APRIL 2015 ISSUE # 21

THALWATCH

BEYOND THALASSAEMIA

THE OFFICIAL NEWSLETTER OF THE THALASSAEMIA SOCIETY OF PENANG

A HISTORIC CLIMB

Penang Thalassaemia Kinabalu Challenge

30 August ~ 2 September 2015

SEE YOU AT THE TOP!!

Message from Mdm. Khoo Swee Hong

Unbelievably I realised that I have spent more than half my lifespan immersed in the world of thalassaemia. And how different the scenario is nowadays. The outlooks for thalassaemics are no longer negative. We are no longer struggling to keep them alive. Now it's to enable them to LIVE. With correct care and management our thalassaemics have flourished. Unfortunately, the public perceptions of thalassaemia have not kept pace. The Society will have to work on this and focus on how to improve public knowledge on thalassaemia. However, first of all, WE ourselves must not be ashamed and hide our status. The uniqueness of thalassaemia is it is a non-fatal condition. Hospital visits are to manage and maintain the thalassaemics and to prevent them from getting sick. Unlike other medical conditions, thalassaemics are unlikely to suddenly collapse. It is no longer acceptable for thalassaemics to not survive if we work together with our medical team. Let's all work towards public awareness to celebrate World Thalassaemia Day, May 9th.

At our camps, I can no longer differentiate thalassaemics from non-thalassaemics. In fact, at the last National Thalassaemia Seminar in Kota Kinabalu, our adult thalassaemics were mistaken for nurses when the approaches our Deputy Health Minister to request for NAT blood and out of hours transfusion. And I also realise that children's activities at camps are no longer for thalassaemics alone, but now includes the children of thalassaemics.

2015 is already packed with activities. Our camp will be in November 14th & 15th. We have been invited by Dato Dr Soo Thean Lian to send 2 transfusion dependent thalassaemics to join them climb Mt Kinabalu from Aug 30th to 3rd Sept. Potential candidates approved by our doctors have started weekly training under Daniel Soo. Our heartfelt gratitude to him for agreeing to our request.

Thalassaemia International Federation has announced that the 2nd Pan Asian Conference on Thalassaemia will be held in Hanoi in September.

And of course we have our Annual General Meeting in May.

Last but not least, members must take the initiative of contacting our office for information on activities and etc. We have received the timeless complaints of not being informed when most of the time members changed their address and contact numbers but did not inform the Society. Do realise that we can put food in your mouth, but you have to swallow it yourself.

See you.

Activities

Thalassaemia Workshops

25th AGM


Pertubuhan Thalassaemia
Pulau Pinang
Mesyuarat Agung Tahunan
Yang Ke25 Tahun 2015
Pada: 01 Mei 2015 Masa: 9.00 Pagi
Tempat: Di Kompleks Masyarakat Penyayang,
Jalan Utama, 10450 Pulau Pinang


Mesyuarat Agung Tahunan

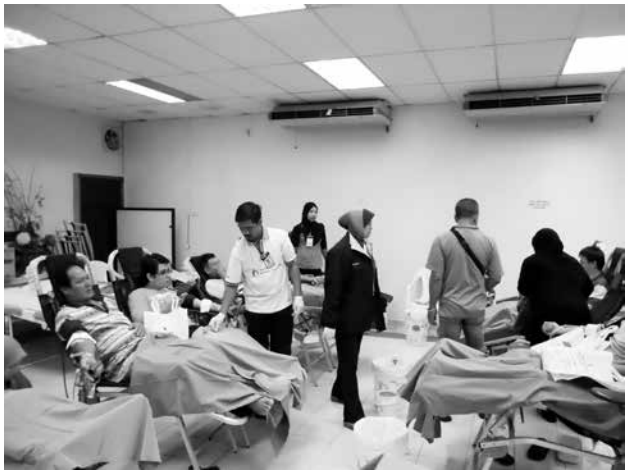

Mesyuarat Agung Tahunan


Apple


TH
25 AGM
Pertubuhan Thalassaemia
Pulau Pinang


POLO JEAN
COMPANY

Blood DONATION



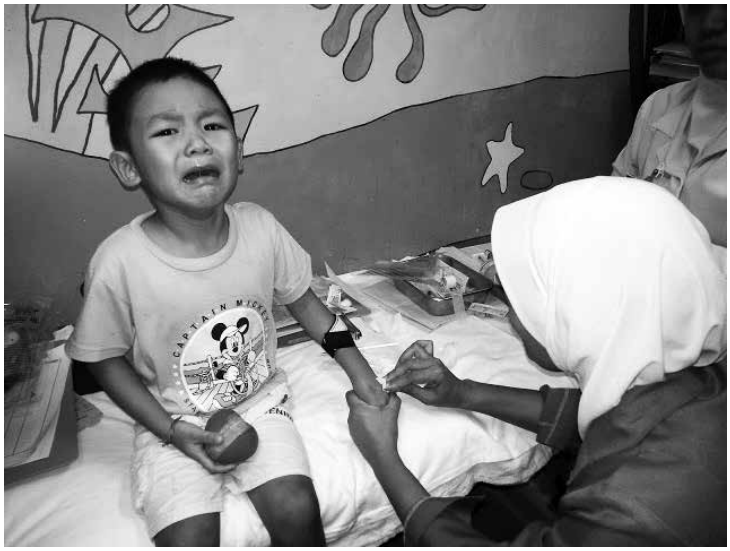
Lee Association,
Butterworth
Blood Donation Campaign

Activities

Thalassaemia Camp

Seberang jaya hospital Radiologists with Dr Tan Ru San (NHCS)

Our Young Thals in Action

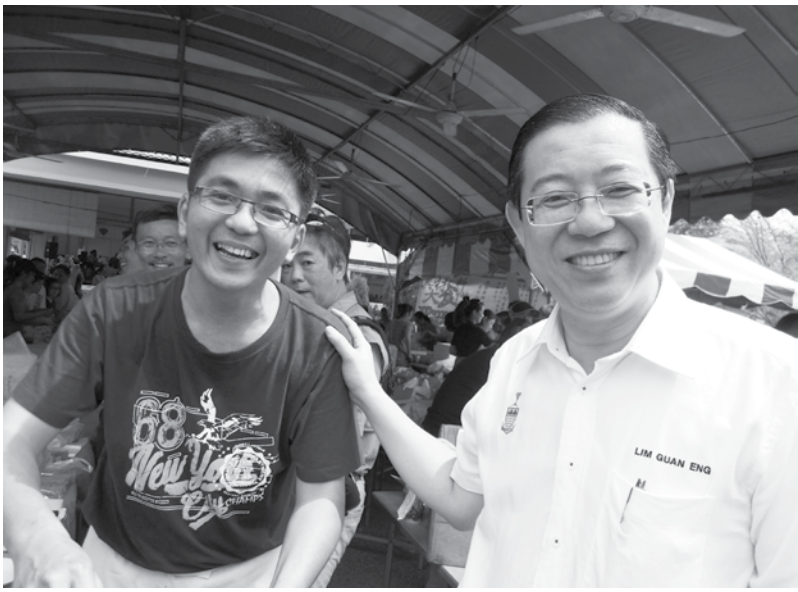


Activities

Chinese New Year Gathering

Activities

Sungai Jubilee Charity Food Fair



Oat King Forward Sports Run

USM Community Services

20th Thalassaemia Camp 2014 : "Back to Basics"

Sunway Hotel, Seberang Jaya

Day 1. 20th September (Saturday)

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

Registration of participants began at 8.00 am. A total of 204 participants attended the camp. Breakdown of participants from Penang and Seberang Jaya were as follows:

Thalassaemics	Parents	Nurses	Doctors / Speakers	Volunteers	Staff	Total
63	36	37	9	23	2	**170**

Participants from other states include:

Kuala Lumpur	Perak (Ipoh)	Melaka	Sarawak	Total
6	24	2	2	**34**

The camp kicked off with Mdm Tan Peck Chin, the Camp Co-ordinator, very proudly brief the participants that the 1st camp was in 1996, in a school, and today we are in the 20th camp. We are fortunate that able to hold it in a 4-star Hotel, with better facilities and environment for learning and get together.

