JULY 2020 ISSUE # 26

THALWATCH

BEYOND THALASSAEMIA

THE OFFICIAL NEWSLETTER OF THE THALASSAEMIA SOCIETY OF PENANG

Report on
DIALOGUE WITH KEMENTERIAN KESIHATAN MALAYSIA

reported by
Cik Nurul Nashuha

TOPIC :
Open Discussion With Deputy Minister of Health YB Dr. Lee Boon Chye About Thalasemia Issues

PLACE :
Casa Bonita Hotel, Melaka

DATE :
8 December 2019

ORGANISER :
Federation of Malaysia Thalassaemia Societies

OBJECTIVE :

1. To request a flexible daycare for transfusion on Saturday, Sunday and public holiday for all facilities in Malaysia.

    - Most daycare for thalassaemia in Malaysia working only during office hours. There are few of facilities open during weekend for blood transfusion. Thalassaemic need to take day off or medical certification every time they came for treatment. This is also including thalassaemic's parents who need to take care of their children during treatment. This situation brings down their quality of life. If Ministry of Health can considerate flexible daycare for thalassaemic, it will improve thalassaemic working performance.

2. To request for a standardized hospital fees and medical equipment to all thalassaemic in Malaysia.

    - Currently in Malaysia, all thalassaemic received a standardized treatment based on the guideline released by Ministry of Health. On the other hand, the hospital fees and treatment fees still different in some facilities. This situation keeps on being questioned by the thalassaemic. There are also issued on the medical equipment supplied to the patient. Some facilities prepared complete medical equipment for their patient but some facilities not doing the same. It increases the burden for thalassaemic who are not lucky.

3. To request for more public awareness and blood donation with the help of Ministry of Health Malaysia.

    - In order to achieve the goal in reduce the thalassaemia generation to minimal percentage, public awareness must be done successfully. Currently, Ministry of Health already has it but still not enough. This is due to the optional of thalassaemia screening for those couple who want to get marriage. There is a lot of married couples in Malaysia doesn't do thalassaemia screening before marriage. They are also not aware of thalassaemia issues and its consequences.

- Every thalassaemic transfusion dependent need blood transfusion every month and every 2 weeks for pregnant thalassaemic. There are still a lot of issues on lack of blood supply in some facilities. Blood donation programs must be increased to help the issues. Ministry of Health had done it at some places but it can be added more in future.

4. To request for 1% job opportunity in public sector for thalassaemic who are qualified to hold the position.

    - There are so many thalassaemic patients who succeed in their study and graduated from various university. Thalassaemic can work like the normal person but the issue comes out when the employee doesn't want to take thalassaemic in their company to work. As the result, many thalassaemic are jobless and working on their own. If Ministry of Health could considerate and open the job opportunity for thalassaemic who qualified, there will be more thalassaemic who successfully in their study.

5. To request Ministry of Health for having a discussion with the insurance agencies in order to ask their insurance coverage for thalasseamic especially for working purpose.

    - The reason why employee doesn't want to take thalassaemic to work in their company is because they cannot take insurance coverage. Most of the insurance agencies don't want to give coverage to thalassaemic for working purpose. There are few insurance companies offer for the life insurance to thalassaemic but only for personal not for working purpose. Due to that issues, thalassaemic struggle to get employed.

DECISION MADE :

1. **YB stated that they only set up several daycares to be open during weekend due to the necessity of patient. For example in Penang, Hospital Pulau Pinang and Hospital Kepala Batas already open during weekend for few thalassaemic. YB also said that if the other facilities also seen to need the weekend daycares, they can write the formal letter and issued out to the Dato Dr Goh to be finalized.**

2. **Dato Dr Goh said that, the issue about medical fees for thalassaemia treatment is still based on the each facilities organization and decision. If thalassaemic want to standardize it at all facilities, it can be considered but the chances to get quite high reasonable fee is there. Due to that, for those who currently paid less will need to pay more in future.**

   Dato Dr Goh also explained that medical equipment which is not being standardized at all facilities is due to the budget separation at each facility. For example in Penang, a budget was given to Hematology department for buying the medicine and medical equipment. So the budget separation was decided by the head of department to buy Desferal, L1, Exjade, needle, syringe and etc. If the head of department decided to buy more on one item, it will be fewer budgets to buy the other item.

