

# THALWATCH

## BEYOND THALASSAEMIA

THE OFFICIAL NEWSLETTER OF THE THALASSAEMIA SOCIETY OF PENANG

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# LAPORAN PROGRAM YANG DIJALANKAN OLEH PERSEKUTUAN PERTUBUHAN THALASSAEMIA MALAYSIA

*by Mohd Shahrul Izzuan B Roslan*

*Nama Program:*

Thalassaemic To Thalassaemic Camp 2017

*Tarikh:*

1 Disember – 3 Disember 2017

*Tempat:*

KOLEJ KEDA SIK KEDAH

## ***Objektif:***

1. Para peserta yang terdiri dari Thalassemic dapat menyesuaikan diri dengan program yang telah di atur oleh pihak urusetia dengan sesi pertama iaitu taklimat dari doktor-doktor yang dijemput khas.
2. Para peserta mendapat maklumat tentang kemudahan-kemudahan dan cara yang terbaik dalam pengurusan Thalassaemia untuk lebih cemerlang.
3. Meningkatkan motivasi diri dari segi pencapaian tahap feritin/iron yang terbaik.
4. Membantu peserta dalam menguatkan diri ketika menghadapi tekanan atau cabaran yang baru yang kian mencabar.
5. Para peserta dapat menjalankan aktiviti yang membina semangat dan kerjasama dari seseorang individu supaya lebih bertanggungjawab.
6. Perkongsian pengalaman dan perkongsian ilmu dari kawan-kawan memberi satu semangat kepada setiap peserta untuk terus melakukan rawatan yang terbaik.

**Pengisian :** Program yang dianjurkan oleh Persekutuan Pertubuhan Thalassaemia Malaysia dan semua ahli persatuan thalassaemia seluruh Negeri, yang terlibat dengan program yang dijalankan selama 3 hari di Kolej Keda Sik Kedah ini memberi semua peserta mendisiplinkan diri dan sikap tanggungjawab dengan penuh motivasi demi mencapai kecemerlangan sebagai seorang pesakit thalassaemia.

# Report Kem di Kolej SIK KEDA, Kedah Darulaman

## Hari pertama (1 Dec 2017)

Disini saya Azwan Faizal Bin Azhar Selaku ajk Pertubuhan Thalassaemia Pulau Pinang. Telah menghadiri kem yang di anjuran kan oleh Thalassaemia Fedaration Malaysia Bersama 2 org lagi Ahli Pertubuhan Sharul Izuan & Hazwani dan juga Presiden PTPP Sendiri turut hadir bersama kami.

Pada hari pertama 1 Dec 2017 kami berhimpun di Hospital Seberang Jaya Menunggu ketibaan Dato. Dr Goh Ai Sim Sebagai Penceramah jemputan, Kami pergi secara konvoi waktu bertolak pada jam 11.30Am dan sampai di Kolej SiK KEDA tepat pada jam 1.34PM tepat waktu perut pon dah lapar. Setibanya kami disana terus ke kaunter pendaftaran mengambil T Shirt seorang sehelai dan kelengkapan menulis seperti biasa kita menghadiri kem<sup>2</sup> yang lain dan jugak penginapan yang sangat<sup>2</sup> selesa dgn udara yang segar dan sejuk. Tidak sesuai bg yang kerap kekejangan kaki diwaktu pagi.

Selesai pendaftaran kami dijemput makan tengah hari yang telah di sediakan secara Buffet layan diri, walaupun lauk pauk tidak lah begitu meriah sepertimana kem<sup>2</sup> Pertubuhan Yang lain di adakan diHotel dengan juadah makanan yang mewah, Kami tetap berpuas hati dan alhmdulillah syukur kenyang dan sedap. oleh kerana ini konsep kem jati diri mesti perlu biasakan diri ditempat orang.



Sesama makan beramai<sup>2</sup> sempat kami berbual<sup>2</sup> bersama rakan<sup>2</sup> pertubuhan dari negeri yang lain. Kita patut bersyukur pertubuhan kita Mantap dan kuat. Ada setengah pertubuhan yang datangnya hanya berapa kerat. Jadikan ini 1 tauladan agar kita terus maju ke hadapan dalam membuat kebajikan bagi thalassaemia di masa hadapan.

Selesai makan. Tepat pada jam 2.30pm Penceramah pertama dimulai dengan Dato Goh Ai Sim dgn topic yang agak menarik buat Pertubuhan Lain<sup>2</sup> dan bukannya Penang! Sebab penang dah selalu dengan kem dan ceramah. Topic yang disampaikan (Iron.. Masalahnya?) (Eh! Saya dah besar?) Menjadi tumpuan buat yang lain dgn penuh khusyuk. Kami dah mula layu mungkin sebab makan banyak sangat hehe...

