



The Journey Begins.....

The Penang Thalassaemia Society started on the road of its Continuing Medical Education programme in 1995. We started with a bang by organising the **1st Asean Congress of Thalassaemia** in 1995. It was held in the Shangri La's Rasa Sayang Resort, Batu Ferringhi from 27 – 30th, October, 1995. The International faculty was impressive with well known speakers like Dr. Beatrix Wonke and Dr. John Porter from the United Kingdom, Dr. Nancy Olivieri from Canada, Dr. Agarwal from India, Dr. Suthat Fucharon from Thailand, Dr. Michael Angastiniotis and Dr. George Constantinou from TIF, Dr. Ivy Ng from Singapore, Dr. Alendry Caviles Jr. from the Philippines and Prof. Dr. Iskandar Wahidiyat from Indonesia. The opening ceremony was officiated by none other than the then Hon. Minister of Health Dato' Dr. Chua Jui Meng. It was a very good learning experience for the Society as we exchanged views and shared opinions in the management of this common condition. It was a good exposure too for our medical staff, patients and parents and it was the beginning of many more seminars to come.

The 1st National Thalassaemia Week for 1996 was launched in Ipoh from the 25 – 31/05/1996. It was held in the Hotel Seri Malaysia in Ipoh, Perak. The programme for medical staff was held over two days followed by a 3 day camp for patients and parents. There was a good turnout from all over Malaysia with nurses from Sabah too. Our Medical Advisers, Dr. Pyar Kaur and Dr. Balveer Kaur were guest speakers and Sister Ooi Ee Ee conducted the Practical Demonstrations during the camp.

We had our **1st Thalassaemia Camp** in SRK Island Girls School, Penang from 09 - 11/11/1996. This camp was held to motivate both thalassaemics and parents to be more compliant with chelation therapy. This was due to the untimely demise of a few of our older members. The children and parents together with the nurses stayed in the YMCA Penang. There were talks on the importance of desferal. This was further stressed by nightly practical sessions and demonstrations of desferal infusion. A total of 22 thalassaemics with their parents participated.

The 2nd Thalassaemia Camp was held on the 12th and 13th, July, 1997 at the Sandy Bay Paradise Hotel. The aim of this camp was to improve the psychological support for our older children. As such the camp was aimed at those who were above 12 years of age together with their parents. The objectives were to prepare our thalassaemics to cope with their condition and to

motivate them to be responsible for their own health and lives. We had an attendance of 25 thalassaemics this time round.

The 2nd Asean Conference on Thalassaemia was held in Jakarta from 8– 10th, September 1997. It was hoped that this would be a regular biannual regional meeting. This conference was organised by the Indonesian Thalassaemia Foundation with the Thalassaemia Centre, Dept of Child Health University of Indonesia, Jakarta. Our senior and founder medical adviser, Dr. Pyar Kaur was invited as a guest speaker. There was a large representation from Penang to the conference too with doctors, allied health personnel, thalassaemics and parents. There was a healthy exchange of views about enhancing ties among the various national associations. Our thalassaemics had a good time interacting with new found friends in Jakarta. There was much hope that the 3rd Asean Conference would be held by the Thais.

In November, 1997, the **2nd National Thalassaemic Week** was held in the Delima Resort, Langkawi over 4 days beginning on the 21st. There was a huge turnout with 115 participants. The Penang Thalassaemia Society sent 17 thalassaemics and parents. The majority were from Perlis and Kedah. There were 6 thalassaemics from Indonesia too and their support was much appreciated. Our Society stalwarts, Sister Ooi Ee Ee and Staff Nurse Saw Cheng Tiew were roped in for the orientation and discussion sessions among the non medical participants. They too were in charge of the practical demonstrations on the correct use of blood filters and desferal syring pumps. Once again, Dr. Pyar Kaur was invited to share her expertise on the management of Thalassaemia among the medical participants.

We held our **3rd Thalassaemia Day Camp 3** on the 6th September, 1998 in the Penang Parkroyal Resort, Batu Ferringhi, Penang. There were concurrent sessions for doctors and thalassaemics with parents. Dr. Beatrix Wonke who by then had become an ardent supporter of our work in Penang, was invited yet again to speak on the management of delayed puberty and cardiac problems in thalassaemia. The parents' programme was geared towards the holistic management of thalassaemia including its complications and how to cope with with thalassaemia. We took the opportunity too to host a retirement dinner for Dr. Pyar Kaur who turned 55! There were endless tributes to her for her sacrifices and contribution to the Society. Her kinds deeds will not be forgotten.

In conjunction with the camp, a **Thalassaemia workshop “Learn and Live”** was organised in the Kompleks Masyarakat Penyayang, Penang. Sister Emma Prescott, Thalassaemia Nurse Specialist from the Whittington Hospital, London ran the workshop successfully. The response was most satisfying and the feedback was that the Penang Thalassaemia Society should

organise similar workshops in future. There were requests for more practical and handson sessions in future workshops.

