

Thalassaemia AUSTRALIA

Unifying support and genetics

Thalassaemia Australia Autumn 2012 Volume 4 Issue 12

Quarterly



8th of May Message 2012 International Thalassaemia Day Theme: Patients Rights revisited

Continuous provision of updated, quality information to patients and their families particularly in the case of genetic (chronic) diseases such as thalassaemia constitutes a major objective for the existence of any patients' orientated organisation in any part of the world.

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Knowledge is our power was the theme of one of TIF's largest Regional Conferences in 2008 and a concept, on which the Federation has since its establishment in the 1986, focused considerable attention and work.

Promoting information and ensuring that knowledge on the disease itself, new advances, results of clinical trials, expressed concerns by experts and upcoming developments in treatment reaches every patient, undoubtedly forms an essential component of our mission, as an international patients' organisation.

In addition, it is equally important for NGOs to focus on the education of patients on existing, new and developing upcoming regulations, directives, recommendations, resolutions, declarations, on policies within and outside the field of health that may affect directly or indirectly the patients' health and quality of life. Particularly essential knowledge in the case of a rare genetic disease such as thalassaemia with immense social and economic repercussions in addition to its medical and public health ones.

Patients' rights were being considered since the very old times in the context of laws and recommendation, binding the medical profession: "**First, Do No Harm**" the father of western medicine, Hippocrates (470-360BC) advised his fellow medical professionals.

Today, the rights of patients to information and access to quality health care, two of the basic important rights, are no longer protected only through Hippocrates Oath, or by the rules of medical bio-ethics.

Patients' rights stem from the UN's universal declaration in the 1940s on human rights, in the context of which a special article (Art.25) focused specifically on "**The right of everyone for a standard of living adequate for the health and well being of himself and of his family, including food, clothing housing and medical care...**"

This constituted a critical first step in establishing the concept of patients' rights reflected also through the words marking the founding on World Health Organisation (WHO) in 1948:

"The enjoyment of the highest attainable standard of health is one of the fundamental rights, of every human being, without distinction of..."

Despite ongoing efforts and work in securing these rights, it was not until the 1960's and 1970's that Patients' Rights began to receive more serious attention.

In today's world, official health bodies, globally, are striving more than ever before to reduce health inequalities to provide better health for ALL.

(Cont. on page 3)

Thalassaemia Australia Inc.



Committee of Management 2012

Executive

Sotirios Katakouzinou – President
Maria Triantafillou – Vice President
George Ambatzidis – Treasurer
Mary Konstantopolous – Secretary

General Committee Members

Dr Jim Vadolas
Bessy Mougos
Helen Kosmarikas/Spiro Bombos
Julie/Billy Costa

Committee meeting dates for 2012

All meetings held at: Thalassaemia Centre,
333 Waverley Road, Mt Waverley 3149
7.30pm start

All welcome!

May	Tuesday 15th
June	Tuesday 19th
July	Tuesday 17th
August	Tuesday 14th
September	Tuesday 18th
October	Tuesday 16th (proposed AGM)
November	Tuesday 13th
December	Tuesday 18th (Christmas Dinner)

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Thalassaemia Australia Inc. is on Facebook

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

<http://www.facebook.com/pages/Thalassaemia-Australia-Inc/198157430216491>

In loving memory of
Fernando Bocanegra

who passed away on
Friday 6 April, 2012.

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



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.



International Thalassaemia Day (cont. from page 1)

Today's world is focusing on the reorientation of health care systems towards more patient centred ones, into which patients would have a role and a voice, and into which their opinion and contribution would be respected and recognised.

"Nothing for the patients without the patients"; "Trust us – We are Patients"; "The wisdom of patients is not effectively harnessed". Therefore phrases that marked the organisation of congresses and the founding of the patients alliances in 2004, specifically focused on the rights of patients, for active involvement, recognition of participation and for equal access to quality health care and safety.

The establishment of the "World Alliance for Patients Safety" by WHO in 2004 was a global initiative and is indeed a key approach addressing issues such as the mobilization and empowerment of patients – "Patients for Patients Safety" and included the **SPEAK UP** campaign, most appropriately describing the responsibilities of patients towards securing and promoting their rights:

- **Speak-up** if you have questions or concerns: It's your rights to know.
- **Pay attention** to the care you are receiving.
- **Educate** yourself about your diagnosis and treatment
- **Ask** a trusted family member or a friend to be your advocate
- **Know** what medication you take and why
- **Use** a health care provider that rigorously evaluates him/herself against safety standards
- **Participate** in all decisions about your care and contribute to the development or reforming of policies that affect your health the quality of your treatment.

It is obvious that Knowledge is a prerequisite to exercising your rights. The WHO, the EU and other health bodies across the world have focused considerable attention on safeguarding the basic rights of patients and it was not until 2002 that these took in Europe at least the form of a Charter (EU Charter) on the basis of which European Countries were encouraged and prompt to build their legislation.