Selesai topik pertama kami minum petang. Dgn juadah yg agak jarang<sup>2</sup> kita jumpa dan rasa iaitu bubur sagu jelly salah 1 pengalaman yang baru sedap mcm tak cukup jer.. hehe

Aktiviti ke2 bermula jam 3.30pm dgn Topik berjudul (Mulanya Disini) Dari Dr. Wong Chin How (Betapa pentingnya kita untuk menjaga atau memantau keadaan kesihatan diri sendiri)

Aktiviti ke3 bermula jam 4.30pm Topik bernama (Memantau hormon, Komplikasi Diabetis dan Ibu Mengandung) yang disampaikan oleh Dr. Shafinaz bt Mohamed..

Pada jam 5.40pm taklimat oleh urusetia tuan rumah berkenaan program<sup>2</sup> yang akan diadakan dimalam hari nanti dan kami bersurai jam 6.00pm ke bilik masing<sup>2</sup> istirehat seketika mandi siap<sup>2</sup> 6.30pm bergegas utk makan malam selesai makan terus ke surau tepat jam 7.00pm. Solat Maghrib & Isyak (Berjemaah) dalam erti kata beramai<sup>2</sup> aktiviti di surau Kami semua Bersama Ustaz Hj Ismudi B. Mohamad Sanusi dengan Kuliah yang berjudul (Terimalah Thalassaemia Seadanya oleh kerana anda insan terpilih) selesai kuliah jam 8.30pm.

Aktiviti 4 dgn topik (Dari Hati ke Hati) yang disampaikan oleh urusetia dan juga role model pesakit kita sendiri. 10.00pm minum malam supper. Jam 10.30pm Rehat / Tidur.

## **Hari ke2 ( 2 Dec 2017)**

Tepat Jam 6.00am kami di surau solat subuh berjemaah. Kuliah subuh Ustaz Ahmad Tarmizi dgn judul (Jangan Putus Harapan atau Mengalah) 7.30. Aktiviti jom sehat bersenam arobik selsai bersenam kami bersarapan.

Aktiviti Mini Explorace bermula pada jam 9.00am memerlukan stamina yg banyak oleh kerana perlu naik turun kawasan yang berbukit<sup>2</sup>. Kami disedia kan bekalan air dan makan sampingan seperti roti utk menjadikan teman sewaktu berjalan mencari clue<sup>2</sup> yang tersembunyi. Perlukan team mate utk selesaikan teka teki dan soalan. Aktiviti tamat jam 12.30pm.

Pada jam 1.00pm makan tengahari dan solat di bilik masing<sup>2</sup> tiba jam 2.30pm Aktiviti bermain perang berpasukan. Salah satu permainan setrategi dlm menumbangkan pihak lawan dgn baling belon air dan menjatuhkan bendera pihak lawan. Amat menyeronokan.

Jam 6.00pm kami bersurai ke bilik masing<sup>2</sup> rehat dan solat berjemaah di surau pada jam 7.00pm. Selesai semua aktiviti seterusnya bermula pada jam 8.00pm dgn tugas yg telah diberikan siang tadi sewaktu mini explorace iaitu dgn cabutan nasib untuk membuat persembahan berkumpulan. Persembahan terbahagi dlm 2 jenis iatu nyanyi dan juga lakonan.

8.30pm bermulah persembahan dari semua kumpulan. Dengan secara seponannya latihan tidak cukup dan sebagainya. Tapi alhamdulillah berjalan dengan lancar dan kami enjoy saat itu bersama yang lain. Menjadi kan salah 1 memori yang tidak dapat dilupakan. Selesai jam 11.00pm

## **Hari ke3 (3 Dec 2017)**

Macam biasa jam 6.00am solat subuh berjemaah disurau. Jam 8.00am sarapan 9.00am aktiviti yang bertajuk (Kau ilham ku) Yang disampaikan dari semua wakil<sup>2</sup> Pertubuhan Negeri Masing<sup>2</sup> menyampaikan kata<sup>2</sup> semangat buat semua..

Dan Majlis Penutup / bersurai pada jam 12.00tgh hari.