There was a lull in our activities for the next few years as Malaysia was going through a difficult economic time dealing with the recession. So, it was with great relief that we managed to restart our medical education programme by having our **4th Thalassaemia Camp** on the 3rd and 4th November, 2002. This was in the Crown Prince Hotel, Penang. The theme for this camp was different, being 'Beyond Thalassaemia'. This was to encourage our Thalassaemics to look forward to the future and to focus on wholesome aspects of their lives. For the first time, we had a child psychiatrist, Dr. Lai Fong Hwa to speak on topics like "Who am I? ; What do I enjoy despite my chronic illness? ; How Has Thalassaemia helped me and Looking towards the Future!" We had a motivational talk by Prof. See Ch'ng Mey too who is an educational psychologist. The following year, we organised our **5th Camp** together with the Perak Thalassaemia Society. It was held from the 5th-7th Dec, 2003 at the Naza Hotel in Penang. The theme was 'Knowing Thalassaemia Better' A total of 98 participants attended the camp and we had Prof. Chan Lee Lee to speak on Stem Cell Transplantation which was the hot issue that year as one of our patients underwent a succesful transplant in University Malaya. We celebrated our 15th anniversary during the camp too.

On the 8th and 9th of May, 2004, **1st National Thalassaemia Seminar for Patients, Parent and Professionals** was held in conjunction with International THALASSAEMIA DAY. This was organised by the Federation of Malaysian Thalassaemia Societies together with the Malaysian Paediatric Association and the Ministry of Health. It was held in the Corus Hotel, Kuala Lumpur. The Deputy of Minister of Health represented the Minister during the opening ceremony. 37 Penang delegates took part in the seminar. There were concurrent sessions with Dr. Antonio Piga from Italy being one of the main speakers. Dr. Pyar Kaur and Dr. Balveer Kaur were invited as speakers in the seminar. The panel discussion was most enlightening as Dato' Dr. Narimah Awin, Pengarah from the Ministry of Health was delegated the responsibility to submit a working paper on the need for subsidised or free desferal in Malaysia. Population screening was also brought up during the panel discussion. This was most heartening as it proved that the societies have managed to pressure the government to take on the responsibility for caring for our thalassaemics. The social nite was memorable as our Penang group presented a Boria session which was very well received by the audience.

During the end of the year, we held our **6th camp** from 3rd-5th, Dec, 2004 in the Hosba Valley Resort, Jitra, Kedah. Our Theme for the camp was "Knowing Thalassaemia Better". A total of 67 persons attended this camp. The highlight of the camp was a sharing session on Bone Marrow

Transplantation by Ivy Teoh Siew Luan who is the mother of Jasmine Khaw. Jasmine is the first successful BMT patient in Penang. There was a patient sharing session too by Noorasyikin Md.Said who spoke on Thalassaemia and me. Dr. Saiful Rijal Muhammad, a paediatrician from Ipoh Hospital who had just attended the Thalassaemia International Federation workshop in Cyprus in November, 2004 updated us on epidemiology, prevention, screening, prenatal and preimplantation diagnoses, blood transfusions, iron overload assessment and chelation. He spoke too on HbF inducers, viral hepatitis and endocrinology. Lastly, there was much emphasis on counselling and the role of support groups.

We took our thalassaemics to Pulau Langkawi for our **7th Thalassaemia Camp**. This was held in Hotel Helang from the 30th, April to 2nd, May, 2005. The theme for the year was geared towards our adolescent thalassaemics and it was "Facing the Challenges of Being an Adult Thalassaemic" The total number of participants was 115 which was our largest to date. We had participants from Kedah, Perak, Kelantan, Kuala Lumpur and even as far as Sarawak. Prof. See Ching Mey from USM spoke on Positive Thinking and Living. She stressed on the need for taking control of one's life with positive thinking with a commitment to control our minds. She taught about using mental tools for thought awareness and the need to challenge irrational thoughts with positive affirmation. Her session was very well received. Dr. Lim Shueh Lin, Consultant Endocrinologist from the Penang Hospital spoke at length about hypopituitarism therapy together with hormone replacement therapy.

George Constantinou, a Past President of TIF shared the hard facts of being a thalassaemic like the daily pain of injections, unpredictable future, the burden of the illness, how time consuming and costly therapy is together with the restriction on lifestyles. However, he stressed on respecting priorities in life, the need to accept the good with the bad like all people and the need to face up to our fears and uncertainties in life. Most importantly he touched on hope and living a balanced life. Christos Sotirelis, a thalassaemic then shared on the need for a society, its role and aims; the psychosocial impact of thalassaemia and the need to integrate into society. Lastly, there was an informative session by Encik Mohd. Ecranizam bin Rapie, Penolong Pengarah Tenaga Kerja, Pulau Pinang who spoke on Careers and Employment. It was certainly one of our best camps to date and its success set a new benchmark for our future meetings.

For our **8th Thalassaemia Camp** which was held in Pulau Jerejak, Penang from the 2nd-4th, December, 2005, we invited Mrs. Shobha Tuli, the President of TIF to speak about her personal experiences as a mother of a thalassaemic. The theme was "The A, B, C's of Thalassaemia". Dr. S.K.

