FEBRUARY 2010 ISSUE # 16

THALWATCH

BEYOND THALASSAEMIA

THE OFFICIAL NEWSLETTER OF THE THALASSAEMIA SOCIETY OF PENANG

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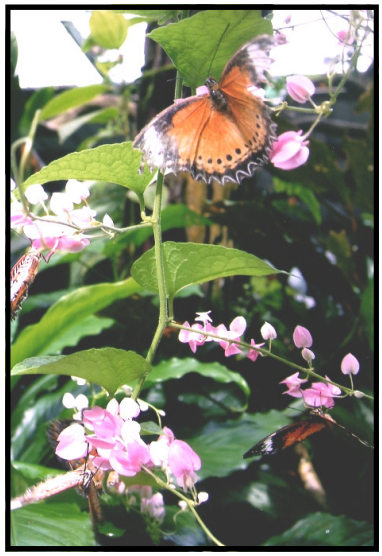
KEM THALASSAEMIA KE-15

Tarikh : 2 - 3 October 2010

Tempat: Hotel Cititel Penang

Tema: Making It Together As Thalassaemic



KEM THALASSAEMIA KE-15

15th Thalassaemia Camp

Making It Together As Thalassaemic

Dianjur oleh:

Persatuan Thalassaemia Pulau Pinang

2-3 Oktober 2010 (Jumaat-Ahad)

Pengalaman sebagai sukarelawan

Kami merupakan sukarelawan daripada Institut Penyelidikan Pendidikan Tinggi Negara, Universiti Sains Malaysia. Kami telah melibatkan diri dalam kem ini melalui Puan Noorliza Abdullah, salah seorang ahli Jawatankuasa Pertubuhan Thalassaemie Pulau Pinang. Sebelum menyertai kem ini, pengetahuan kami amat kurang mengenai thalassaemia. Perkataan ini amat jarang kami dengar. Keadaan ini mungkin berlaku kerana tiada ahli keluarga yang mengidapnya. Pada sangkaan kami, penyakit ini hanya berkaitan dengan darah sahaja. Melalui kem seperti ini, banyak informasi yang kami terima, malah boleh bergaul bersama-sama dengan mereka. Malah kami juga diberi kepercayaan penuh untuk menjalankan aktiviti bersama-sama kanak-kanak ini. Kami juga lebih memahami perlakuan dan tingkah-laku kanak-kanak. Secara fizikalnya, mereka kelihatan sama dan sukar untuk membezakan sama ada di antara mereka yang menghidap thalassaemie atau tidak. Terdapat juga beberapa orang kanak-kanak yang amat pendiam dan berasa malu untuk menyertai aktiviti yang dijalankan.

Untuk kem ini, kami ditugaskan untuk membantu Puan Noorliza dalam menguruskan aktiviti permainan untuk kakak-kanak. Pada hari pertama kem, aktiviti yang dijalankan ialah permainan sukaneka. Kanak-kanak dibahagikan kepada tiga kumpulan dengan lima orang ahli sekumpulan. Namun, nasib tidak menyebelahi kami kerana hujan turun pada pagi itu. Tetapi program tetap dijalankan seperti yang dirancangkan. Kami hanya bermain di hotel. Antara permainan yang dimainkan adalah *catching fingers*, bawa bola pingpong dalam sudu, bawa belon dengan kaki, *animal guessing*, dan bawa belon berpasangan. Pada sebelah petang, kami berpeluang membawa kanak-kanak mengunjungi Taman Botani. Mereka kelihatan sangat gembira setibanya di sana. Malah mereka amat teruja apabila melihat monyet yang banyak di sana. Kami perlu lebih peka dalam mengawasi mereka untuk mengelakkan terjadinya sebarang kejadian yang tidak diingini. Kami berkesempatan untuk mengadakan aktiviti pakaian beragam dan pertandingan melukis. Setiap kumpulan bertungkus-lumus untuk menyiapkan model mereka. Berdasarkan tema yang dipilih iaitu haiwan atau tumbuh-tumbuhan, tiga kumpulan telah memilih untuk menyiapkan pakaian bagi tema haiwan, *Prince of Peacock* dan *Princess of Butterfly*. Selepas itu, mereka berpeluang untuk menunjukkan kreativiti masing-masing dengan aktiviti melukis. Kami pulang semula ke hotel pada jam 5.00 petang untuk aktiviti seterusnya.