Mdm Tan also mentioned that for this year the camp is not only attended by participants from Penang and Seberang Jaya, also participants far from Kuala Lumpur, Melaka, Sarawak and Perak

0900. **Welcome address. By the Society President** *(Ms Janice Kua)*

The President welcomed all participants, especially those from far away, joining this yearly meeting to support each other. She encouraged the participants to learn from each others to better improve in living with thalasaemia. She also thanks those who have been sporting the society and thalasaemics.

0907. **Over view of Thal in Seberang Jaya** *(Dr Angeline Yeoh Aing Chiee)*

Dr Angeline (Pediatrician from Hospital Seberang Jaya) began by thanks the society to invite her for the talk and give a warm welcome to everyone. She further thanks the members from Seberang Jaya in working together to make this camp a success even with limited experiences.

Dr Angline gave an over view of what is Thalassaemia and statistic of cases in Penang. Her focus was on the incidence in Penang especially cases in Hospital Seberang Jaya. Dr Angeline highlighted to the participants that the challenges in treating thalasaemics are varies, from issues of infrastructure to patients belief and cultural practices. Dr Angeline urged the patients and family members to play an active role in their treatment and reminded everybody the important of team work and effective interaction with each others.

Q A Answering to Dr Goh's question on statistic on new birth, Dr Angeline mentioned that the finding of 1 case per-year was under reporting by the registry. She estimated to have 2-3 new cases per-year.

Dr Angeline further answered to Ms Janice by telling that from the statistic there is a lot of cases default treatment. She mentioned the medical staff had been trying their very best to encourage treatment and follow-up, but she believed it was the mindset of the patient leak to low compliance. Some feel well, so no need further treatment and they have their right to accept or refuse treatment. Some even question the treatment on the religious point of view. Ms Janice suggested: to have a hot line or to form support group from patients and family members to support them in the hospital. (Further action by the society)

Mr Chin Yoon Fook (Ipoh) asking if there is any possibility to reinforce treatment with the law. Dr Angeline is aware that in Ipoh the law under Child Act is used. This enforcement needs support from Jab Kebajikan Masyarakat and police, and is not happened in Penang.

0940. **Sharing from Patients — Blood transfusion/6 monthly tests** *(Sazana Bt Don)*

Pn Sazana, the committee member of society, is a mother and patient with β-thal is sharing her experience in blood transfusion.

Pn Sazana began by thanks all present. She shared her understanding on blood transfusion and encourages thalassaemics to compliance to the procedure and practice. She highlighted the important of patient cooperation in the treatment.

Dr Goh thanks Sazana for the sharing. Dr Goh commented that the formula in this sharing is only for β-thal major and E/β thal.

Record keeping *(Slide by Munir Bin Md Noor, brief by Mdm Tan Peck Chin)*

As Pn Murni absent due to unforeseen circumstances, Mdm Tan Peck Chin helped to brief the participants on the important of record keeping for thal patients. The patients will be given a 'Patient Record Booklet'. Patients need to carry this booklet wherever they go. The patients need to record their 6 monthly blood test result, record of Deferasirox chelating as well as the S/E of the chelation e.g. itchiness and any treatment.

Q A Ms Ooi Ee Ee aksed: What the nurses need to do if the patient didn't bring the booklet? Do the nurses aware that the patients need to keep a record?

S/N : All HPP patients use this booklet and the doctors and nurses will make the record for patients every visit. The Housemen will do the monitoring.

Mdm Tan Peck Chin: The Hospital Seberang Jaya is not using this booklet. She makes own record for her children. The hospital will keep the patient's progress record in the hospital.

Dr Goh mentioned: in HPP, the housemen need to monitor and alert the medical officer and pediatrician if there is any abnormality. The advice is it is very important the patients have their own record and aware about their own progress and any complication, when to go for assessment and treatment.

1010. Iron Chelators *(Dr Goh Ai Sim)*

Dr Goh stated and reminded the Important of iron chelation. She enforced that the patient life span depends on the ability and effectiveness of the iron chelation. Patients need to know the drug well.

In this session, Dr Goh informed the participants on treatment aims, monitoring the side effect of the drug, and the management of the side effect. Dr Goh also highlighted the procedure of chelation during pregnancy.

Participant Mizan asked: As there is combination treatment of deferral and L1, is there any combination with Exjade? Dr Goh informed that Exjade is only used as mono-therapy.

1135. Emerging Problems in the Adult Thalassaemics. *(Dr Farrukh Shah)*

In UK, many thal patients are in their 50. Thus, it is needed to look at their wellness as they are able to live longer. Dr Farrukh mentioned that the thalassaemics are able to live well with effective chelation.

Challenges

- Transition from pediatric care to adult care: more independence of thought and care and taking responsibility on own health problems.
- The patients are expected to know about their own progress include blood result and treatment. By that they are able to control their own treatment.
- With good treatment and care they are financially independent and should be able to have their own family and achieve everything as their sibling able to do
- Rebellion and poor compliance become major issues – to manage the 'why me' is the biggest challenge that need to manage to allow good treatment. The clinical psychologist work together to help the patients and family to manage themselves to enable them to live as normal live.
- Help to keep the patients with a full time job, the health care setting arrange a flexible health service, e.g. out of hours cross match, weekend transfusion etc.

Dr Farruth shares some data on the benefit of compliance to chelation and treatment.

There are decreased in cardiac issues but increased in liver complications due to damage done many years ago and maybe related to hepatitis B or C. Patients who are infected with Hep B or C are more likely to develop liver fibrosis. Thus, it is very important to prevent iron overloading.

The longer the patient lives, the risk of liver cancer become more common. Thus there is a need for the patient to do liver monitoring twice a year for early detect and treatment of liver cancer.

Complication of endocrine system is another issue due to leak of proper care during younger adulthood. If the chelation started late (e.g. about 16 year-old +++) complication e.g diabetes mellitus become more common.

Patient with splenectomy done need to keep Hb higher than 10g/dl to prevent pulmonary hypertension. This is a complication that is very difficult to treat and the patient may need heart and lung transplant.

As the patient's age increase, risk of osteoporosis is increasing. Osteoporosis is difficult to treat and may need hormone replacement therapy. The patient may have degenerative spine and leak to more other challenges.

As age increase the renal function decreased. The question is whether the thal patient facing the same issue? The study shows that renal damage found in the thal patient as age increased.

Dr Goh informed that in Malaysia, the hospital policy restrict the blood transfusion over night. In UK, Dr Farrukh said, they try to transfuse during working hour to reduce risk and problem of transfusion. Basically thal patient are more tolerance to blood transfusion, thus the transfusion may be done off office hours If needed.

1223. **Blood-From Donor to Patient.** *(Dr Tuan Hulwani bt Mohamed)*

Dr Tuan Hulwani started by thanks the society to work hard to get fund from the government to give free chelation for patients.

In this session, Dr Tuan Hulwani shared the information on the aims of blood transfusion for thal patients, blood and blood component, the process of blood donation, and the blood transfusion procedure. He also shared the possible transfusion reaction and the management if occurred.

1250. **Preparing for T2*.** *(Dr Mahedzan Mat Rabi)*

MRT2*

Dr Mahedzan mentioned that MRT2* examination only done in Hospital Seberang Jaya, and covered for patients from Kedah and Perak. This examination is done to identify myocardial loading and hepatic loading in order to plan appropriate treatment for patient. Pre-examination, the patient will be assessed with a checklist – to make sure no metal in the body, and other items that may burn the patient during the process. He further informed that if any metal stick to the machine, the machine need to shut down MRI and cost RM20000.