# Screening of donor blood

- Dr. Joong Wai Cheng



When a person has an infection, the infective organism (germ, Hepatitis B, Hepatitis C, HIV virus, etc) can be in the person's blood system. Not everyone with the infective organism will show signs of illness. The person can look and feel perfectly well. So, when this person donates his or her blood, the infective organism could also be in the bag of donated blood. The person who receives this infected blood has a high chance of getting the disease later. Therefore it is important to screen all donated blood for infective organisms.

The screening test we have now is effective to screen for such organisms only if the donor has been infected with such diseases for at least 3 months. This means that within 3 months of infectivity, the screening test may not be able to detect the organism. Therefore it is also important that the screening test has to be effective enough to detect if the donor's blood contains any infection immediately, without the need to wait for 3 months of infectivity.

Nucleic Acid Testing (NAT) is a new screening method to test presence of infective disease such as Hepatitis B, Hepatitis C and HIV in the donor's blood with immediate accuracy without the need to wait for a 3 months of infectivity. As such, this donor screening test should be performed in all hospitals to avoid giving unintended infected blood to recipients.

## Saringan darah penderma

Apabila seseorang menghidap suatu penyakit berpunca dari kuman (virus Hepatitis B, Hepatitis C, HIV, dsb), kuman tersebut boleh berada dalam sistem pengaliran darahnya. Seseorang itu tak semestinya menunjuk sebarang gejala penyakit itu. Jadi, bila dia menderma darah, kuman dalam darahnya juga berada dalam bag darah. Sesiapa yang menerima bag darah tadi akan berpeluang tinggi untuk dapat kuman tersebut. Oleh itu, adalah penting untuk menyaring semua darah penderma untuk kuman yang berjangkit.

Ujian saringan yang kita amalkan sekarang hanya boleh mengesan samada seseorang penderma itu sedang menghidap penyakit untuk sekurang-kurangnya 3 bulan. Ini bermakna bahawa jangkitan dalam masa 3 bulan pertama mungkin tidak dapat dikesan. Oleh itu, adalah penting supaya ujian saringan cukup berkesan untuk mengesan jangkitan kuman dalam darah si penderma dengan serta merta tanpa perlu untuk menunggu 3 bulan. Nucleic Acid Testing (NAT) adalah suatu cara saringan darah yang dapat mengesan kuman seperti Hepatitis B, Hepatitis C, HIV dalam darah penderma dengan serta merta tanpa perlu menunggu jangkitan selama 3 bulan. Jadi, ujian saringan sebegini perlu dilakukan di kesemua hospital untuk elak pemberian darah yang berjangkit kepada penerima.

# **The 14<sup>th</sup> International Conference on Thalassaemia and Other Haemoglobinopathies and 16<sup>th</sup> TIF Conference for Patients and Parents**

*- Dr. Angelina Yeoh.*



The recent 14<sup>th</sup> International Conference on Thalassaemia and Other Haemoglobinopathies & 16<sup>th</sup> TIF Conference for Patients and Parents was held in Grand Hotel Palace, Thessaloniki, Greece from 17 until 19 November 2017. This biennial educational event of Thalassaemia International Federation (TIF) was organised in collaboration with the Greek Thalassaemia Federation (EOTHA) and with the support of the Greek Thalassaemia Association (ESTHA) and the Hellenic Society of Haematology. This event was attended by health care professionals, patients and parents from all over the world.

The city of Thessaloniki, named after the half-sister of Alexander the Great, is located in the heart of Macedonia and the second largest city in Greece. Thessaloniki is a city rich in history, diverse cultures and famous multicultural cuisine with influences from the East.

The opening ceremony was held on Friday 17<sup>th</sup> November 2017 in Voula Patoulidou Hall at 1800 hours with opening remarks by the Ministers of Health of Greece and Cyprus followed by the three keynote presentations. The first keynote presentation by Dr John Porter on 'Hemoglobinopathies Care and Cure: Have we reached the end?' brought the audience through the journey of treatment until the potential cure of Thalassaemia and other haemoglobin disorders. Dr Stephen Lobitz from Germany talked about "Migration: The aftershocks to the provision of healthcare". The issues he brought up were migration of refugees especially from the Middle East countries causing a dramatic increase of patients in Western and Northern European countries in which hemoglobinopathies were very rare and now their health care systems were unable to cope with sudden increase in patients number and complications. The last presentation was about 'Patients' as Equal Partners in Decision Making: The Global Reality'. The opening ceremony ended at 2000 hours.