3. **YB said that, if we want thalassaemia screening same like HIV screening before a couple get married, it is so hard to implement. It also needs to be discussed with several teams to come out with the decision. In law aspect, we cannot force someone to take that screening as it's against human right. Currently, thalassaemia screening involving form 4 students also need consent from their parents before take that screening. If the parent refuses to give consent then the screening will not be done to their children.**

   YB also stated that he will be review back with the public health team in order to improve the education awareness in each facility. He also will find out the best way of education awareness in order to increase the number of voluntary thalassaemia screening.

4. **According to the issue of job opportunity in public sector, YB said he will discussed with the JPA and human resources about the issue. He will find the best way in order to improve the quality of life thalassaemia patient.**

5. **YB stated that is not a big issue for Ministry of Health having a discussion with the insurance agencies, but the issue is the premium to offer for thalassaemic. The insurance agencies will request for so many data especially treatment data in order for them to come out with the suitable premium for thalassaemic. And for sure the premium offered also will be expensive compared to others.**

CONCLUSION :

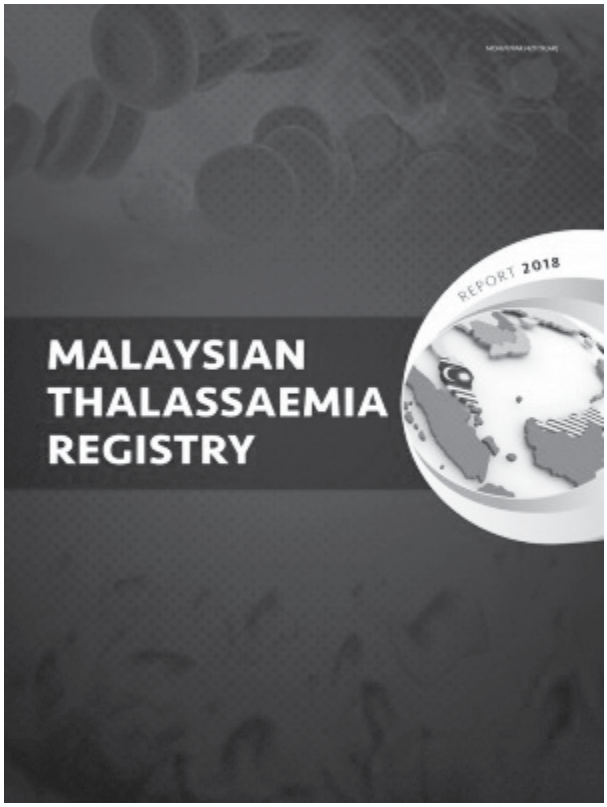
All the pointed issues was noted by YB Lee Boon Chye and to be continued discuss with the other team involved. They will find the best way to improve the quality of life for Thalassaemia patients in the future.

Report on
2ND ASEAN THALASSAEMIA FORUM 2019

by Dr. Fauzana A. Mokhti (Paeds, SJ Hospital)

The forum was held in Women and Children Hospital Kuala Lumpur on 4-5/5/2019 and was officiated by YB Health Minister Datuk Seri Dr Dzulkefly Ahmad in conjunction of launching of the Malaysian Thalassaemia Registry Report 2018 and the much-awaited Clinical Practice Guidelines (CPG) on Management of Haemophilia. This event was organised by Paediatric Hemato-Oncology Unit of WCHKL, Medical Development Division and Family Health Development Division, MOH Malaysia, in collaboration with the Malaysian Society of Paediatric Haematology & Oncology (MASPHO).

About 200 participants were joined to learn the managements, strategies, preventions and new genetic testings in Thalassaemia. Interestingly many speakers were from South East Asean like Prof Vip had shared their strategies and managements towards complicated cases Thalassaemia in Thailand.



According to Thalassaemia Registry in 2018, estimated about 200 new patients were diagnosed to have Thalassaemia every year. In this situation, with the combination of screening of thalassaemia patients had been selected earlier among form 4 students in voluntary programme screening in school on top of premarital screening. This will hope bring down the risk of birth born to affected children.

Here are few notes on the forum held in Kuala Lumpur:

1. The Strategy and Policy (WHO)
   - Policy 4.5/6: Malaysia BPC + Retrospective Genetic Counselling +/- PPMC + Voluntary population based screening, Adolescent + Cascade Family Screening +/- PND +/- abortion (only 25-50% of number of new cases of thalassemia slow over ? years)
   - Total Clinical Diagnosis Malaysia 2018 n=7984. Including TDT 67% and NTDT 32%
   - Cumulative death since 2007 is 608 patients due to cardiac related/failure 42%, infections 38%, MVA 2.9%, Liver Disease 2.6%, tumours/malignancy 2.5%, endocrine 2.14% and so on.

