



## Reminiscences.....

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This year, as our society celebrates its 20<sup>th</sup> anniversary, I look back with bitter sweet memories. Twenty years ago when we started this society,

Thalassaemia was considered a terminal disease with a hopeless prognosis for our children who were unfortunate enough to suffer from this blood disorder. I recall vividly those days long ago when doing the ward rounds as Head of the Penang Paediatric Unit in the Penang General Hospital. Upon reaching the cubicles with our thalassaemic children, house officers would comment, "Oh, these are only the Thalassaemics here for blood transfusions, we need not see them!". Such was the fatalistic attitude of the young medical trainees towards these children in those days. Unfortunately, this mindset was prevalent throughout the whole country then.

It was because of this misconception, that we started our long journey together to change and revolutionise the management of these thalassaemic children under our care. When we had our first society meeting, it was gratifying to realise that we had parents, doctors, paramedical staff and volunteers who were willing to offer their time, effort and support in our fight to improve the lot of these special children.

I have to admit that there were many dark days during the first few years. There were times when I was extremely disheartened due to the heavy burden. We lost some of our children in those early years. Discouraging remarks and comments were passed by fellow doctors about the futility of our efforts in those early days. There was not much support from medical colleagues and it was a battle trying to convince ministry officials to increase allocations for the treatment of our thalassaemic children. There were internal squabbles too within the society which had to be smoothed out so that we did not lose focus. Fund raising to buy desferal and blood filters for our children was always a challenge. We had to appeal to the authorities for approval to start oral deferipone. Looking back now, I can appreciate that those constant struggles and trying times made us tougher and better prepared to push our society to aim higher in seeking the best for our Thalassaemic children.

Now, as we enjoy the fruits of our long labour of the past 20 years, I feel happy and gratified that it was not in vain. It has been worth all those years of educating our children and their parents to persevere with treatment despite not knowing what lay ahead. The constant struggle to keep them well, healthy and motivated in anticipation of new treatment strategies in the horizon. We have won so many victories that I can now savour this moment as I look back at those years long ago. Desferal and filters are now provided free and oral chelators are readily available. Our Thalassaemic children have all grown up and have become parents of healthy children!

As I finish I would like to acknowledge the sacrifices made by our volunteers who have been with our society all these years. Without their help and contributions, I doubt if our society would have succeeded with all these achievements. I am happy that there are new medical and non medical members who are playing important roles in our society now. With new blood and new ideas, I am looking forward to a very bright and promising future as our society continues its efforts to improve the care of our Thalassaemics in Penang. I feel that our last remaining goal should be the universal screening for thalassaemia in our general population.

With this, I would like to end with a word of thanks to all the members of the society for giving me the opportunity to work together with them to make it a better world for our thalassaemic children.

