



Thalassaemia AUSTRALIA

Unifying support and genetics



Thalassaemia Australia Spring 2014 Volume 9 Issue 20

Quarterly

Novartis Thalassaemia Master Class

The master class was held at the Sheraton Melbourne Hotel, on Friday the 8th of August 2014, hosted by Novartis Oncology.

The master class was held at the Sheraton Melbourne Hotel, on Friday 8 August 2014, hosted by Novartis Oncology. It proved to be an invaluable opportunity to meet and gain reliable knowledge into the treatment of various Haemoglobinopathies, from three world leading experts.

The guest presenters were Prof. Taher from Lebanon, Dr. Cappellini from Milan and last, but not least, Dr. Viprakasit from Thailand. Their collective presentations centered on the clinical observations of NTD (Non Transfusion Dependent Thalassaemia) and TDT (Transfusion Dependent Thalassaemia) patients and how best to treat them based on years of experience.

With respect to NTD patients, topics such as the increased risk of Thrombosis due to a hypercoagulable state. This occurs from factors such as iron overload, endocrine and hepatic dysfunction, platelet abnormalities, increased thrombin generation in red blood cells, etc. In managing the prevention of thromboembolic events in high-risk NTD patients, transfusion therapy is suggested, along with aspirin therapy for splenectomised NTD patients, anticoagulants, iron chelation or hydroxyurea therapy.

Patients that were TDT required a more intensive regime of treatment as outlined by our speakers. They spoke about many issues, i.e. the organ systems (pituitary, thyroid, parathyroid, heart, liver, pancreas, bones, gonads) affected by iron overload in Beta Thalassaemia Major, the goals of chelation therapy and optimal doses of the various chelators available. Iron overloading was also discussed for other Haemoglobinopathies such as Diamond Blackfan Anaemia, MDS and Sickle Cell Anaemia. Of particular interest with

chelation therapy was the positive effects of lowering ferritin levels. These included reduction in the Liver Iron Concentration (LIC) and ultimately the prevention of liver disease, reduction of myocardial (heart) iron and the maintenance of normal cardiac function, possible reversal of endocrine complications and finally, the possible cause of reversible, non-progressive, dose-dependent increases in serum creatinine. When it comes to evaluating the status of iron overloading in patients, it was discussed that it is important to assess each individual patient in order to tailor the treatment to suit their needs.

The merits of all chelators were spoken about and in patients with high LIC levels, evidence shows that combination therapy (DFP + DFO) but not DFP monotherapy, significantly reduced LIC. DFX reduced LIC and serum ferritin levels consistently and were halved in severely liver iron-overloaded patients.



cont.

Contents

Novartis Thalassaemia Master Class	1
Introducing Dr Zane Kaplan	2
The National Haemoglobinopathy Registry	3
Thalassaemia Journey	3
Play Therapy at Medical Therapy Unit	4
Interview with Carolyn Greely	5
Farewell to Sarah Burton	5
New staff biographies	5
Community Education and Advocacy:	
• Education at Thalassaemia Australia	6
• Living with Thalassaemia - A patient's perspective	6
• Community Education	7
Health Consumer Advocacy Workshop	8
Remembering my Mum	8-9
Women's Health Conference 2014	9
Special Children's Christmas Party	11
News from NSW	
• Letter from the Centre Coordinator	12
• Thalassaemia Dinner Dance Information	13
• Committee Dates	13
• Funding Grants Awarded!	13
• Health Consumer Advocacy Workshop	14
• Multicultural Health Week	14
• My meeting with an international expert...	15
Diet & Health	16

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Thalassaemia Australia Inc.

Committee of Management 2014

Executive

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

General Committee Members

Dr. Jim Vadolas
Bessy Mougos
Julie Christopher - Costa
Billy Costa

Committee meeting dates for 2014

Committee of Management meetings begin at 7.30pm and are held at the Thalassaemia Centre, 333 Waverley Road, Mt Waverley 3149 on the **3rd Tuesday in every month**

Tuesday 21 October
Tuesday 18 November
Tuesday 16 December

We currently have a few vacant positions on the Committee, if you would like to join us, please contact Spiro Bombos – President on 03 9888 2211 or email info@thalassaemia.org.au

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@thalnsw.org.au to update your records!



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

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Novartis Thalassaemia Master Class

cover story continued.

Excess heart iron was also shown to respond to chelation therapy, however it is slower than in the liver. The use of chelators was also dependent upon individual compliance. This still remains a problem for clinicians as they must balance health and lifestyle considerations for their patients in order to maintain optimal health.

Finally, we were able to meet with other haematology clinicians from leading hospitals in Australia and New Zealand and make vital connections. These connections will serve in our interests as we move forward with community education and a better understanding of the treatment of Haemoglobinopathies moving forward.

Jim Demetriou
Helen Kosmarikas
Thalassaemia Australia



Introducing Dr Zane Kaplan

You would have seen Dr Kaplan in any of your recent visits to the Medical Therapy Unit.

Dr Kaplan is the Thalassaemia Service Haematologist and currently he works Wednesday and Thursday after 1pm. He also calls in some Friday afternoons between his Haematology clinics and going to the Alfred but only while Don is away on Fridays. Stay tuned for an interview with the good doctor in our next newsletter.



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.

This newsletter is supported by an unrestricted educational grant from Novartis Oncology.

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



The national Haemoglobinopathy Registry

An update from Ri Scarborough, Monash University

How many people living in Australia have a haemoglobinopathy that requires treatment? It seems like a simple question, and you'd be forgiven for assuming someone, somewhere knows the answer. But the truth is, nobody knows the answer to this, and many other basic questions about haemoglobinopathies in Australia.