The programme on Saturday 18<sup>th</sup> and Sunday 19<sup>th</sup> of November was very compact without any break for tea or lunch. There were three concurrent events held simultaneously. The Scientific Programme for health care professionals was held in Hall Olympia A and B while the patients/parents programme was held in another hall. There were scientific posters display in Olympia Hall D. The participants wore name tags with barcode which would be scanned each time they entered or left the hall. By this way only registered health care personnel were allowed to enter the hall where the scientific programme was held. The parents and patients were given opportunity to watch the live transmission of the scientific programme during certain intervals.

The speakers consisted of renowned health care professionals in the field of Hemoglobinopathies, and patients. The topics were broad and interesting, ranging from the area of diagnosis and prevention, clinical management and multidisciplinary care and very important on the recent advances in the areas of care and cure for thalassaemia and other hemoglobinopathies. In addition the challenges of delivering the care, improving the quality of healthcare and empowerment of patients were discussed. The issue of pain suffered by the Thalassaemics and quality of life of Thalassaemics were also highlighted.

What is the future outlook for the patients with Thalassaemia? For non-curative aspect, there are ongoing improvement in monitoring of iron overload and use of chelators, improvement in the safety and provision of blood; and trials in methods of improving dyserythropoiesis.

Current potential curative treatments for patients with Thalassaemia major are either by allogeneic hematopoietic cell transplantations, gene therapy or gene editing. There are still ongoing trials in gene therapy with lentiviral vectors, HbF modification by gene therapy, CRISPR technology in gene therapy; and improvement in therapeutic safety and scope of allogeneic stem cell transplantation.

This event which ended by the noon time of 19 November 2017 had provided a forum of sharing knowledges and experiences; building up/strengthening existing networks and promoting patients' empowerment.



# *Report on TIF Conference - Thessaloniki Greece*

On 17<sup>th</sup> to 19<sup>th</sup> November 2017, I received half sponsorship from TIF to attend the International Thalassaemia Conference for Patients & Parents, at the Grand Hotel Palace, Thessaloniki, Greece. I was also sponsored by Penang Thalassaemia Society for my flight ticket.

Dr Angeline and I were travelling together on the same date and same flight. The Conference started on 17<sup>th</sup> November 2017 at about 6.00 pm (Thessaloniki time) with the Opening Ceremony.

On the first day Conference, as patients, I attended the patients & parents session. There are topics from invited speakers from a few countries. One of the speakers in the event was sharing with us about the patient's needs and patient's right. She shared that 'we' thalassaemics need to tell or to let our Government know that what we need and what we want. Nobody will know if we did not come out and tell them on what we need.

We also have a group discussion during the Conference. We were divided to a few groups and had different topics to discuss. My group had to discuss about how to raise fun for our own Societies. Some of us shared that they had Charity Wine Test, they had musical show, and some of them had charity food fair. I have shared with them that Penang Thalassaemia Society also doing charity food fair to raise the fund for the Society.

During the Conference, I met new friends all over the world. They are from UK, Sri Lanka, Indonesia, Bangladesh, Maldives, Mauritius and others. I had an opportunity to chit chat with them and we were sharing about the treatments over in their countries. Something that still fresh in my mind, in Maldives, to get blood transfusions, the Thalassaemic have to find their own blood donor. Then they have to bring the donors to their transfusion centre, withdraw the blood from the donors and do the transfusion to them. Whenever the Thalassaemic are due for transfusion, these are the process they should follow. Each of every Thalassaemic has their own group of donors. In Penang, we are lucky that we don't have to find our own donors.

Being selected by TIF to attend this Conference was such a great experience to me. I had an opportunity to meet Thalassaemic all over the world, getting news or updates on Thalassaemia Management in their countries and etc.

Thank you to TIF and Penang Thalassaemia Society for this great experience.

*Report by :  
Noorasyikin Md Saad*



## **23rd Thalassaemia Camp 2017 :**

**“Working Hand in Hand for Thalassaemics”**

***“Bermuafakat untuk Thalassaemics”***

*Rainbow Paradise Beach Resort, Tanjung Bungah, Penang*



### **DAY 1. 7 OCTOBER (SATURDAY)**

**0800**      Registration (Ms Lily Boey, Ms Too Peng Sim)

Registration of participants began at 8.00 am. A total of 121 participants attended the camp. Breakdown of participants were as follows:

<b>Thalassaemics</b>	<b>Speakers</b>	<b>Doctors</b>	<b>Nurses</b>	<b>Volunteers</b>	<b>Staff</b>	<b>Guests</b>	<b>Total</b>
<b>95</b>	<b>7</b>	<b>6</b>	<b>13</b>	<b>2</b>	<b>2</b>	<b>2</b>	<b>121</b>

Out of the 95 thalassaemics (thal) participated the camp, 32 are from Penang and 63 are from Seberang Jaya.