Answer to Dr Goh's question on if patient wearing braces, can the patient proceed with this examination? The answer is as long as is MRI compatible, can. The patient may feel the heat and burning if it no compatible.

1400. **The Thalassaemias.** *(Penang Medical College Students)*
Quiz and discussions

The thalassaemics were divided into different age group. The Penang Medical College Students facilitated the groups to discuss some questions to enhance their understanding and encourage positive attitude towards their living and treatment. The group then presented their outcome of the discussion.

Group 1 : (below 6 year-old)
The presentation showed that the children in this age-group have basic understanding of what is blood and basic knowledge on low Hb.

Group 2 : (7-12 year-old)
This group of children aware that theThal would not affect their IQ. They also have basic knowledge on blood group, effect of low Hb and the important of blood transfusion and chelation.

Group 3 : Perak (13 – 16 year-old)
This group of participants aware that is important for them to know their own blood result. With this, they can evaluate their health condition and able to control their ferritin level and get effective treatment.

Group 4 : (17 above)
The participants understand that thal is not a communicable disease but is hereditary. They also aware that it is important to keep a good ferritin level to prevent internal organ damage.

The other group mentioned that the live expectancy of the thal is determined by god and affect by diseases. The live span is short due to no motivation to know what is happening, complication and the effect of the disease. Thus, the thal need to have motivation to take care of self and get treatment as advice by the doctor.

Miza
Screening for the family is important to know that the partner is normal or not. With this action can be taken to prevent the next generation with thal.

Sazana
Even though is not easy for the thal to get a job as they need to have frequent follow up and blood transfusion. However, with proper planning, it is not an excuse not to get a stable job.

1432. Non Transfusion Dependent Thal. (NTDT) *(Prof Vip Viprakasit)*

Prof Vip thanks the society to invite him for the talk again this year. With refer to the Clinical Practice Guideline, Prof Vip sharing the information of NTDT. He discussed on definition, types and classification of thalassaemia. He further discussed the definition of NTDT, iron overload in NTDT, diagnosis and management of NTDT.

Prof Vip explain that NTDT patient who need regular transfusion will not consider as TDT. Normally there is an indication for NTDT patient to receive regular transfusion and is reversible. Thus, still consider NTDT.

1521. Equitable (saksama) care for all — The Thai experience. *(Prof Vip Viprakasit)*

Prof Vip shared the equitable care in his clinic.

Fetus
Prof need stated that his work started during pregnancy. Screening will be done to detect the child phenotype. Blood transfusion will be done for the fetus if needed.

Baby
Prof Vip shared his experience dealing with as anemic baby who has HbE/ β thal with AIHA. The baby was treated with steroid and managed well.

Child (2-10 year-old)
Principles :
- treat the thal to prevent iron overload
- management also focus on the psychological and physical growth and sexual development

Adolescent

Principles

- compliance / adherence drop due to rebellion
- transition of care

Management :

- iron chelation amount must be adjusted to maintain the same dose as weight changes.
- endocrine problems are common in TDT and may need treatment by endocrinologist

Prof Vip shared a few cases benefit from adequate blood transfusion and iron chelation. Prof also shared cases that not doing well due to inadequate treatment.

Adult

- treat and prevent other complication related to degeneration and complication of treatment

Answer to Dr God : if the patient only transfuse because of cosmetic surgery, transfusion may stop after the surgery.

The UK experience. *(Dr Farrukh Shah)*

- Collaboration work by the nurses, doctor, patients, family and others with the aims to allow normal live in thal.
- The patients should get same and equal treatment in London and Manchester.
- Services delivered according to patients needs, and the transfusion will not affect the children's activities. E.g. weekend transfusion, monthly party etc. done by the nurses, patient and parents.
- The management and care will be succeed with full support. Patients, parents, health care workers form support group and motivate those facing challenges to go to university, work etc.
- Team work is very important.

1830. **My pump My best friend**

Only 2 participants involved in the SC Chelation, they are:

1. Ain Zaharah, 14 years-old, from Penang
2. Sucithra Mae, 14 years-old, from Seberang Jaya

One observer, Tan Siew Year, 4 years-old.

Day Two. 21st September (Sunday)

0839. T2*- what is it and Why? *(Dr Tan Ru San)*

Dr Tan informed the participants contraindications, indications, preparation and the procedure of MRT2*.

Dr Tan mentioned that patient may need sedation if the patient has phobia. MRI may not harm fetus, however is not encourage unless is indicated. Whatever is stable in the body, e.g. tattoos, implants etc and will not move or interfere with the process. However if is near to the heart, it may cause he image to be less sharpness. The patient may feel warm at the particular area.

In Dr Tan's practice, the MRIT2* examination does not need special preparation. The staff will monitor the patient from outside all the time. Can inform the staff if any problems. Do not worry.

Dr Tan was sharing a few slides showing the iron and heart overload. Dr Tan also shared the method to do the measurement. AS the level of the iron increased, the image becomes darker.

Patients with < 10 ms have the higher risk of heart failure, >80ms have the low risk, and >10 - <80 ms have intermediate risk. As patient with < 10ms has very high risk of heart failure. Thus, it is important to remove the iron to > 20 ms to reduce the risk of heart failure and prolong live. (refer Dr Tan's slide)

Ms Ooi Ee Ee: At what age do the patient need to go for T2* scan? – normally about 10 y-o. Sometime may need earlier. If no chelation done, the assessment may need as soon as 2 year-old. Repeat yearly. If any changes in the regime, may need to re-assess 6 months.

Participant from Ipoh : Any side effect from MRI scan? No so far. Why after chelation the iron still high? During chelation, the blood transfusion still proceeds. Thus, the iron still continues to accumulate.

MRIT2* is free in Malaysia. In Singapore is SD 600. The outcome of this procedure is the same either in Malaysia or in Singapore.

Ms Ooi Ee Ee: As the MRIT2* is so effective, is it possible not to do serum ferritin? Unable to do T2* so often in Malaysia, but serum ferritin can be done more frequent.

0942. Living a Normal Life *(Ms Janice Kua)*

Are you all confident with yourself?

- Self acceptance
- Facing reality
- Self-sustainable
- Getting a job – need to study hard and work hard. Sickness is not the excuse not to go to school
- Commitments and responsibilities – towards self and the duty
- Health managements – thal need to learn to manage own health, need to be aware when to follow up and need for any treatment.
- Knowing my limits - Even there is physical limitation, still need to try to do the best and no excuse if the task is assigned to.

Working Life

- Full-time job – should not give excuse to self. Work hard to prove that she can do the job. If not, may not get a job. Try to take limited medical leave (only if needed) and try to compromise with good arrangement with the health care need.

- Full-time stress – every job there is stress. Learn to tolerate and manage. Mom will only say this is life when she complain.
- Full-time wages – allow her to manage her own living

Managing Treatments
Make sure the treatment do not interfere with her career. Knowing her limit and try the best to manage and arrange.

Nothing is impossible!
Even may not as able as the normal people, but do the best as she can. Believe that you can live as normal as possible.

What is it of me is abnormal?
When asking unable to living as normal life, she will ask her self what is abnormal? She still unable to answer to this question till now. She is aware that she has physical limitation but is not because of thal.

What is the reason normally the patient did not inform the boss about the health issue? Tan Peck Chin informed that there is no column to inform that they are thal during application of job.

1005. **Parenting.** *(Puan Baheyah bt Mohd Jafaar)*

Pn Baheyah is mother to 2 Thal kids.
Pn Baheyah shared her anxiousness and worry when the doctor informed her that her children have thal. She also shared her frustration that the doctor unable to diagnose earlier.

