

Thalassaemia

A U S T R A L I A

Unifying support and genetics



Thalassaemia Australia Autumn/Winter 2014 Volume 7 Issue 18

Quarterly

Australian Haemoglobinopathy Nurses Network – AHNN

By Grainne Dunne, CNC Haematology/Apheresis SCH, NSW

Haemoglobinopathies are a group of genetic blood disorders whereby the haemoglobin molecule is unable to form correctly and over time the body becomes chronically anaemic.

Examples of haemoglobinopathies are Thalassaemia, Sickle Cell Disease, Sickle-Thalassaemia and Black Fan Diamond Disease. There are different severities and sub-types of these individual disorders, which together with other elements can make haemoglobinopathies complex disorders to manage well.

Treatment of the most severe forms require chronic, regular (mostly 4 weekly), red blood cell transfusions. Without these transfusions, many patients would not survive to adulthood. However while administering such lifesaving chronic blood transfusions; it also adds another layer of complexity of the management of haemoglobinopathies.

Managing chronic disorders can be very challenging for any healthcare professional. Of course, when the disorder is rare it only makes the challenges greater again and even more isolating for both the health carer and for the patient. In Australia, haemoglobinopathies are primarily managed in a small number of haematology centers around the country; centers who are committed to specializing in this area of care. As such, this requires specialized haematologists and specialized nurses experienced in the needs and treatment of a somewhat small and yet challenging population of haematology patients.

Medical professionals often need to seek advice and medical support from known peers, both nationally and internationally. In the area of Australian haemoglobinopathy care, this appears to be more commonly practiced amongst medical clinicians than it does amongst the nursing specialists – up until now.

On May 18 2014, a small group comprising of 6 nurses and 4 members from Thalassaemia Australia and The Thalassaemia Society of NSW met in Melbourne to formulate the first ever "Australian Haemoglobinopathy Nurses Network" (AHNN). The fundamental purpose of this group is to provide a forum through which Australian nurses in this specialized area of care can come together to give/receive support, advice and education. As such, improving haemoglobinopathy nursing care and services within Australia.

The Australian Haemoglobinopathy Nurses Network was established as a sub-committee of the Thalassaemia Australia/Thalassaemia Society of NSW and is supported by Thalassaemia Australia/Thalassaemia Society of NSW. It is hoped that over time, the group will grow successfully in number, strength and functionality.

At a starting point, the group will meet face to face once every two years. It will maintain ongoing telecommunications via group email, teleconference and as required internet web usage. In general, the group will act as a repository for knowledge learning amongst Australian nursing peers.

Membership is through application to the group chair and is free of charge. Australian nurses working in a role which has a specialty component of haemoglobinopathy patient care are encouraged to become members and participate in this specialist group.

For more details and membership information, please contact the current chair of this new group: Adrienne Woods: adrienne.woods@health.nsw.gov.au or telephone: 02 9845 0000 and page 6273.

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Thalassaemia Australia Inc.

Committee of Management 2014

Executive

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Vice-President – Mary Triantafillou
Secretary – Mary Konstantopoulos
Treasurer – Sotirios Katakouzinos

General Committee Members

Dr. Jim Vadolas
Bessy Mougos
Julie Christopher-Costa & Billy Costa
Helen Kosmarikas
Julie Dascoli

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**

22 July	16 September	18 November
19 August	21 October	16 December

We currently have two vacant positions on the Committee, if you would like to join us, please contact Spiro Bombos – President on 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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Community Education and Advocacy

Thalassaemia Australia has had a busy few months co-ordinating with Australian Haemoglobinopathy Nurses Exchange meeting with the Thalassaemia Society of NSW and Haemochromatosis Australia.

Haemochromatosis Australia is a not-for-profit organisation like ourselves, kindly invited us to participate in their first-ever Australia-wide conference at the Austin Hospital in Melbourne. The area of interest that all three groups have in common is secondary iron overload. On this basis, we were all able to come together and share our experiences, not only with the condition, but also the way that we educate the public and raise awareness of these conditions.

The beauty of these collaborations is that we have now developed a new partnership with Haemochromatosis Australia where we can exchange information and help each other's organisations to move forward in a strong, positive manner. A special mention must go to Tony Moorhead – Secretary of Haemochromatosis Australia for his support and encouragement during this time. For Thalassaemia Society of NSW and TA this meeting also gave us the opportunity to house our first ever Australian Haemoglobinopathy Nurses Exchange.

Many of you will be aware of the workshops that TA and Thal NSW has held for our nurses throughout Australia over the last few years. With the support of our sponsors and friends of both organisations, we have now been to take the next step and form the Australian Haemoglobinopathy Nurses Exchange – to better assist our patients and their families in the long-term. It is very important that we acknowledge the people that participated in this inaugural event, for giving up their own personal time to dedicate it to this worthy cause. Together with the support of the both Thalassaemia Australia and Thalassaemia Society of NSW we look forward to some great outcomes for our community.

