

2nd NATIONAL THALASSAEMIA SEMINAR
by Siang A/L Lim (a parent)

Forty of us from Penang Thalassaemia Society left Seberang Jaya Hospital at 7am on Friday 5th of May 2006 by coach. We were on our way to attend the **2nd National Thalassaemia Seminar** in Kuala Lumpur. Our first stop was for breakfast at the rest area in Bukit Merah.

We reached KL around noon and had our lunch at the Muzium Negara Restaurant. After lunch, we were given time to visit the museum. Everbody seemed happy especially Mizal. He had his photo taken with a mannequin dressed in a wedding attire!

We reached The Grand Central Hotel at 3pm. After checking in, it's free time for us. Since I was too lazy to go anywhere, I took a nap in the hotel room. We had our dinner at The Legend Hotel nearby (where the seminar would be held) . Our boria group "**Boria Thalassaemia Pulau Pinang**" practiced after dinner for we were going to perform at the seminar the next day.

Day1 - After breakfast, we adjourned to The Legend Hotel for registration for the seminar. We were each given a bag and a T-shirt. "**The 2nd National Thalassaemia Seminar and The International Thalassaemia Day 2006**" was officiated by the Deputy Health Minister. This was followed by a pledge "To Conquer Mount Kinabalu 2007" by Thalassaemics and a multimedia show.

This day was filled with talks by experts from overseas as well as locals. Among the interesting topics were "**The Global Burden of Genetic Disease: Thalassaemia As A Model**" by Professor Dr. Suthat Fucharoen and "**The Thalassaemia Prevention Programme in Malaysia : Big plans and Big Hopes**" by Dato' Dr. Narimah Awin.

The invaluable information I gained from the talks was also an eye opener . Now I know more what my two Thalassaemic children can eat and cannot eat. All this while is my wife who knows more. Unfortunately, all the talks are delivered in English. I am not sure whether some of the participants understood the speakers. I noticed that many were not attentive during the talks. Some were even seen loitering outside the seminar hall. Was it because they did not understand, not interested or just bored?

During the 4th symposium (**Perspective of patients and parents**), relevant issues were raised - the abilities of parents to care and raise their Thalassaemic child , the abilities of adult Thalassaemics to be successful in life. Shajaratuldur Suhaimi was cited as an example of a successful Thalassaemic. She's currently doing her Master's degree. I, too have big plans for my children but I was not confident whether it will materialized because of their Thalassaemia. Seeing this girl , Shajaratuldur , gives me hope that my children too can aim for their best and not let their condition be a deterrent.

Day 2 started with a Q &A session . Participants were given the opportunity to raised any issues of their concern.The forum on "**Ethical,Legal and Religious Issue In Thalassaemic Prevention**" was indeed thought provoking . I recalled the decision we had

to make when my wife became pregnant with our youngest child. We were advised to do the test on the foetus. Although we are Buddhist, we never really looked from the religious point of view. We were just too worried and scared. After two weeks of sleepless nights and inner thinking, my wife decided that she couldn't abort the baby even if she's thalassaemic. She didn't want to do the test - our daughter was born thalassaemic (intermedia) like her brother. We have never regretted our decision, we accept our children as God's gifts and also as a test of our faith in Him.

After the forum and lunch, it was time for relaxation! We went window shopping in the Bukit Bintang area. We started our journey back to Penang late afternoon and arrived in Penang around 11pm.

Though it was a tiring trip, I am glad I have this opportunity to further understand and have better insight of Thalassaemia. It was indeed an informative, fact-filled seminar where all of us get together for a common cause.