Pn Baheyah feel upset every time looking at her kids getting the treatment but still proceed for the good of the kids. She is trying her very best to make the kids live as normal as possible. Some time feel embarrass to inform the teachers and others her kids condition as many people do not know what is thal. (Refer the notes from Pn Baheyah)

A few participants respond to Dr Goh questions on why some parents scare to be transferred to other hospital to continue treatment?

1. There are a lot of problems in the admission process in Hospital Seberang Jaya. The investigation and treatment in Hospital Kepala Batas very slow.

2. Mdm Tan Peck Chin shared her experience in transferring her son to Klang Hospital for further treatment where her son is study. There will be some differences in the management. Mdm tan stress that it is very important that the patient need to know her own progress and treatment, and need to be firm to request for what is appropriate.

3. A participant shared 2 Scenario 1. One scenario, the patient was treated as outsider and being ignored. The second scenario, the patient was treated well after transfered.

4. Participant from Sabah (Encik Francis): In some hospital, the patient need to wait for months for blood result and treatment. He shared his experience that the delay is related to the attitude of the medical office in the hospital. He concluded that it is all depend on the facilites and system of each individual hospital.

1028. **Patients' Rights and Responsibilities.** *(Mr Doraisingam A/L Rethinam)*

Mr Doraisingam shared the right of patients and ways to know what are their rights. Read and ask is the key to knowledge. With the adequate knowledge self-esteem will improve. He also stress to the participants that is very important need to know their own progress and treatment. He further thanks all the doctors and health care staff to provide efficient and free treatment.

1112. **New Approaches to Management of Thalassaemia.** *(Dr Farrukh Shah)*

Dr Farrukh brief the participant the history of managing thal. Currently there is a possibility to cure thal patient by gene therapy or transplant and other new treatment.

Gene Therapy
It takes about 20 years to understand this treatment and able to do it successfully.
Bone Marrow Transplant (BMT) only able to do for patient with sibling but not for gene therapy as the stem cell was take from the patient.

For gene therapy, some BM and gene will take from the patient to growth the stem cell and improve it to normal stem cells, and then transplant back to the patient.

Dr. Farrukh shared the challenges and 2 successful cases with gene therapy in Paris. The outcomes of the cases prove that this therapy is able to cure thal.

Sotatercep (ACE-011)
A new drugs used to reduce the need of blood transfusion. In the beginning, the medication was given to patient with osteoporosis and was found to cause polycythaemia. Thus, it can be used for thal patient to increase Hb. The actual action of the medication is still not clear. The 3rd phase of clinical trial will be done next year and will be focused on patient with intermediate thal.

JAK2 inhibitor
A new drug to help in improve production of RBC and reduce spleen size in the trial on mice. Preclinical studies suggest that JAK2 inhibitors may restore normal erythropoiesis and reduce splenomegaly in thalassaemia. Clinical trial just opened in TDT patients

Hepcidin
Dr Farrukh briefs the participants on the used of this medication.

Conclusion
The latest treatment allow possible cure for thal. but will not help in the complication such as, DM, endocrine etc. Patients need to take care of themselves to prevent all possible complication.

1. Is there any need of chemothepy at any point? Dr Farrukh said that small dose of chemotherapy needed to allow the new stem cells to growth and prevent rejection. There is no age limit and can be done for all.

2. The injection sotatercept helps to increase the healthy portion of stem cells to produce healthy RBC. It is a live long treatment. JAK2 is injected and Hepcidin is given orally.

3. Gene therapy is much cheaper as is for cure. Patient does no need to worry about transfusion and other treatment. There is no gene therapy in Malaysia yet.

1505. Working as a Team:

Doctor's point of view *(Dr Nalia Fauziah bt Hamzah)*
Nurses' point of view *(S/N Yuniza bt Md Yunus, S/N Hezuawani bt Tasarudin, S/N Che Merah bt Othma)*

Dr Nalia

The medical officers are trying their best to provide best services. Some system and procedure are implement to enhace the effectiveness of the services, e.g. appointment for follow up etc.

Challenges:

- Compliance of patients and patients fair in keeping the appointment
- Parents unable to accept the treatment and advices, maybe related to stigma?
- Coorperation from the patients, parents are needed

S/N Che Merah Othman

- Encourage to keep to the appointment (before 11 am). – need time to prose the treatment according to the patient's condition
- Hope the parents motivate their children to take treatment and control the serum ferritin level
- Suggest parents to discuss with the doctor to improve the patients' heatlh

S/N Yuniza

The staff in the daycare trying their best to help the patients to reduce waiting time.

Comments

Q A

Seberang Jaya

Sazana mentioned that there is no doctor in the day care when needed.
Dr Nalia belief that the must be a reason the doctor fail to see the patient as soon as informed.
Dr Goh suggested Sazana to make written complaint to the head of department for improvement.

Mr Doraisingam thanks the health care team for their help and service. Suggest to get appointment maybe 6 months once, instead of monthly, with more time to interact with the doctor and staff.

Dr Angline : Try to make arrangement for the patient and doctor to meet and discuss. But not all patients can give longer appointment, example 3 – 6 months. Need to see patient's condition.

Mdm Tan: Suggest and request to do blood transfusion on Sunday to prevent the child from skip classes. Dr Goh : Still not able to do that, but will try to give the transfusion on that day so patient can discharge on that day.

1231. Organizing a Thal Camp. *(Sister Ooi Ee Ee)*

Sister Ooi shared with the participants on the planning and organizing a Thalassaemia Camp. The discussion includes the preparation of the camp, how to organize the camp as well as post camp evaluation were shared. Sister shared that a lot of cooperation among the members, volunteers and speakers are needed.

Sister Ooi was also appreciate that now a day the thalassaemics are actively participates in the organizing and running of the camp as well become the committee members of the society.

1400. **Understanding your Medications.** *(Mr Phang Chia Seng)*

Mr Phang shared information on medications for thal patients.

During transfusion
1. IV Frusemide – prevent circulation overloading
2. IV Hydrocortisone – treat the allergic reaction
3. IV / Orsal Chlorpheniramine Maleate – treat the allergic reaction

During Chelation
1. SC Deferoxamine – the safer medication
2. Oral deferiprone (L1 / Kelfer) – able to protect the heart
3. Oral deferasirox (Exjade) – dissolve in water / fruits juice, once daily kombinasi a) and b) -

Others
1. Vit C – improve the effectivenss of SC desferal
2. Folic acid – help in RBS synthesis
3. EMLA cream / Lignocaine gel – reduce pain during SC
4. Water for injection – dissolve the desferal (5mls and more pervial)

Drugs to treat Complication
1. Penicilin V – post splenectomy : BD
2. Calcium Lactate –
3. Calcitriol – to reduce risk of osteoporosis

Q A Dr Goh : Not enough syringe and needles and other accessory for the SC Desferal. They also need appropriate size of the syringe. What can the pharmacist do?

Is the pharmacist's duty to provide the advice and adequate size of syringes for the patients. The patients may need to highlight to the pharmacist. Will look into this issue.

For the day care, the nurses are looking after cancer patients as well. So needed, they give the patients the thala set that they have.

1430. **Diet for Thalassaemics** *(Dr Foong Wai Cheng)*

Brief the symptoms of low HB. Need more iron from the food. If not enough need transfusion.

Dr Foong explain the important of appropriate and adequate diet intake to thal. to maintain HB and prevent iron overload. She also brief the participants the type of food that is essential form thal, and food to avoid.

Q A Dr Foong highlight that need to be more careful with iron contents in the nutrient food in the market. Most of the multi-vitamin content high iron need to avoid.

1615. **Group Discussions — Time Spent in hospital**

Suggestion :
- to take blood specimen the same day of blood transfusion
- blood transfusion during weekend or holiday
- doctor assessment in the same day of transfusion
- use the waiting time properly, e.g. reading and do revision.

- make a clear record on blood result
- parents need to know their children's blood group and make a complete record for referring.