Earlier this year TA took part in the Rare Voices National Plan Engagement Roadshow (for Rare Diseases) in

Victoria held by Genetic Support Network of Victoria. The national plan of engagement for rare diseases sets out what has been learnt over the last few years, and details how we can collaborate together to achieve greater things for people with rare diseases and their families in this country. Much has been learnt from international organisations, and is relevant to many groups here in Australia and can be now implemented through Rare Voices Australia. Being part of these meetings ensures that our needs are represented. It must be noted, although thalassaemia is not considered a 'rare' condition world-wide, the needs of our small number of patients in Australia still need to be recognised in these forums. Please note that Rare Voices has some great information for you to download at their website www.rarevoices.org.au.

Donations: This quarter we have had the pleasure of receiving donations on behalf of Steve Pantazis for his '50 for 50 birthday' celebrations to go towards much needed equipment at MTU – please see the article later in this newsletter highlighting the efforts of many for one special occasion – happy birthday again Steve!

We also received a donation with thanks from the Melbourne University Greek Association as well as the Lemnian Community. These donations help us to continue our work in the community.

Special thanks also goes to ApoPharma Inc. for their recent donation of the children's back packs and activities for our young ones at the hospital, and Bon Appetit for their supply of the much enjoyed ice-creams at the Medical Therapy Unit.

TA recently has been reviewing its strategic plan, and looking at the direction in which the organisation is heading for the future – more information to come in the next newsletter!

Artificial blood made from stem cells to be put to trial

Artificial blood made from human stem cells is to be tested in patients for the first time in a ground-breaking trial. The study, planned for 2016, could pave the way for the manufacturing of blood on an industrial scale, which scientists say could ultimately supersede donated blood as the main supply for patients.

The trial comes as a wave of technologies aimed at re-engineering the human body are making their way towards the clinic – from 3D-printed bones and cartilage to genetically reprogrammed immune cells and synthetic liver tissue.

Marc Turner, medical director at the Scottish National Blood Transfusion Service, who is leading the £5 million project at the University of Edinburgh, said: "We have made red blood cells, for the first time, that are fit to go in a person's body."

The trial is likely to involve three patients with thalassaemia, a disorder of the red blood cells that requires regular transfusions. They will receive about 5ml of blood initially to test whether the cells behave normally in the body.

Professor Turner stressed the trial should not be taken as a signal for people to stop donating blood but speculated that in 20 years, artificial blood could be the norm.

John Hunt, director of the British Centre for Tissue Engineering at the University of Liverpool, agreed.

"If people stopped donating blood, the healthcare system would crash," he said. "It's a brilliantly managed risk, but if you could take that risk out, why wouldn't you? This could affect red blood cell provision for the world."

Professor Turner has spent several years refining a technique to grow mature red blood cells from induced pluripotent stem cells – adult skin or blood cells that have been genetically reprogrammed into a stem cell-like state.

The IPS cells are cultured in biochemical conditions similar to those in the human body that trigger their transition towards mature red blood cells.

The team has reached an efficiency of 40-50 per cent of initial cells turning into red blood cells, and the process takes about a month. The usable cells can then be separated from immature blood cells and remaining IPS cells using standard blood separation methods, such as centrifuging.

Artificial blood would be made from cells taken from someone with the relatively rare universal blood type O, which can be transfused into almost any patient, and in the long term could prove cheaper than the £120 per unit for donated blood.

There may also be health advantages. Blood cells last about 100 days in the human body and are constantly being regenerated, meaning that donated blood is a mixture of new cells which will last for several months and old ones, which are likely to die soon after being transfused. Artificial cells would all be new.

Professor Chris Cooper, director of the centre for sports and exercise science at the University of Essex, who is working on a different blood replacement product, said: "If they solve the problem of making huge amounts of red blood cells then that would be spectacular."

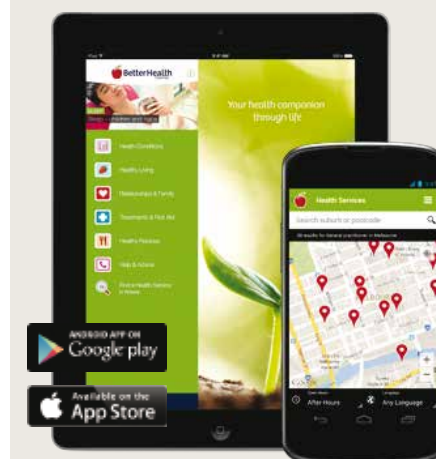
Source: Hannah Devlin, The Times, April 15, 2014 <http://www.thetimes.co.uk/tto/science/article4062424.ece>

RESEARCH

Better Health Channels App now available on Android and recommended by Thalassaemia Australia as one of our favourite Apps.

Anytime, anywhere access to Australia's most trusted and reliable health information. Download the app now and:

- browse our full range of nutritious healthy recipes and create a customised shopping list for when you're next at the store
- access our full range of health articles on the go (including conditions and treatments, healthy living and relationships and family) and share with family and friends
- conveniently locate health services such as doctors, dentists, pharmacies and physiotherapists wherever you are in Victoria, and
- create personalised health alerts and notifications for heat, UV, smog and pollen.





MTU NOTICES

Did you know...

The Medical Therapy Unit is a whole of life service providing care to patients from their early infancy and continuing throughout their life journey.