Pada hari kedua kem, kami pergi melawat Taman Rama-rama Pulau Pinang. Setibanya di dalam taman tersebut, mereka seolah-olah hilang kawalan. Masing-masing sangat teruja untuk melihat rama-rama yang berterbangan di dalam taman. Mereka sangat gembira dapat melihat serangga, dan binatang lain selain daripada rama-rama. Kami juga berkesempatan menyaksikan persembahan serangga oleh kakitangan taman. Mereka amat seronok melihat dan dapat menyentuh serangga-serangga tersebut. Malah ada di antara mereka yang amat geli dengan serangga sehinggakan terpaksa menyorok di bawah kerusi.

Berdasarkan kepada penglibatan kami dalam kem ini, kami amat menghargai jalinan kerjasama dan kepercayaan yang diberikan kepada kami. Sekiranya kami diberi peluang lagi, kami pasti akan melibatkan diri dalam aktiviti sebegini. Kami juga ingin mengambil kesempatan ini untuk mengucapkan terima kasih kepada Puan Noorliza dan khususnya semua ahli Jawatankuasa PTPP kerana memberi peluang kepada kami untuk melibatkan diri dalam kem pada kali ini dan menambahkan lagi pengetahuan dan pengalaman kami mengenai penyakit thalassaemia.

Disediakan oleh:
Noraini Mohamad Yusof dan Ooi Poh Ling

KEM THALASSAEMIA KE-15

DAY 1 – 2 OCTOBER 2010 (SATURDAY)

1. Welcome Address by Society President

Ms Tan Peck Chin, as President of the Penang Thalassaemia Society extended her welcome to all participants to this year's camp, especially those from Kuala Lumpur, Singapore and Medan.

As experts on the various aspects and updates of thalassaemia from London and Thailand as well as locally are invited as speakers, Madam President advised participants to seize the opportunity to ask questions to broaden their knowledge or to clear their doubts.

2. Thalassaemia – Gift or Curse?

Speaker: **Mr. George Constantinou** – Secretary, Thalassaemia International Federation, a thalassaemic himself, is married and has a 13 year old daughter.

Having gone through this condition, he thinks the GIFTof LIFE refers to being able to live a NORMAL life, best described as being able to INTEGRATE and be part of SOCIETY.

A recent survey in U.K. found that thalassaemics aged 10 – 40+ years are involved with society and they define social integration as:

Getting an Education - Having a Job - Getting Married – Having Children

From the same survey, a good percentage of them are educated, hold jobs and are married. So it can be concluded that if thalassaemics are well treated according to protocols and standards of treatment, they should be able to cope with life's difficulties, in the same way as any other "normal people".

He advised a) **Parents** to:

Stop feeling guilty

Not to feel pity for their thalassaemic children

To help them grow up strong and confident to achieve as much as their other siblings

Expect and demand the same expections and demands from your other children

Encourage them to participate in activities that a normal child would.

b) **Friends not to transfer pity but to:**

Treat thalassaemic friends as equal and not as sick

Show friendship to the person and not to his suffering

c) **Patients to change people's attitude by:**

Behaving maturely and complying to treatment.

Working hard at school and at work to succeed like everyone else

Stop thinking you are disabled

Demanding and fighting for what you think you deserve and should have

He concluded by reiterating that today you cannot differentiate between a normal person and a thalassaemic patient so it depends on **YOU** really:

whether you want to run your life **as a CURSE or as a GIFT**

Reported by: Ms Wong Ah Soo

KEM THALASSAEMIA KE-15

3. Endocrine Complications: Why I need to check for Diabetes?

Why do I need a Bone Scan?