2. Role of Nurses
   - Medication compliance
   - Advocating, education, motivation
   - Education ad schooling
   - Social and financial support

3. Community based thalassaemia prevention.
   National Policy > public awareness > carrier detection > pre-marital screening > genetic counselling > antenatal diagnosis > ? termination of pregnancy

4. Pre-implantation Genetic Testing (PGT)
    - Possible due to advances in assisted reproductive techniques
    - Has a crucial role to play in community prevention of thalassaemia
    - Newer genetic analysis techniques allow faster detection of single gene disorder at high accuracy even in the absence of reference samples
    - Concurrent aneuploidy screening allows the selection of the most optimal embryo for implantation, reducing the time to pregnancy

5. Transfusion therapy and iron overload.
    - Screening iron overload: se ferritin, LIC, cardiac t2* MRI
    - Approaches to Chelation;
      maintance therapy, reduction therapy, rescue therapy
    - Selection chelator: rate of transfusion iron intake, therapeutic goals, current iron overload status, patient age and weight, patient preference.

6. Chelation strategy algorithm
   = as per protocol

7. Novel targets and agents for thalassaemia by Prof Vip
    - Several targets and agents are in development aiming to modify or cure the disease with targets including ineffective erythropoiesis, anaemia, red cell deformities and primary iron overload.
      Ie: transferrin therapy, minihepcidins, BCL11A (CPIPR), Gene therapy (HBB), TMPRSS (SiRNA), JAK inhibitors (ruxolitinib), ACE536 (Luspatercept)

8. HSCT
    - Source: BMT, PBSCT, Umbilical cord blood transplant
    - Not life saving procedure- aim allow normal life free of transfusion dependent, chelation, frequent hosp visit
    - Effective when patients with good risk/chance of cure are transplanted
    - Factors: age, when regular transfusions commenced?, iron chelation history, se ferritin trend, hep c status, donor type/stem cell source (siblings who are normal or carrier/ other source of stem cell)
    - Follow Lucarelli staging class 1, 2, 3 or PESARO group
    - Haplo-identical transplants using T cell depletion is a effective alternative for those lacking fully matched related/unrelated donor
    - Newer depletion strategies like TCR alpha/beta and CD 45 RA depletion may improve the outcomes
    - Post transplant immune reconstitution and viral infections are still a concern

2nd ASEAN THALASSAEMIA FORUM 2019 IN CONJUNCTION WITH WORLD THALASSAEMIA DAY 2019

reported by
SN Noor Hazlida Binti Abu Bakar

DATE : 4th - 5th MAY 2019
VENUE : AUDITORIUM PERDANA HOSPITAL WANITA DAN KANAK-KANAK KUALA LUMPUR

DAY 1 (4th MAY 2019)

7.45 am Registration with small light refreshment

THALASSAEMIA PREVENTION AND CONTROL PROGRAMME (PROF AURELIO MAGGIO)

Prof Maggio have carried out a three-month training on the methodology of prenatal diagnosis of hemoglobinopathies at the Department of Internal medicine of the university of Athens, currently directed by him, has allowed a reduction in the birth rate of 80% af patient with Cooley's disease in Sicily (data from the regional Epidemioloical Observatory).

In addition, he is also involved in the study of beta and delta globin genes and on gene therapy projects using retroviral vectors.

In order to develop the "in utero" transplantation of fetal stem cells in fetuses affected by hemoglobinopathy, this activity allows to improve method of cryopreservation, immunophenotyping.

MALAYSIAN THASSAEMAEMIA REGISTRY DATA (DR HISHAMSHAH IBRAHIM)

Seperti selalu, Dr Hishamshah akan memberi statistic terkini Thalasemia registry di Malaysia.

Sepeti biasa, Sabah mencatatkan jumlah pesakit yang paling ramai dan kadar ferritin yang tinggi.

EMPOWERING NURSES IN THALASSAEMIA MANAGEMENT (MATRON JULAIHA)

Matron Julaiha bertugas di Hospital Wanita dan Kanak-Kanak Sabah (HWKKS) menyatakan bahawa terdapat 10 hingga 15 orang pesakit akan menerima tranfusi darah sehari dan jumlah keseluruhan adalah 308 transfusi darah sebulan.

Jumlah staff di sana adalah 14 orang, terdiri daripada 9 orang jururawat terlatih, 4 orang jururawat masyarakat dan seorang pembantu perawatan kesihatan.

