of which the Nelune Foundation has contributed \$5 million. This has been complemented by funding from the Commonwealth Government and UNSW. The contract for the early works construction on the building has been awarded to Australian construction company, Richard Crookes Constructions. Completion of the new radiotherapy bunkers expected to be completed in March 2014.

The second stage of the project is expected to be completed in 2015.

Reproduced from a media release by: Jillian Skinner MP, Minister for Health Minister for Medical Research, 7 September, 2012



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:

Rosa Dimitrakas 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 20 March
Wednesday 17 April
Wednesday 15 May
Wednesday 19 June
Wednesday 17 July
Wednesday 21 August
Wednesday 18 September
Wednesday 16 October
Wednesday 20 November
Wednesday 18 December



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Counselling can offer many benefits

Counselling offers the client many benefits, in this article I will talk about three main benefits.

The first is the opportunity to hear yourself report to the counsellor your issue(s) which allows you a clearer understanding of them. Some clients/patients gain enormous relief from sharing with an objective person what they have not been able to share with loved ones or people close to them. The counsellor contains the client/patient who is feeling overwhelmed, distressed, confused, depressed, emotional or in crisis. You will build a safe, trusting therapeutic relationship in which you feel accepted, non-judged, and valued for who you are.

The counsellor sometime will ask the client/patient some effective questions in order to make a professional assessment as to what the issues, achievable goals, and treatment plan are for your unique situation and needs.

Some counsellors work from a particular theoretical approach such as emotionally focused, grief, narrative or trauma model therapy. While others choose to work from an eclectic approach, selecting the theories and techniques which match the client's/patient's needs.

Once insight has been gained, the second benefit of counselling begins when you and the counsellor collaboratively set the goals for your therapy.

The counsellor's knowledge about psychology, psychoanalytical development,

personality, motivation, mental conditions, mood states, addiction, interrelationship, grieving and loss, aging, attachment and family systems, and so on, will guide the processing of the client's issue(s).

The counsellor will offer you strategic interventions, techniques, and effective ways of bringing about positive changes so you may achieve your goals. As you move through this work, you may notice a lowering of psychological defences, increased self-esteem, improved mood states, a sense of returning to yourself, a more balanced lifestyle, a return to better health, less emotional flooding, more motivation, an improvement in your relationships, better focus at work, more positive attitudes, and so on.

The third benefit of counselling is the growth, maturation, and sense of genuineness, self-confidence and well being that the client achieves through attending to his/her personal therapeutic work. Not every goal need be achieved to the maximum for you to feel that your investment of time and money was worthwhile. Counselling may only be a 'drop in the bucket' of your life, one small influence that you and others will build upon in the future.

Amy Elzahaby
Counsellor for the
Thalassaemia Centre NSW
February 2013



Letter from the Centre Coordinator

Hello everyone, I hope this newsletter finds you well. I hope everyone had a great festive season with loved ones and I hope you all had a little rest at some stage.

With work and school back along with all the extra activities my son has decided to do this year I am run off my little feet... and I bet I am not alone in feeling that!!! I cannot believe that we are in the third month of 2013, it is going to be another busy eventful year I can feel it. Firstly I would like to start off by thanking last year's committee for their support and welcome the new committee this year as I look forward to working with you all to achieve our goals.

You will notice in this issue that we welcome a new (covering) CNC working closely with the team at POWH looking after our adult patients at POW. I would like to welcome Kristen, I look forward to developing a working relationship with her to continue the best care for our patients. Again this year we will be out raising awareness about Thalassaemia, the Society and the work we do. Be on the look out for us in the foyer of your treating hospital as each month we will be at a different hospital.

If you or anyone you know are interested in having a presentation/information session at your work place, school or in your community please come to me with your details and suggestions as I am always on the look out to educate in new areas.

Thank you to supporters and sponsors

Thank you to supporters and sponsors throughout 2012 your support and sponsorships allows us to extend ourselves in projects and activities which intern benefit our patients and community group.

- NSW Health Sydney Local Health District
- Australian Red Cross Blood Service
- Novartis Pharmaceuticals
- Aspen Australia
- MBE Parramatta
- Lisa Malaxos
- Hellenic Club of Canberra

Personal donations and or support that was given to us throughout the year, thank you, thank you, thank you! With the money raised throughout the year the Thalassaemia Society of NSW was able to make the purchase of 5 new pumps at a total of \$10,000 for our patients.

Up coming events

GPCE

Once again we are taking part in the General Practitioner Conference in Sydney from the 17-19 May 2013.

International Thalassaemia Day May 8

Celebration event & community awareness stands to be held – Location to be advised.

Greek Festival

Sat 16 and Sun 17 March at Darling Harbour

Patient, parent workshop

This is something that we are working towards and are asking for any feedback from parents and patients on what sort of information you would like to see executed as part of the work shop, at this stage it is early days in the planning process however it is important that we get feedback to help us in the planning process on what you might like to get out of the workshop for yourself as a patient or your child.

Aug 3rd – Annual Awareness and Fundraiser evening organised by Lisa Malaxos

Lisa is the mother of little Ariah who has Thalassaemia Major. When Ariah was diagnosed with Thalassaemia, Lisa wanted to raise awareness about Thalassaemia along with funds to go towards research and the Thalassaemia Society of NSW. The event will be held at the Grand Roxy. More details to follow on this event.



Going Electronic!!!

To move with the times and reduce paper waste we are starting to go electronic with the issuing of our newsletters, we are however happy to continue sending out paper copies to those of you who would prefer. Please drop me a quick line at coordinator@thalsw.org.au if you are happy for me to put you on our electronic list only.

Nancy Lucich
Centre Coordinator

A note from Kristen Brown, covering CNC at POWH

I just wanted to write a quick note to update the cover for Liz McGill (CNC Thalassaemia/Blood Transfusion) whilst she is on leave. I will be covering for Liz for the next few months, and most of you will know me from the day unit already. I have been working in the area of Haematology for several years and over this period of time have gradually learnt more about many of you. I look forward to learning more about Thalassaemia and getting to know you all a little better to ensure I am able to coordinate care as effectively as possible.

If you have any questions or need assistance with anything, please don't hesitate to contact me via email or phone.

Kristen.brown@sesiahs.health.nsw.gov.au
Telephone: (02) 9382 4982
Monday-Friday 8am-5pm

Regards
Kristen Brown

RECIPE

Hawaiian Sticks

Preparation time: 10 mins
Cooking time: 5 mins
Serves: 6 sticks

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. Cut the ham into strips 2cm wide.
2. Place a cube of cheese at one end of a toothpick. Follow with a cherry tomato, weave a slice of ham back and forth, then a pineapple chunk at the other end.
3. Repeat with remaining ingredients. Place in an airtight container or snaplock bag and serve 3 as a snack in kids' lunchbox.

Tip: Replace the toothpicks with drink umbrellas for some festive food fun!

Enjoy!



Hi Kids!

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



Q: What do insects learn at school?
A: Mothmatics!

Q: What do frogs order when they go to a restaurant?
A: French Flies

Q: What do you call a fancy insect dance party?
A: A moth-ball!

Colour me in!