This year, one speaker from oversea (Thailand), participated the camp.

**0855**      Welcome address by the Society President (Pn Noorasyikin Md Saad)

The President welcomed all participants joining this yearly meeting. She also thanked all thalasaemics, family and those who have been working hand in hand, supporting thalasaemics to better improve in living with thalasaemia.



## 0900 Address by Organizing Chairperson (Dr Angeline Yeoh Aing Chiee)

Dr Angeline (Consultant Pediatrician and Head of Department from Hospital Seberang Jaya) began by welcome and thanked the participants and supporters for attending the meeting. She stressed the important of working hand in hand, within the thal and family members as well as health care workers. She urged the participants to continue supporting each other and sharing appropriate knowledge and information to help improving the treatment and health of the thal.

Dr Angline also thanked and welcomed all speakers, local and international, for their support and sharing of experiences in this two days camp.

## 0905 Genetic and Family Screening (Prof Dr Vip Viprakasit)

Prof Vip thanked the society to invite for camp again this year. Prof Vip started by brief information of normal anatomy of red blood cell and its function. He then discussed on Thalassaemia & Haemoglobinopathy as common genetic disorder. He further explained on types, classification, and the common factors on different types of thalassaemia. He highlighted that management of NTDT and TDT should be individualized as people are different. (refer slide from Prof Vip and guideline on Management of NTDT and TDT from TIF)

## 1000 How to Optimise and Improve Compliance of Iron Chelation? (Prof. Dr. Vip Viprakasit)

In this session, Prof Vip explained the cause of iron overload (IOL) in TDT and NTDT. He then summarized the indication of Iron Chelation Therapy (ICT) for TDT and NTDT as recommended in the guideline. Prof Vip further highlighted that better monitoring, dosing matter, mode of administration and ways to deal with non-compliance were essential to maximize ICT. The serum ferritin level, Myocardial iron and liver iron concentration detected by MRI-T2\*, used as a guide to adjust the dosage of ICT. Chelator dose adjustment is important to balance the side effect of chelation and iron overload. Prof Vip informed that a Greek study in TDT patients showed that the mean survival was 10.8 years vs. 14.6 years in patients with poor and moderate ICT compliance, respectively. Thus, new Deferasirox formulation : film-coated tablets (FCT) were introduced to enhance compliance. (refer slide from Prof Vip)

## 1140 Splenectomy : Does it still Plays a Role in the Management of Thalassaemia? (Prof Dr Vip Viprakasit)

Prof Vip covered the issues on causes of splenomegaly, indication for splenectomy and splenectomy related complications in this session. According to Prof Vip, splenectomy in TDT patients is much less since transfusions control ineffective erythropoiesis. He informed that splenectomy may improve growth and cytopenias and help to reduce transfusion demand in some patients. However, post-splenectomy may associated with a general increase in TI-related complications, and a high risk of infections and thrombosis, particularly in patients with high NRBC or platelet counts, and those who were transfusion naïve. Transfusion therapy is not routinely used in NTDT or TI, although patients who do not receive transfusions often develop life-threatening complications. Thus, regular transfusion therapy may reduce disease-related complications. Transfusion iron intake inevitably increases the risk of iron overload. (refer slide from Prof Vip)

**1200      Transfusion Issues in Thalassaemia  
(Dr Khairulnisa Abdul Manap)**

In this session, Dr Kharulnisa shared that in thalassaemia, the aims of blood transfusions not only for live saving but also to suppress extramedullary haemopoiesis, to minimize complications of anaemia and to maintain normal wellbeing of patients. She further explained the blood transfusion procedure, from the recruitment of blood donors to donor screening, preparation of blood component, screening test, quarantine process, compatibility testing, medical reason for transfusion and issues in transfusion. He also shared the steps to ensure safety in the transfusion procedure. (refer slide from Dr Khairulnisa)

**1430      Pregnancy in Thalassaemia  
(Dato Dr Goh Ai Sim)**

Effective blood transfusion therapy and optimize iron chelation therapy improve survival rate in thal. More and more thal are surviving to adulthood, as well as having own family and children. Dato Dr Goh informed that the pregnant thal need multidisciplinary care as the mother and the fetus are in high risk. Pre-pregnancy counseling on physical assessment, treatment, drug used and risk of pregnancy are needed to reduce the risk. The pregnant women also need adequate information on blood transfusion, iron chelation therapy, drug treatment, genetic counseling and feeding of baby. Dato Dr Goh also shared detail information on antenatal, during delivery and post-natal treatment and cares for thal. (refer slide from Dato Dr Goh)