Jumlah terkini pesakit mengikut Thalasemia Registry adalah 812 pesakit.

Peranan jururawat dalam menguruskan pesakit Thalasemia di sana adalah

- Memastikan pesakit mengambil ubat kelasi dengan betul
- Memberi motivasi berkaitan dengan penyakit
- Sokongan social dan bantuan keewangan
- Pendidikan kesihatan dan pembelajaran berterusan

Pihak hospital juga berkerjasama dengan JKN Sabah untuk memberi input terkini dan menjadi pusat latihan untuk doctor,jururawat sekitar daerah negeri Sabah.

Mereka juga ada menghasilkan borang untuk kes baru thalassemia dan borang pemberitahuan kematian melibatkan kes thalassemia.

Di samping itu, pihak hospital juga bekerjasam dengan Persatuan Thalasemia Sabah, dan juga NGO yang lain.

PRE-IMPLANTATION GENETIC DISORDER DIAGNOSIS (GIGD) IN THALASSAEMIA (DR WONG PAK SENG)

Pre-implantation Genetic Diagnosis (PIGD) is an alternative to prenatal diagnosis that provides couples the opportunity to start a pregnancy with an unaffected fetus.

The objective of this study was to develop and use a single-cell, sensitive and accurate PCR protocol for PGD beta-thalassemia and Down Syndrome detection. Two couples carrying beta-thalassemia codon41-42 mutations underwent routine IVF procedures.

Embryo biopsy was performed on 3-day working days and single-cell dual fluorescence PCR was used for the analysis of mutations, detection of contamination and trisomy diagnosis of 21 cases.

Seventeen embryos were tested in two clinical PIGD cycles. This resulted in the first birth after PIGD for a single gene disorder in Thailand and Southeast Asia, confirmed by prenatal testing. Two embryos were found to be affected by Down's syndrome. Successful strategies for PIGD beta-thalassemia and Down Syndrome detection using fluorescent multiplex PCR have been introduced.

IRON CHELATION IN THALASSAEMIA (TDT & NTDT) (DR ZULAIHA MUDA)

Each unit of transfused red blood cells contains approximately 200 mg of iron. In addition, anemia and erythropoiesis do not effectively reduce hepcidin synthesis.

The purpose of iron chelation is to prevent the complications of iron overload such as heart and liver function. Chelation therapy significantly improves T2 myocardium * (magnetic resonance technique to assess tissue iron concentration) and left ventricular function.

Aims of iron chelation therapy

- Maintenance Therapy
Serum ferritin and liver overload are in optimal range
Chelation is needed only to remove iron that is added with each transfusion.

- Reduction therapy
Serum ferritin and liver iron are elevated and/ or cardiac iron overload is detected.

- Rescue therapy
Critical organs are failing or at imminent risk or failure.
High dose chelation is needed to rapidly lower iron burden and remove iron added with each transfusion + provide continuous protection off the organs from label plasma iron.

Takeaway Note
Individualized dosing increase treatment success

- Tailoring chelator dose to patient need increase probability of treatment success
- Adjustment maybe made to chelator choice, dose or mode of administration
- Dose should be adjusted based on :
  - Rate of transfusion iron intake
  - Therapeutic goals
  - Iron parameters (serum ferritin trends, changes in LIC and myocardial T2*)
  - Adverse events

ENDROCRINE COMPLICATIONS IN THALASSAEMIA (PROF WU LU LING)

Endocrine complications, growth and pubertal delay are common manifestation of iron overloading in thalassemia and carry significant morbidity. As such, patients with thalassemia need regular monitoring for signs and symptoms of endocrine complications.

Preventation remains the first priority, and there are limited data to support a role for chelation therapy in this.

Once endocrine complications have developed, management should focus on halting the progression of such complications and treating associated symptoms.

NOVEL TREATMENT IN THALASSAEMIA (PROF VIP VIPRAKASIT)

DEFARASIROX FOR CHRONIC IRON OVERLOAD: INTRODUCING EXJADE FILM-COATEDTABLETS

Implications for the management of patient

DFX FCT offers patients an improved formulations that does not require administration in a fasting state and has better palatability.

Enhanced patient satisfication with the new DFX FCT formulation may improved adherence, thereby reducing iron overload related complications.

Longer follow up to determine the impact on iron chelation of DFX FCT on treatment outcomes is warranted.

