

9th Thalassaemia Camp
“ Working Towards A Better Tomorrow “
Date: 9 & 10 September 2006
Venue: Crown Jewel Hotel, Penang
Organized by: Pulau Pinang Thalassaemia Society

Total no of participants: **127** .

1st Day 9th September 2006 Saturday

Emcees were Noorhafizah Bt Noor Hamdan and Misal Roslan, both adults Thalassaemic. President Mr Ng Chor Huat gave a welcoming speech . A group photo taking session followed.

The 1st speaker was Ms Emma Prescott, a Thalassaemia Nurse Specialist from London, UK. Emma, with 13 years experience of taking care of thalassaemics, presented on **Overview of Thalassaemia Care.**

She discussed on a Care Package for Thalassaemia, ie having a multi-disciplinary dedicated Thalassaemia clinic with specially trained staff and easy access to or liaison with specialist services. Emma also touched on blood transfusion, chelation, factors influencing compliance , both practical and psychological issues.

She concluded that with good chelator compliance, a safe blood supply and a much improved new developments, quantity & quality of life would be excellent.

Speaker no. 2 , Encik Nur Hisyam Ismail, a Dietician from Hospital Bear Pulau Pinang, gave a talk on **Nutrition in Thalassaemia.** He advised that the diet for Thalassaemics should be low in iron and has plenty of antioxidants. Avoid heme iron food like red meat, liver, instead take food which will decrease non-heme iron absorption eg dairy product, tea, coffee, spices and cereals.

Desferal Therapy – Factors Enhancing Compliance by Dr Peter Lim, Regional Medical Advisor, Novartis Oncology. Dr.Lim elaborated on Desferal – its importance, compliance in treatment and minimizing side effects. He also discussed about blood transfusions, effects of iron overload and the use of T2* for cardiac iron measurement.

Prof Chan Lee Lee, Consultant Paediatric Haematologist & Oncologist, Universiti Malaya Medical Centre, presented an interesting subject, ie **Role of Stem Cell – Transplantation(SCT) in Thalassaemia** . She talked about the pros and cons, unrelated BM and unrelated CB. Prof Chan concluded that SCT is better for younger patients and also depending on the status of patient's health (Pesaro risk group).

Next, **Complications in Thalassaemia** by Dr Yeoh Seoh Leng, Paediatric Oncologist & Haematologist, Hospital Pulau Pinang. Dr. Yeoh explained the complications due to excessive erythropoiesis, transfusion, iron overload and iron chelators. She advised to transfuse as needed and regular follow-up of weight & height. Psychosocial and social aspects of care were also explored.

Mdm. Ivy Teoh Siew Luan, whose daughter Jasmine(5 yrs old) underwent a successful allogenic **Bone Marrow Transplant**, shared her experiences during the period of Jasmine's BMT. Her feelings ranged from frustration, anger in the initial stages to finally excitement and

happiness. Jasmine was warded in University Hospital for 54 days. She stressed that a family needs to be prepared physically and mentally for BMT.

Next, Sister Ooi Ee Ee handed out **Questionnaires** to the Thalassaemics' to gauge their experiences in school, psychological and social aspects, treatment, employment prospect. To give feedback on ways the Thalassaemia society and hospital can help them and suggestions for future camp topics and activities.

After dinner, it was **Desferal time** for the thalassaemics. Assisted by Sister Ooi Ee Ee, S/N Khadijah A Rashid and S/N Saw Cheng Tiew, young and older thalassaemics administered their own Desferal using the pump. The room was full of lively activity – kudos to the little ones, they were very brave!

Before we said goodnite, Noorasyikin Md Saad coordinated the **adults get-together** with various games. Everyone had a good laugh and an enjoyable time.

2nd Day 10th September 2006 Sunday

Beach games for children 15 yrs and below was coordinated by Noorliza Abdullah and 3 volunteers. Among the games played were 3 legged race, catch the bombs, musical ball and a gunny sack race. The children enjoyed themselves and everyone went back with at least a prize each.

Meanwhile back in the lecture hall, the participants(without the children!) listened attentively to Dr Yeo Tun Wee, Medical Affairs Manager of Phamaforte on **Oral Chelators** – the choice. Currently approved iron chelators are Deferoxamine (Desferal, DFO) and Deferiprone (Ferriprox)

Next, Dr Tan Ru San, a Consultant Cardiologist from Singapore Heart Centre, gave an informative and comprehensive talk on **What is T2* Scan.** Besides measuring iron in the heart, it can also be used to measure iron in the liver. This guides treatment strategies of Thalassaemics and can save lives. It is not currently available in Malaysia.

Khoo Swee Hong coordinated in the **Sharing of Experiences**. Four thalassaemics couples shared their experiences of how they met their spouses, family acceptance, settling down and starting a family. They were Aminah Dahalan/Mohd Rawi Abd Latif, Noorasyikin Md Saad/Mazfiza Mahamad Badawi, Zeti Aktar/Kudus Kadermasthan and Hasmiza Hassan/Noor Kamsani Abd Wahab.

Next, Misal Roslan, 27 yrs old bachelor thalassaemic, stated that initially he did not know what is thalassaemia. He started Desferal when he was 18 yrs old but was not consistent. Now he is on L1 and his iron level has dropped to 1750.

Janice Kua, 23 yrs old is currently studying in a university in UK. She emphasized that there should not be a difference between a thalassaemic and non-thalassaemic. What her sister can do, she can do too. She is optimistic in life and thalassaemia is not a problem for her.

Ms Emma Prescott returned to present another topic **Towards a Better Tomorrow**. She emphasized that as there are better and more tolerable treatment regimens, thalassaemics are living into 5th and 6th decades. Pregnancy is now a real possibility in well treated patients.

The camp ended about 2.00pm After lunch , it was checkout from the hotel.

Conclusion

This Camp has been successful. Our thanks to our guest speakers both local and abroad. Their talks are inspiring and positive. The participants themselves too were more interactive and some even vocal in expressing themselves. A thalassaemic does face many challenges but with support of family, peers and care givers , he /she will surely be able to cope better.

Highlights from feedback from the questionnaires:-

- Have a Thalassaemic clinic,
- More subsidy for treatment including assessories
- Have professional counseling services
- More camps to update Thalassaemia care and management, motivational talks
- More social interactions eg outings, sharing of experiences,entertainment
- Continue Penang Thalassaemia society good work – be the voice for Thalassaemics

Report compiled by:
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