This Charter described 14 basic rights in total. The right to:

- Preventative medicines
- Information
- Consent
- Free choice

- Access to health services needed according to the disease without discrimination
- Privacy and Confidentiality
- Respect of patients time
- Observance of quality standards
- Safety
- Innovation
- Avoid unnecessary suffering and pain
- Personalised treatment
- Complaints
- Compensation

Many countries in Europe have already transformed this Charter into national laws, tailored to each one's needs and existing regulations on prevailing cultural and societal norms. Of course many countries outside Europe (mainly industrialised) have developed their own Charters or regulation based on and encouraged by and following mainly the work of WHO and its regional offices in the different parts of the world.

However, a common devastating realization is the vast gap existing in many of these countries between the transposition into law and the implementation and evaluation of the impact of these on patients' quality of life and active involvement in discussions on health care services.

Still more worrying and painful is the realisation that patients in many more countries across the world including in many industrialised ones, have no defined rights, recognition and respect as patients and certainly no room for active involvement or participation in policy making.

On behalf of the patients, the great concern is that patients themselves are Not Aware, Do Not Know, are incompletely informed or misinformed in what exists or does not exist in their country.

In Europe for example, a plethora of other policies, directives, recommendations are also in place and many others are planned for the near future, all aiming to safeguard the rights of patients in many areas of health, including: those in rare Diseases, participation in clinical trials, protection against counterfeit medicines, establishment of rights of patients for Cross Boarder Health Care, for safe and adequate blood and blood products, protection of personal data and many others, which complement the rights of patients.

Patients in Europe, thus, need to become more knowledgeable in order to be in a position, to utilise more effectively what has

been already granted to them and in order to become actively and truly involved in the reforming processes in their countries that affect their healthy ageing, quality of life and free mobility across Europe.

In other regions of the world, with the exception of North America, patients need to fight to learn what exists in their countries in term of patients rights, charters or legislation and fight to put those to the forefront to support their efforts for better health and quality of life.

In other countries, unfortunately, patients have to fight from scratch for their rights, having the UN and WHO declarations as their solid basis and TIF as their closest ally.

Dear friends, let us join hands – Unity Is Our Strength – and let us focus this year for the 8th of May activities on **"Patients Rights"**. On behalf of TIF, I urge every patient to look and learn about his/her rights, how these are protected and respected in their country, to ensure that they are continuously and accurately informed through their authorities, national patient associations, TIF and accredited sides on the internet in a unified effort to overcome the barrier of ignorance, misinformation and misguidance on what your Rights are.

Join TIF on this 8th of May theme: "Patients Rights Revisited" and organise events, workshops, discussions, print educational material, investigate and write to TIF how patients' rights are protected in your country or region. A special webpage will soon be uploaded on TIF's website especially for this theme.

Let us collect this year what the current state of affair is in each country, aiming to put forward for 2013 campaigns specific tailored to the needs of each country. I encourage everyone to visit the WHO web-site which includes a list of documents on human rights <http://www.who.int/genomics/public/patientrights/en/>

Best regards,

Panos Englezos
President

Thalassaemia
International Federation

The Australian Charter of Healthcare Rights is detailed on page 7.

The Australian Charter of Healthcare Rights

A guide for patients, consumers, carers and families

In support of TIFs May 8 International Thalassaemia Day Message, we have provided to you, the members of the Australian thalassaemia community, a summary of the Australian Charter of Healthcare Rights. This information is provided by the Australian Commission on Safety and Quality in Health Care (ACSQHC) a government agency which was established by the Commonwealth, with the support of State and Territory governments.

Access

A right to health care. You have a fundamental right to adequate and timely health care. Sometimes this may not be at the healthcare facility you first attend as not all services are necessarily available everywhere. You can contribute to the right of access by trying to meet your appointments and telling the facility when you cannot.

Safety

A right to safe and high quality care. If you are unsure about what is happening to you or if you think something has been missed in your care, alert your healthcare provider. Let your provider know any circumstances that might make your health care riskier.

Respect

A right to be shown respect, dignity and consideration. You are entitled to receive care in a way that is respectful of your culture, beliefs, values and characteristics like age and gender. It is important to tell your healthcare provider of any changes in your circumstances. Respect also includes being mindful of healthcare staff and other patients.

Communication

A right to be informed about services, treatment, options and costs in a clear and open way. Healthcare providers will tell you about the care you are receiving and help you understand what is happening to you. You can contribute to communication by being as open and honest as you can be. To understand the instructions given to you, you can ask questions if you would like more information. You can use interpreters if English is not your first language. Interpreter services are free and can be provided in person or by phone.



Participation

A right to be included in decisions and choices about care. You are encouraged to participate in decisions about your care. Ask questions if you are unsure about what is happening to you. Involve your family or carer if this makes you more comfortable and sure.