Speaker: Dr. Farrukh Shah – Consultant Haematologist, Whittington Hospital, U.K. and also Mr. George Constantinou's doctor.

All complications develop due to iron overload. Iron is stored in the liver, but if the storage capacity is exceeded, iron is deposited in other body tissies leading to; endocrine damage, Diabetes, Cardiac failure

Fatal complications e.g.,cardiac – dysrythmias, heart failure, infections, liver – cirrhosis, viral hepatitis, liver failure

Non-fatal complications e.g. growth retardation (25-60%), Diabetes (7 %), Hypothyroidism (6 %), Hypoparathyroidism (3-7 %), Osteoporosis (80 %)

Therefore chelation must be started early.

Once endocrine complications set in, it will be for life. There is no cure for endocrine complications, so it is important to carry out endocrine monitoring to prevent them from happening.

Dr. Farrukh went on to relate a story of a thalassaemic major case who from age 15 years was diagnosed as Diabetic, but refused to comply with treatment. He had many admissions to hospital, some of them near fatal. He also developed other endocrine complications e.g. hypothyroidism – all due to non compliance to treatment.

Today, he is only 30 years old, but is staying in an institution, because of his very poor health. In this institution, because of regular chelation, his iron load is good, but diabetes control remains bad.

Osteoporosis is difficult to treat – may take years. Bone density scan is required for bone pain, microfractures and macrofractures,

Therefore it is very important to **prevent complications** by **good chelation therapy and exercise.**

4. Types of Thalassaemia

Speaker: Professor Vip Viprakasit – Consultant Paediatric Haematologist, Bangkok, Thailand.

Prof. Vip started his talk by explaining Red Blood Cell (RBC) morphology for normal persons and that of thalassaemics.

Haemoglobin is the major component of RBC and in thalassaemics, the problem is in the haemoglobin itself.

Haemoglobin chains are made up of 2 alpha globin chain and 2 beta globin chain and every such chain has 1 Heme, whose function is to carry oxygen, so if there are less haemoglobin chains, there will be less heme to carry oxygen.

Thalassaemia is one of the most common genetic disorder in humans.

Defects are: quantitative, causing an imbalance of globin production resulting in Thalassamia Syndrome, qualitative, leading to haemoglobinopathies.

Classification of Thalassaemia

Thalassaemia major

- homozygous disorder, with significant imbalance of alpha & beta globin chains, severe anaemia presenting early in life

requires lifelong transfusion, if untreated, death occurs in first decade of life

Thalassaemia Intermedia

various genetic interactions, globin chain moderately impaired, mild anaemia, usually diagnosed in late childhood, may require occasional blood transfusion

Thalassaemia Minor

heterozygous condition, asymptomatic, may require genetic counselling

Alpha thalassaemia could result in:

Hydrops fetalis, Haemoglobin H Disease, Haemoflogin H / Haemoglobin Constant Spring

Beta thalassaemia could be:

beta thalassaemia major, beta thalasaemia intermedia, beta thalassaemia / Haemoglobin E Disease

All these explains why some thalassaemics rneed to be transfused every 3 – 4 weeks and why some only once every 3 – 4 months.

KEM THALASSAEMIA KE-15

5. **Importance of Monitoring**

Speaker: Dr. Farrukh Khan

As advised earlier, that **Prevention is Better than Cure,** Dr. Farrukh stressed the importance of controlling total body iron to prevent:

damage from anaemia, organ damage from iron as when the capacity for iron storage in the liver is exceeded, iron is deposited in other tissues causing damage to the heart and the endocrine system.

to prevent side effects from drugs – monitoring chelators, to optimise lifelong health

WHAT SHOULD BE MONITORED

Hb – to maintain above 9.5 g?dl, Spleen & liver size, HbsAb 5 yearly, HCV Ab yearly, HIV yearly

Iron overload – liver iron concentration to enable doctors to monitor chelators and make right adjustments in treatment, pre-pubertal and pubertal growth, Endocrine monitoring

Is the relationship with the health team a **Partnership?**

Factors which make patient's adhering to therapy easier:,Acceptance of condition, Good emotional & instrumental family support, High health value, A desire to control health condition, Newer equipment e.g. pumps, Early intervention

All members of the team are involved in continuity of care. The patient himself is the key coordinator of care and staff expertise and interest is of importance for adherence to therapy.

