



THALWATCH

BEYOND THALASSAEMIA

THE OFFICIAL NEWSLETTER OF THE THALASSAEMIA SOCIETY OF PENANG

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INTERNATIONAL THALASSAEMIA CONFERENCE

International Thalassaemia Conference 2008

11th International Conference On Thalassaemia & Haemoglobinopathies and

13th International TIF Conference For Thalassaemia Patients & Parents

8-11 October 2008, Singapore

Suntec Singapore International Convention & Exhibition Centre

Full report
INSIDE!

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Pertandingan Logo Baru
Sila lihat mukasurat 10

INTERNATIONAL THALASSAEMIA CONFERENCE

Report by : Sister Ooi Ee Ee

The overall programme consisted of a comprehensive and updated overview of many aspects of medical care of individuals with Thalassaemia. There were distinguished international and local speakers providing various plenaries and symposia which stimulated the minds and inspired us to care better for our patients. There were also topics on current research in Thalassaemia through the free paper and poster presentations. The conference also fostered interaction and collaboration among doctors caring for individuals with Thalassaemia, scientists working in the field of Thalassaemia and the patients and families themselves. It is in this way through working together that we can hope to achieve excellent medical care for every person with Thalassaemia.

There are 6 plenary sessions comprising the following topics:- Thalassaemia as a global health problem, Survival in Thalassaemia, New insights in iron chelation Fertility and Pregnancy in Thalssaemia Major, ,Emerging Infections in Blood transfusion and The Future of Haemopoietic Stem Cell Transplantation in Thalassaemia. Other symposia covered topics like endocrine and cardiac problems, blood transfusion safety, infections and other complications. Important topic such as Iron Chelation was presented in details focusing on monitoring and impact on survival. At the same time, we learn about new developments in oral iron chelators and pre-implantation genetic diagnosis. Thalassaemia screening programme in Malaysia was also presented.

The patient/parent programme's aim is to provide up-to-date information on a holistic approach to Thalassaemia treatment besides blood transfusions and iron chelation. It is about embracing the condition, acceptance, learning, sharing and growing. The patients and parents sessions covered topics on blood transfusions, blood donations, cardiac problems and solutions and also endocrine problems. A few sessions were devoted to interactive sessions among patients and parents where they freely interacted with one another with friends all over the world. They shared topics such as hospital visits, problems with I/V cannulation, coping with complications, education, relationships and employment. The oldest patient present at this conference is a 57 years old English male gentlemen who is happily married with children. The above sessions were fruitful and motivating for all of us. Participants were given the choice of using earphones for translations either in Bahasa Malaysia or Mandarin.

(see page 3)

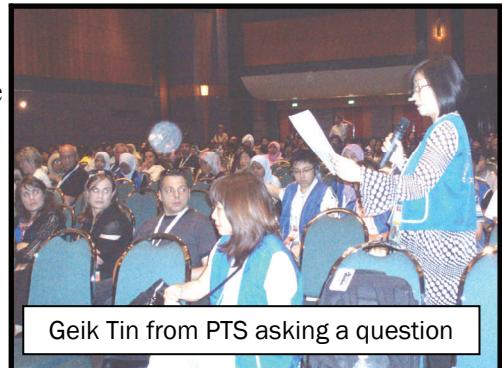


<u>Breakdown of participants from Penang</u>	
Doctors	5
Nurses	10
Parent	7
Patient	17
Others	4
Total	43

INTERNATIONAL THALASSAEMIA CONFERENCE

The Singapore Thalasaemia Society also organized the Asean night where societies from all over met and interacted. There were magic show and presentations by the Thailand patients and parents. All of us were invited to a sumptuous dinner. It was very enjoyable session.

One of the important news that I learnt from this conference is that Malaysians are very fortunate to have our Government giving free medications to all Thalassaemia patients. Our patients should then look forward to patients in other developed countries eg. European, American ,Australian etc as they are living as normal individuals in spite of being Thalassaemics.