Until recently, I was not aware of how unique this service is in Australia. Throughout other parts of Australia, people with haemoglobinopathies such as Thalassaemia and Sickle Cell Disease are often treated by the Haematology team and receive their transfusions or red cell exchange in a day treatment centre that cares for other conditions such as cancer. We are very fortunate to have a specialised team that focuses solely on Thalassaemia, Sickle Cell Disease and other haemoglobinopathies. We are also one of the few (if not the only) centres where patients are reviewed by a Doctor each time they receive a transfusion. I recently met a person with Thalassaemia from another part of Australia, and to quote her she said to me, "What you have at Monash is like gold! Your patients are so lucky!"

Another benefit of our whole of life service is that we reduce the issues with 'transitioning'. This term refers to the process of changing care from a paediatric hospital to an adult hospital. After many years of attending the same place and having the same carers, the young adult, usually around the age of 18 is required to start attending an adult service which is often new and foreign to them. This can be a really difficult time for the young adult and their family.

Transition difficulties occur with many chronic conditions that require ongoing care such as Cystic Fibrosis and diabetes. This time of transition often occurs at a time in a patient's life their lives when many other changes may be taking place such as finishing secondary school, starting a job or University. This is something that we have never had to worry about in the Monash Medical Therapy Unit since the late 80's- early 90's when all of the patients were transferred from the Royal Children's Hospital and Queen Victoria Hospital.

One of the great benefits that I have seen in my short time in the Medical Therapy

Unit, is the interaction between the children, their parents and adult patients. It is also wonderful for our parents to see the many possibilities for their child's future while living with Thalassaemia and Sickle Cell Disease. There is wonderful role modelling taking place every day with our very productive and successful patients showing our paediatric patients that anything is possible.

National Standards: Every 4 years the organisation is required to undergo accreditation to ensure that we are running a safe health organisation that delivers a high standard of healthcare. There are 10 National Healthcare Standards that we must comply with in order to obtain accreditation. We now have a National Standards board that has information about the Standards and also showcases any audit results from our unit. I encourage you to have a look at the board and see how we are going.

As part of the National Healthcare Standards, we are required to perform additional blood pressure monitoring. We have purchased portable blood pressure monitors – similar to ones seen at retail pharmacies. Each patient will have an allocated cuff for the entire day of transfusion. If you wish, you can leave the cuff only, attached to your arm and the nursing staff will be able to connect the cuff to the machine when you need to have your blood pressure taken, with minimal disturbance. This will be especially helpful for people who like to catch up on a few zzz's during treatment. We have tested the machines and they have proven to be very accurate. We have chosen the small hand held models to avoid causing increased trip hazards in the unit if there were more poles. Blood pressure will be taken when you are admitted, 15 minutes after the commencement of each transfusion, hourly during the transfusion, and on completion of the transfusion. This practice is keeping in line with Australian National Healthcare Standards. It is also in keeping with our

hospital policy while providing the best standard of care.

What time should I be there for my transfusion: Please make sure you arrive before 0930 for your transfusion! We have had a lot of late comers recently. If you have any difficulties with this please see Carolyn.

Are you pregnant or considering a family? If so, we need to know. Please contact Carolyn or let one of the other nurses know. This is very important as we need to let our Blood bank staff know as they may need to change your transfusion prescription. We also need to have discussions about your iron chelation therapy and contact your pregnancy care team so that we can work together to ensure you and your baby receive optimal care.

Play Therapy is coming...

We can now inform you that we will have a play therapist commence working in the unit in the near future. At this stage she will be attending the unit on a Friday. We are very happy for you to swap your child's transfusion day to Friday so they are able to participate in the program. We are really excited about Play Therapy and want to thank the amazing donation from 'Mates on a mission' who have made this possible. A huge thankyou guys!!!

Who's who in the MTU!

Thalassaemia Service Staff: Within the hospital, you may come into contact with a number of medical professionals. Each of these individuals plays an important role in providing patient care.

Doctors: Consultants/Specialists – Doctors trained in a specific field of medicine. They the patient care process. In the Medical Therapy Unit our specialists are called:

Haematologist: A doctor specialised in diseases of the blood. Our haematologists are Professor Don Bowden & Dr. Zane Kaplan.

Registrar: Qualified doctors undertaking training to become consultants/specialists. A Registrar has been a qualified Doctor for at least 5 years. They have completed basic physician training and are training in the advanced haematology training program. They rotate through different areas of Haematology every 3 months. Our current Registrar is Schuen.

Resident: Qualified doctors who may have been qualified for 1-3 years. They are usually deciding which area they will specialise in. They rotate through our unit every 2 months. Our current Resident is Steph Sparrow.

Intern: Doctors-in-training for one year after completing their university studies. We don't have any Interns in MTU.

Residents and Interns work in close collaboration with Registrar and Consultant. They discuss patients they have seen on a weekly basis with the Unit.

Nurses Division 1: (Registered Nurse or RN) Have completed a 3 year university degree. All of the Registered Nurses in MTU are Division 1.

Division2: (Enrolled Nurse) Have completed a 12 month diploma.

Thalassaemia Service Coordinator: Registered Nurse in charge of day-to-day operations of the Medical Therapy Unit. Have usually completed other Post-graduate nursing qualifications. Reports directly to the Acting Head of the thalassaemia service.

Play therapist: Play therapy provides a way of working through emotional, psychosocial and behavioural difficulties in children. Play therapists develop trusting relationships with children, and create a safe environment for children to express themselves through toys and learning materials. Play therapy may be extremely helpful in helping children with thalassaemia work through difficulties with treatment of their condition.