This is why the national Haemoglobinopathy Registry (HbR) was established. In a nutshell, the HbR is a voluntary database of people with haemoglobinopathies, which records their exact diagnosis, where they are treated, their current transfusion pattern, other treatment and monitoring they receive, complications they have experienced, and so on. The registry will continue collecting information over a period of several years, so we can monitor how things change over time. The HbR national steering committee is chaired by Professor Joy Ho from Royal Prince Alfred Hospital in Sydney.

It might not sound like groundbreaking stuff, but establishing this information is a vital step in assessing how our health system is meeting (or not meeting) people's needs, and helping plan for the future.

The registry also provides an important scaffold for other research projects – already, the registry has inspired a study of haemoglobinopathy screening in Victoria and a study of how red cell exchanges are done in different centres around Australia. There are also current discussions about using the HbR as a starting point to create a national red cell antibody register, which would help provide matched blood for people who have antibodies, and increase transfusion safety.

We are really pleased with the response the registry has received at the first two sites: Monash Medical Centre and Royal Prince Alfred Hospital. Almost all patients who have been invited have been very happy to participate. We have collected Stage 1 data on more than 130 participants so far, and we have many more still to collect. Thank you very much to all of you who have already agreed to take part, and for everyone else, please say yes when you're asked! The more people in the registry, the more the data will be able to

drive improvements in the systems that care for you. And that's good for everyone. The next step is to roll out Stage 1 of the registry to the other 8 major hospitals who have already agreed to participate. There is a great deal of paperwork to get all the required approvals for each hospital, and this happening gradually.

Once we have gathered the basic data about most cases, we can move on to Stage 2, where we gather more details on each person, including things like blood test and MRI results, follow participants' progress over time, and involve more hospitals. Our hope is that over the next few years, everyone in Australia with a diagnosed haemoglobinopathy that requires treatment will be invited to participate in the HbR.

Many of the patients and families I have spoken to so far have mentioned that they are keen to hear the results of our work, as they become available, which is great to hear. We love to know that the people who matter most here are interested in what we are doing and we will continue to keep you all updated via TA and TSNSW.



Pictured. Top, Members of the Haemoglobinopathy Registry Steering Committee at the 2013 seminar of the Transfusion Outcomes Research Collaborative.

Bottom, Ri presenting on the Haemoglobinopathy Registry at the seminar of the 2013 Transfusion Outcomes Research Collaborative.

THALASSAEMIA AGM

Thalassaemia Journey

Prof. Don Bowden, has been heading the Medical Therapy Unit Team over the past 30 years, and will be sharing his journey with us, as seen through his eyes.

He will speak about the changing face of Thalassaemia, the increase in the number of patients, treatment methods and longevity of our patient group. There will also be an introduction of Dr Zane Kaplan who is replacing Prof. Bowden. Dr Kaplan will briefly explain the way forward with respect to the current face of Thalassaemia and what the future holds for all our patients.

Also, meet the new Thalassaemia Staff.
Jim Demetriou – Community Educator
& Helen Kosmarikas – Office Manager

Light refreshments provided

When: Tuesday 18 November, 2014

Time: 6:30pm for a 7pm start

Where: Monash Medical Centre – Clayton
246 Clayton Road
Clayton VIC 3168

Venue: Lecture Theatre 3

Parking: Nearby street parking or the car park within the hospital grounds. (Please note normal parking charges apply)

RSVP: Friday 13 November, 2014

P. 9888 2211

E: info@thalassaemia.org.au



Play Therapy at Medical Therapy Unit (Monash Health)

Play Therapy has arrived to the Medical Therapy Unit – Monash Medical Centre every Friday.



This service has been funded by the outstanding event held last year from our friends – Mates on a Mission.

Play is an integral part of a child's life. From birth play helps children to learn, to relate to others and to have fun. Play can enhance a child's development physically, emotionally, intellectually and linguistically. When children or adolescents are admitted to hospital they are at their most vulnerable. They are separated from their friends, family and familiar surroundings which may lead to increased stress.

Play therapy can really make a difference. It allows children to express their concerns whilst in hospital. Play Therapy facilitates an understanding of the hospital experience and educate patients in adapting coping strategies to assist them with this.

Welcome to Play Therapy at the Medical Therapy Unit.

Often you see Play Therapists encouraging children who are old enough to use breathing/blowing as method for assisting with injections. When children are able to blow something (a pinwheel, a party blower, a balloon, bubbles) at the point of needle insertion it assists with a muscle relaxation response for easier needle access and also is a powerful distraction tool.

Play Therapy in hospital can:

- Distraction is well researched and assists with emotional wellbeing and the reduction of pain
- Enhance the children's understanding of their treatment and condition.
- Help children regain confidence and self esteem

- Provide a safe outlet for feelings of frustration and anger
- Serve as a diversion to keep child's mind off pain and medical procedures

(Courtesy of Monash Children's Hospital – website).

Introduction of the Play Therapist:

Jodi: Commenced training in child development with a Diploma in Children's Services and then followed on with a Bachelor of Early Childhood Development and Education. She is currently studying part time doing a Diploma in Allied Health services. Jodi has worked as a kindergarten teacher in both 3 and 4 year old groups over the past 4 years. She enjoys floristry (has a qualification in this too), photography, camping and loves animals. She is passionate about her work with children and is keen to work with and assist children in a health setting.

Paula Matthews-Rogers: Head of Educational Play Therapy & Creative Arts Therapy.

While studying a Bachelor of Arts Degree, I worked part time as Kindergarten Assistant. I developed an interest in working with children and then completed a Bachelor of Early Childhood Education. I worked as a kindergarten teacher for a number of years teaching both 3 and 4 year old groups. I then worked part time kindergarten teaching and part time lecturing in Early Childhood Development. Following this I worked for a number of years in a Multi-Cultural Early Childhood centre, which I think was one of my most enjoyable and rewarding roles and at the same time did part time contract work in Early Childhood in-service training.

