HAVING A THALASSAEMIC CHILD........

by Khoo Swee Hong

Khoo Swee Hong with daughter Janice

When you bring a child into this world, you make a commitment to nurture and ensure this baby grows up to be a successful adult achieving his/her highest potential. It is no different if the child has a chronic blood disorder like thalassaemia. You have the same hopes and aspirations for her and expect her to achieve her full potential. And you provide her with the best opportunities that you are capable of. Thalassaemia is only part of your child. Just like having to teeth that must be brushed, hair that must be washed. And for her, she has to top up her blood when it is low and get rid of her excess iron accumulated from the multiple transfusions. Thus, you incorporate her hospital visits into your daily life, together with her daily chelation regime and the many monitoring tests. And ferrying her for kindergarten, music etc etc

You have the same expectations from her as from your other child and do not allow her to use thalassaemia as an excuse to not do her best. She has to follow the same rules as her sister and bear the consequences of her mistakes or reap the rewards from her hard work.

Living with thalassaemia makes you realize, as a parent, that you've got to make sure that the family is familiar with her care and you are not the sole carer, in case something happens to you. You must train her to be responsible for her own management when she is old enough, to be knowledgeable of her condition and be aware of her treatment regime. In other words, she must be able to look after herself and knows what it takes to be in the best of health.

As a mother, I take the initiative to learn as much about thalassaemia as I possibly can. It is unfair to expect the medical team to do so. They have to look after all other illnesses that exist. As my daughter grows older, we work as a team and specialize in thalassaemia care and management. So long as we understand and are knowledgeable about thalassaemia, it is no longer a burden. We deal with any complications that arises and try to overcome it in the best possible way. Isn't this what life is all about?? Each and everyone of us has our own challenges. However, we are really privileged to have a whole team of doctors, nurses, lab technicians, volunteers and family (thalassaemia family and our own) to support us in dealing with ours.

Thalassaemia is not a problem. It is only a problem if we allow it to be. We can accept that thalassaemia is in the family and deal with it, or we can let its problems consume us and curl up in a corner and fade away in self pity. From the way I see it, I owe it to my daughter to incorporate it into our lifestyles and live the life that we are blessed with, with a positive and optimistic outlook. In fact, thalassaemia has made us stronger , with greater empathy to everything else.