Geik Tin from PTS asking a question

Abstract on Nurses' Relationships & Responsibilities- the Asian Experience

Presented by Sister Ooi Ee Ee @ 13th TIF Conference For Patients and Parents in Singapore

My experience as a nurse caring for Thalassaemic children started in 1986 when I was working in the Paediatric Ward in General Hospital Penang, Malaysia and later on when I joined the Penang Thalassaemia Society. Over the years, my relationship grows with the Thalassaemic families.

To build good relationships with parents and patients, nurses need to be considerate and courteous. Be genuine in helping them. Motivate and encourage them. Parents are advised not to over protect their Thalassaemic children as they will be dependent. Patients and parents tend to cope better in treatment and psychosocial issues and challenges when they know more about their conditions. Because of this, the Society organizes camps and workshops . Camps provide opportunities to learn about the latest treatment and complications for both patients, parents and health care workers. The objective is to motivate parents and patients on the importance of using Desferal, parental involvement and support. During presentations, patients and parents freely express their thoughts and feelings about their lives. They learn better in groups. Newly diagnosed children accepted the Desferal Injection and they were doing it by themselves. Camps also play an important role in promoting interaction and bonding between parents, patients, nurses, doctors and society members. Patients are more positive and show signs of improvement in coping with their conditions.

As for the nurses' primary responsibilities, I would like to focus on my role towards patient care – i.e. to be skilful and competent in all nursing procedures. Any problems must be reported to the doctors. It is important to maintain accurate and concise records for easy references in view of the long term management and follow ups. Nurses should also update their knowledge concerning Thalassaemia by attending conferences and workshops. I am certain that together - patients , parents and healthcare workers - we can look forward to

**'A BETTER TOMORROW FOR
ALL THALASSAEMIA PATIENTS '**



Sister Ooi Ee Ee

INTERNATIONAL THALASSAEMIA CONFERENCE

Adapted from feedbacks of Patients , Parents and Spouses

**Positive feedback**

- mendapat pelbagai maklumat-maklumat penting yang telah dibentangkan oleh pakar-pakar dari luar dan dalam negara yang sangat berpengalaman.
- mendapat banyak maklumat mengenai penyakit Thalassaemia misalnya mengenai ubat-ubatan yang ada dalam pasaran dan kaedah-kaedah menggunakannya. Pembentangan kertas kerja oleh pakar-pakar Thalassaemia dari seluruh dunia membuka mata saya dan pandangan saya tentang penyakit ini. (bapa pada seorang pesakit Thalassaemia)
- memahami lebih mendalam tentang Thalassaemia (dari seorang suami pesakit Thalassaemia)
- semangat persahabatanberkenalan dengan kawan- kawan Thalassaemia serata dunia, bertukar pendapat dan juga berkongsi pandangan dan masalahberkongsi tentang budaya kehidupan sosial seorang pesakit thal dari negara luar .
- mengetahui banyak tentang kegiatan-kegiatan persatuan Thalassaemia dari negara luar, juga maklumat tentang bantuan yang diberi oleh kerajaan dari negara lain dalam membantu persatuan dan pesakit Thalassaemia.
- Dari perbincangan antara pesakit dan doktor membuat saya mendapat semangat atau satu kehidupan yang perlu kami lalui dengan hati yang tabah.
- Mengeratkan lagi hubungan antara pesakit dan para doktor.
- sesi yang dikelolai oleh Mr. George Constantinou dari UK adalah sangat bagus untuk ibubapa dan pesakit bagi berkongsi dan menyuarakan pendapat dan masalah yang dihadapi oleh mereka
- amat bersyukur kerana ketika ini masalah perubatan harian untuk kegunaan Pesakit Thalassaemia Malaysia tidak lah teruk sepertimana negara luar yang ketika ini masih lagi harus membayar untuk setiap perubatan harian mereka.
- Selepas bertukar-tukar fikiran dan pendapat serta pergalauan dengan perserta dari luar negara dapat menringankan tekanan untuk menjaga anak-anak Thal. (ibu pada seorang pesakit Thalassaemia)
- Finally, I have definitely learned a lot on how to say no and refuse if I am not happy with what I have been given as well as other important things that I should be aware of with managing my life well.