I have had some wonderful opportunities and so then worked on a research team for indigenous education in Early Childhood. I also taught kindergarten part time, as being in the 'company of children' has always been my favourite thing.

I then did a psychology degree part time and worked as a kindergarten teacher again. I have worked in both inner city and rural kindergartens and just loved each experience.

In 2008 I commenced employment at Monash Children's Hospital as Head of Educational Play Therapy & Creative Arts Therapy. This has been another amazing opportunity for me and I continue to enjoy my work with children in a different role.



Interview with Carolyn Greely - Thalassaemia Service Coordinator - Medical Therapy Unit

Play Therapy has arrived to the Medical Therapy Unit – Monash Medical Centre every Friday



1. How do you feel the introduction of a Play Therapist will positively effect the unit?

Last Friday saw the commencement of our Play Therapy program. We would like to extend a warm welcome to Jodi, who will be our play therapist, and Paula who will be with us for the commencement of the program. The room was abuzz with excitement as children arrived to see the 'play table' full of fun activities. The children really enjoyed their play activities while catching up with friends they hadn't seen for a while as well as getting to know others they had not met before.

The distraction techniques used by the Play therapist during cannulation were extremely beneficial for the children, their parents and the nursing staff. With the guidance of the play therapist, we have

also rearranged the play corner to make it more conducive to play.

2. How will this change the treatment process for the young patients? ie: scheduling of dates & times of treatments.

Due to availability of the Play Therapist, at this stage we are only able to run the program on a Friday so we are encouraging parents to book their children on this day. We understand that this may be difficult for some families who already have work arrangements in place. Parents will also need to start bringing their child in for treatment earlier, before 9am to fully benefit from the program.

3. During the treatment process are their guidelines/protocols on how the

nurses & Play Therapist engage with each other?

The nursing staff have fully embraced the program and look forward to working closely with the Play Therapist. The nursing staff will be able to learn new distraction techniques that they can utilise during cannulation and venepunctures.

4. How will you measure the success of this program, what criteria will you utilise to do this?

The program will be evaluated after 6 months. The children, their parents and staff will all be asked to fill out an evaluation to assess the program including ways in which they feel the program can be improved. (Younger children will be interviewed).

Farewell to Sarah Burton

Thalassaemia Australia would like to thank Sarah Burton for all her hard work and many contributions to our organisation. Sarah worked at the Thalassaemia Australia for 11 years. During that time her good networking skills on both a national and international level helped build our organisation. One of her many achievements was the organising of the Australian Thalassaemia nurses workshops which brought together nurses from around Australia to discuss and share their experiences in issues that may arise in the treatment of patients with a Haemoglobinopathy.

Sarah will be greatly missed. We wish her all the best in her future endeavours.



Thalassaemia Australia Inc – New Staff Biographies

Community Educator/Business Development: Jim Demetriou

Hi everyone, I am the newly appointed Community Educator for Thalassaemia Australia. I have been married now for 26 years to Irene and we have a beautiful 8 year old boy named Arthur.

I have a Science degree in Biochemistry and a Diploma of Education which enables me to teach Chemistry, Science and Maths in secondary schools. I have also held positions as a Scientific Sales Rep and staff trainer in a stem cell company called CellSense.

I'm an all round mad sports fan and follow the Richmond tigers in the AFL, Melbourne Storm in the ARL and Melbourne Victory in the soccer.

I also have an Advanced Diploma in Music and worked as an entertainer mainly in the Greek industry as a Bouzouki player, Guitarist and singer.

Office/Project Manager: Helen Kosmarikas

I have been a Thalassaemia committee member for the past four years and currently appointed as the Office Manager for Thalassaemia Australia. I have been married for 17 years and have 2 boys, Jared, 6 and Jasper, 4.

I have worked in Banking and Finance sector for the past 17 years, and held several middle office positions within the National Australia Bank.

I made contact with Thalassaemia Australia Inc when I needed parent support in navigating the Thalassaemia and Sickle Cell world, when my son was diagnosed. I was greatly appreciative with all the assistance and support I received from the society, that I wanted to give back by joining the society as a committee member. Enabling me to provide that same support to families undertaking the same journey.

In my little spare time I have left, I enjoying reading and socialising with friends.

COMMUNITY EDUCATION AND ADVOCACY

Education is a vital part of the core work of Thalassaemia Australia

Thalassaemia Australia was invited by Monash Children's Hospital to present to the – Play Therapy Unit.

The presentation was an introduction to the conditions of Thalassaemia and Sickle Cell, and the current issues faced by our paediatric patients and families dealing with chronic illness. From being treated in the treatment unit for their blood, to presenting with illness in the emergency departments through to stays in the wards.

Jim Demetriou, also presentation to Student Social Workers at Monash Health.

The presentation was from a patient's perspective in living with Thalassaemia. Referencing Diagnosis and treatment standards in the early years through to current diagnosis and treatment levels in the MTU. The integral role of social work, in dealing with patients with a lifelong chronic illness. Understanding all the "all of Life" issues that patients face and how social worker facilitates and assists in the process.



Living with Thalassaemia – A patient's perspective

This presentation was given at the Monash Medical Centre in Clayton in the main lecture theatre and attended mainly by nursing staff.

I was invited by Nurse Terri Dunstan in my capacity as Community Educator for Thalassaemia Australia to present some important facts relating to Thalassaemia but to also give a patient's perspective.

During my presentation I was able to highlight the major differences between the treatment I received as a patient during the 60's and 70's with that given today. The major points outlined were the routines for cross matching (done via a lancet) and the multiple attempts to cannulate me (6-10 times) by medical personnel. This is in stark contrast to the methods employed today and the relative ease and skill with which all patients are treated.