Challenges
- No blood result even the specimen had been taken two weeks ago. When asked, the patients will not be able to answer.
- Limited parking space and is very far away. If the machine to check Hb is spoil in the clinic, the patients need to go to the lab which is far away and need to wait for 3 hours.
  Long waiting time for treatment and to take medication.
- Long waiting time to see doctor. The doctor will repeat the same question and take up a lot of time to wait for the blood result. Appointment date for blood transfusion and see the doctor are different.
- Time for transfusion and blood taking is not flexible.
- Thal-set not functioning.

Respond
- Mdm Tan said that waiting is something common. Parents need to understand the limitation of the process. Parents and patients need to learn to adjust and manage with it.

Employment
1. Leave and M.C.
- Patient need to plan their working schedule and leave for tansfussion, blood taking and treatment.
- Some superior contacted the hospital to confirm the patient's M.C.
- Request for unrecorded M.C. for promotion

2. Employer lead of understanding (Ipoh)
- may be terminated if too many M.C.
- only able to cope with the work that will not cause tiredness.

Conclusion
1. Important of record keeping.
2. Patients need to learn to cope and adjust to live changes.

1642 : The Camp end by dance performance from 20 young thal. titled : **If you happy and you know it clap your hands**. The Children also were awarded with some toys for the games that they were participated.

The camp concluded at about 17.00.

Reported by :
Miss Lim Chooi Leng

Thals and volunteers receiving their prizes.20th. camp

20th Penang Thalassaemia Camp
– A Reflection from Penang Medical College Volunteers
(Medical Students)

What have I learned

- get to know more about thalassaemia e.g. types, blood transfusion
- awareness of the disease among the patients
- Cooperation of everyone involve in the treatment of patients *(including patients themselves)* is of utmost importance in successful treatment.
- The cooperation of the patients in a treatment plan is largely determined by how eager about surviving.
- It's good practice for team leader to always give credits to his/her cooperative subordinates.

On our session with the kids
The kids were very receptive, especially after we expressed interest in their condition and their current lives. We took care of 13-17 year olds. They were also very smart, and knew how to answer even the questions for the >17 group.

I have learnt more about challenges faced by parents for thalassaemia and about the disease itself, I like the talk given by Dr. Farukh and the activities provided for the children

On Dr Farrukh's session:
I felt it was by far the best of the morning talks. However there was a language barrier.

Firstly, I would like to start with compliments of good things that I've learned during the camp. This is my first experience ever helping in such camp and I'm impressed with the hardwork showed by the committees throught the camp. I personally think that they were being so helpful to the participants and to us as volunteers. We felt welcomed by the committees eventhough I think our contribution was small and insignificant. However, I think it was a good start for me as I now realized there are many ways for me to contribute to the society. I can see different approach used by the doctors in conveying educational information about the disease to the audience who were mainly thalassaemic, parents to thalassaemic and also non-thalassaemic people. I realize how useless it is if I just learn all the sophisticated medical jargons but fail to convey the information to the patient in a manner that they can understand.

I just want to emphasise about the parents were not informed where the children were at the time and that has caused some distress.

- Children making too much noise during the talks. Parents should have taken steps to ensure that their children do not cause nuisance.

Moving on to the question I discussed with my groups. The questions are as follow:

1. *Jika saya kurang masukkan darah, zat besi dalam badan saya tidak akan bertambah*
2. *Adalah sesuatu yg baik jika zad besi terkumpul dengan banyak dalam badan saya*
3. *Sebagai seorang thalaesemia, saya tiada pilihan untuk buangkan zat besi yang berlebihan dalam badan saya*
4. *Penyakit thalassemia boleh merebak dan berjangkit*
5. *Exjade merupakan ubat pembuangan zat besi yang terbaik*

In my opinion, some of the questions were really good and appropriate questions and some of them can be changed. Even though the time for discussion was short, my colleague and I manage to go through all of the questions. However, we chose the best two questions to be presented that were question 2 and 4. I was quite surprise to know that the participants have a good background knowledge about the disease. They answered every question with no difficulty at all. However, only a few of them managed to justify the answer of each questions. If the time given was a bit longer my colleague and I would be very interested to find out more of their level of understanding about the disease such as why some of the parents don't have the disease, what are the long term effects of the disease etc.

What do I like the most about the camp

- the talks were very informative
- Dr Goh did a very good translation

- **The speakers**

What do I like least

- the schedule was not well planned, causing last minute changes that made the situation a bit chaotic
- the committee did not inform the parents that they have arranged other activities for the children and the children were brought to another place out of the hall. This has caused unnecessary worries to the parents

Suggestions on how to improve Thalassemia Camp or other issues or comments

On children

We noticed many of the young ones were not paying attention during the sessions, but were playing in the back with their friends. We felt that we could have taken the younger age groups in separate sessions, simultaneous to the lecture sessions for the older patients.

Organizational issues

Many parents were unhappy that their children were taken away (over lunch break?) but were not informed beforehand. Organizers should at least inform them, or put it in the conference schedule.

Next, I can see a few room for improvements in especially in how the volunteers could maximize their contribution in the camp. I personally think that the talks given were appropriate to participants above 16 years old but to participants below 16. So, I think that it would be best if the volunteers were given the opportunity to play with the children under 16 years old in the beginning before the quiz session starts. This is because I can see that most of the kids gave no attention to the talks after sometime they rather play at the back of the auditorium with their friends. I know we can't force them to give their full attention at all time because if they were able to understand even a little bit about their illness I think it's a huge success. However, I think they could gain more if they have more time to play and share with us. My colleague and I were looking forward to spend more time with them so that good relationship can be established among them and ultimately we can learn from each other better. This is because it was slow to get their response initially because they were quite shy to give any due to they don't know about each other Apart from that, our session had been brought to during the tea break. Initially I think it was not a good idea however, I realized that delay gave us about 25 minutes to discuss with them. Unfortunately not all groups had the advantage. This was due to unclear instruction given to the participant. My small group (13-16 years old) had about 10 minutes of discussion because the participants were not aware that they should be taking their meal and eat in the group while discussing.

Last but not least, I think this idea of getting volunteers to spend time doing quizzes with the participants is a good idea as both parties can benefit from it. I hope this is not the end of my participation in such event and also this kind of opportunity will be always available for future medical students especially PMC students to gain and learn something out of the textbook. I'm truly glad and thankful for the opportunity given to me and I'm deeply sorry on behalf of my colleague if we didn't meet the expectation required in conducting the session. I believe that we gave our best to contribute to the event.

- Some participants fell asleep during the talks. It will be great if they can pay more attention.

PERKHEMAHAN KE-20 PERTUBUHAN THALASSAEMIA PP di Sunway Hotel, Seberang Jaya, 20 & 21 September 2014.

Assalamualaikum dan salam sejahtera para hadirin, doctor, nurse dan sahabar semuanya.

Berdiri saya di sini pada hari ini adalah untuk berkongsi pengalaman saya sebagai seorang ibu kepada dua orang puteri yang menghidap thalasemia.

Pada mulany anak saya kerap demam, setiap kali dibawa pergi ke klinik doctor cuma kata demam biasa dan bagi ubat paracetamol, selang beberapa minggu demam lagi dan akhirany saya bawa pergi ke HPP. Bila diambli darah untuk diuji dapatlah jawapannya. Secara jujurnya, pada mulanya saya tidak dapat menerima kenyataan yang doctor katakana yang anak saya menghidap thalasemia, pada masa itu saya buntu dan memikirkan kenapa Allah uji saya sedemikian.