Privacy

A right to privacy and confidentiality of provided information. You are able to see your records and ask for information to be corrected if it is wrong. In some situations your health information will need to be shared between healthcare providers. You can also contribute by respecting the privacy and confidentiality of others.

Comment

A right to comment on care and having concerns addressed. Healthcare providers want to solve problems quickly, but they need to be told about the problem first. If you have any suggestions about how services could be improved please let staff know. The procedures used by the health service organisation to comment about your care should be made available to you. You can provide verbal or written comments about the procedures and your experiences. To commend health workers, to complain about your health care and/or to be advised of the procedure of expressing concern about your care please contact your health service provider's patient liaison representative.

The Charter

Everyone who is seeking or receiving care in the Australian Health system has certain rights regarding the nature of that care.

These are described in the Australian Charter of Healthcare Rights which is available to everyone in the healthcare system. The rights relate to access, safety, respect, communication, participation, privacy and comment.

A genuine partnership between patients, consumers and healthcare providers is important so that everyone achieves the best possible outcomes.

Healthcare providers are aware that in some circumstances, your ability to interact with the healthcare system may be restricted. Where possible they will alert family or support services about your circumstances if they consider that you need assistance.

You are entitled to raise issues about your healthcare rights. You are encouraged to read the Charter, or have it explained to you, and to discuss the Charter with your healthcare provider or family or carer. Healthcare staff should be able to advise you how to obtain further information about your rights.

Source: Australian Commission on Safety and Quality in Health Care. <http://www.safetyandquality.gov.au/publications/about-the-australian-charter-of-healthcare-rights-a-guide-for-patients-consumers-carers-and-families/> with permission, with thanks. Please go to this website for the full version of this document.

Thalassaemia Day/Week in VIC/NSW

Join in the celebrations during the month of May as part of International Thalassaemia Day/Week



TA will be out and about during Thalassaemia Week, starting with our children/family function on the 6 May at **Kidspace in Cheltenham**. This will be a great opportunity for families to get together and share experiences, whilst having a great day out.



TA will also have an information table at **Monash Medical Centre** on the 8 May, please come along and say hello.



Come and visit the Thalassaemia Society of NSW information stand at the **Prince of Wales Hospital**, Sydney on 8 May.



The Thalassaemia Society of NSW invites you to help raise awareness and increase understanding about thalassaemia amongst our community at **Vivo Cafe**, 388 George Street, Sydney on 8 May 2012, from 6.30pm to 8.30pm. Tickets are \$40 inc. cocktail food and drinks. Phone 0400 116 393.



The Thalassaemia Society of NSW & Fix Function Centre, invite you to join us at **"FIX Thalassaemia"** on Saturday May 26 at Fix Live Function Centre, 588 Princess Highway, Rockdale. Tickets are \$65 inc. dinner. Phone 0403 328 973.

SAVE THE DATE. MAKE A DIFFERENCE!

fix

THALASSAEMIA

SAT 26 MAY

GUEST DJ Sam Boutros + the FIX LIVE band.
TICKETS \$65 includes dinner. For bookings call
0403 328 973

FIX LIVE FUNCTION CENTRE
588 PRINCESS HWY, ROCKDALE

The Thalassaemia Society of NSW & Fix Function Centre, invite you to join us at the "FIX Thalassaemia" event on Saturday May 26 at Fix Live Function Centre, 588 Princess Highway, Rockdale.

Tickets are \$65.00 including dinner.

It will be a great night with the Fix Live Band and also our special guest DJ Sam Boutros from the Soul Express Radio Show on 2RDJ FM to spin some great hits to have us dancing all night long.

For more information or bookings call 0403 328 973.

The Thalassaemia Society of NSW
www.thalns.org.au

"Help raise awareness and increase understanding about thalassaemia amongst our community..."

8th May 2012
from 6:30pm to 8:30pm

VIVO CAFE
388 George Street, Sydney
\$40.00 per person

Includes 2hrs Cocktail Food & Drinks
beer, wine, champagne and soft drinks

Patients Rights Revisited...

Celebrating International Thalassaemia Day 2012

To purchase your tickets complete the form and return via either:
 mail Thalassaemia Society of NSW, Attention: Coordinator, PO Box M120, Missenden Road, Camperdown NSW 2050
 email coordinator@thalns.org.au | phone 0400 116 393

☒ I would like to purchase _____ tickets @ \$40.00 per person = \$ _____ total cost

Mr/ Mrs/ Miss/ Ms _____

First & Last Name _____

Address _____

Phone _____

Email _____

Cheque ☐ Cash ☐ or debit my Credit Card - Visa ☐ Mastercard ☐

Card Number _____

Expiry Date _____ Signature _____

Please issue a receipt Yes ☐ No ☐

Cheques should be made payable to The Thalassaemia Society of NSW
Tickets will not be issued. Names will be available on the door on the night!