Due to excessive iron overload as a child and teenager, I was also able to impress upon the audience the difficulties I experienced in being well on a consistent basis.

As such I needed to attend special schools for disabled children. With the advent of iron chelation, I was then able to decrease my iron levels and maintain a very good level of health. I explained the use of the slow infusion pump for chelation and was met with many puzzled faces. Hence, further education and awareness of the treatment regimen would be of immense benefit.

The audience was then given an opportunity to ask me various questions of interest in order to gain a greater understanding of the condition. Overall the presentation was a resounding success and opened the door for future opportunities to address an audience of similar nature.

Jim Demetriou
Community Educator
Thalassaemia Australia



Community Education

Hi everyone, as the new Community Educator for Thalassaemia Australia, I can honestly say it's been an amazing experience over the last 2 months.

In that time I have visited close to 20 schools and spoken to over 600 students. All of them are absolutely spellbound by the presentation with respect to the information and the personal story I have to share with them about my journey as a Thalassaemia patient. As an experienced high school teacher and scientist, being able to relate this information is a pleasurable experience for me.

I manage to show them animations on Thalassaemia and Sickle Cell along with all the facts and data relating to where most of our patients come from, transfusions, iron overload and treatment, how to donate blood, blood screening for carrier status, etc. However, when I show and get them to handle the pumps, and explain that I had to put it on for 10 hours at least 5-6 times a week, they are shocked at what I went through for so many years. This really helps them understand that having blood transfusions is only part of the solution.

Putting on a pump almost everyday is the harsh reality of what it takes to remain healthy and alive as a person living with these conditions. At times you can hear a pin drop as they listen intently and absorb

all the details and ask relevant questions to gain a better understanding of what we go through.

An astonishing fact for me during the presentations is how only about 1-3 students in any class know their blood group. I encourage them to at least know this fact in case of any future emergency but to also make an attempt to have a genetic test for carrier status.

It may appear that the presentations are all about the difficulties associated with having a blood condition. I point out that with all the medical research conducted around the world we are hopeful and optimistic of having better treatments in the very near future. Perhaps some of these students listening to our presentations will be inspired to take up a career as a medical researcher. Quite often, it doesn't take much to ignite a passion and a dream to inspire someone on a mission of greatness.

Cheers,
Jim Demetriou
Community Educator
Thalassaemia Australia

BECOME A MEMBER

Your support in becoming a member is very vital to us for many reasons:

- Raising funds for urgent medical equipment such as slow infusion pumps.
- For world class Medical Research Projects such as Stem Cells, Gene Therapy, Foetal Haemoglobin, Bone Marrow Transplants, Iron Chelators etc.
- Other Medical services such as a Play Therapist for our younger patients.
- Equipment for our Medical Therapy Unit such as chairs, vein finder, blood refrigerator, etc.
- To promote greater awareness and education in the wider community through publications, newsletters and materials for health professionals (i.e. GP's, Nurses), community groups (CALD-Culturally and Linguistically Diverse Communities), secondary and tertiary institutions.
- Keeps you informed of important events, or issues relevant to patients, parents and health professionals.
- Assists in the day to day operations of Thalassaemia Australia and maintaining a strong profile in the general community.
- The greater the membership base, the greater our voice is with the State/Federal Government in understanding the health issues and the need for greater Government assistance.
- To continue our valuable Community Education programs in Secondary Schools, Hospitals, GP clinics, etc.

Thalassaemia Australia
Contact Details: 03 9888 2211
Email: info@thalassaemia.org.au

Our memberships are currently divided into categories:

Life: \$200
Annual: \$20
Non-profit organization: \$20
Private Sector/Corporate: \$30



Health Consumer Advocacy workshop 2014 – HCA2014.

This annual event has been running for the last three years. This event is supported by an educational grant from several pharmaceutical companies, Pfizer, Novartis, Amgen, Bayer, Janssen-Cilag, MSD and Roche. It was facilitated by Zest Health Strategies.

It brings together approx. 40 different Health Non for Profits (NFP) organisations, some with a large community profile and some with small community profiles. This was my first attendance to such event in my current role as the office/projects Manager for Thalassaemia Australia. I was able to secure a last minute invite to this event which was held over 2 days Sunday, 24th and Monday 25th of August. I can you; I thought it was a misprint - "as who runs a conference on a Sunday". I seek clarification for our NSW counterparts and the delightful Nancy Lurich informed it was not a misprint and went on to list the wonderful diverse group whom attend this event and the importance of the topics discussed.

Sunday morning I board a 7am flight to Sydney, and arrive just before 9am to the venue. Greeted by Nancy at the front doors I enter the conference room and I am swiftly impressed by the number of NFP's in attendance and how everyone was reuniting again. I was introduced to many people from many organisations, many I have heard of before i.e. Rare voices, leukaemia Foundation, Asthma Foundations and many I could barely pronounce. It became very clear to me from the onset that everyone in this community valued each other's causes and many partnerships and alliances were evident.

The Agenda for this Conference was split under the headings of:

- Getting the House in order
- Partnerships and Alliance
- Community Engagement and
- Community Advocacy

As I first time attendee, I was quite enthralled by the ranges of topics discussed under each heading. I sat in my table trying to absorb as much as possible and take down the key points. Many reference

points were made in accessing important information and were to go to obtain assistance. By far the key moment of day 1 was the 'speed dating'. It introduced me to all the other NFP organisation's and meet with key individuals driving their cause. It was opportunity to hear other group's achievements and struggles, establish relationships and identify common goals and ways we could work together. It ignited conversations and identified that no matter what the size and community profile of the NFP Organisation, we all have common issues. Whether it was Governance, IT solutions, Harassing volunteers, measuring social impact getting new treatments across the PBS line, etc.

