



# THALWATCH

## BEYOND THALASSAEMIA

THE OFFICIAL NEWSLETTER OF THE THALASSAEMIA SOCIETY OF PENANG

**1ST. PAN-ASIAN  
CONFERENCE**

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# 1st. Pan-Asian Conference

## on Haemoglobinopathies

### Royal Orchid Sheraton Hotel & Towers

#### Bangkok, Thailand

#### 8 - 10 February 2012



Welcoming Message from the President of the Thalassaemia foundation of Thailand  
- Prof Khunying Soodsarkorn Tuchinda

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Boarding @ Penang International Airport

# 泰國曼谷舉辦的第一屆亞洲研討會

2012年2月8日，泰國曼谷舉辦的第一屆亞洲研討會，我們幾位檳城地中海會員有幸參與，第一天的開幕儀式並沒有浩大的場面，舉辦單位只發表簡單的歡迎詞，間中還介紹了幾個參與組織，接下的就是一個非常特別的頒獎儀式，一位九十歲的泰國籍醫生Pro Khunying Soodsarkorn Tuchinda女士，她將自己的一生都奉獻在這個領域，專心研發，無私的付出，深切的關懷還有金錢上的幫助，給社會一群不幸人士倍感窩心與感動。

大會也介紹了一個特別的獎勵金，那是Sultan Bin Khalifa International Thalassaemia Award,此獎勵金目的在於獎勵有貢獻人士，研發人員，社會團體或有關單位。根據報道全世界有490million地中海帶因子人士，每天有十二個重型地中海嬰兒誕生，患者之數量真的叫人擔心。每當執行一項預防重型地中海嬰兒計劃，都必須動用一筆龐大的金額確非一般人所能擔當，希望此基金能有效的被善用，也希望它能逐步控制與減少這一類病患者。

第二天，各國參與者相續報導該國病歷，這次研討會課題主要集中在東南亞各國家，有巴基斯坦，印度，尼泊爾，斯里蘭卡，印尼，馬爾代夫，緬甸，中國，越南，香港，寮國，馬來西亞，菲律賓，新加坡，孟加拉和主辦國家泰國。

Dr VIP Viprakasit (泰國) 特別附註在亞洲比較普遍的地中海病症簡歷。可是種類之複雜與繁多必須通過DNA的檢驗才能真正掌握自己到底屬於哪一種病因。

Prof Suthat Fucharoen(泰國) 提及最為關注也讓人擔心的仍舊是要如何預防這種病症。大會也強調三大口號：

## 1) 知識就是能量

## 2) 長期優質對患者的照顧與幫助

## 3) 相關單位瞭解患者與其密切的聯繫

要提升患者的生活方式與質量，需要有合適的有關單位的輔導，監督，培訓，實施政策，服務精神，種種基本策略和自身的自願與意願也至關重要，所以多方面的配合以讓人們瞭解到對重型地中海貧血症預防勝於治療的重要性。因預防的費用遠遠底過治療的花費何止幾倍，呼籲各國政府和相關單位有必要提供相關輔助設施，撥款與監督的政策於其國內地中海協會才能引領功效。在每一個重型地中海貧血症家庭漫長的治療過程中患者與家人所承受的煎熬和痛苦，種種不便和困擾也非金錢所能一一解決的。

經過多國參與者的陳述報導之後，我們身為馬來西亞地中海患者深感幸福。國家政府為我們提供政府醫院的免費血液與相關排鐵藥物，還有舒適的病房和訓練有素的醫護人員為我們服務，反觀一些國家連最基本的血液供應和相關藥物也必須用錢購買。雖然說知識是力量，可是沒有指南，沒有方向，沒有資訊，根本就叫人無從著手。

與其他病症如心臟病，腎臟病，糖尿病，愛滋病，血友病。。。。。。，重型地中海病症普遍被醫學界所忽略，此課題或症狀往往都不被群眾所關注，宣傳和預防訊息或擺在不起眼的角落和不入列在其範圍之中，原因可能是人們普遍上對此沒有認知與關注吧？

預防勝於治療還是我給大家最深表的提醒，尤其對每一對將組織家庭的年輕朋友們，婚前務必做好地中海檢驗以確保將來孩子的健康成長，這就是我參加這次泰國研討會的心得和感受，願在此與大家分享。

謝謝！

## 1st. PAN- ASIAN CONFERENCE ON HAEMOGLOBINOPATHIES Venue : Royal Orchid Sheraton Hotel & Towers Bangkok, Thailand 8 – 10 February 2012

Day 1 – 8/2/2012 @ 4pm. - The conference was attended by 25 countries and 300 + participants according to the record of registration.