INTERNATIONAL THALASSAEMIA CONFERENCE

Negative feedback

- ramai yang tidak memahami apa yang disampaikan, kerana tidak begitu arif dalam bahasa Inggeris .Walaupun ada translate tetapi fungsinya seperti tidak ada kerana hanya pada ¼ permulaan sesi sahaja yang diterjemahkan.
- Tiada penggunaan bahasa yang mudah difahami bagi pesakit dan ibu bapa..... banyak menggunakan bahasa doctor
- some of the talks are too complicated and I find it hard to understand and concentrate.
- speaker menyampaikan fakta yang sama disetiap seminar yang diadakan.
- Tiada tempat sembahyang di tempat conference bagi golongan Muslim.
- Not optimized as parents/thals could not get into scientific sessions.
- Some of talks too general in globe aspect - not helpful.
- No access to poster and free papers presentation - so do not know new ideas.
- Too many negative talks by different speakers.
- memohon agar persatuan memberi lebih satu hari dari seminar untuk membawa pesakit thal berjalan atau melawat ditempat menarik untuk menghilangkan bosan ulang alik hospital (tambah darah)

Oo Geik Tin (Parent of a Thalassaemic child)

“回到起点”是这次研讨会（Conference）让我从新有这种领悟。前前后后我也参与不少大大小小的 conference, workshop, camp ..., 所以不由自主的觉得自己好像什么都懂，什么都能掌握，一切已能驾轻就熟了，所以对这次“Singapore” Conference 所安排的讲座会就难免有种闷与不耐烦的感觉。为何老是在这几种课题中打转呢！What is Thalassaemia? => Blood Transfusion => Iron Overload => Cheration => Prevention ... 一次又一次地重复讲着。

忽然，主人之一传达了大会所委辩演的角色就是无时不叮咛，帮助，开导，讲解，也许我们这一群蕉人已有点麻木了。可是对一些新人来说，一切是那么的陌生，那么的可怕与恐慌。所以必须从头开始。我才从中体会到“对极了”，我们真的要从开始做起，虽然过程不断地重复又重复。可马虎不得，不然那可要闹出种种令人意想不到的后果。我想这可不是人人所能担搭得起的责任。严重也可能搞出人命的呢！

所以我们也要不断学习，学习，再学习。虽然不能一百巴仙明白，了解或掌握。但至少如果有何差错，我们也知道如何寻求解决的方法或管道。非常的感谢。

妈妈 => 余玉珍

孩子 => 谢宏宇

Adult Thalassaemics :-

Ang Hai Ping, Lai Beng Khye

Thor Zhi Xiang, Kelvin Lim

我们觉得这一次的会议很有意义，会议中我们结识到很多国外的朋友，我们互相了解彼此的医疗方式。

医生的讲解也让我们获益良多，也让我们知道我们是有希望的。有些国家连最基本的医疗需求都没有，相比起来我们幸运得多了。

最后，我们要感谢 Penang Thalassemia Society. Society Sponsor 我们参加这一次的会议，也帮助我们改善我们的情况。

以上都是我们的肺腑之言，最后我们衷心感谢大家。

INTERNATIONAL THALASSAEMIA CONFERENCE

Feedback from : Dr Foong Wai Cheng

Overall the organization was satisfactory. Many people were assigned for different assignments ie registration, baggage, etc. and they were good in their respective tasks. However, when matters out of their designated task arise, many were really at a loss – this included knowledge of the overall sponsored lunch/dinner programme. The security system were too efficient. I was really surprised with this Singapore law on patient / parent – health personnel segregation.