Day 2, and I was completely overwhelmed and suffering from Conference fatigue. With lots of caffeine in my system, I regrouped and eagerly awaited the day's session topics. The valuable component of each session where I obtained lots of insights into the other NFG groups workings. Such as their successes and struggles were during the discussion time. You could draw parallels, you could utilise their approach and you could learn from their struggles, what made it extremely interesting for me, was how helpful other org's were to offer assistance, lend out working models and contact points. It really surprised me, coming from Banking and finance, this sort of sharing of information amongst competing organisations is unheard of.

In summary, the new kid on the block learnt heaps. Took lots of notes, made valuable connections, had intriguing conversations and had many light bulb moments. All in all, this is a terrific educational event I'm honoured to had the privilege to attend. The critical step post event is to put some of this information learnt during the sessions into practice.

My Mum *a story by Liana L'Rowse*

My mum's name was Dora Aloisi. She was born on the August 30 1953 in Adelaide to Italian parents who were originally from Reggio Calabria. She was born with Thalassaemia Major and spent a lot of her childhood dealing with her illness. Her parents were told that she may not live through her childhood, but she was determined and courageous and she fought on. She finished school and was able to work, whilst continuing to have blood transfusions. The doctors were amazed at her progress and Dora dreamed of having a family of her own. She fell in love and was married in 1977. She travelled to Europe and was living her dream life, whilst continuing to battle her illness. In 1980 they travelled to Sri Lanka to adopt a baby girl. Liana bought a lot of joy to her life and she felt blessed to be experiencing motherhood. Sadly in October 1983, at age 30, Dora passed away surrounded by her parents and husband.

Despite all of her struggles, Dora simply loved life. She was able to achieve her dreams of getting married, traveling and becoming a mother.

Our family have all been blessed to have had Dora in our lives. Her strength, determination and courage are her inspirational gifts that she has left with us.

Although I was young when my mum passed away, there is not a day that goes by that don't feel her presence, strength and encouragement by my side. I know that she would be very proud of me and I am forever grateful to her for the life that I have been given.

My Nonna, Rosina Aloisi (Dora's mum) has been a strong influence in my life, and stepped in to help raise me after my mother's passing. She has been a major part of my life, and I lived with her for many years. She is now 86 years old and will be walking me down the aisle our wedding.

In brief, Liana and her fiancé, Simon met in Adelaide and now live together in Melbourne. They were engaged in Sicily, Italy in 2013.



Their wedding date is set for the December 14 2014 at the National Wine Centre in Adelaide. They decided to make a generous donation to Thalassaemia Australia Inc, in lieu of purchasing traditional bonbonniere for their 250 guests. This wonderful donation made to commemorate your beautiful mother for your special day. We wish you and Simon a magical Wedding day and a lifetime filled with love, health and happiness.



In loving Memory

In loving Memory of Efrosine Patista.

On behalf of Thalassaemia Australia Inc. we would like to take this opportunity to thank you John Patista and the Patista family and friends for the money bequeathed to us in memory of Efrosine Patista.

On behalf of Thalassaemia Australia Inc. we would like to take this opportunity to thank you Gisella Mazzilli and the Maiolo family and friends for the money bequeathed to us in memory of their Dad – Salvatore Maiolo. Amount received is to be allocated to the purchase of medical pumps for patient community.

On behalf of the Thalassaemia Australia Inc. we offer our deepest condolences and sincere thoughts to Jothathan Leaks on the sad passing of his beloved wife Fortini on the April 6 2014.

That her memory live on, that she is missed and forever in all our hearts.

Women's Health Conference 2014 – Dorevitch Event

The event sponsored by Dorevitch Pathology at the Grand Hyatt in Melbourne was a fabulous opportunity to meet approximately 500 GP's throughout the course of the day.

The actual title of the event was 'Women's Health Conference 2014 for GP's'. As the title suggests the day centred around presentations given by health professionals on issues relating to Women in particular.

During the breaks, Helen Kosmarikas (Thalassaemia Australia Centre Co-ordinator) and I, were able to make crucial connections with these GP's and other health professionals. We were able to gain vital contact details and inform them of our primary functions as an organisation. They showed enormous interest in having specific education at their place of practice with other colleagues. This provides us at TA with the opportunity of giving them the latest up to date information with regards to antenatal screening, initial diagnosis of Haemoglobinopathies, current treatment regimens (i.e. blood transfusions, iron chelation therapy, monitoring of liver and heart iron levels and other potential complications).

As the Community Educator for TA, this represents further opportunities for me to open up further contact with GP's who see patients in our CALD demographic. We were encouraged by the amount of brochures and general information that was taken from our display. This showed keenness on their behalf to gain vital knowledge and answer any questions of specific interest to them and their patient group. Many were also surprised to see the slow infusion pump and how it was used to treat iron overload. They were also pleasantly surprised to hear that our educational service was free and that they could access that resource at any time. Perhaps this suggests that we need to send all major GP practices in Victoria a general TA email every quarter to prompt them in making a time where we can go out to see them.

Finally, the presentation given by Dr. Mark Levin on 'Thalassaemia in the Antenatal Population' was simply outstanding. He is the Head of Haematology at Dorevitch Pathology and has a wealth of knowledge in this area and would be a great resource to TA whenever required. Dr Levin's clinical expertise and advice assists in the diagnosis and interpretation of Haematology related pathology results. Therefore, he was a very worthy expert to speak at this event. We had the privilege to meet him after his presentation and made it clear that he was very happy to meet us again in future and to assist us in any way possible.