6. **Chelation Therapy**

SPEAKER: PROF. VIP

Treatment for Thalassaemia depends on the severity of the disease e.g.

Transfusion management which significantly improves survival in severe thalassaemia.

Trained Nurse Specialists are essential to provide proper and safe transfusion & use of pumps.

Goals of iron chelation therapy is to maintain iron balance with safe tissue iron balance

to prevent iron from reaching levels which causes tissue damage, to rescue excess iron and reverse dysfunction, Iron intake and existing iron burden are crucial to determine the right

chelation plan, however compliance on any drug is most the critical factor for, successful management.

Prof. Vip also enlightened participants on Thailand's production of GPO-L-ONE which is available at a cheap cost of RM 1 for 3 tablets.

Fertility Issues and Assisted Reproduction for Infertile couples

Speaker: Dr. Narinder Singh Shadan – Consultant Obstetrician and Gynaecologist, Island Hospital, Penang.

He defined Infertilty as the inability to conceive after at least 1 year of trying.

Treatment goal is to help ovum and sperm fuse and fertilize to become an embryo which eventually develops into a healthy pregnancy.

Occurrence: 1 out of 6 couples will experience infertility at sometime.

Causes: In women -Hormonal disorders, damaged/blocked fallopian tubes, endometriosis
In men – low sperm count or non production , poor sperm motility, in poor shape,
previous vasectomy etc.

In thalassaemic patients, because of chelation therapy, women present with hormonal problems and in men, low sperm count and abnormal sperm morphology.

1. Good compliance & long term gonadotrophin therapy may be successful. However endocrine disorders may influence outcome of treatment.

Other treatment options

Assisted conception e.g. with fertility drugs to induce ovulation or

Intrauterine insemination e.g. AID, IVF, GIFT etc.

Dr. Narinder also informed participants that infertile couples can seek help at Island Hospital to be referred to the TAFF Hospital in Kuantan.

KEM THALASSAEMIA KE-15

1. **My Family – How will my Husband / Wife affect Thalassaemic Status of My Baby?**

Speaker: Dr. Goh Ai Sim, Consultant Haematologist, Hospital Pulau Pinang.

As most Thalassaemics are now adults, this topic is very timely and appropriate.

She explained:

Thalassaemia is passed down from parents to children by an autosomal recessive pattern.

The child inherits one beta-globin gene from each parent.

How Thalassaemia is inherited:

Thalassaemia Carrier marries a Normal Person

Children = 50% Normal & 50% Carrier

Thalassaemia Carrier marries a Thalassaemia Carrier

Children = 25% Normal, 25% Thalassaemia & 50% Carrier

Thalassaemia Patient marries a Thalassaemia Carrier

Children = 50% Thalassaemia & 50% Carrier

Thalassaemia Patient marries Thalassaemia Patient

Children = 100% Thalassaemia

5 % of the Malaysian population have thalassaemia carriers (trait) and because of this, it is important that future spouses should have:

premarital screening screening for thalassaemia

full blood count, blood film, Hb analysis

Severe thalassaemia births **CAN** be avoided by carrying out prenatal testing during preganancy:

1. Chorionic Villous Sampling at 10-11 weeks of pregnancy (chorion removed for DNA)
2. Amniocentesis at 18-22 weeks
3. Cordocentesis (foetal blood sampling)at 22 weeks

In Malaysia, the centre for DNA testing is University Malaya.

Prenatal diagnosis must be done early to give parents a choice to continue or end the pregnancy.

When asked about the cost involved, Dr. Goh said that in the year 2002, prenatal screening package cost around RM 2000, and she believes it will cost more today.