Celebrate International Thalassaemia Week

Sunday 6th May 2012
11AM — 1PM

Venue:
Kids Space Cheltenham
15c/56 Keys Road
Cheltenham, Vic 3192
Melways ref. 78 A4

Free entry for kids and adults

Party food for children provided

Want to meet other families within the thalassaemia community?
International Thalassaemia Day provides an opportunity for families to meet, share experiences and have a great day.

.....

RSVP by April 22nd, 2012

Contact: Thalassaemia Australia
 Phone: (03) 9888 2211
 Email: info@thalassaemia.org.au

Thalassaemia AUSTRALIA
Uniting support and genetics



**THE SOCIETY FOR INHERITED AND SEVERE
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(A CHARITABLE ORGANISATION - REGISTRATION NO. 178)

Patron:
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OFFICE: Haematology Treatment Centre
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Charlotte Street, Port of Spain.
Tel: (809) 624-3261

Address:
P.O. Box 421
Port of Spain,
Trinidad, W.I.

January 31, 2012

Australian Thalassaemia Association
C/O 333 Waverley Road
Mount Waverley
Victoria 3149
AUSTRALIA

Attn: Mrs. Maria Kastoras

Dear Mrs. Maria Kastoras,

We acknowledge receipt of your generous donation of six (6) pumps to our Society for Thalassaemia patients. We can assure you that it will go a long way in the treatment of our patients.

We wish to thank you sincerely for this great gesture.

Sincerely yours,


Indra Rampaul (Mrs.)
SECRETARY
Tel.: 627-9456-8

Affiliations - World Federation of Haemophilia, Thalassaemia International Federation



The Power of Three...

When three people get together, they can do amazing things.

On Saturday 25 February, 2012 three people namely Con Goltios, Vitano Vitanopoulos and Maria Goltios with the support of TA held a Thalassaemia Cocktail Charity Night, at the Oxford Lounge in Phahran.

The night was an opportunity for people to come together, have a fabulous night out, learn about thalassaemia and contribute in many different ways to the fundraiser, whether it be by having their photo taken in the 'booth' or bidding for one of the many silent Auction items.

The Silent Auctions items were gathered together by the organising committee and TA staff/committee and we would like to personally thank the following individuals and organisations for their contribution:

- Exoticar
- Granite Deli – Chadstone
- Grundfos Pumps
- Helen Goltios
- Knowledge Space
- Liana James Hairdressing
- Motor Mechanics Melbourne
- Mr. Detail
- Music Creations
- Nikpol
- Orange Windsor Cafe
- Oxford Lounge
- Star Fitness
- Step Into Life – Vermont South
- The Publican Group
- The Yorkshire Hotel
- WBS Pumps Australia

A special mention must also go to Pauline Coulepis-Kalaitzis our M.C. and to Dr Jim Vadolos (MCRI) and our very own Maria Kastoras, for speaking about thalassaemia on the night.

This cocktail function would not have been possible without the support and professionalism of George Seoud and his team from the Oxford Lounge in providing a great venue, DJ and catering.

The evening was a great success due to the hard work and dedication of Con, Maria and Vitano, with \$7,180 being raised for Thalassaemia Australia. These funds amongst other things, will enable the purchase of a specialised recliner for Medical Therapy Unit.

On behalf of Thalassaemia Australia Committee, members and families we again thank this special trio for their wonderful efforts and welcome them into the thalassaemia family!

P.S. Watch this space for next year's function!

Community Education and Advocacy

The 2012 Thalassaemia Australia (TA) community education program is well and truly on the way.

We have completed over twenty presentations so far to secondary schools and universities within Melbourne metropolitan area and regional Victoria. A number of these schools are new to our program and we welcome their feedback.

We have again partnered with the Monash University for their Community Based Placement Program, and have two students working with us. Please make Marek Bak and John Kuan, second year medical students welcome, as you may see them at the TA office or around MTU.

The Melbourne University Principles of Clinical Practice Small Group Patient Perspective Sessions is also continuing this year; this is an opportunity for first year medical students to learn first-hand from a patient, their experiences with dealing with medical staff, as well as the importance of community support groups in health promotion and advocacy.

These sessions are rewarding as our future medical professionals are always eager to learn and take notice of what is said to them.

Medical Therapy Unit

TA staff and Committee members have met regularly with the Medical Therapy Unit Team to discuss issues relevant to our patient group such as: current research being held in the unit; new resources for carrier couples; day to day operations of the unit; and changes to hospital policy.

When needed, TA staff will address patient concerns with MTU staff.

National Disability Insurance Scheme

The National Disability Insurance Scheme represents a fundamental reform to the way services are funded and delivered in Australia as recommended by the Australian Government Productivity Commission.

To see these please visit www.everyaustraliancounts.com.au, where you can also have an opportunity to voice your opinion.

TA through its partners, such as the Chronic Illness Alliance, have attended forums to glean a better understanding of how these reforms will affect our community.