I met the Mother of Thalassaemia – Prof. Tuchinda who is still active at her age of 90 years old. I was surprised to find out that quite a number of countries who are not as fortunate as us in Malaysia getting free blood transfusion, medication and treatment.

Day 2 – 9/2/2012 – Presentations from countries on their datas which I would like to stressed that I am still in the learning process but of course it is good to know that some of these countries are way back behind time.

Day 3 – 10/2/2012 – With regard to gene therapy by Philip Lebouich- future thals will have better treatment with their ongoing research.

Overall view :

Have a session with thals – giving them more time to interact with others so that they could have hands-on information.

We look forward to more on clinical treatment as information from other countries.

View by Gary Toh

22/2/2012



## 1. Wonderful News -

**Society got her own house@**

**No. 22A Lorong Janggus Jaya 1/1, 13500 Permatang Pauh, Prai.**

**- Suggestions are most welcome from members to hold workshops  
- handycrafts, cooking, etc..**

**for our members to improve their financial standing.**

**Please submit suggestions to society office in Penang.**

**Thanking you in advance.**



## 2. 6th. Workshop

**- Thalassaemia Workshop for Health Personnel**

**Date: 10th October 2011 (Monday)**

**Venue: ACC Auditorium, Hospital Pulau Pinang**



# THE 17TH CAMP & TANJUNG BEACH HOTEL



Our group photo



Busy time for volunteers - Registration



Our lovely young thals



Participants deep in thoughts



Winners of the colouring contest @ Golden Sands Resort, Penang

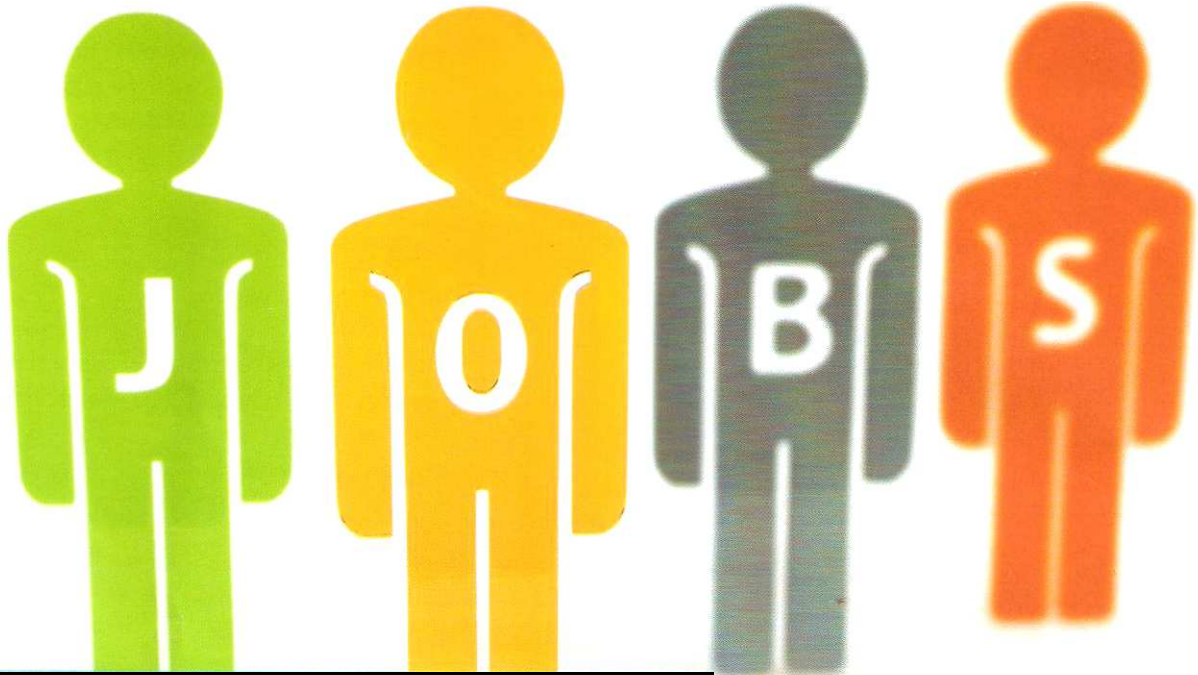


Medication time for thals



Thals Boleh!