I have gained a lot of new knowledge, especially on genetics and transplants, although some were, in fact ,too technical and sophisticated for me. Some were repetitions of earlier topics but they helped as a re-enforcement to a particular fact. I did go to the patients section from time to time. There were good interaction between parents – patients- speakers during the Q & A time. However, there are some speakers whom I felt gave their topics in a too technical / medical manner. I truly wonder if the patients or parents can grasp what was being said, especially those with a poorer command of English. I asked some of our delegates who were sitting right at the back of the hall on their understanding, and I got ‘blank’ smiles. The free papers were good . Inthanet is something new I have learned available as a tool to gather data on Haemoglobinopathies.

About the poster presentation, the area was located at the ‘ONLY FOR MEDICAL PROFESSIONALS’ section which was quite isolated. Not many people came because, I think , they were either busy eating at the tea sections or were at the other booths. (There were no food nor drinks there yet, on the day of my poster display). I was told only to standby at 11.40am and the place was perpetually empty because everyone were then at the halls listening to the talks. Nevertheless, we, posters presenters stood by our posters waiting... A crowd finally came during lunch time. I remembered the poster presentation for some other conferences, there were food and drinks near the poster display sections and the delegates can actually browse through posters while eating.

Some of our delegates ended up with food poisoning from the lunch provided, which was very unfortunate. I also got to know that their complaints were initially ignored. Attention was only to them given after much commotion. Without this incidence, the meals provided were OK – all economically packed with few choices.

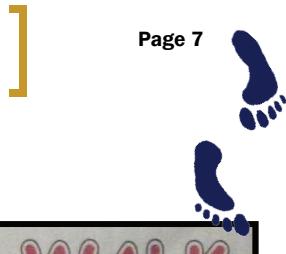


Interactive session among participants

From the Nurses (8 nurses from Penang & Seberang Hospitals):-

- increase our knowledge and view point on thalassaemia management, care and the amount of research being put in for better management
- enable us to improve our care service for our thalassaeemics
- understand our thalassaemic better after been given this golden opportunity to spend this few days together with them.

AKTIVITI PERSATUAN



Charity fun walk organised by Lions Club of Penang Light on 09 November 2008 @ Botanical Gardens - Society represented by Rosita and family, Harison and daughter, Mr. Look and daughter and Noorliza

Pada 16hb Januari 2009, Presiden Chor Huat, Mizal dan Noorliza telah mewakili Pertubuhan Thalassaemia Pulau Pinang ke Rumah Kebajikan Kanak-kanak Tunas Bakti di Kepala Batas. Di situ terdapat tiga adik-beradik yang mengidap jenis B Thalassaemia Major, iaitu Fatimah (8 tahun), Khatijah (7 tahun) dan Abdul Rasyid (4 tahun). Nasib malang mereka kerana di tinggalkan oleh orang tua mereka yang sudah meninggal. Sebelum lawatan ini, Mizal telah mengadakan satu sesi pengenalan mengenai apa itu Thalassaemia dan cara-cara untuk membuat suntikan Desferal kepada pesakit Thalassaemia. Seramai 17 orang yang terdiri daripada kakitangan Rumah Kebajikan Kanak-Kanak telah menghadiri sesi tersebut.

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- **McCare Social Outreach Program** -
- Mcare, a group of pharmacies with 34
- retail outlets in Penang , Seberang Perai
- and Parit Buntar . As part of its social
- outreach, the group has planned to
- have each outlet contribute a minimum
- of RM 125/ month towards a fund . For
- year 2008-2009 Penang Thalassaemia
- Society is the recipient of this fund.
- President Ng Chor Huat represented our
- Society for the launching on November
- 9, 2008 @ Gurney Hotel. He also gave a
- presentation of Society's objectives and
- activities. Vice-President Mdm Oo Geik
- Tin and Azwan accompanied Mr. Ng.
- • • • • • • • • • • • • • • •