Health Literacy Forum - Practical steps for health literacy and patient centred care - 'In their shoes' Royal Womens' Hospital

TA staff attended a one-day forum for health professionals, health care administrators and quality and safety managers interested in exploring health literacy and how it is linked to patient centred care. This type of forum enables TA to review the way it communicates with the community, and how we can best ensure that our message is being effectively received and used.

Medicines Australia Code of Conduct Review

TA staff actively participated in the Medicines Australia Code of Conduct review held in Melbourne.

Medicines Australia is a self-regulatory body representing members of the Australian pharmaceutical industry.

The code of conduct has been developed by the industry, to regulate its members to bring about high outcomes for patients, general public and the medical industry. It ensures that they are transparent and uphold the laws relating to advertising and promotion of pharmaceutical products.

This particular meeting was held to address consumer's issues and perspectives on the code, and give them an opportunity to put forward suggestions as to how it can be improved.

We are looking forward to a great international thalassaemia week, and urge you all to put the 6 October, 2012 into your calendar so that you can join us at this year's Thalassaemia Dinner Dance to be held at Ultima Receptions in Keilor.



A visit from Vasili Berdoukas

TA staff had the pleasure of meeting with Vasili Berdoukas during his recent visit to Melbourne to discuss the emerging issues in Thalassaemia.

Vasili Berdoukas is the Visiting Professor from University of Southern California, Keck School of Medicine and Children's Hospital Los Angeles.

New areas of research in thalassaemia include investigations into the iron stores in various parts of the body including the pituitary gland¹ and pancreas² through MRI testing.

The new oral iron chelator FBS 0701 is now entering in to Phase 3 of testing, evidence is showing that the capsules have a good half-life and have no bad effects on the kidneys³.

There is also new research into nutritional deficiencies in thalassaemia patients⁴,

particularly when looking at a patients' cardiac function that is not related to iron overload.

1. Noetzli LJ, Panigrahy A, Hyderi A, Dongelyan A, Coates TD, Wood JC. Pituitary iron and volume imaging in healthy controls. *AJNR Am J Neuroradiol.* 2012;33:259-265.
2. Noetzli LJ, Mittelman SD, Watanabe RM, Coates TD, Wood JC. Pancreatic iron and glucose dysregulation in thalassemia major. *Am J Hematol.* 2011.
3. Neufeld EJ, Galanello R, Viprakasit V, et al. A phase 2 study of the safety, tolerability, and pharmacodynamics of FBS0701, a novel oral iron chelator, in transfusional iron overload. *Blood.* 2012;119:3263-3268.
4. Wood JC, Claster S, Carson S, et al. Vitamin D deficiency, cardiac iron and cardiac function in thalassaemia major. *Br J Haematol.* 2008;141:891-894.



Donations keep coming in...

During this quarter Thalassaemia Australia has been fortunate to receive a number of donations from the following organisations and schools:

- Philanthropikos Syllogos – Dimos Meligala Messinias Profitis Elias Inc. Melbourne - \$ 5,000
- Philanthropical Associaton Vamvakiton Lakonias (NSW) H. Vamvakou - \$1,000

- St. John's Regional College - \$500

On behalf of Thalassaemia Australia, we would like to take this opportunity give our heart-felt thanks for their generosity.

Multivitamins for Kids with Vitamin D and with **no IRON**

The Kids Smart Complete Multivitamin + Fish oil has **100 units of Vitamin D**. This is the preferred option if your child has been Vitamin D deficient in the past.

The Kids Smart Vita Gummies – Multivitamin + vegies has only **50 units of Vitamin D**.





Research:

New Iron Chelator

FerroKin BioSciences Announces Start of a Phase 2 Clinical Trial of FBS0701 Chelator.

FerroKin BioSciences announced on September 19 that the first dose has been administered in an international Phase 2 study of FBS0701, a novel once-daily oral iron chelator in development for the treatment of transfusional iron overload.

This is an Open Label, Multi-Center, Single-Dose Pharmacokinetics, and Multiple Dose Study of the Safety, Efficacy and Tolerability of FBS0701 in a Pediatric Population with Transfusional Iron Overload.

"We remain enthusiastic about the progress this molecule has made in clinical development. Children represent a significant proportion of the population of patients with hereditary anemias who also have iron overload from transfusions. Our hope is to extend the clinical benefits of a new chelator to these patients. We are grateful to be working with such high quality clinical investigators who appreciate the need for new chelators," said Hugh Young Rienhoff, Jr., MD, founder and chief executive officer of FerroKin BioSciences.

This Phase 2 open-label study will assess the pharmacokinetics, safety, efficacy and tolerability of FBS0701 in pediatric patients with transfusion-dependent anemias such as β -thalassaemia. The study consists of two phases: the pharmacokinetic phase, using a single dose of FBS0701; and the chronic dosing phase, during which patients will receive an additional 48 weeks of FBS0701 dosing.