## FEATURED Articles



### FOCUS: THALASSAEMIA & EMPLOYMENT

## TIF Statement on the Employment Rights of Thalassaemia Patients

“Never allow thalassaemia to hinder your road to success. I take it as a challenge and not a problem, a different ability rather than a disability—one that comes with deeper insights into the possibilities of what life may bring to us. Disease is inevitable. But whether or not it causes ‘dis-ease’ is entirely optional, just as pain is inevitable but suffering is altogether optional.”

*Sukhsohit Singh (patient with  $\beta$ -thalassaemia major, India)*

#### Introduction:

The preparation of this statement was inspired by the experience of Sukhsohit Singh, a thalassaemia patient in India who was rejected for employment by the Indian Civil Service (ICS) on the basis of a Medical Board decision focused exclusively on the fact that he had thalassaemia major—despite his presenting no debilitating complications associated with the condition. Mr Singh has an excellent academic record and performed brilliantly on the ICS exam. The case follows that of Dr Anjali Sardana, also in India, who was rejected for an academic post on the same grounds.

#### Current Global Situation:

The problem of employment discrimination against patients with thalassaemia and other chronic disorders is by no means confined to India. Indeed, patients in India are in many ways better supported than those in many other countries. As a result of sustained advocacy work by local patients’ associations and specialist physicians, both of the above-mentioned cases have been reconsidered. Dr Sardana is now an Assistant Professor, and the ICS is reviewing the ruling regarding Mr Singh.

Consider the startling results of a recent survey conducted by TIF as part of the ENERCA project on rare

## FEATURED Articles

anaemias, funded by the European Commission and involving more than 300 patients over the age of 20 with thalassaemia (90%), sickle cell syndromes (8.5%) and other congenital anaemias. The survey found that a total of 30.7% were unemployed (13.9% through choice), with a further 19.3% working part-time. Only half of patients surveyed were fully employed.

Europe has robust health and social services resulting in the best survival rates for thalassaemia, and takes a lead role in declarations and conventions on patients' rights, the rights of the disabled and the chronically sick. But the continent can only employ 50% of the adult affected population. What, then, is to be expected of lower resourced parts of the world?

Another TIF survey, conducted in the Middle East in 2009 and involving 96 patients, found that over 80% felt healthy and strong enough to undertake a full-time job. Despite their desire to work, however, many reported obstacles—from prospective employers and society in general. Less than 20% of respondents felt they faced 'no problem' in getting a job. Just over 30% of patients stated that employers were reluctant to employ people with thalassaemia, while

11.4% stated that they faced outright refusal. While a few patients (9.4%) cited job shortages as a contributing factor, others referred to prospective employers' own biases. The following are examples of the reactions some job-seekers faced

'They think it (thalassaemia) is catching'

'Repeated absences'

'Fear that something is going to happen because of the disease'

'They think that we can't do the job'

'Short height'

'Difficult to get a job if features, facial or skin colour are obvious'

'They see us as parasites'

'There is pity which is not a good feeling'

Modern treatment has dramatically increased the life expectancy of patients with thalassaemia major, especially those who adhere to treatment regimes. However, a longer life is not a gift unless accompanied by the fulfilment of one's expectations and abilities, in terms of education, employment and marriage.

The TIF/ENERCA survey of patients in Europe found that 27.5% of 273 respondents were married, with another 7.7% cohabiting and 2.9% divorced. A total of 35 children have been born to those surveyed and 48.6% of 150 respondents were university graduates. All of which only reiterates what we already know: it is possible for thalassaemia patients to fulfil their aspirations to be productive members of society, supporting themselves and their families.

### Responsibility of Employers and Governments to Ensure Patients' Employment:

Article 23 of the Universal Declaration of Human Rights, 1984, states, 'Everyone has the right to work, to free

## FEATURED Articles

choice of employment, to just and favourable conditions of work and to protection against unemployment.'

This document has been further bolstered by the 2006 United Nations Convention on the Rights of Persons with Disabilities, which has been ratified by a number of countries, including India in 2007 and Cyprus in 2011. The Convention binds signatories to meet the needs of persons with disabilities, guaranteeing their full human rights without discrimination and with equal opportunity, including to work and employment. Article 27 states that 'State parties recognise the right of persons with disabilities to work on an equal basis with others,' prohibiting discrimination on the basis of disability, assuring equal remuneration for work of equal value, and safe and healthy working conditions. Furthermore, state parties must 'Promote employment opportunities and career advancement for persons with disabilities'.