Aggarwal, Regional Medical Advisor, Asia Pacific, Novartis touched on improving compliance of iron chelation. This was the first time too that there was a session on the new investigative modality of T2* MRI and the new oral chelator 'Exjade/ICL670'. There was a touching sharing session by Noorasyikin Mohd. Saad, Khoo Swee Hong and Baheyah Mohd. Jaafar. Once again, we counted on our stalward, S/N Saw Cheng Tiew to run the practical demonstration session on iron chelation. We had 67 participants who enjoyed themselves thoroughly.

In 2006, we decided to tackle the issue of our thalassaemics in Seberang Jaya. As such our **9th Thalassaemia Camp** was geared towards them with the theme being "Toward a Better Tomorrow". It was held in the Crown Jewel Hotel, Tanjung Bungah, Penang from 9-10th September, 2006. There were very special rates for the thalassaemics and parents as most of them could not afford to pay the fees. We were most satisfied to have an attendance of 127 participants. Once again, we were fortunate to have Sister Ms Emma Prescott – Thalassaemia Nurse Specialist, Whittington Hospital, London, UK. She touched on all aspects of Thalassaemia from the basics up to the recent developments. It was basically a revision for the thalassaemics and their parents from the Seberang Jaya hospital. Encik Nur Hisyam Ismail, the dietitian from Penang Hospital spoke on Nutrition in Thalassaemia stressing on the need for low iron diet with plenty of anti oxidants and dairy products with tea, coffee, spices and cereals to decrease absorption. Prof. Chan Lee Lee was invited to give a balanced talk on the role of Stem Cell Transplantation in Thalassaemia including its risks and complications. We took the opportunity to invite Dr. Tan Ru San from the Singapore Heart Centre, to speak on the T2* MRI Scan. Our Thalassaemics shared their experiences too with patients like Aminah Dahalan/ Mohd. Rawi Abd Latif; Noorasyikin Md. Saad/Mazfiza Mahamad Badawi, Zeti Aktar/Kudus Kadermastan, Hasmiza Hassan/Noor Kamsani Abd Wahab, Janice Kua and Mizal Roslan taking turns to talk about living with thalassaemia. The following day on 11th September 2006, there was a **1st Thalassaemia Workshop for Nurses and Health Personnel** at the Dewan Sinaran Ilmu Penang General Hospital. It was organised jointly with the Paediatric and Haematology Departments of the Penang General Hospital.

Our **10th camp** in 2007 was an outing for our Thalassaemics as we had it in the Bukit Merah Laketown Resort, Perak from 8th-10th, June, 2007. The theme was "Chelation, Chelation, Chelation". We had 130 participants and for the first time, our members proudly wore their distinctive Blue Vests. Besides the talks which emphasised on iron chelation, there was a session on thalassaemia screening by Public Health Nurse, Jenny Lee Poh Lean who shared on the pilot project by the Ministry of Health with Penang being one of the 3 selected centres. A total of 37 schools were picked with Form 4 students being screened for the carrier status. There was a useful talk too on Improving Compliance with Desferal by M/s Sharon Loh, Clinical Resource Liaison Nurse Novartis.

We had one session dedicated to stressing the Importance of Updating Patient's Record Books. This was touched on by Khoo Swee Hong and Mizal.

Before bedtime, sessions on desferal administration was organised for all the thalassaemics and their parents. During the interactive sessions, a feedback survey revealed that the most common excuses for lack of compliance were laziness, fear of pain, illness, business, denial and wrong expectations. This feedback proved very useful in helping the society to address this issue.

Our **11th Thalassaemia Camp** touched on “Compliance, Compliance, Compliance”. This was organised on the 17th–18th, November 2007 at the Crown Jewel Hotel in Penang. We had Paul Telfer, a Consultant Haematologist from Royal London Hospital and Queen Mary University of London. He spoke about recent advances in the care of Thalassaemia, HbH Disease and Thalassaemia Intermedia. There was a very interesting topic on Preparing for Pregnancy and Fatherhood. Prof. Elizabeth George, spoke on the Importance of Screening for Thalassaemia. Once again, we were very happy to have Dr. Tan Ru San Consultant Cardiologist Singapore heart Centre who presented his progress reports on the T2* Scan studies on our thalassaemics. There were very important sessions on the Problems that thalassaemics face. Doctors, patients and parents spoke on their respective aspects. The camp attendance jumped to a record 165 participants with some coming all the way from Singapore.

The weekend camp was followed up with a **2nd Thalassaemia Workshop for Doctors, Nurses and Health Personnel** which was jointly organised with the Haematology Unit of Penang Hospital. The same speakers spoke on medicals topics like iron chelation therapy, the role of T2* and new advances. Case discussions proved to be extremely interesting with many participants requesting for more case discussions in future workshops.

As we enter our twentieth year in 2008, we can look back proudly on our achievements in the field of continuing medical education. We have had successful seminars, workshops and conferences with international and national guest speakers. We have seen the participation in our camps growing exponentially and we have seen the success stories of our camps. We look forward to organising more activities in future and we hope for greater support from our thalassaemics and their families, the public, nurses, doctors and our ever loyal supporters and volunteers.

Report by Dr. Dan Giap Liang