Tapi saya bersyukur saya tidak keseorangan, saya mendapat semangat dari suami, keluarga dan orang pertama yang memberi banyak tunjuk ajar kepada saya ialah Mdm Khoo Siew Hong, staff nurse Saw dan sister Ooi Ee Ee dan merekalah juga yang memperkenalkan saya dengan persatuan thalasemia,

Pada tahun 1992, semasa anak saya transfuse darah yang pertama, saya terpaksa tinggal di hospital selama 2 atau 3 hari, hari pertama ambil darah untuk check HB, hari kedua transfuse darah dan selepas itu check tahap ketinggian HB pulak, bayangkan saya terpaksa ambil cuti dan cuti akan habis sebelum akhir tahun dan dipotong gaji. Tapi saya tidak meyesal. Bila tiba masa untuk ke hospital transfuse sarah saya akan merasa susah hati kerana anak saya akan mula membuat perangai, dari jauh bila nampak baju putih tidak kira doctor atau nurse dia akan mula menangis kerana takut, yang bermain di minda mereka adalah akan disuntik walaupun bukan giliran mereka.

Setelah 12 kali anak saya mendapat transfuse darah dan tibalah masanya untuk menggunakan desferal. Pada masa itu desferal dan peralatannya dibeli sendiri dan saya tidak tahu untuk membuat dan suntik. Setiap malam saya akan pergi ke rumah Mdm Khoo Siew Hong untuk belaar care suntikan desferal sehinggalah saya pandai membuatnya. Pada masa itu hat saya sangat rasa sakit kerana sudahlah setiap bulan transfuse darah dan kena suntik desferal pulak. Tapi saya tetap membuatnya walaupun mereka menagis tidak mahu disuntik desferal. Saya akan menghadiri setiap kem yang dianjurkan dan dari situlah saya dan anak akan memahami tentang thalasemia dan perlunya suntikan desferal. Anak saya mul membuat desferal dan suntik sendiri seawal umur 11 tahun.

Setiap empat minggu mereka akan mendapat temujanji dari doctor untuk transfucse, tapi kadang-kadang saya tidak akan mengikut jadual yang doc tetapkan, bila saya Nampak anak saya pucat atau letih saya akan terus bawa mereka ke hospital untuk check HB sekiranya perlu akan terus masuk darah walaupun bukan tarikh yang doc tetapkan sebenarnya.

Semasa mereka di sekolah rendah lagi saya tidak menyekat mereka dari membuat aktiviti-aktiviti, saya menjaga dan mendidik mereka seperti kanak-kanak yang biasa, saya akan biarkan sekiranya mereka hendak mebuat sukan atau apa pun acara normal.

Sekiranya mereka membuat salah say akan marah, mereka tidak akan mendapat layanan yang istimewa walupun mereka thalasemia.

Sekarang mereka telah belajar di universiti, saya lepaskan mereka pergi walupun juah. Mereka juga tidak merasa malu untuk menceritakan pada kanak-kanak dan tenaga pengajar yang mereka menghidap thalasemia. Ada juga yang tidak faham apa itu thalasemia dan mereka akan menceritakannya. Bagi saya ini adalah ujian Allah pada mereka Mereka bukanlah seorang pesakit. Mereka Cuma kekurangan darah merah sahaja yang lain mereka boleh mebuatnya sendiri. Kita janganlah mengagap mereka sebagai pesakit.

Sekian terima kasih.

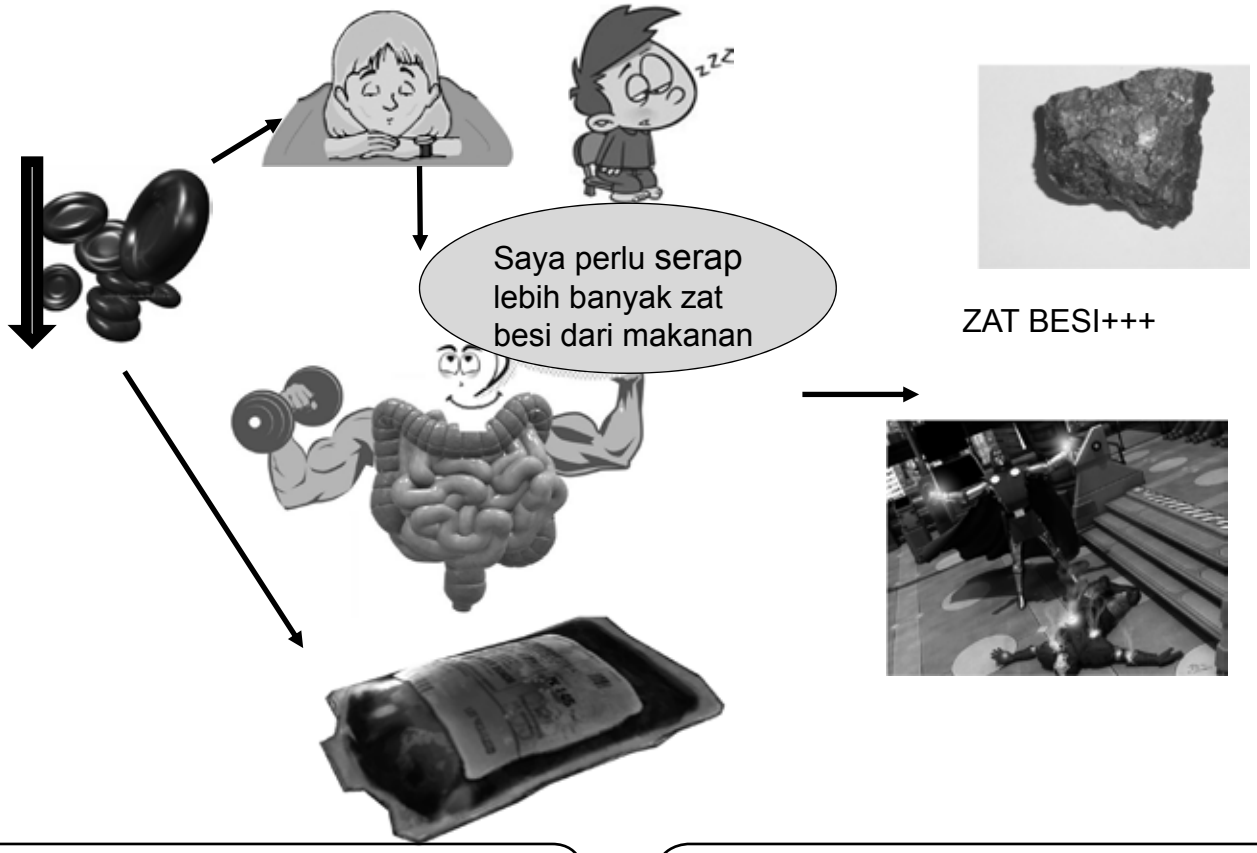
Pn. Baheyah Bt Jaafar
(Parent)

Pemakanan untuk Pesakit Talasemia

Dr Foong Wai Cheng

KANDUNGAN

- Tingkah laku badan terhadap kekurangan darah merah
- Cara pemakanan yang dicadangkan
- Antioxidants
- Makanan yang perlu dielakkan



KESAN BURUK

- Zat besi yang berlebihan dalam badan
- Tulang yang rapuh
- Kelebihan 'free radicals'

CARA –CARA MENGATASI

- Ubat pembuangan zat besi
- Kemasukkan darah yang berpatutan
- Pemakanan yang seimbang yang **kurang** zat besi

Makan untuk…

- Pembesaran
- Kecergasan fizikal dan mental
- Kekuatan tulang

- Zat besi terkumpul
- Terhad jika adanya kencing manis

MACAM MANA NAK KURANGKAN PENYERAPAN ZAT BESI MELALUI MAKANAN?