Ruxolitinib Conclusion

In addition to a noticeable reduction in spleen volume over time with ruxolitinib treatment, a trend for improvement in transfused red cells and a slight improvement in pre transfusion hemoglobin was noted with ruxolitinib treatment.

A majority of patients continued with the treatment beyond the core study.

Ruxolitinib was well tolerated in the study population with modest incidence grade 3 or 4 and serious AEs, with no new safety findings.

Given the sustained decrease in spleen volume, ruxolitinib treatment may be an alternative option in patients with TDT who are potential candidates for splenectomy.

MRI T2* IN THALASSAEMIA
(DR HAFIZ GIT KIM ANN)

Cardiac T2* magnetic resonance identifies patients at high risk of heart failure and arrhythmia from myocardial siderosis in thalassemia major and is superior to serum ferritin and liver iron.

Using cardiac T2* for the early identification and treatment of patients at risk is a logical means of reducing the high burden of cardiac mortality in myocardial siderosis.

Quantification of iron overload
- Blood Test
- Iron – paramagnetic effect – shortening T1 & T 2
- Signal

TRANSITIONING TO ADULT CARE
(DATO DR GOH AI SIM)

ADULT SETTING
Doctors are trained in adult medicine and adult health issues
Staff communicate directly with patients promoting self care, decision making and independence
In-patient admission easier.

HOW TO FACILITATE TRANSITION
- Ideally combined transition clinic (adult hematologist and peads)
- Seamless transition protocols and care pathways
- Medical summary including any complications, medications and test
- Closely monitor and feedback to each other to ensure patients are cop well and compliance to treatment and appointments
- Back-up transfusion slots at pediatric Unit during transition phase.

DAY 2 (5th MAY 2019)

HSCT IN THALASSAEMIA
(DR IDA SHAHNAZ)

The only radical cure for homozygous thalassemia is to transplant bone marrow from an HLA-identical donor who is normal or heterozygous for thalassemia, which is capable of producing and maintaining a normal hemoglobin level in the recipient.

All thalassemic patients, together with their parents and siblings, should be HLA typed for this purpose. When an HLA donor is available, we believe that bone marrow transplantation is mandatory in thalassemic patients of class 1 and 2, as well as for those of class 3 who are aged <17 yr; adult patients should also be offered this possibility of a cure, but 30% will die of transplant-related mortality.

Patients without matched family or unrelated donors could benefit from haploidentical mother-to-child transplantation, which has shown encouraging results, although it is still in the experimental phase.

A high cure rate has also been achieved by performing HSCT on children with SCA following current myeloablative conditioning protocols. Again, we think that HLA typing should be performed for all family members of an SCA child.

If a genotypically identical sibling or phenotypically identical parent is identified, hematopoietic stem cell transplantation should be performed in all SCA patients aged <17 yr, before the major complications of the disease affect the child.

The novel non-myeloablative transplantation protocol for SCD patients could serve as a platform for its wide application, not only in adults but also in high-risk pediatric patients with SCD.

SHOULD UMBILICAL CORD BLOOD BE KEPT IN SIBLINGS OF THALASSAEMIA PATIENTS
- Prenatal diagnosis required as potential sibling may have disease
- Still needs siblings to be HLA matched
- If siblings is alive, sibling's bone marrow is preferred over stored cord blood
- Risk of rejection / non engraftment is higher with cord blood

TCR ALPHA BETA DEPLETED TRANSPLANTS IN THALASSEMIA (DR SUNIL BHAT)

HAPLO – IDENTICAL HSCT

ADVANTAGES
- Immediate donor availability
- For every child, both parents can serve as donor
- For older patients - 80%-90% chance that either siblings, parents or childrens will be haplo-identical
- Donor available for second graft if required
- Donor available for DLI / immunophenotherapy
- Potential less expensive

MAJOR OBSTACLES
- Trasplant across HLA barriers
- Graft rejection
- Graft Vs Host Disease
- Blunted GVL and increased relapse risk
- Slower immune recovery
- Increased infection risk

Conclusion
- Haplo SCT with Cy Post – transplant is feasible and gives the favorable outcome for hemoglobinopathies.
- All thalassemia patiens should be considered for HSCT. (No matter what age of patient or type of donor)
- The only major morbidity is hemorrhagic cystitis
- HSCT in any aspect is personalized medicine
- Gene therapy in hemoglobinopathies is practical now and will be for a clinical use soon
- Health economic questions (cost effective and cost utility) are needed

Novel therapist Vs HSCT Vs Gene Therapy

QUALITY OF LIFE IN THALASSEMIA (PROF ASRUL AKMAL SHAFIE)

More patients reported problems on the pain / discomfort and the anxiety / depression domains compared to the mobility, self care and usual activity domains.