Genetic counsellor: A medical professional whose role is to help individuals, couples and families understand the basis behind genetic conditions, as well as providing support and advice.

Ward Clerk: Member of a nursing unit responsible for arranging patient schedules,

answering phones and performing other administrative duties within a hospital ward.

The ward clerk of the Medical Therapy Unit may be contacted at (03) 9594 2697. Our Ward Clerk is the amazing Trish.

Social Worker: The Social Worker in the Medical Therapy Unit is part of the multi-disciplinary team and is available to help you and your family at a difficult time or times of crisis.

The Social Worker can assist:

- You to understand the illness and how it may affect you and your family, your lifestyle and your future
- By providing practical, emotional and social support to help you and your family with your adjustment to the illness and its treatment
- By providing counselling and support to patients and/or their families experiencing family, financial and personal distress including Bereavement counselling
- By advocating for patients when liaising with other professionals and Community Agencies to help you address your needs
- By helping to access information and Community Services ie Employers and Employment Agencies, Schools, Centrelink, Psychologists, Migrant Resource Centres, Domestic Violence Services
- By empowering you to take an active role in understanding and managing your treatment together with your treating team
- By advocating for patients to help promote greater community understanding of Thalassaemia and the many successful achievements of our patients

Social Work together with the MTU treating team will help you and your family look forward to a positive future!

Our social worker is the wonderful, Mary. You can call her through the Social Work Department directly on 9594 2290 or leave a message in the MTU.

We now have signs on the doors with the names of the Doctor's and office staff.



A letter from Steve Pantazis

I organised a fundraiser in celebration of my 50th birthday on Saturday 7 December 2013 with over 200 family and friends attending. I wanted to support the Medical Therapy Unit because my daughter has been attending the unit since she was diagnosed with Thalassaemia Major when she was 6 months of age. She will be 22 years old in June.

In lieu of gifts, I requested that people either donate money for equipment for the unit, or donate blood themselves, as people with Thalassaemia rely heavily on blood donations. Unofficially, I can confidently say that there have been more than 50 donations on account of my birthday request. I feel that the \$10,000 raised from my party to purchase important equipment for the unit is a drop in the ocean in the overall scheme of things. It's the continuation of 'chipping away' for a good cause. There has been a lot of incredible fundraising over the years to make life better for those attending the unit. There will be many more to come, no doubt about that!

Sadly many patients have died since our daughter has been attending the Medical Therapy Unit. These people are often in our minds and dearly missed. The people my family and I have met through the unit has highlighted the importance of living a meaningful life and making a positive contribution to the lives of others no matter how big or small. People at the unit have taught us that courage comes in many different forms, and provided strategies for how to cope and move on in the face of adversity and how to live a fulfilling life even though the chips may seem to be down or going against you.

I would like to take this opportunity to recognise the Medical Therapy Unit and the staff as a whole, over the years, as it is a very busy hospital unit, that provides life-long care for a unique group of patients and families at Monash Health.

– Monash Health News 11 June 2014



SUPPORT

15 Things Not to Say to Someone with a Chronic or Invisible Illness

Invisible illnesses are illnesses that you can't see just by looking at someone. Things like Type 1 diabetes, Chronic Migraines, Lupus, Postural Orthostatic Tachycardia Syndrome, which I live with, and Fibromyalgia, may not affect your appearance, but they affect how your body functions and feels. Every day. Probably for the rest of your life.

When you say the following things to someone with a chronic illness, you probably don't mean to hurt their feelings. A lot of the time you are just trying to understand or sympathize. Well, from the perspective of someone who lives with a chronic illness, here are 15 things you should never say to someone with a chronic illness:

1. You don't look sick

Not everyone "looks like" what is happening to them. You would never say "you don't look like someone who is going through a terrible divorce" if your stressed out friends still manage to put on a brave face and pull themselves together. Not all illnesses are manifested outwardly.

2. You're too young to be sick

I get this one more than #1. You can get ill or go through any kind of stressful situation no matter your age. Age is completely irrelevant here. Young, unfortunately, does not always equal disease-free. When you tell someone they're too young to be sick, it just makes them feel even more guilty or embarrassed for having an illness they have no control over when society expects them to be healthy. And, moreover, just because you have an illness, doesn't mean you want to be called "sick."

3. Everyone gets tired

That may be true. And most people are not getting enough sleep and rest. But the difference between someone with chronic illness associated fatigue and an otherwise healthy person is the level of fatigue. If I go out drinking with friends and stay up late, it could take me a week to recover. I have to carefully plan every activity of the day so that I can save energy to do all of them. The best line I've heard for this one is: you don't know what fatigue is until you've had to rest after taking a shower. Unless you literally think to yourself "how much energy will that take?"

for every single action you take during the day (including brushing teeth, combing hair, standing to do dishes, putting on makeup, cleaning, driving, etc.) then you experience a completely different kind of tired than people with certain chronic illnesses. I'm not saying you aren't tired. Everyone does get tired. But my kind of tired is not the same as a healthy person's kind of tired. If I push myself past the amount of energy I have in a given day, the consequences are pretty bad. See the spoon theory for more about this one.