- Kurangkan makanan yang kaya dengan zat besi
- Kurangkan kombinasi makanan yang akan menggalakan penyerapan zat besi
- Makan kombinasi makanan yang seimbang tetapi masih dapat menghalang penyerapan zat besi

MAKANAN YANG MENINGKATKAN PENYERAPAN ZAT BESI

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

Kombinasi yang kurang elok: sajian haiwan yang kaya dengan zat besi dengan makanan yang kaya dengan vitamin C / jenis asid

Multi-vitamin yang mengandungi zat besi

Iron Content in Food

HEME IRON	Iron (mg)	NON-HEME IRON	Iron (mg)
Clams	25.0	Instant enriched oatmeal**(1 cup)	4.0 – 13.2
*Liver, pork	16.0	Enriched, cold cereal** (1/2 cup)	1.6 – 8.3
Oysters	8.0	Enriched cream of wheat, cooked** (1/2 cup)	7.5
*Liver, chicken	7.5	Amaranth (1/2 cup)	7.4
Mussels	5.7	Soy beans, cooked (1/2 cup)	4.4
*Liver, beef	5.5	Quinoa, dry (1/2 cup)	3.9
Beef	3.0	Molasses, blackstrap (1 Tbsp)	3.5
(Based on 90 g (3 oz) portion)		Lentils, cooked (1/2 cup)	3.3
Other sources of heme iron: Shrimp, Sardines, Turkey, Lamb, Pork, Chicken, and Fish		**Other sources of non-heme iron:** Potatoes, Wheat germ, Tofu, Kidney Beans, Chickpeas, Enriched Pasta, Whole Wheat Bread, Nuts and Seeds, Dried Fruit (apricots, dates, figs, prunes, and raisins), Eggs, and Dark Leafy Vegetables	

*Pregnant women should avoid liver because of its high Vitamin A content. Liver is also high in cholesterol.
**The iron content of enriched foods varies with different brands. Check the label for most accurate information.

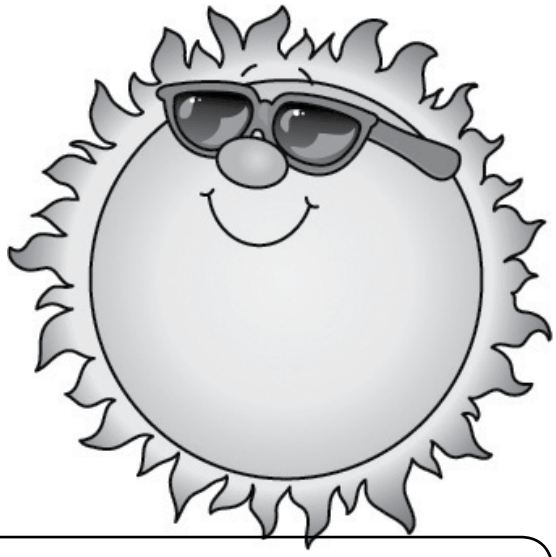
Anemia Institute for Research and Education.
www.anemiainstitute.org

MAKANAN YANG MENGURANGKAN PENYERAPAN ZAT BESI JENIS NON HEME

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

LEBIHKAN KOMBINASI SEBEGITU

Elak dari mengunakan bahan buatan besi sebagai peralatan memasak seperti kuali



MASALAH TULANG RAPUH DI KALANGAN PESAKIT TALASEMIA

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

Vitamin D

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

ANTIOXIDANTS

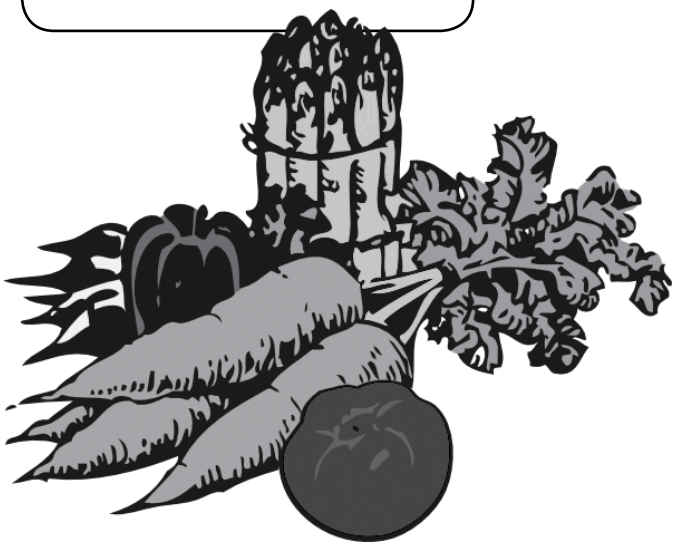
Vitamin C
- <250mg selepas memulakan infusi Desferral
- Dari buah-buahan : dimakan secara bersendirian
- Makan bersama kekacang
- Rebus sayuran

Vitamin E :
- Minyak sayuran (olive, palm, soya, sunflower)
- Makanan tenusu, cereals, kekacang, telur, daging

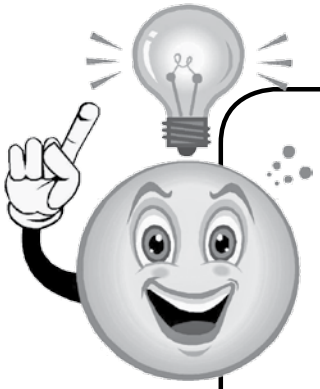
Carotenoids:
- Karot, jagung, tomato, betik, oren, sayuran hijau
- Penyerapan dipertingkatkan jika makanan tersebut mengandungi lemak / minyak

Flavonoids :
- The, 'red wine', buah- buahan , sayur-sayuran

LAIN-LAIN RAWATAN
- Asid folic
- Vitamin D
- Calcium carbonate / lactate
- Rocaltriol
- Zinc



ADA KOMPLIKASI
- Kencing manis
- Kekurangan hormon tiroid
- Kerosakan hati
- Kerosakan jantung



PETUA:

bergantung kepada jenis komplikasi

- kurangkan manisan – kencing manis

makan ubat tambahan mengikut masa

– sebelum / selepas makan

RUJUKAN

- 2003-2005 Children's Hospital & Research Center Oakland
- Diet in Regularly Transfused Thalassemics , Jagdish Singh
- Northern Comprehensive Thalassemia Centre http:www.thalasemia.com
- Diet for Thalassemia : Part 1 and Part 2, thalassaemia International Fedration Magazine, Dr. Dona Hileti-Tefler
- Pemakanan untuk talasemia, Dt Ruzana Abdullah dari PPUKM

TANGGUNGJAWAB AHLI PTPP
(TAN PECK CHIN)

Pertubuhan Thalassaemia Pulau Pinang (PTPP) ditubuhkan pada tahun 1988. Sepanjang 27 tahun penubuhannya, semua ahli pertubuhan dan pesakit Thalassaemia di Pulau Pinang khususnya telah mendapat banyak manfaat. Kalau dahulu, ubat-ubat pengkelatan zat besi seperti Desferal khususnya perlu dibeli oleh pesakit tetapi kini semua ubat-ubatan ini telah diberikan secara percuma oleh kerajaan hasil perjuangan PTPP bersama-sama pertubuhan thalassaemia yang lain di Malaysia.

Sebelum ubat-ubatan pengkelatan zat besi ini diberikan secara percuma, masalah utama yang dihadapi oleh pesakit thalassaemia adalah untuk mendapatkan ubat-ubatan tersebut kerana kosnya yang terlalu tinggi. Namun kini, apabila masalah itu sudah dapat diatasi, masalah lain pula yang timbul. Masalahnya sekarang ini ialah ada pesakit yang tidak "compliance" atau tidak berdisiplin dalam melakukan suntikan desferal atau memakan ubat-ubat pengkelatan secara oral seperti L1 atau Exjade mengikut jadual. Akibatnya kadar serum ferritin (takungan zat besi) di dalam darah dan organ-organ penting seperti hati dan jantung adalah tinggi. Kesannya amat membimbangkan kerana pesakit yang mengandungi serum ferritin yang tinggi akan mengalami banyak komplikasi lain seperti kegagalan hati dan jantung yang boleh membawa maut.