The question, however, is whether a thalassaemia patient is a person with a disability. In the case of Mr Singh, the Prime Minister of India responded to initiatives by the National Thalassaemia Association and the wider medical community by proposing to 'include thalassaemia as one of the disabilities covered by the Disability Law, which presumably arises from India's ratification of the Convention on the Rights of persons with disabilities. The definition of disability in the Convention is stated in Article 1 as follows: 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers (attitudinal or environmental) may hinder their full and effective participation in society on an equal basis with others'.

If the Indian Medical Board, which rejected Mr Singh on the grounds of thalassaemia, did not regard him as disabled, i.e. as not having a long-term physical impairment, then it should not have rejected him. If, on the other hand, they did regard him as having an impairment, then their rejection was illegal according to the Disability Law of the country. The fact is that Mr Singh's application to the ICS was rejected out of prejudice and ignorance, guided by the belief that his health might pose a liability to the Service. This is an illogical argument based on the idea that thalassaemia is a fatal condition that prevents patients

leading a normal life. And such as argument then raises the following questions:

- Does not the adult Mr Singh prove that modern treatment has changed the disease outcome?
- Given his many years of consistent academic achievement, in the course of which he has bettered the majority of his peers, not prove him eminently suited to performing the duties of a civil servant?

Employers and governments alike should carefully consider the issue of health as a condition of employment. In addition, medical boards should include specialists on the conditions under consideration. Indeed, the medical communities of many countries include a good number of thalassaemia patients who are themselves medical practitioners.

### The Role of Thalassaemia Expert Centres and Medical Centres:

Traditionally, a doctor's duty to a patient ends with the provision of appropriate medical treatment. In the case of chronic conditions, psychosocial issues have normally been left to others—or to patients themselves. However, with education, employment and other social issues increasingly recognised as important factors in overall patient well-being, this must change. After all, it is the medical experts who are most aware of how their treatment can change patient survival and quality of life. It is therefore also their duty to raise awareness in broader society. It is also their duty to advocate their patients' interests in whatever forums may affect patient well being, including educational authorities, potential employers and government services.

Above all, however, expert centres should ensure that the treatment they recommend does not itself hinder patients' social integration. A key issue here is time of transfusion. Even the best care providers in Europe tend to offer transfusions in the morning (62%) or the afternoon (32%), with only 5.3% arranged in the evenings or at weekends. This means that thalassaemia patients attending school or those who work are more frequently absent, leaving a negative impression on teachers or employers. In this way, health services are at least partly responsible for the social prejudice patients face.

*The fact that people with thalassaemia are living well into adulthood means that older patients now face additional responsibilities in terms of taking the initiative to act as advocates for their right to fulfil their dreams.*

## FEATURED Articles

The question of how to bring service provision in line with broader patient needs is a long-standing challenge that will require concerted pressure from adult patient populations and their support associations. TIF's recently established Expert Patients Group should prove a valuable source of help in spreading the message.

### **The Role of Patients in Changing Attitudes Concerning Employment:**

The fact that people with thalassaemia are living well into adulthood means that older patients now face additional responsibilities in terms of taking the initiative to act as advocates for their right to fulfil their dreams. However,

patients are not alone in this fight: associations and health providers stand ready to offer support and encouragement, just as their families have done in the past.

Perhaps this is provocative. Every individual with thalassaemia spends each day fighting. Who has the right to say, do more?

But I know we can do more. Everyone—TIF, national thalassaemia associations, friends and families—can learn more about the legal rights of thalassaemics and work to ensure that these are enforced. Most of all, it is the duty of us as thalassaemics to recognise our duty to ourselves and to society.