Improved centre efficiency to reduce productivity losses and transportation cost of TDT patient and family

Review resource allocation especially at remote area.

Measuring the quality of life and economic impact of TDT patients is important to understand their needs and implications beyond the clinical parameters.

The forum ends at 2 pm

25th THALASSAEMIA CAMP 2019

Rainbow Paradise Beach Resort, Tanjung Bungah Penang
12 October 2019 - 13 October 2019

reported by
Sn Elliyana Tajidin

I would like to thank Thalassaemia Society Penang for the opportunity to share Thalassaemia activity in Penang. 25TH Thalassaemia Camp 2019 was held at Rainbow Paradise Beach Resort Tanjung Bungah Penang on 12.10.2019 untill 13.10.2019.

The Camp organized by Thalassaemia Society Penang in collaboration with Paediatric Department Penang Hospital. The participants are about 127 includes health care, Thalassaemia patients and family members. Our camp mission this year was "Growing up well together with thalassaemia".

Day 1 (12.10.2019)

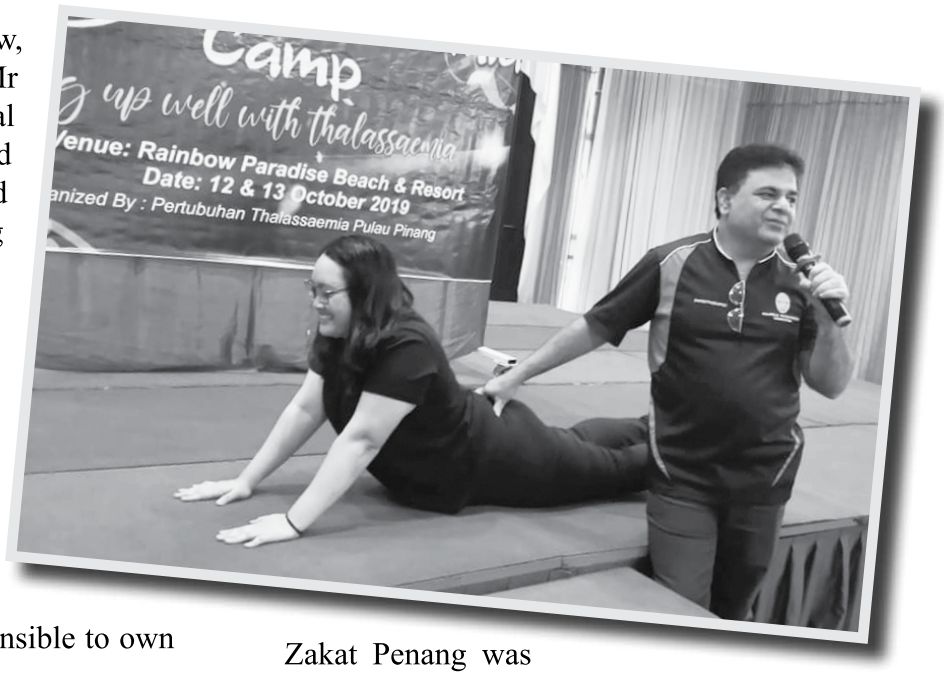
The camp began with welcoming speech from Pn Noorasykin Bt Md Saad, the President of Thalassaemia Society Penang. She also thanked all thalasaemics, family and those who have been working hand in hand, supporting thalasaemics to better improve in living with thalasaemia. On behalf of Thalassaemia society she also thanked and welcomed all speakers for their support and sharing of experiences in this camp.

Our camp begin with 1st topic Back to Basic given by Dr Angeline Yeoh Paediatric Consultant Hospital Seberang Jaya. She explained about optimising thalassaemia care in healthcare perspectives.

Iron overload, the unwanted damage it does and chelation by Dr Shoba Anne Thomos Pediatric Specialist Oncology/Hematology Penang Hospital. In this session Dr Shoba explained the cause of iron overload, then summarized the indication of iron chelation therapy as recommended in guideline.