4. You're just having a bad day

I know you are trying to motivate someone and make them feel better when you say this, but it doesn't come off like that. Personally, only about 10 people in my life see me on my bad days. If I am outside, dressed, and active, that is a good day. So instead of making someone with a chronic illness feel supported and motivated when you say this, it feels like you are brushing off their symptoms. Chronic illnesses are with you for life. You can change your lifestyle and find treatments to help them, and some of them can be "managed," but for the most part, that person will have to deal with a lot of bad days for many years to come.

5. It must be nice not having to go to work/school

This one. Oh man. If you only knew. Sure, it can feel that way when you take a day to play hooky or a long vacation. But when you are forced not to go to work or school, even when you want to be there, it is a different story. People with chronic illnesses don't want to fall behind in school and fight with the school district to get the accommodations they need. People with chronic illnesses don't want to miss work and not be able to generate an income. Everyone wants independence. Personally, I loved school and hated every day I wasn't there. It is

way more stressful not being in school and knowing all the work you will have to do to make up for it than being there on any given day. And I have loved the jobs I've had and been sad about every day I have missed. Believe me, it is not nice having to stay home instead of being productive, just trying to find ways to distract yourself from pain or exhaustion. It's fun to watch TV for a day or two, but after that, I feel trapped. I guarantee anyone with a chronic illness would gladly trade in their symptoms for a full time job.

6. You need to get more exercise

Exercise is really important and no one is denying that. It helps pretty much any health condition. But it isn't a cure-all. For someone like me, whose heart rate regularly reaches 120 bpm just from standing still, exercise isn't always doable. I do "exercise" but it is more like physical therapy exercises than what most people would consider a good work out. But remember, everyone has limitations. For people with chronic illnesses, their physical limitations may make it harder for them to do traditional exercises. And even if they do, it will probably not be a cure for a condition that is caused by something totally different like an immune system that attacks itself or a nervous system that doesn't regulate itself correctly.

7. I wish I had time to take a nap

See numbers 3 and 5, which relate to this one. To someone with a chronic illness, to whom napping is not a luxury but in fact a necessity, hearing someone say this is as much a slap in the face as hearing someone say they wish they could take a break from work or school too. Hearing anyone "wish" they could have a part of a chronic illness just shows how misinformed they are when they say this. Wishing you had more time is pretty much a universal wish. But wishing you had the time that a person with a chronic illness has is not the same. If your wish is

granted, you can get more time, but you also have to get the pain, the exhaustion, and the difficulty figuring out how to be productive in society. Remember that next time you have the desire to say this.

8. The power of positive thinking

Positivity is really important and having a negative outlook can negatively affect an illness. But having a positive outlook will probably not cure it. I've gone through all the stages of positive thinking and denying my illness. I have thought, if I just put my mind to it, I can do that. And then I've suffered the consequences of pushing myself beyond my limits.

Positive thinking that is productive for chronic illness sufferers is not telling someone that thinking positively will help them with their symptoms. Instead, productive positive thinking is finding the positivity that comes with their illness. For me, if I hadn't had POTS, I wouldn't have gone to Lake Forest College to stay close to home and my doctors. It was there that I learned and discovered my passion for environmental studies and met the love of my life. I wouldn't have found an inner strength in myself and learned to value the time I have in the same way I do. That is productive positive thinking. But it's not a cure.

9. Just push through it

Hearing this makes me want to hit my head against a wall. This goes along with #3 "Everyone gets tired/ headaches/ back pain/ insert symptom, just push through it." The problem with this statement is the underlying assumption that a person with a chronic illness is not already pushing themselves. Every day I push myself. I push through my symptoms all the time. If I didn't, on my bad days I would not eat, walk, or shower. And the same is true of anyone with a chronic illness. Remember: there is a difference between pushing and pushing past your limits. Pushing yourself is good and necessary. But pushing past your limits can set someone with a chronic illness back for a while as they recover from overextending themselves. Suggesting to someone to just push through it may not feel insulting, but it is like telling a marathon runner to just go faster on their last mile.

10. It will get better, just be patient

I'm sure everyone who says this truly means well. And it is true of a lot of things that patience is important. But not all chronic illnesses will get better. Patience is a virtue, and an important one. But please don't say

this to someone who has an illness that they will have for their entire life. It could get better, but it also may not. So figuring out how to live within the confines of your illness and make the most of it is more productive than expecting to get better. This is not to say that you shouldn't hope to get better- just that you shouldn't count on it. That's denial.

11. Have you tried...

... the paleo diet, acupuncture, super magic moon crystals, this weird new therapy that I heard about one time but know nothing about? Unless you are a medical professional and/or a person with a chronic illness has asked for your advice, please keep it to yourself. I haven't tried super magic moon crystals, but I have tried just about everything else including alternative and new treatments. I'm actually trying a new one now. And I probably won't stop trying because science makes advances. But someone with a chronic illness doesn't want to defend themselves to you on how they have already tried or don't trust the efficacy of a certain treatment, especially if your evidence is only anecdotal. I know you probably mean well and are trying to help, but just assume that someone with a chronic illness has tried every option available to them. Everyone wants to feel good.