HEALTH PERSONNEL WORKSHOP

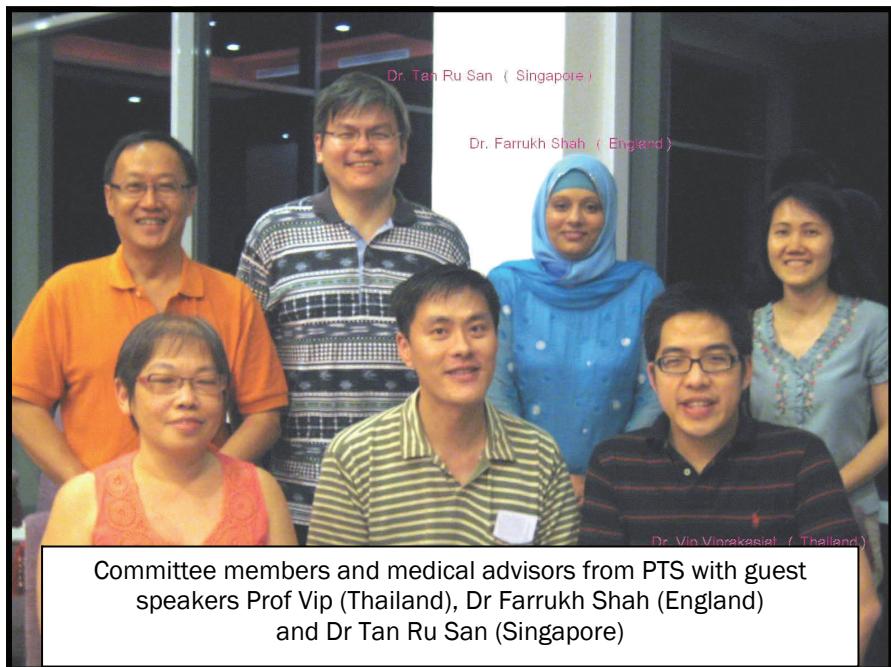
Report by : Dr Yeoh Seoh Leng

Thalassaemia Workshop for Doctors, Nurses and Health Personnel was held successfully on 13 October 2008 at Auditorium, 4th Floor, Ambulatory Care Center, Hospital Pulau Pinang. A total of 138 participants attended the workshop. They comprised doctors, nurses, laboratory staff and other health personnel.

The workshop started at 840am with welcome address by Dr R Nallusamy, Head of Paediatric Department, Hospital Pulau Pinang. It was officiated by Director of Hospital Pulau Pinang, Dr Hajjah Juita.

Plenary lecture on “State of the Art in Management of Transfusion Dependent Thalassaemia” was given by Dr Farrukh Shah, Consultant Haematologist from Whittington Hospital, United Kingdom. Her lecture was very comprehensive and stressed on important aspects in blood transfusion, iron chelation and complications of Thalassaemia.

Dr Keng WT, Consultant Paediatric Geneticist from Institute Paediatric, Hospital Kuala Lumpur, gave the second lecture on “Ethics in Screening for Thalassaemia”. He touched on ethical issues such as screening of minors and importance of patient’s autonomy.



After a tea break of 30 minutes, Prof Vip Viprakasit, Consultant Paediatric Haematologist from Mahidol University, Thailand, spoke on “Management of Thalassaemia Intermedia”. He emphasized on the latest findings of increased incidence of pulmonary hypertension in splenectomized thalassaemia intermedia patients.

Subsequent lecture on “Osteoporosis and Delayed Puberty in Thalassaemia” was delivered by Dr Shah. She discussed about the

many difficulties in management of ‘high turn over’ and ‘low turn over’ osteoporosis, as well as advances in management of hormonal problems in Thalassaemia .