Dr Hafiz Git, Radiologist from Hospital Selayang explained about various methods to measure iron overload in thalassaemic patients: serum ferritin, tissue sampling and T2* MRI. Statistics had shown that usage of MRI T2* closely resembling tissue biopsy result, proving its benefits as non-invasive and sensitive tool. He explained about normal iron loading in human cells and iron overload tend to deposit in various organs including heart, pituitary, endocrine, liver and pancreas. Benefits of MRI T2* include no X-ray will be taken, no fasting, sedation or contrast needed. Whole procedure will only take place about 10 minutes. Data interpretation on the report was discussed. Lastly, he concluded that MRI T2* will be a good method of investigation as MRI facilities will be soon available in most hospitals with both commercial or open-source software installed.

Keeping fit for a better tomorrow, the importance of exercise slide by Mr Raspal Physiotherapist Penang hospital and followed by stretching activity lead by Physiotherapist teams. Patients and family members enjoyed the stretching movement and they understood the importance of keeping fit.



Transition of care from Paediatrics to Adult slides was presented by Sn Elliyana bt Tajidin. In a nutshell, successful transition of care involves multidisciplinary team. As Healthcare professional we work hand in hand with both family and child in preparing the child to be responsible to own care.

Zakat Penang was invited to brief us regarding procedure and criteria to apply for assistance among muslim Thalassaemia patients.

E.g.:- Financial and Machine

Sharing session is valuable moment for this camp. Where healthcare provider can identify their problem. The patients and family member also can shared about their experience and knowledge about Thalassaemia.

Hand on session led by Doctor and Nurses. The nurse demonstrated on reconstitutes of desferal and self infusion of desferal was taught to patients. That session also have open-ended question. Patients was enjoyed.

Day 2 activity (13.10.2019)

Our second day activities were interactive, practical and enjoyable. Participants were grouped and were actively involved in role play, quiz as well as games. They had shown good level of knowledge and management of Thalassaemia, from lectures they had attended in this programme.

At the end of session, the organiser thanked all patients and family members who came to provide useful feedback and addressed suggestions to improve the services for thalassaemia.

The camp concluded at about 13.00.

HAPPENINGS 2019

2019 Blood DONATION

To all our blood donors...

THANK YOU

30th Annual General Meeting

Thalassaemia **Workshop**

World Thalassaemia Day at Penang General Hospital

World Thalassaemia Day 2019

World Thalassaemia Day at Seberang Jaya Hospital

Paeds Thals Workshop

Penang General Hospital

LET'S WALK FOR Thalassaemia 2019

Thalassaemia Public Awareness at IPG

Hari Raya Open House

Report on
1st National Thalassaemia Conference for Thalassaemia and Carers

Laporan oleh Noorasyikin Md Saad

Pada 14 & 15 September 2019 yang lalu, saya bersama Mizal dan Nur Hazwani telah menghadiri satu persidangan Thalassaemia, iaitu, "1st National Thalassaemia Conference for Thalassaemia and Carers" dengan tema "EMPOWERMENT THROUGH KNOWLEDGE". Persidangan tersebut telah diadakan di The Klagan Regency Hotel, Kota Kinabalu, Sabah. Persidadangan tersebut telah dianjurkan oleh Persekutuan Pertubuhan Thalassaemia Malaysia dan dihoskan oleh Persatuan Thalassaemia Sabah.

With Mdm Khoo (2nd left), the president of PPTM

Kami tiba di Kota Kinabalu sehari sebelum hari Conference. Setibanya di KK, kami menghadiri mesyuarat Persekutuan Pertubuhan Thalassaemia Malaysia (Federation). Setelah selesai mesyuarat, kami pulang ke hotel.

Registration day

Hari pertama Conference bermula jam 8 pagi. Kami bertemu ramai rakan-rakan seperjuangan Thalassaemia dari seluruh negeri. Kami bertanya khabar masing-masing dan kerinduan sedikit terubat. Selain peserta dari Malaysia, peserta dari luar negara seperti Indonesia, UK, Philippines, Singapore dan Thailand juga hadir.

George Constantinuou from the UK

Hari pertama dan kedua Conference, pelbagai topik telah dikongsikan oleh doktor-doktor pakar dari dalam dan luar negara. Selain dari pembentangan oleh doktor-doktor, kami juga berpeluang bertemu dengan Thalassaemic dari luar negara yang berkongsi pengalaman dengan kami semua. Kami juga bertemu George Constantinuou, thalassaemic dari UK yang tidak asing lagi dengan kawan-kawan di Pulau Pinang. Banyak ilmu dan maklumat yang kami perolehi sepanjang Conference.