**1500      My Pregnancy – Sharing  
(Pn Nur Ezdianni Rosli)**

Pn Nur Ezdianni was happy and excited to know that she was pregnant even it was not a planned pregnancy. She was under the care of Haematologist and Obstetrician. She shared her problems during antenatal such as infection, increased serum iron level and thyroid function. Even so, she went through the pregnancy successfully as she was compliance to follow-up, treatment and advised by doctors. Her pregnancy was overdue. She was admitted for induction of labour. Blood transfusion was done prior to induction as her serum Hb level was low. She was in labour only after two inductions. Epidural injection was given to her to reduce pain during labour. Unfortunately she was having high lever in the process of labour. On 1 June 2017, LSCS was done to deliver her baby girl to prevent further complication. Pn Nur Ezdianni was happy and thanked all the doctors for their help and care.

**1515      Never GIVE UP – Thalassaemic Sharing  
(Cik Nur Alifah Illyana)**

Cik Nur Alifah Illyana is a patient with b-thal. She is a cheerful, caring, active and positive young girl. She is glad that she is lucky to have all love, care and support from her family, friends and people around. She was managing her study, her illness and her life well. In 2015, she was not able to graduate together with her classmate from UNIRAZAK as she was very sick. She was unconscious and treated in ICU for pneumonia with septic shock. She was intubated and was unable to win off the tube for three times. Even though she was in coma, she felt the love, support and care of her mother, friends, and health care workers. She sensed that everybody never give-up to treat her, so she also should not give-up to fight with her sickness. Finally, she recovered. Now she is a successful business woman running a shop named “Lens D’Cantik”. Her interest is to make-up herself and others to make people look beautiful. She thanks everybody for their continue love, care and support to her.

**1545      How to make Day Care more conducive?  
(Nurses from Hospital Pulau Pinang and Hospital Seberang Jaya)**

S/N Hezuarni Tasaruddin, Hospital Seberang Jaya, explained the definition, aims and services provided in the Day-Care in the hospital. She also shared how the Day-Care is operated. She explained that due to staff, facilities and safety of patients especially during emergency, the Day Care only able for 4 patients per-shift. (refer slide from S/N Hezuarni)

S/N Noorizah Ahmad from Adult Day-Care, Hospital Pulau Pinang, brief the aims, facilities and services provided in Day-care. She explained that there is no limit in the number of patient per-day. Due to limited space in the setting, the thal may not have bed for procedure and may only have chair for them. She urged the thal to give cooperation and bear with this. She encouraged the participants to compliance to the appointment. She also advised those needed blood transfusion to come early in the morning in order to be able to complete the transfusion in time. S/N Noorizah also reminded the thal to settle their billing for the transfusion.

S/N Noor Hazlida Abu Bakar from Pediatrics Day-Care, Hospital Pulau Pinang, informed the thal that cancer patient and other patients with haematology problems sharing the same facility. She urged thal to give cooperation and compliance to the appointment schedule. If needed to change appointment date, please informed early.

Participants Pn Noorasyikin shared her experienced related issue not following the queue for the number. She also appealed to the S/N for the arrangement of getting her blood taking earlier as she need to rush back for work. Dr Goh and S/N Noorizah had looked into the issues.

**1600      Indoor and Outdoor Games  
(Hotel Staff)**

The thal and family members participated in varies games organized by the staff from the Rainbow Paradise Beach Resort. The games aims to encourage the participants to learn to work together enhance relationship besides enjoying the day together. A few hampers were given out as rewards to their participation. (refer the list of games and awards)

**Desferal Session**

This year, we had 3 adult participants involved in the SC Chelation session. Two of the participants are from Seberang Jaya and one from Penang. There are 3 nurses from Hospital Seberang Jaya and two nurses from Hospital Penang supervised them throughout the session. The thal were able to perform the injection well.