Menyedari hakikat ini PTPP telah menganjurkan kem setiap tahun. Tujuan kem ini adalah untuk memberik pendedahan kepada pesakit dan waris pesakit tentang kepentingan menjalankan rawatan pengkelatan zat besi dengan betul dan mengikut jadual, rawatan-rawatan terkini, risiko komplikasi yang dihadapi oleh pesakit, pemakanan, kesan-kesan sampingan, symptom-simptom yang perlu diberi perhatian dan sebagainya. Bayaran yang dikenakan kepada pesakit hanya RM50 sahaja. Pesakit boleh membawa seorang ahli keluarga untuk menemani mereka dengan bayaran RM 50 seorang juga. Bayaran ini teramat murah kerana untuk seorang peserta, PTPP terpaksa membayar subsidi lebih daripada RM200. Ramai ahli yang mempertikaikan kenapa mereka perlu bayar. Sebenarnya bayaran RM50 itu adalah sebagai cagaran kerana sebelum ini ada peserta yang tidak hadir walaupun sudah mendaftar. Jika perkara ini berlaku, PTPP akan mengalami kerugian. Sedangkan wang itu boleh digunakan untuk perkara-perkara yang lebih penting untuk kebajikan pesakit dan ahli.

Sebagai ahli PTPP, kita semua perlu bekerjasama untuk memastikan PTPP dapat meneruskan perjuangan demi kepentingan pesakit-pesakit Thalassaemia di Pulau Pinang. Tanpa sokongan dan kerjasama semua ahli, amat sukar untuk PTPP meneruskan perjuangan untuk menjamin kesejahteraan hidup para pesakit Thalassaemia di Pulau Pinang. PTPP faham bahawa kebanyak ahli PTPP dan pesakit Thalassaemia bukanlah golongan yang kaya. PTPP sememangnya tidak mengharapkan simbangan kewangan daripada anda semua sekirana anda tidak mampu. Namun sebagai ahli PTPP, kita juga mempunyai tanggungjawab

masing-masing. Sekiranya tidak mampu memberikan sumbangan kewangan, sumbangan dalam bentuk lain juga boleh diberikan. Contohmya;

i) Menjadi sukarelawan sekiranya PTPP menganjurkan apa-apa bentuk program .
ii) Mewakili PTPP untuk menghadiri apa-apa program yang dianjurkan oleh pihak luar.
iii) Memberikan cadangan untuk PTPP menganjurkan apa-apa program yang dianggap sesuai untuk memberikan manfaat kepada pesakit Thalassaemia.

Sebelum ini PTPP sudah banyak kali menganjurkan program. Malangnya penglibatan ahli amat mengecewakan. Apa yang boleh dirumuskan ialah kebanyakan ahli PTPP dan pesakit hanya berminat untuk melibatkan diri dalam aktiviti-aktiviti sosial sahaja. Program-program lain seperti kem kurang mendapat sambutan. Setiap kali diadakan kem, pesertanya adalah orang yang sama. Sepatutnya pesakit yang tidak pernah menghadiri kem mesti hadir kerana banyak maklumat yang akan diperolehnya melalui kem-kem ini.

Semua ahli PTPP harus ingat bahawa kesejahteraan hidup pesakit Thalassaemia hari ini adalah hasil perjuangan PTPP dengan sokongan padu daripada pihak hospital. Hasilnya, sekarang di Klinik Pakar 3, Hospital Seberang Jaya, sudah ada klinik pada petang Isnin. Transfusi darah juga boleh dilakukan pada waktu petang dan hari Sabtu. Oleh itu, pesakit Thalassaemia yang masih bersekolah tidak perlu ponteng sekolah lagi.

PTPP amat berharap semua ahli dapat memberikan sokongan dan kerjasama kepada PTPP untuk terus berusaha dalam memastikan kesejahteraan hidup pesakit Thalassaemia di Pulau Pinang. Ingatlah bahawa "tangan yang memberi lebih baik daripada tangan yang menerima" dan "harimau mati meninggalkan belang, manusia mati meninggalkan nama".

Oleh itu, marilah kita sama-sama membantu PTPP meneruskan perjuangan demi pesakit-pesakit Thalasasaemia di Pulau Pinang khususnya. Jangan lupa bahawa sebagai ahli PTPP, kita mempunyai tanggungjawab masing-masing. Jangan hanya mengharapkan bantuan sahaja. Hidup kita akan lebih bermakna sekiranya kita dapat membantu orang lain pula setelah kita dibantu.

Pulau Pandan jauh ke tengah,
Gunung Daik bercabang tiga,
Hancur badan dikandung tanah,
Budi yang baik dikenang jua.

Tidak ada sesiapa yang boleh membantu kita sekiranya kita tidak membantu diri kita sendiri. Kalau sebelum ini kita sentiasa memberikan alasan apabila bantuan kita diminta, kali ini cubalah membantu. Ingatlah bahawa "kalau hendak seribu daya, kalau tak hendak, seribu dalih".

Announcement 2015

Hadiah Prestasi Akademik

1. Tahun 1–6 UPSR 2. Tingkatan 1–3 3. Tingkatan 4-5 4. Kolej, Universiti

Fotostat keputusan peperiksaan dan hantar kepejabat untuk hadiah diterima semasa AGM
Hadiah Tahap Ferrintin
Tahap Ferrintin dibawah 1000 akan diberi hadiah semasa AGM (Tahap yang disarankan oleh doctor)

Tarikh akhir untuk menghantar keputusan peperiksaan dan ferrintin : 18/4/2015

Fund Raising

Route 68 Challenge

Tempat : Gombak, Selangor to Betong, Pahang
Tarikh : 10/05/2015
Dianjurkan oleh: Ms Dhia Danishe Reita Bt Kanagarajah
(Thalassaemia HbH Disease)

Ms. Dhia Danishe Rita visiting office

World Thalassaemia Day

Public Awareness

Venue : Lebuh Pantai, 10050 Penang.
Date : Sunday 10/5/2015
Time : 8 am – 1 pm

Thalassaemia Kinabalu Challenge (TKC) 2015

Date : 30/8 – 2/9/2015
Venue : Sabah
Organised by : Datuk Dr. Soo Thian Lian
Organising Chairman

Condolences to their family ..
Nurul Syuhada Bt Jasni - 18/09/2014

Announcement 2015

AGM Ke – 26
Perhimpunan Tahunan

Tempat : Kompleks Masyarakat Penyayang, Jalan Utama, 10450 Pulau Pinang.
Tarikh : Ju'maat 01/05/2015
Time : 8.30 am – 12.30 pm

Makanan ringgan akan disediakan
Sebuah bas akan disediakan bagi ahli Seberang Jaya – maximum 40 orang saja

Kehadiran anda sangat dihargai!

10th Workshop for Health Personnel

Date : Monday 16/11/2015
Time : 8.30am – 4.30 pm
Venue : ACC Building, 4th. Floor, Hospital Pulau Pinang.

21st Camp

Date : 14-15/11/2015
Tempat: Hotel di Pulau Pinang

Sila hubungi pejabat untuk keterangan lanjut.

T2* Workshop

Date : Tuesday 17/11/2015
Time : 8.30 am - 2 pm
Venue : X-Ray Seminar Room, Hospital Seberang Jaya.

Congratulations

to the proud parents,
Hai Ping & Sin Yeen
Baby girl -
Olivia Ang
23/6/2014

Please call office for further enquiries : 04 2272133

This newsletter is published by:

Pertubuhan Thalassaemia Pulau Pinang
CO38-39UP Komplex Masyarakat Penyayang
Jalan Utama 10450 Pulau Pinang
Tel/Fax : 04-2272133
Email: penthal88@yahoo.com

Laman web: www.penthal.org
Penang Office Hours
Monday to Friday: **9.30am-5.30pm**
Saturday / Sunday / Public Holiday: **Closed**
Contact: Ms Too

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