Pada malam hari pertama, kami telah menghadiri majlis makan malam yang istimewa yang telah dihadiri oleh YB Timbalan Menteri Kesihatan, Dr Lee Boon Chye. Pada malam tersebut, saya, Mizal dan Hazwani telah berpeluang untuk memakai pakaian tradisional dari negeri Sabah. Terima kasih buat kawan-kawan Sabah yang meminjamkan pakaian cantik kepada kami. Kami kelihatan sangat cantik dan kacak pada malam itu.

Sabah traditional attire

Setelah tamat Conference, kami meluangkan masa berjalan-jalan di negeri Sabah. Kami menyewa home stay bersama kawan-kawan di Kundasang dan berpeluang menikmati suasana yang sangat istimewa di kaki Gunung Kinabalu. Kami juga melawati tempat-tempat yang cantik dan menarik di sana.

Jutaan terima kasih kepada Pertubuhan Thalassaemia Pulau Pinang kerana memberi peluang kepada kami bertiga untuk menghadiri Conference ini. Kenangan ini tidak akan kami lupakan.

Conference ini telah disokong oleh TIF.

Jangan pernah bagi alasan untuk berjaya.

Assalamualaikum hampa. Saya ***Nur Alifah Ilyana***. Sebagai pesakit talasseamia, kita perlu kuat untuk menghadapi segala cabaran. Selagi kita bernama manusia, kita takkan pernah berhenti diduga.

Walaupun dalam keadaan saya seperti ini sekarang, saya tetap membuat business sebab menjadi seorang ahli perniagaan yang berjaya adalah cita-cita saya. Kita tak boleh lemah atau menunjukkan yang kita sakit dan tak boleh buat apa seperti orang normal boleh buat. Kita juga boleh buat.

Walaupun kita seorang thalaseamic, jangan bagi alasan. Kita perlu kuat semangat dan jangan pernah putus asa. Jangan pernah kita putus asa atau malas. Jangan pernah bagi alasan untuk berjaya.

– Nur Alifah Ilyana

Saya telah berjaya mendapat banyak informasi mengenai talasemia.

Saya berasal dari Kedah dan semasa mendapati rawatan di Baling, saya tidak sedar adanya pertubuhan yang membantu para pesakit talasemia.

Sejak berpindah ke Pulau Pinang dan menerima rawatan di Hospital Seberang Jaya, saya telah menjadi ahli Pertubuhan Talasemia Pulau Pinang dan mengambil bahagian dalam aktiviti-aktiviti yang dianjurkan oleh Pertubuhan. Penyertaan ini sangat berhasil dan saya telah berjaya mendapat banyak informasi mengenai talasemia. Saya dapat berkongsi pengalaman dan matlumat dengan rakan-rakan seperjuangan saya. Di samping itu, saya juga dapat merasai banyak kemudahan-kemudahan di hospital mahupun dalam pembelian ubat atau vitamin serta peralatan talasemia, contohnya pam desferal, melalui Pertubuhan.

Saya amat berterima kasih kepada Pertubuhan atas bantuan yang telah dan akan diberi kepada saya.

– Marwadi

Congratulations

for the **BIRTH** of

Muhammad Azfar Fayyadh

to
Mr & Mrs Azwan Faizal bin Azhar

Qaseh Medina Binti Mohammad Khairul Annuar

to
Mr & Mrs Mohammad Khairul Annuar

NEWLY WED COUPLES

Faiz Jamaludin
weds
Hazwani binti Mohd Fazil
2 March 2019

Nurul Hidayah
weds
Muhammad Hazim
20 October 2019

Announcement 2020

Dear ahli-ahli,

Kindly take note, all events of Penang Thalassaemia Society has been postponed due to Covid 19 till further notice.

We will update once we have dates from MBPP, doctors and ROS.

If you need further clarifications, please call office 04 2272133 or 0164216839

Thank you.

Penang Thalassaemia Society

Dear friends / Supporters,

Pulau Pinang Thalassaemia society needs your generosity to continue funding our society's yearly activities which we organise Public Awareness, Workshops for health personnel/patients, Camp for patients and, if and when medication is needed for them.

****All donation will be tax exempted.****

Cheque issued to
' PERTUBUHAN THALASSAEMIA PULAU PINANG

Direct Bank - in PUBLIC BANK BHD - 3097195032

Kindly email/fax the bank-in slip to -
email : penthal88@yahoo.com

Tel/Fax : 042272133

Please call office for further enquiries : 04 2272133

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Penang Office Hours

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

Seberang Jaya Office Hours
Monday to Friday: **8.00am-4.00pm**
Contact: Puan Azemah
H/P: 012-555 1667