**DAY TWO. 8 OCTOBER (SUNDAY)**

**0900      Living with Thalassaemia – From Dr's Perspective  
(Dr Yeoh Seoh Leng)**

Dr Yeoh shared that as a doctor who treat thal, she is looking at 3 main aspects; physical, mental and psychosocial. The aims are to plan appropriate and optimal treatment and care for the patients. For physical aspect, she wanted her patients not to have thal features by compliance to blood transfusion, optimal chelation therapy and monitoring. She further explained the normal and abnormal physical development during puberty. She also explained on the physical monitoring and assessment needed in thal. Dr Yeoh also wanted her patients to have normal mental development and able to deal with blood transfusion, chelation

therapy, any possible complications and etc. From the perspective of psychosocial, Dr Yeoh wished that her patients able to performance all activities on their own abilities. Thus, she encouraged the thal to empower themselves with the knowledge of their illness, treatment needed and all assessment result. She also urged them to share their opinion and make decision regarding their treatment. (refer slide Dr Yeoh)

#### 0945      MRI T2\* - How Much Do You Need to Know? (Dr Angeline Yeoh Aing Chiee)

Dr Angeline started the session by sharing the statistic of major causes of death in thal. Cardiac issues are the main cause of death and are related to iron overloading. She informed that MRI T2\* is one of the important measures used to monitor and assess myocardial iron. Dr Angeline further explained the important of MRI T2\*, degree of iron overload, preparation before the procedure and contraindication of MRI T2\*. She also mentioned that the examination may fail if the patient is claustrophobia, unable to hold his breathing or unable to follow instruction. Dr Angeline brief the participants on the interpretation of MRI T2\*. The patient need to keep the MRI T2\* reading to >20 ms. If the reading is lower, the risk of cardiac complication is increasing. Finally, Dr Angeline stressed early detection and treatments are important for live saving. (refer slide from Dr Angeline)

#### 1045      Emerging Problems as Thalassaemics Grow Older (Dr Tan Sui Keat)

Dr Tan Sui Keat started the session by sharing the statics showing that the thal are able to live well with effective treatment. More and more thal are surviving to adulthood and needed to look at their wellness as they grow older. Dr Tan shared that there are three main challenges in them. These challenges are complication of their illness, psychological challenges and problems with compliance to treatment. Dr Tan further explained each complication throughout the adolescence to older adulthood. He also explained the causes and the management of the challenges suggested by TIF. He stressed that psychological factors are one of the important cause to non-compliance. He urged the thal to compliance to the treatment to prevent further complication in old age. (refer slide from Dr Tan)

#### 1130      Dealing with Thalassaemia – Thalassaemics Sharing

##### En Mohammad Hasan Al-Asyraf Mohamad

En Mohammad Hassan is a very talented, cheerful, active and positive young adult. Currently he is in his final year, doing law in UIAM. He is also sharing a telecommunication business with his senior. He always trying to live as normal as possible even he is a thal. With a good family support, he learns to accept, improve and submit in life. (refer slide)

##### En Charandee Soon Siang

En Charandee shared that he was passive; easily get sick and over-protected by his parents during primary school. When he was in secondary school, he wanted to be as active as others. He joined clubs in school and participated in varies competitions. He was motivated to show that he can do what normal people can. He was a bit upset when his opportunity to study in oversea was turned down by JPA due to his sickness. Finally, he continued doing Degree in Bio-Medical Science in MSU, Shah Alam. He continued to be active even in university. He also requested to change his medication to fit his lifestyle during his study. He



graduated in Jan 2016 and currently working under AIA Shared Services. He informed the company about his illness and he is glad that he is surrounded by people with compassion and accepted him. He urged the thal to be honest about their condition but do not show it as a weakness but as a strength. He believed in no matter what we are, we only have one life. So, live life to the fullest. He also believes that thalassemia can be the source of strength or pain. It is up to individual to shape they own life. (refer slide)

## 1200 Endless Love – Parent Sharing (Pn Norfishah Zakaria)

Pn Norfishah is mother to Cik Nur Alifah. She shared her experiences when her daughter who was in coma for 12 days and admitted to ICU for 19 days. She was with her daughter day and night in the hospital, to give her daughter support, love and care to her. She thanks Dato Dr Goh and all the doctors and nurses in the hospital for helping and treating her daughter. She also thanks everyone who supported and cares for her daughter throughout the critical time. (refer slide)

## 1215 Thalassaemics Motivation Session

### Pn Noorasyikin Md Saad

Pn Noorasyikin is attached to a well-known company in Penang mainland, as an important officer in the HR department. She expressed that as a thal, she has the responsibilities to compliance in blood transfusion, chelation therapy and routine assessment. She understands that chelation therapy plays important role to control serum ferritin level. She also shared her chelation agents and her serum ferritin level from 2006 to 2017. She is working very hard to reduce her serum ferritin level to below 1000ng/ml. She believes by compliance to treatment, consistent monitoring and self-discipline, she can do it. Her motivator to compliance to her treatment is her son. She wants to love and care for her son. She wants to see her son growing up, to have his career and family. She also shared the treatment and facilities provided by the hospital ways back and urged thal to appreciate what they are having as there are much better now. (refer slide)

### En Azwan Faizal

En Azwan urged thal to bring the thalassaemic identity card along at all time. He shared his experience being suspected as a drug addict as he had his chelation agents in the pocket. Thus, it is important to hold the card to verify the need of having chelation agents.