"I am pleased the FBS0701 development program is progressing to this pediatric study. This is a significant step forward for a promising agent. We will be very interested to learn the pharmacokinetics,

safety, tolerability and efficacy in children and adolescents requiring chronic transfusions." said Ellis Neufeld, MD, Professor of Pediatrics, Associate Director of Hematology at the Children's Hospital Boston and the Lead Investigator.

The study is being conducted at multiple sites in North America, the Middle East, and Europe. For a more detailed description of the clinical trial protocol, inclusion and exclusion criteria, and a list of participating sites, please visit clinicaltrials.gov and enter the study identifier - NCT01363908. Additional Phase 2 and Phase 3 studies with FBS0701 are being planned.

About FBS0701

FBS0701 is an iron chelator currently in development for the treatment of transfusional iron overload. FBS0701 has received Orphan Drug Status from both the United States Food and Drug Administration (FDA) and the European Medicines Agency (EMA). FerroKin BioSciences has completed four clinical studies on the safety, pharmacokinetics, tolerability, and iron clearing activity of FBS0701: one in healthy volunteers and three in patients with iron overload resulting from transfusion therapy.

Source: Cooley's Anemia Foundation
http://www.cooleysanemia.org/index.php?option=com_content&view=article&id=508:ferrokin-biosciences-announces-start-of-a-phase-2-clinical-trial-of-fbs0701-chelator&catid=1:latest-news.
April 2011, with thanks.

Research at the MTU

In the next few months, patients attending the Medical Therapy Unit may be asked if they would be interested in participating in research projects.

These projects will help improve understanding of Thalassaemia and its treatment, and possible help other patients at the MTU, in Australia, or even worldwide. In some cases, involvement in a project may also offer you an opportunity to directly improve your own health.

All research projects undertaken at Monash Medical Centre (including at the MTU) have been evaluated and approved by the hospital Ethics Committee.

The doctors or researchers undertaking the study will explain to you why a study is being undertaken, what is involved, and what the possible benefits or risks might be. You are able to ask any question you like, and your decision to become involved is entirely up to you.

The doctors and nurses looking after you will not be upset or change the way you are looked after based on your decision to participate.

Dr Sant-Rayn Pasricha
Acting Head, Thalassaemia Service
Southern Health Clayton



Report: 1st Pan-Asian Conference on Haemoglobinopathies

In February 2012, Dr Sant-Rayn Pasricha (Acting Head, Thalassaemia Service), Ms Joanne Shaw (Thalassaemia Service Co-ordinator) and Ms Yoke Wong (Research Nurse) attended the 1st Pan-Asian Conference on Haemoglobinopathies.

The conference covered topics such as genetics, current situation in control (prevention and management) strategies and health systems, management policies, advances in curative methods and future prospects.



Dr Sant-Rayn Pasricha presented our current prevention and management strategies for Australia and his presentation was well received and much positive feedback given.

There were many clinicians and patients present from a range of countries which included Thailand, Pakistan, India, Nepal, Sri Lanka, Indonesia, Maldives, Myanmar, Bangladesh, China, Laos, Malaysia, Hong Kong, Philippines, Singapore, Vietnam, Cambodia, Australia, Taiwan, Lebanon, United Kingdom, United States of America and France.

Information gained from the conference has been adapted to suit the needs of the Medical Therapy Unit and staff unable to attend have been informed and teaching aids made available.

By Joanne Shaw
Thalassaemia Service Co-ordinator

Rare Disease Day Seminar

A function was held by the Genetics Support Network of Victoria in conjunction with their regular Friday clinical seminars to celebrate Rare Disease Day.

GSNV President Moira Rayner presented the results of their survey into the Top 5 issues for people affected by rare diseases which related to equity, access to specialists, financial assistance and support. There was also a strong interest in developing a National Registry of genetic conditions.

In terms of rare diseases, it was noted, that with time, some of these rare diseases are now viewed as chronic conditions, due to the discovery of new treatments and significant improvements medical management and care of patients with these conditions.

GSNV members Anna Hickey, from the Australian Gorlin Syndrome Mutual Support Group and Tina Costanzo from the Prader Willi Syndrome Association of Victoria presented their own personal stories and were very inspirational. A great morning was had by all in support and recognition of Rare Disease Day 2012.

By Sarah Burton

genetic support network of victoria

The Genetic Support Network Victoria (GSNV) is a vibrant and active organisation committed to promoting the interests and well-being of people affected by genetic conditions.

The GSNV is committed to advocating for and highlighting issues relating to genetic, rare and complex conditions.

The GSNV is an international Rare Disease Day partner and is a keen participant in national and international events and education around Rare Disease.