Reported by: Ms Wong Ah Soo

KEM THALASSAEMIA KE-15

2. **Living with Thalassaemia – a sharing session of perspectives from:**

a Mother – by Ms Khoo Swee Hong

She said that after a lot of soul searching she decided:

she would not reject her child, Janice, but accept her with her condition, to learn all about thalassaemia, to seek out and use support groups, update knowledge by attending events on thalassaemia

When growing up, she made sure she treated Janice not any differently from her sister.

She taught Janice not to feel ashamed or use thalassaemia as an excuse. She lets Janice know that she has the same hopes, expectations and ambition for both her daughters. With her very positive attitude she has made Janice realize that she can succeed in life and will want to live and will comply with her management.

Most importantly, she felt that to be accepted by society, thalassaemics must project a confident and positive image and remove the stigma attached. However, although special considerations are needed for day to day routine, it is up to thalassaemics themselves to adapt and make changes in order to gather support and demand their rightful place in society.

As a mother she wants and expects the best for Janice. The health carers are working hard to improve quality of life for them and because Janice is so closely monitored she is confident that Janice will not suffer cardiac and endocrine complications.

She has taught Janice independence and skills to succeed and thrive in life.

b) **a Father – Mr. Look Keng Weai**, an Hb H carrier whose daughter is now

12 ½ years old and was diagnosed as a carrier at age 6 months.

At a young age the child was very inquisitive and asked a lot of questions, but now she seems to understand and accept her condition. She is a happy, normal child and her school friends know and accept her and she educates them if they are ignorant of thalassaemia. She is independent and follows treatment.

Mr Look's main worry is job seeking when she grows up. He hopes that in future, there will be better treatment options for thalassaemia.

e) **Patient – Pn. Zeti Aktar Bt. Mohd. Tahir** – 37 years old and is married. She was diagnosed when she often had fainting spells while attending kindergarten. She used to have to go for regular transfusions at G.H. Penang and each time the hospital stay lasted 3-4 days.

She married at the age of 20 years and had made known her condition to all concerned.

She revealed that during a follow-up visit, the Dr. introduced the Penang Thalassaemia Society to her. She was then 22 years old.

She is very positive and not ashamed of her condition, therefore has no significant problems.

BLOOD DONATION CAMPAIGNS

31 October 2010 Blood donation drive by Soko Gakkai (Total Donors: 31)

Working as a Team – an informal discussion session to deliberate issues & problems faced.

Mr George Constatinou - thalassaemic, **Dr. Angeline Yeoh -** Head of Department, **Dr. Foong Wai Cheng -** Doctor, **Sister Leong Guat Lay** - Nurse

Mr. George Constantinou started the discussion by stating that it is important to understand that changes are taking place. With new treatment and care, thalassaemics are living longer, are now more demanding and are organizing themselves to live normally.

Although Doctors have changed their ways in looking at thalassaemics, but are unfortunately blocked by the bureaucratic medical system beyond their control.

Parents voiced their problems and concern e.g.

Parental consent is required each time even for routine blood transfusion.

It was explained that the hospital policy demands this. Dr Goh suggested that perhaps she could help by talking to the clinician concerned as in her hospital, parental consent is given once only.

No Day Care Centre, so has to be admitted for transfusion.

Participants were told that in General Hospital Penang there is a Day Care Centre, but Sbg, Jaya Hospital will have one soon and then this problem will be solved.

Children attending morning school sessions – requests for transfusion in the afternoon rejected as transfusion may be prolonged & completed only after working hours of nurses.

Nurses reiterated that even though patients come in the afternoon, they have never been rejected. They explained that nurses assigned to look after patients receiving transfusions are drawn from the wards as there is no special allocation of staff for this purpose. Nurses outside in the wards do possess the skill to look after patients who are transfused in the afternoons, but they already have their hands full and are kept very busy. Perhaps when the Day Care Centre mentioned earlier is ready, this will not be a problem anymore.

Long waiting time

Doctors' concern was that patients do not keep their appointments. They were advised to keep to their appointments otherwise they will have to wait.

One parent had a positive observation to make – he said that since the year 2003, he has seen a lot of improvements in General Hospital Penang and he is very happy with the service accorded to him there.