12. You should stop...

See number 11. I know you mean well and you want to help. Everyone has bad habits they should probably stop. Did you know that one of the parts of my treatment is to increase sodium in my diet? So if you want to tell me how you or someone you know of feels so good because they cut out salt, it will go in one ear and out the other. What works for one person does not always work for another. Please keep your unsolicited unprofessional anecdotal medical advice to yourself, because you are wasting your time and possibly insulting or discouraging someone with a chronic illness.

13. It's all in your head/ you're just stressed/ depressed/ anxious

If I had a nickel for every person (including doctors) who told me this before I was diagnosed with POTS (and some afterwards) I would have really heavy pockets. I guess when we don't understand something and don't look physically sick we assume it is mental. It must be cultural or part of human nature based on how often this is said to people with chronic illnesses. Stress, depression, and anxiety can all make symptoms of chronic illnesses worse. But they do not usually cause them.

Chances are when you say this to someone you are only contributing to their stress, not helping them see something they never saw before.

14. You need to get out more

A change of scenery can do some good. And I believe that spending time outdoors is good for your health. But when you say this to someone with a chronic illness, it doesn't sound encouraging. Someone with a chronic illness wants to get out more (see number 5). All it does is make them feel guilty for not being able to do something they already want to and are probably trying to do. So before you say this, remember that they probably agree with you and they don't need the guilt on top of it.

15. You take too many medications

People differ on their opinions of whether medications help or are bad for you. In some cases they are medically necessary. This is one of those things where you should probably keep your judgement to yourself. If I take a medication, I have researched the side effects and I have tried every other lifestyle change and vitamin that I can before I get to that point. Not everyone wants to just pop a pill to solve a problem. If someone is having a symptom that is controlling their life medication is sometimes the best way to manage it. People with chronic illnesses do many things to try to live as normal life as possible, and medication is one small piece of that puzzle. It is part of a lifetime of adaptations, treatments, and figuring out how to live with a chronic illness. So now that you know better than to say these things, you can relate better to the people in your life with chronic or invisible illnesses.

And remember: the absolute best and most powerful thing you can ever say to someone with a chronic or invisible illness: I believe you. You would be surprised just how much that will mean to them.

Source: A version of this article originally appeared on Pins and Procrastination. Susie Helford is a Chicagoland-based blogger writing primarily about homemade green cleaning and beauty products. Her blog, Pins and Procrastination, is about pinterest-inspired projects (that also happen to be great for procrastination purposes). She lives with Postural Orthostatic Tachycardia Syndrome, a form of dysautonomia.

See more at: http://asweetlife.org/feature/15-things-not-to-say-to-someone-with-a-chronic-illness-or-invisible-illness/?utm_content=bufferba378&utm_medium=social&utm_source=twitter.com&utm_campaign=buffer#sthash.gxzWyEZQ.3yoBW1u.dpuf



Letter from the Centre Co-ordinator

Hello everyone, I hope this newsletter finds you all well and not too cold...

...it seems that the warm weather was trying to give us a false sense of security that it would keep us warm even if it was winter but then... SNAP! Its got cold... keep warm, put your feet up, make warm dinners and enjoy the indoors with loved ones, that's my advice for winter.

I don't know about anyone else but I still feel like it's the beginning of the year and I have so much time ahead of me this year to get stuff done! But then when I go to put something in my diary its JUNE, yes that's right, I am in shock that it's the middle of the year already, where has this year gone??

When I look back over the past 6 months then I realise why it seems to have flown by me so quick, we have been very busy the first half of the year doing lots of fun and some new but all very exciting things.... as you read the newsletter you will notice that we were very busy over the very important month of MAY, our celebrations for International Thalassaemia Day kicked off at Westmead Children's Hospital on the 7th of May and we basically continued to celebrate until the end of May with our Family Picnic.

This year we held a Picnic for Patients and Families from Westmead Children's hospital at the end of May to coincide with world Sickle Cell Day which is on the 19th of June. Again I will attend the Children's Hospital to show our support and raise more much needed awareness about Sickle Cell on Thursday 19 June.

We are proud also in this edition of our newsletter to announce to you the initiation of our new nurses group for patients with Thalassaemia, Sickle Cell and related haemoglobinopathies, we have been working very hard with TA to collaborate and get a specialise nurses

group running for our patients for some time now and our hard work came together and paid off in a positive way... more on this in our featured article.

I am happy to inform you all that our community awareness programme and presentations continue as a strong focus, over the past few months I have been welcomed into work places and schools to talk about Thalassaemia with a strong focus on the importance of blood donation.... after my talk at Birrong Girls High School 121 students registered to donate blood, what a fantastic effort, well done Girls!!!

For the first time ever this year I attended a Refugee Event in Marrickville. What an amazing event, entertainment, food and guest speakers all there for one cause, I was offered an area to set up our resources, give brochures, flyers and information on anyone interested. Sickle Cell Anaemia is a strong focus as it is growing among this community of people.

Please remember that we have various information resources and materials in different translations available for download from our website or in hard copy at the centre, if you or anyone you know would like any further information please do not hesitate to contact me and I will arrange to have it sent out to you.

Now I will leave you to continue reading our newsletter and getting more of an insight to what we have been up to.

Please feel free to come forward with any questions, feedback or suggestions you might have.

Keep warm and take care,

*Nancy Lucich, Coordinator
Thalassaemia Centre of NSW*

Prince of Wales Hospital Sunday Short Stay Service...