## 1420 Motivation Session – Value Yourself (En Muhammad Yusuf Abdul Ghani)

En Muhammad Yusuf started the session by group the participants to 8 groups. Then, he asked the participants to write down their wishes and how they are going to achieve the wishes. He encouraged the participants to share their wishes and work hard to achieve their wishes.

En Muhammad then asked the participants to give themselves a price from 1 cent to 10 cents. He called out a value and asked the participants to gather together to get the value. This game allowed the participants to look at the different in self and other's value.

Finally, En Muhammad encouraged participants to learn self-motivate. He also urged the participants to focus at own strength and work hard to achieve own wishes.

## 1520 Quiz and Group Discussion (Dr Tan Sui Keat)

Dr Tan asked 10 questions related to topics discussed in this camp to the participants and encouraged them to answer. Participants were awarded with a bag for the correct answer. Majority of the participants showed awareness and understanding of thal, effect of iron overload, chelation agents, blood transfusion, and other related information. (refer list of quiz from Dr Tan)

## 1600

The Camp end by dance performance from 4 young female thal. The participants were awarded with some hamper for the indoor and outdoor games that they were participated. The children also were given some prizes for the drawing competition. (refer the list of games and rewards)

## 1700

The camp concluded at about.

Reported by :  
Miss Lim Chooi Leng



# WORLD THALASSAEMIA DAY

## Public Awareness

8th May 2017





# Activities 2017



Charity  
Food Fair



28TH AGM



Tun Sardon Foundation



Floods





# HARI RAYA OPEN HOUSE

02 July 2017



## *Report by mizal*

Menu : laksa, satay, nasi tomato, ketupat, lemang kuih, minuman

Participants : 130

- 09.00 am - penyediaan makanan bagi tetamu
- 10.00 am - ketibaan tetamu yang hadir
- 12.00 noon - jamuan bermula
- 02.00 pm - bersurai

Kami sangat bergembira melihat ahli ahli pertubuhan bergaul bersama sama dan berkerjasama untuk to make a success of the event.



# PUMP WORKSHOP





# Announcement 2018

## 29<sup>th</sup> Annual General Meeting (AGM) / Mesyurat Agung Tahunan 29

Venue: Allied Healthcare Centre of Excellence

63, Jalan Sungai Pinang, George Town, 10150 George Town, Pulau Pinang.

Date: Tuesday 01/5/2018

Time: 9am - 1 pm

\* Makanan ringan akan disediakan.

## World Thalassaemia Day Public Awareness

a) Venue: Penang General Hospital Foyer

Date: 04/05/2018 (Friday)

Time: 8am - 12 noon

b) Venue: Seberang Jaya Hospital Foyer

Date: 07/5/2018 (Monday)

Time: 8am - 12 noon

## 24<sup>th</sup> Camp 2018 + 30<sup>th</sup> Anniversary Dinner

Date: 6-7 Oct 2018 (Sat & Sun)

Venue: Rainbow Paradise Resorts & Hotel, Jalan Tanjung Bungah, 11200 Penang.

Sila hubungi pejabat untuk pendaftaran kem 24

**Telefon: 04 2272133**

*Lovely baby Eisha*



Congratulations to  
En. Redzuan & Pn. Ezdianni  
on the arrival of your baby girl  
Nur Eisha Raihanah

## 13<sup>th</sup> Workshop for Health Personnel 2018

Date: 05/10/2018 (Friday)

Time: 8am - 4.30pm

Venue: Ambulatory Care Centre  
(ACC)

Penang General Hospital  
Penang.



# *Announcement* **2018**

## *30th* **ANNIVERSARY DINNER**

Date:  
6 / 10 / 18 (Saturday)  
Time:  
7pm - 10pm

Venue :  
Rainbow Paradise  
Resorts & Hotel,  
Jalan Tanjung Bungah,  
11200 Penang.

*Please contact office at  
04 2272133  
for further details.*

**Please call office for further enquiries : 04 2272133**

*This newsletter is published by:*

**Pertubuhan Thalassaemia  
Pulau Pinang**

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Monday to Friday: **9.30am-5.30pm**  
**Closed:** Saturday/Sunday/Public Holiday  
**Contact:** Ms Too

**Seberang Jaya Office Hours**

Monday to Friday: **8.00am-4.00pm**  
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