In summary, because of bureaucracy, doctors & nurses face tight constraints and it is very obvious that perhaps outside pressure is required. It was suggested that the very strong and influential Penang Thalassaemia Society and the Hospital should work together and come out with solutions so that thalassaemics:

do not miss school

do not waste time waiting

KEM THALASSAEMIA KE-15

What is TIF (Thalassaemia International Federation) ?

Speaker: Mr George Constantinou

7% of global population are carriers of an abnormal haemoglobin gene. He highlighted the magnitude of the problem. Over 500,000 children with Hb disorders are born annually. 80% of them in low and medium resource countries, where more than 100,000 thalassaemics die each year. Figures are only estimates as there are regions still lacking accurate, up to date and even with no epidemiological data.. 12,000,000 units of blood required to for basic transfusion needs. Basic iron chelation cost around US $5.5 billion. Costs 3 times more if multi-disciplinary services are added. Thousands of new patients born every year in the absence of effective prevention.. These figures demonstrate an urgent need for effective prevention and clinical management.

So TIF was created to:

- Strengthen the knowledge of patients globally about their condition, treatment, and parents' & patients' involvement
- Motivate and update the medical community on the latest development
- Encourage and support research & clinical trials for improving treatment and achieving total care
- Support epidemiology work
- Support development and implementation of control programmes
- Establish new and supporting existing patients' or parents' organizations

MISSION: "Equal Access to Optimal Treatment for All Patients with Thalassaemia across the World"

TIF is a non-profit, non governmental organisation

- based in Cyprus, founded in 1986 & registered under Cyprus Company Law
- governed by an 18-member international board of directors – 50% of whom are patients
- supported by an advisory network of over 200 health professionals from over 60 countries

TIF is growing rapidly, starting with a membership of 20 patients/parents and doctors from Italy, Cyprus, Greece, U.K. and U.S.A in 1987.

Today, TIF is a global umbrella federation with 98 member associations and a total of 196 members from 57 countries.

In 1987 it was based in a "borrowed" office with 1 part-time staff. Today it is housed in its own premise with 8 full-time staff.

TIF activities& achievements include: global educational programmes – conferences/workshops/seminars, publications and magazines, projects, other communication tools e.g. TIF website, global awareness – worldwide International Thalassaemia Day since 1994, on **8th May**, has a theme every year – 2010 theme- "The Informed Patient- Knowledge is Power" , successful productive & sustainable collaboration with international partners e.g.

- WHO, International Public Health NGOs, Medical & Scientific committees, industry and other disease-orientated patient/ parent organizations

In Malaysia, current situation with thalassaemia treatment:

- Malaysian government provides treatment i.e. iron chelation & blood transfusion to Malaysians
- Cases with complications are referred to paediatricians and haemotologists within the hospital
- In 2004, a national programme for prevention and management commenced.
- Prenatal diagnosis- special laboratories exist, but hampered by religion/legal implications regarding termination of pregnancies.

However there are still issues that need to be considered and addressed.

TIF activities in Malaysia

- in the form of Delegational visits, workshops and camps, Associations – Malaysian Thalassaemia Federation, Pulau Pinang Thalassaemia Society, Johor Thalassaemia Society, Persatuan Thalassaemia Malaysia
- Publications/Educational Materials – translation into Bahasa Malaysia in 2009 & 2010 by Penang Thalassaemia Society
- Sponsorships & Donations – TIF sponsored patients/members to international conferences/ workshops/delegation visits and donated 8 pumps & financial support for the formation of the Malaysian Collaborative Committee.

Reported by: Ms Wong Ah Soo

KEM THALASSAEMIA KE-15

Can I Live with Thalassaemia?

Group Members

Benita Aryani, Charendee Soon, Doraisingam A/L Rethinam, Gary Toh Guan Hong, George Constantinou, Khoo Swee Hong, Lim Siew Leng, Siang A/L Lim, Tan Peck Chin

Report

Benita started the discussion by saying that thalassaemia was something special in her life and it was not a sickness. Gary did not think of thalassaemia when he woke up in the morning. He followed his routines and did not want to think of thalassaemia. George shared with the group that he needed 16 days in a year for blood transfusion and he did not allow blood transfusion to interfere with his work. He emphasized that as long as it did not interfere with his work, then it was not an issue.