As you may be aware, the Haematology Short Stay Unit has recently been approved to run a 6 month trial...

Sunday service for patients starting May 2014. We understand that for many of you this service will have a significant impact on the quality and flexibility of your lives.

If you would like any further information regarding this service please do not hesitate to discuss with the Haematology Short Stay department staff or contact Kristen Brown (Thalassaemia Clinical Nurse Consultant) on (02) 9382 4982.

Calling for Expressions of Interest for Research Grants

The Thalassaemia Society of NSW is calling for Expressions of Interest for Grants-in-Aid of all fields of research that will improve outcomes for patients with Thalassaemia and related haemoglobinopathies.

The Thalassaemia Society of NSW is a non-for-profit Society dedicated to care and cure for patients with Thalassaemia, Sickle Cell and related haemoglobinopathies.

Please email your detailed expression of interest to coordinator@thalnsw.org.au attention: The President.

RVA Parliamentary Event

On Thursday 6 March, Marianne and I were invited by Rare Voices Australia to attend the Rare Voices Australia BBQ at Parliament House.

It was an honour to attend and be given the opportunity to network with not only some of the MP'S but also other organisations whom are on the same playing field as us...some even less fortunate than us. It was interesting to listen to the speakers and to learn more and more about Rare Diseases in Australia.

A staggering half a billion people worldwide are affected by a rare disease and collectively there are around 1.2 Million Australians Suffering from one or more of the 7000 registered rare diseases. A key focus for Rare Voices Australia is to implement a National Rare Disease Plan in order to make a significant different to Australian Families. Rare Voices Australia is the Voice for all Australians affected by rare conditions, uniting for one cause, to raise awareness in the public and political arenas of the daily burdens faced by those affected. We thank the Executive Director of Rare Voices Australia Megan Fookes for inviting us to be a part and congratulate Rare Voices on a successful event, we look forward to hearing of some positive outcomes.



#makeitcountformaria Campaign

The #makeitcountformaria campaign was launched in the last week of February and was a campaign designed to celebrate the life of Maria Kastoras.

...and continuing her great work in educating the community about thalassaemia and other haemoglobinopathies, as well as encouraging people to donate blood and share their experiences with the wider community.

Despite our original intentions of concluding this campaign on International Thalassaemia Day – May 8th, we have decided to keep it going as we are still being contacted by people either wanting to make a blood donation, or sharing their photographs with the slogan on our Facebook and Instagram pages.

In terms of blood donations, 35 people registered with the Club Red – Thalassaemia Australia – division: Make it count for Maria, which equates to 105 lives saved. However, unofficially we know that our tally is significantly higher – as some people donated blood but did not register. We also know that some of our friends have also donated plasma!

Please remember that you add your details by going online to the following link: www.donateblood.com.au/who-can-give/club-red/join-group. By doing this, you can make them count, and we can officially recognise you for your efforts!

We would like to thank Theodore Kastoras, the Thalassaemia Society of NSW, staff from our treatment centres, corporate connections and our friends and family members from both within the Australia and overseas for supporting this campaign. Receiving photographs from places such as the USA, Maldives, Canada, Cyprus and the UK to name a few, has been very special and shows how just one person can have such a big impact on a community.

Don't forget, if you would still like to be part of this campaign, you can download the #tag on our website thalassaemia.org.au, we look forward to receiving or hearing about your contribution.

2014 Committee of Management

President – Rosa Dimitrakas
Vice President – Nicholas Kotrotsos
Treasurer – Lela Dallas
Secretary – Marianne Dimitrakas
Assistant Secretary / Treasurer – Stella Stilianou
Communications Officer – Position Vacant

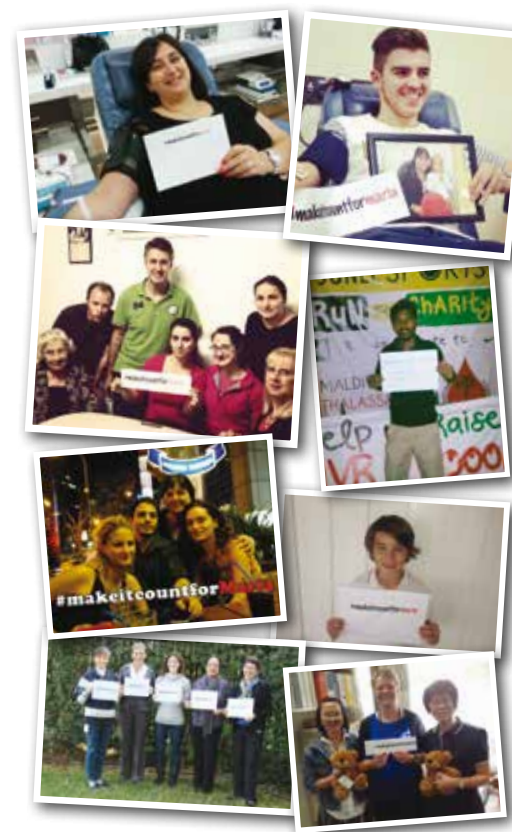
Executive Members:
Maria Chate Haroula Volvozidis
Theodora Michalopoulos Glenda Hughes

2014 Committee meeting dates

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

Wed 20 August Wed 17 September
Wed 15 October Wed 19 November
Wed 17 December

All meetings take place in the board room on Level 8, 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.