(see page 9)

HEALTH PERSONNEL WORKSHOP*(from page 8)*

Four cases were discussed during the 1st case discussion session, chaired by Dr Yeoh SL, Consultant Paediatric Oncologist, Hospital Pulau Pinang. The cases presented were: complicated Thalasaemia intermedia, difficult to manage iron overload and pregnancy in Thalasaemia.

After a sumptuous lunch, Prof Vip gave a very interesting lecture on “Fine Tuning in Quality of Life for Thalasae-mia”. He stressed on cooperation and the importance of the different roles played by patients, health personnel and voluntary organization.

Dr Chew TK, Consultant Haematologist, Hospital Pulau Pinang chaired he second case discussion session. Two cases were presented : difficulties in diagnosis of alpha Thalassaemia and complicated osteoporosis in Thalassaemia.



Lecture on “The Heart in Thalassaemia and the role of T2* MRI” was given by Dr Tan Ru San, Consultant Cardiologist, National Heart Center, Singapore. Various methods in monitoring of heart iron and management of cardiac iron overload was discussed.

The last session was presented by Ms Janice Kua, on “My experience and My Wish as a patient”. She expressed her wish to be treated the same as all normal people, and the need of specialized Thalassaemia nurse.

There were questions and answer session after each of the lectures. Participants raised questions regarding treatment as well as diagnostic dilemma and were satisfied with the answers by the speakers.

The workshop came to an end at 400pm.

The response to the workshop was very encouraging. As the majority of the participants were nursing staffs, we will include more topics on the role of nursing personnel in future. In addition, hand-outs will be given if the speakers are able to submit their lecture notes in advance.

Post workshop evaluation forms were submitted by 78 participants. However, some of the participants did not answer all the questions on the evaluation form.

PENGUMUMAN / ANNOUNCEMENT

Congratulations!!!



Congratulations to Sister Ooi Ee Ee on being conferred the Anugerah Perkhidmatan Emas by Majlis Dato' Dato' Negeri Pulau Pinang on 26 November 2008 @ Evergreen Laurel Hotel. Ee Ee has generously donated RM 10,000 of the award money to Penang Thalassaemia Society

The Award was to honour individuals with outstanding track record in voluntarism in welfare and charitable services.

"I've been working with the Society for more than 20 years now and it is rewarding to see my patients living healthily and leading their lives to the fullest," Ee Ee said.

TIF invites contributions from thalassaemia patients, parents or health professionals to share their inspirational stories. Some will be published in TIF magazine or in presentation whenever appropriate. Photos to be included.

Articles can be e mailed to Society for proof reading or editing if you wish, before submission to TIF

Pertandingan Logo Baru

Pertubuhan Thalassaemia Pulau Pinang (PTPP) akan menganjurkan pertandingan mereka cipta logo baru untuk melambangkan aspirasi baru PTPP. Kaedah perubatan dan pengendalian Thalassaemia baharu ini menampakkan suatu transformasi yang maju, justeru memberi pandangan lebih positif kepada kehidupan para Thalassemics. Dengan ini, pihak PTPP mengalukan logo baru yang melambangkan mesej positif Thalasemia, Harapan and Bergerak Maju.

Syarat - Syarat Penyertaan :

- Terbuka kepada semua ahli-ahli pertubuhan.
- Lukisan logo haruslah original dan kreatif.
- Logo haruslah berunsurkan dari 3 warna.
- Logo mestilah mempunyai moto / maksud tersendiri .
- Moto / maksud logo haruslah diterangkan tidak melebihi 10 patah perkataan.

Hadiyah-hadiyah menarik akan diberi kepada 3 rekacipta logo yang paling kreatif. Penyampaian hadiah akan berlangsung pada Mesyuarat Agung pada Mei 2009.

Tarikh tutup pertandingan : **31 March 2009.**

Takziah kepada keluarga Nur Sakinah bt Jasni, 15, atas pemergian anak yang disayangi pada 19/9/2008 di Hospital Seberang Jaya. Al-Fatihah. Amin

www.penthal.org

This newsletter is published by:

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