Benita felt positive about her condition even though through this camp she had learned that there were many problems associated with thalassaemia.

Regarding problems related to blood transfusion, Mr George explained that sometimes even though the system existed but no one wanted to follow it. He suggested that everyone should find out about the system and learn about it, rather than trying to manipulate it from outside. Hence, there was a need to know the methodology in order to find a solution to the problem. He further suggested speaking to the highest authority and not the head of department as the message might not reach the top management. It was important to create an expert centre where the waiting time is reduced and quality service is provided. He emphasized that it was important to use statistics of lost hours to convince the administrators to change the system.

Mr Dorai asked Benita whether she would terminate her pregnancy if she knew that the baby was thalassaemic. She said the baby was given by God, hence she would not abort it. Ms Tan Peck Chin also shared her experience of having to wait for the results of chorionic villi sampling (CVS) for two weeks but in the end, she decided not to abort the baby (her daughter).

Charandee Soon A/L Siang (Ms Tan Peck Chin's son) was asked whether he was independent, ie, he was able to attend follow-up on his own. He replied that he knew when he should have blood transfusion and he would not allow his Hb to be less than 9 gm%. His mother usually accompanied him during the follow-up appointment. Ms Tan Peck Chin expressed that she was concern where her son would continue his education and how he would cope on his own.

Benita shared that she had learned a lot about thalassaemia but felt that her parents were not willing to let her be independent. They preferred to do things for her rather than allowing her to do it herself. She was advised that she must learn to cope and show her parents that she was truly capable of being independent. She felt that she would not be able to learn to cope on her own if her parents did not give her the opportunity.

Benita's mother was asked to join the discussion group. She shared that after Benita had come to Penang for treatment and especially after attending the thalassaemia camp, her outlook of her condition had changed. She had become more positive. Lastly, Benita's mother was advised to let her daughter be more independent.

Reported by Chuan Ooi Loo

October 2010

5TH THALASSAEMIA WORKSHOP

For Doctors, Nurses and Health Personnel

Date: Monday, 04/10/2010

TIME	TOPIC	SPEAKER
800-840	***Registration***	
840-900	***Welcome address***	
900-945	***Standard of care : Genotype phenotype***	Prof Vip Viprakasit
945-1015	***Monitoring in transfusion dependent Thalassaemia***	Dr Farrukh Shah
1015-1045	TEA BREAK	
1045-1120	***Iron Chelation: Is there an optimal strategy?***	Prof Vip Viprakasit
1120-1200	***Bone disease and Hepatitis in Thalassaemia***	Dr Farrukh Shah
1200-1230	***Case discussion***	
1230-1400	LUNCH	
1400-1500	***Endocrine complications in Thalassaemia: Malaysia's perspective***	Dr Fuziah Md Zain
1500-1530	***Patient-centred care***	Geroge Constantinou
1530-1600	***What is TIF***	Androulla Eleftheriou
1600-1630	***Case discussion***	
1630-1700	***Closing remarks***	

PENGUMUMAN /ANNOUNCEMENT

Upcoming Events

Please do not miss this opportunity. Call or register in office.

Penang Office Hours

Monday to Friday: **9.30 am — 5.30 pm**
Saturday / Sunday / Public Holiday: **Closed**
Contact: Ms. Too Peng Sim

Seberang Jaya Office Hours

Monday: **8.00 am — 4.00 pm**
Tuesday: **9.00 am — 4.00 pm**
Thursday: **9.00 am — 2.00 pm**
Contact: Nurse Rafiah (016-4720687)

Congratulations!!!

Mizal's Wedding 24/10/2010

Society's Sponsorship

Donation Pledge by Philips Lumileds
(Penang Bridge Marathon on 21/11/2010)

www.penthal.org

This newsletter is published by:

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