2012 Committee of Management

President/Chairperson –
Martha Gerolemou

Vice President – Marianne Dimitrakas

Treasurer – Lela Dallas

Secretary – *Open Position, if you are interested please contact coordinator@thalnsw.org.au*

Assistant Secretary/Assistant

Treasurer – Theodora Michalopoulos

Executive Member – Glenda Hughes

Executive Member – Nicholas Kotrotsos

Executive Member – MD Faisal

Executive Member – Rosa Dimitrakas

2012 Committee meeting dates

All meetings held at:
Thalassaemia Centre,
Level 7, King George V Building
Missenden Road, Camperdown 2050.
Meetings start at 7pm.

All welcome to attend
and join!

Wednesday 2 May
Wednesday 6 June
Wednesday 4 July
Wednesday 1 August
Wednesday 5 September
Wednesday 3 October
Wednesday 7 November
Wednesday 5 December



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The Thalassaemia Society of NSW has the 2012 – 2013 Entertainment books for sale. \$13.00 of each book sale goes to the Thalassaemia Society of NSW. Order your copy from the website below, pick one up from the office or phone us and we can post one out to you.

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Letter from the Centre Coordinator

Happy Easter to everyone, I hope you all had a nice festive time with family and friends and ate loads of Chocolate..... I know I did!

I cannot believe it is almost the end of the 4th month of this new year.....time is getting away from me and we have loads of events coming up over the month of May that are going to keep up very busy, I suggest that you make yourself a nice big cup of tea as you sit and read on as I have lots to say....enjoy!

The month of February saw functions and events for World Rare Disease Day. I attended two events to raise awareness of the impact of rare disease on individuals and families it was a great opportunity to come together with similar organisations and individuals, to share stories and experiences and most of all to have one strong voice in the community about the importance of raising awareness for Rare Diseases.

I was also a busy bee in February with the ARCBS attending thank you presentations to organisations that got behind the Club Red Program in their work place. They work very hard to drive and motivate colleagues and staff to donate blood. ING in Sydney were the winners for last years' Club Red Challenge, so a BIG THANK YOU goes out to them for their donations and support.

The youth ambassador programme has also kicked off for another year with many schools taking part, I attended and presented to over 150 students over three days about the importance of blood donation and how blood donors are a Thalassaemia Patients life line. Thank you to all the students for being so attentive, asking questions and giving such positive feedback to my talk.

The Thalassaemia Society of NSW along with Amy and myself are of course working hard again this year with community awareness stands around our main hospitals, already holding stands at RPA and POWH, it is nice to see familiar

faces on the days that we are there so if you do happen to walk past and see our stand please come up and say hello!

It was with great pleasure and sadness all at the same time in March when I attended a farewell function held by the Westmead Children's Hospital in honour of Dr Lammi and Dr Webster's retirement from the Westmead Children's Hospital. I say thank you to two special men who were very positive figures and touched the life's of many patients and their families. (See special article)

The month of May is an exciting and busy month to come, as you would all know the 8th of May we will be Celebrating International Thalassaemia Day. "Patients Rights Revisited", supported by Thalassaemia International Federation and World Health Organisations. See flyer for information, and please join us as we create awareness, celebrate, advocate for our patients and give thanks to our health professionals and supporters.

The Thalassaemia Society of NSW has also organised a Greek night at Fix, in order to get together have some fun while raising funds for a very important cause. Without the support from our members, family and friends the Society would not be able to continue the good work and support for their patients. See attached flyer for information and ticket sales.

Coming up on the 18th – 20th May for the very first time The Thalassaemia Society of NSW will be exhibiting at the GPCE – General Practitioner Conference and Exhibition in Sydney. We are working very hard to get all our resources together and ready for the GP's that attend the conference. We are also very excited to be holding a "meet the expert" segment at the conference and would like thank in advance Professor Robert Lindeman for giving up this time to come along and present. I look forward to the experience and a positive outcome; I will update you all in our next newsletter.

I think for now I have loaded you up with enough information, however if any one has any questions, suggestions or feedback please contact me anytime.

Thank you!

Nancy Lucich
Centre Coordinator

P.S. Care Flight is holding their Magic Mania fundraiser shortly, and free ticket will be available to our members and families, stay tuned!





Greek Festival of Sydney

A huge thank you to the Greek festival for once again welcoming us with open arms.

The day started off exciting and fun. Setting up our stall was a team effort with the Thalassaemia Society's committee members making sure that our stall was noticeable and they did a fantastic job at that.

It was rewarding to see so many people, young and old, stopping to grab a pamphlet and educate them more on Thalassaemia.

The Thalassaemia Society has been attending the Greek Festival for many

years but this year we were overwhelmed with the interest of the community.

The hard work we put into our charity work as a committee is rewarding when we can reassure a Thalassaemia Minor patient about family planning and providing them and other interested parties with more information about this very common blood disorder.