# Pemakanan untuk talasemia

Dr WC Foong PMC / HSJ

Sumber dari Dt Ruzana Abdullah dari PPUKM

## Zat besi – baik atau buruk?

- \* Keperluan seharian = 1mg setiap hari
- \* Untuk pembentukan sel terutamanya sel darah merah
- \* Badan kita tiada cara untuk pembuangan zat besi yang berlebihan. Ia hanya boleh simpan.
- \* Penyimpanan zat besi berlebihan dalam organ dalaman yang menjadi racun pada badan

## Penyerapan zat besi

- \* Dari makanan
- \* Dari transfusi darah

Penyerapan zat besi dari makanan dipertingkatkan jika makanan tersebut mempunyai rasa masam (medium asid) atau kaya dengan vitamin C

## Macam mana nak kurangkan penyerapan zat besi melalui makanan?

- \* Kurangkan makanan yang kaya dengan zat besi
- \* Jauhi sajian haiwan yang kaya dengan zat besi dengan makanan yang kaya dengan vitamin C / jenis asid



## Makanan yang kaya dengan zat besi

*Heme iron (penyerapan sebanyak 20-30%)*

- \* Organ dalaman haiwan
- \* Daging merah
- \* Bahagian daging ayam yang “gelap”
- \* Kerang, siput, lala

*Non heme iron (penyerapan sebanyak 5-10%)*

- \* Telur
- \* Kekacang
- \* Cereal / makanan yang diperkayakan dengan zat besi (iron fortified food)
- \* Coklat
- \* Buah-buahan yang dikeringkan
- \* Sayuran hijau / akar sayuran
- \* Jus buah-buahan terutamanya jus prun
- \* Jam kacang (peanut butter)

## Makanan yang meningkatkan penyerapan

- \* Buah-buahan dan sayuran yang kaya dengan zat besi
  - 1 potong betik sederhana=85mg Vit C
  - 1 potong jambu batu kecil = 90mg Vit C
- \* Hasilan dari fermentasi soya spt. tempe, sos soya, miso
- \* Jeruk, acar
- \* Cuka
- \* Makanan / minuman manis seperti coca-cola, cordial “iron disorder institute”
- \* Alkohol - beer



## Makan apa???

Seseorang perlukan makanan untuk kehidupan - supaya mambesar secara normal dan bertenaga. Makan merupakan suatu aktiviti yang dinikmati

Pengubahsuaian yang boleh dilakukan

- \* Kurangkan makanan yang boleh meningkatkan penyerapan zat besi
- \* Lebihkan makanan yang menghalang penyerapan zat besi



## Makanan yang mengurangkan penyerapan zat besi jenis non heme

- \* Makanan yang kaya dengan phytyes seperti bijirin oat, bran, kekacang, gandum yang belum diproses ( "unmilled" )
- \* Makanan yang kaya dengan polyphenols, tannins atau catechins seperti teh dan kopi
- \* Makanan yang kaya dengan kalsium seperti susu dan bahan tenusu (keju, yoghurt)

## Masalah tulang rapuh di kalangan pesakit talasemia

- \* Lebihkan makanan yang kaya dengan kalsium
- \* Kalsium boleh didapati di kacang almond, ikan bilis, tauhu, makanan yang diperkayakan dengan kalsium
- \* Vitamin C meningkatkan penyerapan kalsium

### Vitamin D

Penting dari segi penyerapan kalsium ke dalam badan /tulang  
sumber percuma : cahaya matahari

## Antioxidant

- \* Vitamin C
- \* Vitamin E (minyak sayuran, kekacang, hasil tenusu, telur)
- \* Carotenoids (buah / sayur yang berwarna kuning / merah / jingga)
- \* Flavinoids (teh)



## Kemasukan darah yang mencukupi

- \* Kandungan darah merah yang kurang dalam badan merangsangkan usus supaya menyerap lebih banyak zat besi dari makanan (suatu proses semulajadi) [terutamanya di kalangan pesakit talasemia intermedia]

## Ada Komplikasi

- \* Kencing manis
- \* Kekurangan hormon tiroid
- \* Kerosakan hati
- \* Kerosakan jantung

### Petua:

- \* bergantung kepada jenis komplikasi
- kurangkan manisan – kencing manis
- \* makan ubat tambahan mengikut masa – sebelum / selepas makan

### Sajian seharian

Sarapan pagi	Nasi lemak sambal kerang Kopi
Minum teh pagi	Horlicks, pisang goreng
Makan tengahari	Nasi putih Kari ayam Acar Sayur campur dengan hati ayam Teh Betik sepotong
Minum teh petang	Teh tarik, kuih talam
Makan malam	Sizzling beef noodles Jus perahan oren