In conclusion, this event was one that TA was grateful to attend in order to gain vital contacts in the GP population. Furthermore, a secondary gain from the event was the opportunity to meet other professional companies with their particular displays. These included the display from the Bank of QLD and Amity property group. Moving forward, perhaps we can form alliances with such companies. This is certainly worth further investigation from us as an organisation.

Jim Demetriou
Community Educator, Thalassaemia Australia Inc





Handy Apps

Here is a cool new App that empowers you to keep track of your Ferritin & HB Levels. Great to have information at your fingertips and a conversation piece when you consult with your health professional.

The App has been developed by the Canadian Hemochromatosis society as a graphical tools to deepen understanding of hemochromatosis treatment. Its Application also reaches our Thalassaemia and Sickle Cell community as a way of keeping track of your results each treatment.



What is health translations?

Health Translations enables health practitioners and those working with culturally and linguistically diverse communities to easily find translated health information.

www.healthtranslations.vic.gov.au

In Kind Support to Thalassaemia Australia Inc.

On behalf of Thalassaemia Australia Inc. we would like to take this opportunity to thank the following people/ organisations for their support this quarter:

- IT Centre
- Troiano & Associates
- Harry Christopher

www.thalassaemia.org.au



Thalassaemia Australia Inc. is on Facebook



Like us to receive updates regarding our community awareness program and access links to important websites.

www.facebook.com/pages/Thalassaemia-Australia-Inc/198157430216491



Christmas Party for Special Children



Flemington Racecourse 2014

Held by Melbourne Party – Invites Thalassaemia Australia Inc.

On Sunday 14 December we are once again hosting the largest, FREE, Christmas Party for Special Children. This is our 20th year Anniversary and it will run from 9.30am until 1.30pm at Moonee Valley Racing Club. A 4 hour stage show featuring many artists will keep the children entertained. There will be activities such as merry go-rounds, jumping castles, face painting and much more. With all this fun to be had, they will need food, drinks, and ice creams, which we will provide for free.

Of course no Christmas party is complete without Santa! After Santa's arrival the toy room will be opened & each child will receive two beautiful presents. We would like to extend an invitation to some of the children in your care to attend this wonderful event.

ELIGIBILITY

The children eligible to attend

- Children with Chronic Illness

REQUIREMENTS

- Children aged between 3-16 years of age
- Only ONE child can attend on each invitation. Only ONE parent, carer or teacher must accompany them. Each child's invite entitles ONE adult entry.

INVITES FOR SIBLINGS

- Siblings of the child that meets the above criteria are also eligible to apply for an invitation; this is for immediate family only, not cousins etc.
- Siblings must also meet the age criteria.

Please complete the "Expression of Interest Form" and hand it to Carolyn or Trish (MTU). Once we (Thalassaemia Australia Inc.) receive all the "Expressions of Interest" we will collate the information and send it to the organisation holding the event (Melbourne Party). They will in turn assess all the Organisations applications, in a fair and honest manner before invitations are issued.

If you have any questions please don't hesitate to contact Thalassaemia Australia & speak with Helen or Jim on 9888 2211 or you can email any queries to info@thalassaemia.org.au





Letter from the Centre Coordinator

Hello everyone, I hope this spring edition newsletter finds you all well. I am still trying to come to terms with the fact that it's almost the end of another year, and boy what a massive year it has been.

I would like to make a special mention, to show gratitude and thanks to an amazing lady. Sarah Burton left Thalassaemia Australia after 11 years of hard work. As much as I would love to sum up in words what Sarah has taught me over the years I simply cannot.

I remember when I was first introduced to Sarah, I thought she was a wealth of knowledge. I knew that I could teach her so much about being a patient and living with Thalassaemia, but Sarah taught me so much about our role working for a non-profit-organisation, which is what was an important element to become successful in what we do. I will be forever grateful to Sarah and would like to thank her on behalf of myself and the Thalassaemia Society of NSW for her time, passion and effort.

On this note I would like to welcome the two new staff members of Thalassaemia Australia, Helen Kosmarikas and Jim Demetriou. I look forward in continuing the strong and positive working relationship that TA and ThalNSW have formed over the years, in order to provide optimum information and care to our patient's and their families on a National level.

Within my role at the centre and being an Ambassador for the Australian Red Cross Blood Service I am constantly doing and learning new things and being given once in a lifetime opportunities, that I am so grateful for. Early August I was given the opportunity to be interviewed live on the Morning Show Channel 7.

I was able to very quickly share my story on live television to try and encourage as many people as possible to donate blood. As many of you who know me would know, that my nerves were due to the 4 minute time restriction that was set for the our interview.

Rather than being nervous that I was going to be on live national television it was that I had to stick to a timeframe and keep my answers short and brief. This for me was nerve-wracking as I could literally talk under water especially about a topic so close to my heart.

Thank you to the Australian Red Cross Blood Service for once again giving me the opportunity to spread the word about Thalassaemia and the importance of blood donation.

As the end of the year draws near, I will be starting to gather ideas of little Christmas gifts for our young patients, to receive when they go in for their last blood transfusion of the year.

In previous years I have sent out letters to local businesses regarding donations or vouchers. I would like to open up the opportunity this year to anyone whom would like to donate a gift or gifts to our special patients.

If you have a business or know someone who has a business and you think they may be interested in helping out or if you as an individual would like to donate please contact me via email; coordinator@thalnsw.org.au or by calling 0400 116 393 all donations will be greatly appreciated.

Please remember that anyone wishing to share a story or an article in our newsletter please come forward and contact me as well as ideas, suggestions and feedback are always welcome.

Until next time, please take care and enjoy the weather as it warms up!

Nancy Lucich – Coordinator Thalassaemia Centre of NSW





Thalassaemia

supporting what matters...