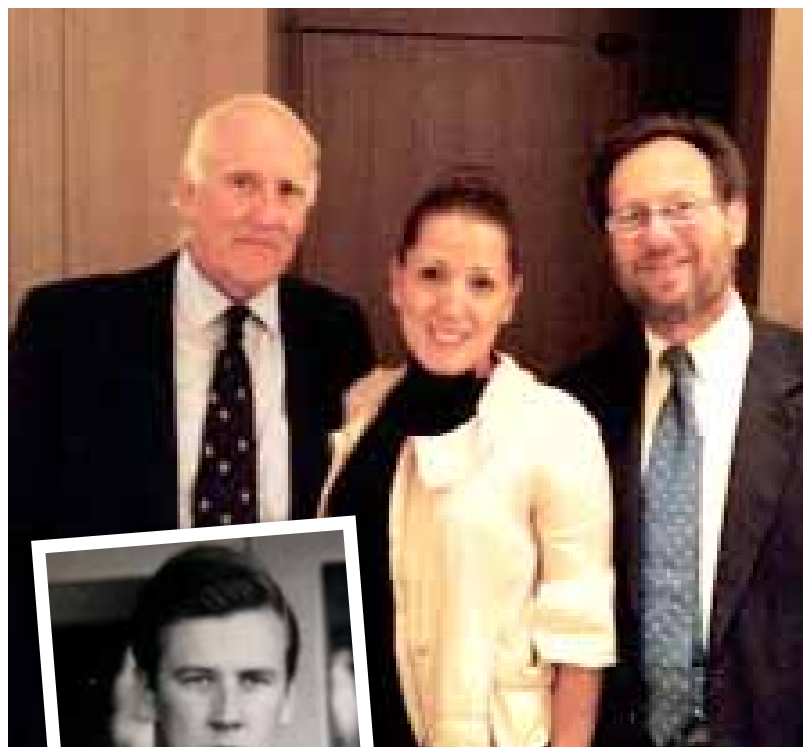
A special mention to Dimi Lafazanos and the Greek Festival committee for all her help.

Without your fantastic organisational skills, the day would not be as successful as it was. You all do a fantastic job.

A great effort from Theodora Michalopoulos, Rosa Dimitrakas, Lela Dallas, Marianne Dimitrakas and her niece Angelique Dimitrakas and Martha Gerolemou who volunteered their weekend to educate our community.

THANK YOU SYDNEY ☺





Farewell to

Dr Lammi and Dr Webster

On the Saturday 17 March 2012 a farewell dinner was held, for Dr Ahti Lammi and Dr Boyd Webster.

A fitting venue to honour two great people as they step into retirement, the elegance of the Gallery Room at the Hyatt Sydney added to the moment.

The room filled with colleagues, friends, patients and messages poured in from those who couldn't make it.

There were speeches and many stories told illustrating careers, achievements and dedication. The scrapbook of stories shared made everyone feel proud to know either of these two men.

Described as the "Odd Couple" added humour; Dr Lammi with his infamous messy office who loved nothing more

than to talk and Dr Webster, the quiet and organised one. They both worked together to produce great things.

From their days at Royal Alexandra Hospital for children to the Children's Hospital at Westmead haematology unit, these two humble specialists serviced more than just their patients, but whole families and communities.

For the Thalassaemia community Dr Lammi was fundamental in connecting families experiencing similar hurdles to form networks and a medical advisor for the Thalassaemia Society of NSW.

Dr Webster respected on a national level by patients and members of all state societies for his dedication and time he has volunteered to the Australian Thalassaemia Association.

They have retired though they continue to work as volunteers. Dr Boyd Webster and Dr Ahti Lammi continue to research various aspects of haemoglobinopathies and other oncology disorders.

On behalf of the Thalassaemia community, I would like to thank both Dr Webster and Dr Lammi for all their hard work, support, and wish them all the very best and a magnificent retirement.

RECIPE

Tiger Toasts

(adapted from *Gourmet Sandwiches* by Suzanne Blythin)

To make 2 toasts

Ingredients:

- 2 slices of bread (brown/white)
- 1 slice of cheese
- Vegemite

Method:

1. Preheat your oven grill / use the "top heat" setting and set the temperature to 200°C.
2. Lightly toast the fresh bread.
3. Spread the Vegemite on the toast.
4. Use kitchen scissors and cut out strip of cheese (mimicking "tiger stripes") and arrange them on on top of the toast to your liking.
5. Put under the grill and cook until cheese has melted (about 3 minutes).

Enjoy!

Hi Kids!

Hope you had a great Easter and didn't eat too many Easter Eggs! Have some fun with the spot the difference below and try out a new yummy recipe!



Q: What do you get if you pour hot water down a rabbit hole?

A: Hot cross bunnies!

Q: How does the Easter Bunny keep his fur neat?

A: With a hare brush!

Q: How can you tell where the Easter Bunny has been?

A: Eggs (X) marks the spot!

Spot the Difference

Find the 12 differences between the two Easter pictures below.