## Sajian yang baik? Perlu pengubahsuaian?

### Sajian seharian

Sarapan pagi	Nasi lemak (sambal kerang) Kopi
Minum teh pagi	(Horlicks), pisang goreng
Makan tengahari	Nasi putih Kari ayam (Acar) Sayur campur dengan (Hati) ayam Teh (Betik) sepotong
Minum teh petang	Teh tarik, kuih talam
Makan malam	Sizzling (beef) noodles (Jus) perahan oren

Sarapan pagi	Nasi lemak sambal kerang Kopi	Nasi lemak biasa / bijirin / sandwic Kopi dengan susu
Minum teh pagi	Horlicks, pisang goreng	Buah-buahan
Makan tengahari	Nasi putih Kari ayam Acar Sayur campur dengan Hati ayam Teh Betik sepotong	Nasi putih Ayam bahagian dada, sedikit kuah kari Sayur campur Teh
Minum teh petang	Teh tarik, kuih talam	Yoghurt / jus perahan oren
Makan malam	Sizzling beef noodles Jus perahan oren	Mee hoon goreng Teh tarik

### **Rumusan**

- \* Zat kalsium dan protein yang mencukupi
- \* Susu sebanyak 500ml setiap hari
- \* Kurangkan jenis yang kaya dengan zat besi
- \* Teh dan susu merupakan minuman yang digalakkan semasa makan sajian besar
- \* Buah / jus di antara sajian besar
- \* Folate
- \* Vitamin C – ada kebaikan dan keburukkan
- \* Tengok label makanan – diperkayakan dengan zat besi?
- \* Kehidupan yang sihat – bersenam



**Pengumuman / Announcement**  
**Condolence** to the family of :  
**Pn. Zeti Aktar Bt Md. Tahir**  
**- 03/03/2012 (Patient)**

# Aktiviti

## Akan Datang



### AGM Ke-23 Perhimpunan Tahunan

Tempat : Kompleks Masyarakat Penyayang,  
Jalan Utama, Pulau Pinang.

Tarikh : 01/5/2012, Selasa @ 9.00 am - 2.00 pm

Masa Pendaftaran : 8.30am

- \* Sebuah bas akan disediakan bagi ahli Seberang Jaya - 40 orang saja
- \* Makanan ringan akan disediakan Kehadiran anda sangat dihargai.

### Hadiah Prestasi Akademik

- a) Tahun 1 - 6 UPSR      b) Tingkatan 1 - 3  
c) Tingkatan 4 - 5, Kolej, Universiti Fotostat keputusan peperiksaan  
dan hantar ke pejabat untuk hadiah diterima semasa AGM.

Hadiah Tahap Ferrintin Tahap Ferrintin di bawah 1000 akan diberi hadiah semasa AGM  
(Tahap yang disarankan oleh doktor)

\* Tarikh Akhir : 15 April 2012 Hadiah Tahap Ferrintin Tahap Ferrintin di bawah 1000  
akan diberi hadiah semasa AGM (Tahap yang disarankan oleh doktor)

\* Tarikh Akhir : 15 April 2012

### Pertubuhan Thalassaemia Pulau Pinang - Charity Food Fair

Tempat : Padang Kompleks Masyarakat Penyayang,  
Jalan Utama, Pulau Pinang.

Tarikh : 16/9/2012, Ahad

- \* Pesta amal makanan ini diadakan bertujuan untuk mengutip dana  
untuk tujuan 'Perubatan thalassaemics'
- \* Sokongan daripada semua ahli amat dihargai.
- \* Sila hubungi ofis society untuk sebarang pertanyaan tentang project ini.

### KEM Ke-18: Hotel di Pulau Pinang 6 & 7 Oktober 2012

- \* Sila hubungi Pejabat Pertubuhan untuk keterangan lanjut.  
**PENTING** - Campaign Derma Darah
- \* Semua ahli diminta hadir untuk memberi sokongan  
sekiranya ada.



*This newsletter is published by:*

**Pertubuhan Thalassaemia Pulau Pinang**  
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**Penang Office Hours**  
Monday to Friday: 9.30-5.30pm  
Saturday / Sunday / Public Holiday: **Closed**  
Contact: Puan Siti Fanziah

**Seberang Jaya Office Hours**  
Monday: 8.00am - 4.00pm  
Tuesday: 9.00am - 4.00pm  
Thursday: 9.00am - 2.00pm  
Contact: Temporarily no staff till further  
notice. Please contact Penang office for  
your medical supplies