Thalassaemia Fundraising Dinner Dance

DATE: Friday 7th November 2014

TIME: 7:00pm

DRESS CODE: Formal

VENUE: The Renaissance, Piano Room.

ADDRESS: 3 New Street East, Lidcombe NSW 2141

TICKETS: \$100.00 per person

RSVP by 17th October 2014 to Therese El-Bayeh

EMAIL: tbayeh@hotmail.com **PHONE:** 0424 246 906

Therese El-Bayeh has organised a fundraising dinner dance to raise funds for Thalassaemia, please contact Therese direct for ticket purchase.

Therese will allow up until the end of October for any last minute ticket purchases however please get in asap as tickets are selling fast!

EMAIL: tbayeh@hotmail.com **PHONE:** 0424 246 906

2014 - 2015 Committee of Management

Executive

President – Rosa Dimitrakas
Vice President – Maria Chate
Treasurer – Lela Dallas
Secretary – Marianne Dimitrakas
Assistant Secretary / Treasurer –
Stella Stilianou

General Committee Members

Communications Officer –
Haroula Volvozidis
Executive Members;
Glenda Hughes
Tracey El Bayeh
Nicholas Kotrotsos
Martha Gerolemou

2014 - 2015 Committee meeting dates

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

Wednesday 15 October
Wednesday 19 November
Wednesday 17 December
Wednesday 18 February
Wednesday 18 March
Wednesday 15 April
Wednesday 20 May
Wednesday 17 June
Wednesday 17 July
Wednesday 20 August

All meetings take place in the board
room on Level 7, King George V
Building, Missenden Rd, Camperdown
2050 NSW.

If you would like to attend please notify
the coordinator@thalnsw.org.au so
you can be added to the introductions of
the Agenda.



Find us on Facebook
Thalassaemia Society
of NSW Inc.



NOTICES

Funding Grants Awarded!

In August 2014 the Thalassaemia Society of NSW called for expressions of interest for research funding grants.

The Thalassaemia Society of NSW is proud to announce the approval to award the two following research grants;

- \$30,000 to the Murdoch Children's Research Institute towards the research that Dr Jim Vadolas and his team are currently conducting into Gene Therapy and
- \$20,000 to Monash University for the Haemoglobinopathy Registry which is a national database for collecting medical information from patients with Thalassaemia and Sickle Cell disease.

This database is of great importance to our patient community as we do not have accurate statistics on these blood disorders.

Health Consumer Advocacy Workshop

We came together again for another two days of networking, information sharing and learning new things.

Well done to the 2014 Steering Committee for all the work they put in over the year to keep things rolling and then to come through with great sessions over the two days.

Topics discussed during this meeting were issues that we could all relate to and ones that were important to the individual organisations. The varied agenda addressed topics including good governance for small organisations, building and managing a website in the social media age, practical tips for harnessing volunteers, measuring your impact, using Cloud based solutions to better manage small organisations, partnerships and alliances, developing a community campaign, advocacy activities to get new treatments across the PBS line, managing an online community, social media, advocacy and campaigns, fundamentals of consumer advocacy, insight into PBAC, collaboration and impact in rare diseases research and of course lots of

time for networking and information sharing which is a priceless exercise. It was again great to come together with familiar faces and of course a pleasure of meeting new ones also who are working hard to make a difference just like us.

As the HCA workshop was supported by education grants from the following pharmaceutical companies it goes without saying that we are grateful to them for the support. Thank you to; Pfizer, Novartis, Amgen, Bayer, Janssen-Cilag, MSD, and Roche.



Why become a member of the Thalassaemia Society of NSW?

Your support in becoming a member is very vital to us for many reasons:

- Raising funds for urgent medical equipment such as slow infusion pumps.
- For world class Medical Research Projects such as Stem Cells, Gene Therapy, Foetal Haemoglobin, Bone Marrow Transplants, Haemoglobinopathy Registry, Iron Chelators etc.
- Other Medical services such as a MRI T2* for our patients.
- Equipment for our Main Treating Centres such as chairs, vein finder, TV's, etc.
- To promote greater awareness and education in the wider community through publications, newsletters and materials for health professionals (i.e. GP's, Nurses), community groups (CALD-Culturally and Linguistically Diverse Communities), secondary and tertiary institutions.
- Keeps you informed of important events, or issues relevant to patients, parents and health professionals.
- Assists in the day to day operations of The Thalassaemia Society of NSW and maintaining a strong profile in the general community.
- The greater the membership base, the greater our voice is with the State/ Federal Government in understanding the health issues and the need for greater Government support & assistance.
- To continue our valuable Community Education programs in Community Groups, Secondary Schools, Hospitals, GP clinics, etc.

Thalassaemia Society of NSW
Contact Details: 02 9550 4844
Email: coordinator@thalnsw.org.au

Our membership is an annual fee of \$20.00

Multicultural Health Week

This year to celebrate Multicultural Health Week we took part in an awareness stand at RPA Hospital with a number of other members from the Multicultural Access Committee. The stand was bright, colourful, fun and informative. We had a variety of information on offer from various services to the multicultural community in the district.

We were successful in attracting attention to our stand from all age groups with balloons and sweets for the young ones to guessing competitions for the adults.





My meeting with an international expert...

On the 7th August I was invited to represent the Thalassaemia Centre of NSW by attending the Thalassaemia Masterclass sponsored by Novartis Pharmaceuticals.



This allowed me to enter and listen to the Thalassaemia experts from overseas. I was given the opportunity to meet one on one with Prof. M.D. Cappellini, Professor of Internal Medicine University of Milan, Italy.

During my interview with Prof. Cappellini we discussed patient treatment and care in Australia in comparison to that in Italy and other parts of the world. Topics of interest which I asked Prof. Cappellini about were the following;

How do patients get funded or supported for treatment in Italy?