MELBOURNE

This year's International Thalassaemia day celebrations were held at the Medical Therapy Unit at Monash Health. With the assistance of Thalassaemia Services Co-ordinator, Carolyn Greely and TA committee member, Helen Kosmarikas, we were able to bring a little cheer to the Unit, with a special visit from Billy The Blood Drop from the Australian Red Cross Blood Service, cake and gifts for the children.

International thalassaemia day is an important day on our calendar, as it is our opportunity to reflect on those living with or touched by thalassaemia both in the past and present and thank those people in our local, national and international thalassaemia community: medical professionals, carers, families and blood donors for their ongoing care, support and strength.

This year the Thalassaemia International Federation's message was "Economic Recession: Observe – Joint Forces – Safeguard Health" – looking specifically at reducing the health inequalities that exist in countries hit by the global economic crisis, and how it can affect and individual on so many different levels.

SYDNEY

Thank you to the Staff at Westmead Children's Hospital, the Australian Red Cross Blood Service and the Executive Committee for all pulling together and making our three days at Westmead Children's Hospital fun, bright, informative and eventful. A fantastic way to celebrate International Thalassaemia Day!

We held an information stand in the foyer of Westmead Children's hospital and had the pleasure of meeting many people who were interested to learn about who we are and what we represent.

Our children enjoyed the ward round with our special guest "Billy Blood Drop"..... it was priceless seeing the look on the children's face as Billy walked the corridors of the hospital and on to the ward, Billy and his helpers handed out goodies and treats to the patients.



Westmead Children's Family Picnic Day

An amazing day for our Patients and Families from Westmead Children's Hospital who came together for a picnic day. It was great to see young families come together away from the hospital seen and share stories, exchange details form friendships and enjoy the beautiful gourmet BBQ Lunch put on by Staff from WCH together with the Society.

Thank you for those of you who attended and supported the feedback from this has been positive, it is something that will be held again so spread the word to your friends who could not attend and tell them to look out for the next fun opportunity to come along and join in the fun!



Thalassaemia Gala Dinner

The Thalassaemia Society of NSW is proud to announce that this event was a sell-out, with 280 enjoying the celebrations. The eating, prizes and celebrations started as soon as our guests arrived at the front door where they were greeted by wonderful staff from Novella Events serving a mouth watering selection of canapé's and drinks to welcome each guest...

Our executive committee members were also present and assisted with greeting and guiding guests to their seats.

During the evening our guests heard from patient guest speakers and our president. Together we celebrate, continued to raise the awareness of thalassaemia and related Haemoglobinopathies and paused to remember the past patients who are no longer with us.

Our guests were entertained by wonderful belly dancers while they enjoyed their meals and were also given plenty of opportunities to participate in prize draws, raffles and auctions. There was also plenty of time to enjoy some music and have a dance.

All the hard work and preparations made by the Executive Committee and staff in the lead up to this event certainly paid off within the first few hours of the night when the positive feedback started flowing in and to this day has not stopped! The Thalassaemia Society of NSW were commended by many many guests about the whole night being, "just beautiful". We also heard comments of it being "a long time over due and a fabulous night"!

We were asked by many if we can hold a similar function next year, so a big congratulations to the Society for hosting such a successful event and raising much needed funds to enable us to continue to the outstanding work of informing the public, supporting our community and research about thalassaemia and other haemoglobinopathies!

The amount of funds raised from this event was \$24,000, an amazing effort by all. Thank you again to our sponsors, donors and attendees, without you we could not continue to do this vital work for our community.

Finally, a massive thank you to John, Franca and staff at Novella Events, your hospitality, service and food was outstanding!



RECIPE Fruity Rocket Ships

Preparation time: 15 mins
Difficulty: Easy
Serves: 4

Ingredients:

- 1.5cm-thick slice of seedless watermelon, peeled
- 2 strawberries, washed, hulled
- 1 small banana, peeled
- 1.5cm-thick slice of pineapple, peeled cored

Method:

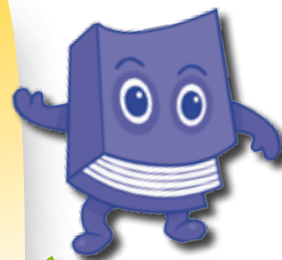
1. Cut watermelon into 4 small triangles. Trim one corner from each triangle. Thread watermelon triangles, long-side down, onto small wooden skewers.
2. Cut strawberries in half lengthways. Thread, hulled-side down, onto the skewers.
3. Cut banana in half crossways, then cut each piece in half lengthways. Thread onto the skewers.
4. Cut pineapple into 4 small triangles. Thread onto the skewers to make the top of each rocket ship.

Enjoy!



Hi Kids!

Get ready to take flight with our out of this world jokes, recipe and colouring in drawing!



Q. Why did the boy become an astronaut?
A. Because he was no earthly good!

Q. How do you get a baby astronaut to sleep?

A. You rock-et!

Q. How do spacemen pass the time on long trips?

A. They play astronauts and crosses!

Q. Where do astronauts leave their spaceships?

A. At parking meteors!

Q. What do astronauts wear to keep warm?

A. Apollo-neck sweaters!

Colour me in!

