



WHY THE PENANG THALASSAEMIA SOCIETY EXISTS..... by Khoo Swee Hong

It was the year 1986, and for the first time I was using a blood filter for Janice's blood transfusion. As usual, we were in the children's ward in General Hospital in a section furthest away from the nurses' station where all the thalassaemics were. None of the staff have used a filter before and I was desperately looking for help to fix it. When the filter was finally fixed and blood was running smoothly through the filter into Janice, the other parents came to me to ask what it was and how come they were not given the filters. I had to explain that it is important that the blood has to be filtered so that the thalassaemics do not get most of the white blood cells, thus minimizing reactions to the transfusions. And also that the hospital was not giving the filters and I had to buy it myself. I could see in their eyes that they were keen to do the same for their children. But their shoulders sagged and eyes dropped as they started to move away from Janice's bed when they learnt about the cost involved. Their helplessness filled me with guilt. I knew that I would not be able to face them every fortnight by giving my daughter the best that I could afford while they could not. Something had to be done so that all thalassaemics will have a chance of equal treatment.

I called up some old friends of mine, knowing that I could depend on them for support. Through the press, we got more support and formed a pro-tem committee and sent an application for registration with the Registrar of Societies. The Penang Thalassaemia Society was officially registered on 20th January 1988.

The first task for the Society was to recruit blood donors so as to ensure enough blood supply for the thalassaemics. There were times when the blood bank was not able to supply blood and haemoglobin levels dropped to below 5. We managed to work out an arrangement whereby all thalassaemics were given blood on the understanding that we will replenish the blood bank whenever needed.

Once the problem of blood supply was taken care of, it was time to raise funds so that treatment subsidies can be offered. We started with subsidizing only 2 vials of life saving chelation drugs per month out of the minimum 20 required. Over the years we were able to give up to a maximum of 90% subsidy on full treatment to compliant and proactive members. Now the Society is relieved of these subsidies as the government is supplying them. We can further support our doctors in improving monitoring tests so that our thalassaemics are in the best of health as far as possible.

In order for thalassaemics to grow up to be productive adults, they must not miss school during their hospital visits. Hospital time must also be minimal. Visits for treatment must be hassle and stress free. The hospital started day care services for thalassaemics from the early 90's, allowing transfusions to be done within one day as opposed to a minimum of 3 days of ward admission. Arrangements were made with the hospital for school going thalassaemics to have their treatment without missing school. Now, some thalassaemics are working adults and continue to require treatment outside working hours. 20 years ago, life expectancy for thalassaemics was until their late teens and early 20's. Now, we have working adults with some married and becoming parents.

Credit must be given to our medical team who has given us total support in whatever we do and for allowing us to implement treatment schemes (some viewed as controversial by their colleagues in the medical fraternity) that our finances enabled us to. Without their support and co-operation, we would not have been so successful in improving the quality of life of our thalassaemics.

The thalassaemia community in Penang is most privileged to have a group of supporters who are working wholeheartedly and tirelessly for the cause. They willingly spend time and effort in the cause of thalassaemia, raising funds, spreading awareness and continuing to improve the level of care and quality of life of our thalassaemics.

Having a chronic disorder, thalassaemics need life-long medical management, continuous support and motivation. To address these aspects, the Society regularly organizes motivational camps and educational workshops for both thalassaemics and carers. To ensure continuing medical and health education, members attend local and international conferences on thalassaemia.

The future for thalassaemics is so much brighter and more positive now that the government is finally giving chelation therapy. The Society can now focus on public education and awareness to ensure that thalassaemics will grow up to be productive adults and useful members of the community. However, for this to happen, they must be able to be assimilated into society with no discrimination and must not be viewed in a negative light. We must work to empower thalassaemics so that they are not looked upon with fear and pity. Thalassaemia may be an inherited disorder but it is not worse than diabetes or hypertension. It is no longer a fatal condition in Malaysia. The Society must now work towards a better understanding of thalassaemia by the general public.



27 October 1988 - Official launching of Pulau Pinang Thalassaemia Society by Patron, TYT, Tun Datuk Dr. Haji Awang Bin Hussan @ Shangri-la Hotel Penang



The volunteers of The Penang Thalassaemia Society