The National Health Service pays for all treatment, medications and supplies for each patient. As well as supplying new and updated pumps to each patient, pumps are changed every 4 years to ensure they are current functional and up-to-date.

Support Service for patients in a Social & Psychological way

Most treatment centres have a counsellor or psychologist who meets with patients. Family and relationship issues are becoming more and more common amongst the patient group as they are growing older and reaching different milestones in life. This was

not common amongst this patient group in the past.

About any Italian Thalassaemia Societies

There are many small societies in each region or local associations however they do not work in collaboration with one another. Recently an adult patients association by the name of UNITED was formed however Prof. Cappellini was still unsure if it will be successful. Prof. Cappellini at this point complimented the Thalassaemia Society of NSW and Thalassaemia Australia and said that we should count yourself very lucky and be proud that we have two great organisations who work tirelessly to provide the best support and information base for our community here in Australia.

Routine Screening

As for the screening all was the same and current testing that is carried out on patients in Australia. Ferritin being checked every three months instead of monthly with the yearly testing being MRI, Fibroscan, abdominal ultrasound in adults, Audiology and ophthalmology.

Current Research

This was an interesting and lengthy conversation, basically there are 3 main groups of researchers involved in Gene Therapy overseas, and all are at different stages and some which have already entered into pre-clinical trials. There is also research into finding new alternative treatments and new iron chelators.

Thalassaemia and old age

As in Australia one of the major problems that the patient population in Italy are facing as they age is Osteoporosis. In saying this they too are trying to keep calcium and vitamin D levels within the normal range. Treatment for patients with Osteoporosis is with Bisphosphonate and Neritronate.

Is Italy seeing an increase in other haemoglobinopathy's?

Yes, as there are migrants coming in from Africa, the Middle East, south East Asia and

other countries they are seeing a rise in Sickle Cell and Haemoglobin H.

How are the Thalassaemia Patients with Hep C treated?

The same medications as here in Australia are used, Interferon and Ribavirin. As you can imagine my questions were flowing and she was interested about patient care here in Australia however our time was limited.

I must say however that after speaking at length with Prof. Cappellini and listening to the rest of the speakers at the meeting, it would seem that our patients in Australia are receiving optimum treatment and with the new advances in research the future looks brighter for Thalassaemia patients throughout the world.

On behalf of all the patients, carers and families I would like to thank Prof. Cappellini for her time and thank you again to Novartis for making this meeting possible.



Reducing the Iron Absorbed from Food

Thalassaemia is a complex condition and the ideal diet would need to take account of many factors. Although most of iron overload is due to blood transfusion, increased absorption of iron from the diet is also important.

Only a small amount of iron from the diet is absorbed into our body. The amount absorbed is higher when hemoglobin in the blood is low.

People with low hemoglobin such as those with thalassaemia intermedia or those with thalassaemia major, in-between transfusions could therefore adapt their diet so that not only the total amount of iron in their diet is low but also the amount of iron absorbed into their body is low.

There are two kinds of iron in the diet: iron which is present in red meat (Meat iron) and iron which is widely distributed in the diet (Non-meat iron).

Meat Iron

Meat iron is present in red meat such as beef, lamb and pork and the dark meat of chicken as well as in seafood such as sardines, cockles and mussels. Liver is a very rich source of meat iron.

Try to cut down on these and perhaps substitute meat with soy protein. It is not, however, a good idea to exclude meat, chicken and fish completely from your diet because they contain other important nutrients, particularly for children. Choose the white part of chicken rather than red meat as it contains less iron.

On average, after a meal with red meat, about 35% of iron will be absorbed into our body. However, this may vary between 10-40%, depending mainly on whether the meal contains milk or milk products. The calcium, present in milk, cheese, yoghurt, cream decreases the absorption of meat iron.

Try to drink a glass of milk with a meat-containing meal and to use milk in cooking. Milk intake should be at least half a liter daily, particularly because it helps to prevent osteoporosis, as it will be discussed later.

If you are worried about your weight, semi-skimmed or skimmed milk is just as rich sources of calcium as whole milk.

Non-Meat Iron

Non-meat iron is widely distributed in the diet, present in eggs, chocolate, cereals, vegetables, fruits roots (potatoes, parsnips), beans and lentils.

The absorption of non-meat iron from the diet into our body is much less than that of meat iron, but it may vary more than 20 fold, depending on the composition of a meal.

The foods which decrease its absorption are:

- Cereals
- Dairy products.

The foods which increase its absorption are:

- Fruit & Vegetables rich in vitamin C
- Meat, Fish, shellfish & Poultry and
- Pickles, Sauerkraut, Soy Sauce, Vinegar and Alcohol.

It is difficult to avoid taking non-meat iron because it is present in most foods. However, diet can be modified by taking more of the foods which decrease and less of the foods which increase the amount of iron absorbed into our body.

(Information courtesy of UKTS – WWW.UKTS.org)

EASY STRAWBERRY SPINACH SALAD WITH CANDIED PECANS

- 2 TBSP BUTTER
- 1 CUP PECAN HALVES
- 2 TBSP BROWN SUGAR
- 6 OZ BABY SPINACH LEAVES
- 1 1/2 CUPS SLICED STRAWBERRIES,
- 1/4 CUP CRUMBLED GOAT CHEESE
- BALSAMIC VINAIGRETTE

METHOD.

1. Melt the butter over medium heat. Toss in the pecans and brown sugar, stirring to coat. Cook over medium heat until the sugar begins to caramelize (about 3 mins). Spread pecans on a wax paper lined baking sheet to cool.
2. In your salad bowl layer the spinach leaves, strawberries, goat cheese and pecans. Don't pour dressing on salad until ready to serve. Enjoy!

Recipe & image credit www.inashyoudry.com

