



Bone Marrow Transplant - A Parent's Experience

by Ivy Teoh

When the doctor first informed me that Jasmine's blood results confirmed that she has Beta Thalassaemia Major, I was in shock and could not believe it – that my little girl was going to suffer a life time of monthly blood transfusions and long term painful invasive treatment. It was very difficult to accept that she inherited this blood disorder from both my husband and I!

Thus we tried to seek different doctors looking for medications to cure her. However, after every consultation, we went home feeling like an empty shell, frustrated and disappointed. I felt incredibly sad, helplessness and terribly guilty that I have not been able to find a cure for her. I felt very angry and extremely bitter at myself and also upset at my husband for not knowing that both of us are Thalassaemia carriers! I kept asking why it has to happen to my little girl ??.. Why didn't we give pay attention to and focus on our health history or have a proper medical check-up before ?

Each time I attended to Jasmine's blood transfusion, I felt so awful and wept secretly inside my heart. Emotional support from family can be invaluable, but seeing needles poking into my little girl's small tiny hand was very difficult and painful for me to accept.

As both my husband and me are working, we had to re-adjust our plan between working and taking care of our family. From the early stage, we compromised with me giving full concentration on Jasmine while he handled the rest of the family needs. Not only did our working life change but we had to also give more focus on our diet - especially with less iron content. She had rashes each time after her blood transfusions and we also tried to avoid sick people cuddling her as we were so worried for her health. I continued to find out more on how to handle and give proper care to Jasmine. I attended the Thalassaemia seminar arranged by Penang Thalassaemia society in Dec 2003. Through this seminar, we learnt that Bone-Marrow Transplant, if successful can offer a complete cure for Thalassaemia.

We were very excited and happy to know more about BMT and at the same time were fearful and worried of the risks that we might face. However, we decided to go ahead with sending both my older boys for HLA typing hoping to find a match for Jasmine while she continued with her regular blood transfusion at ~ 3/4 weeks interval. Meanwhile we could only hope and pray.. “ please, let every thing be OK “ and each day, we looked forward for the result. Finally, 2 months later we got the complete result and...very fortunately, my eldest son was found to have a HLA full-match with Jasmine ! We were so relieved to receive this news.

It was time for us to take a huge step... It was a very difficult and tough decision for us to make. Should we take the risk and proceed with BMT ?... If we don't, will we deprive Jasmine of the only opportunity for a complete cure. Finally... a call from UMMC Professor Chan Lee Lee and the very next morning at 8am, we arrived at her office. We listened carefully to her advice on the BMT procedures as well as her explanation of the risks and finally we consented to proceed with the BMT.

A tentative date was given and we waited. Meanwhile, I started to make preparations to stay in KL and sought my employer's permission for long leave from work since we could not predict how long we needed for Jasmine to recover after her BMT.

During BMT, I had to stick to the schedule given for Jasmine's medication. As she went through her 1st 8 days of conditioning, she got weaker each day. I focused on her needs and diet. I also started to monitor her input and output round the clock. I monitored her intake of both solid foods and liquid juices and water and her output too in the form of stools & urine.

During this period, she was particularly vulnerable to infections and naturally I wanted to do everything I could to protect her. Keeping the bedroom and bathroom clean, sterilizing all her feeding equipments and with careful attention to preparing, cooking and storing her food & drinks. I also made a habit of brushing her teeth and gargling

with salt water after every meal.

Making sure that her CVL was not accidentally pulled out was also very important. I remembered the incident when she fell from her baby-cot while I was washing her feeding bottle and this gave me many sleepless nights ! I blamed myself for my carelessness and made sure that I would not leave her alone unless she was sleeping. Thus, physically and mentally, I had to be very alert and strong while staying in the hospital to take care of her.

I would say that despite her young age, Jasmine was very cooperative and did not give me much problems. In fact, she was very strong and understood the need to take regular medications with frequent cleaning of her wound. Each morning I would be excited waiting for her blood result as this would give us the indication of her condition. I recorded all her blood result each day so that I could discuss with my husband as he could not be with us. It was such a relief to see Jasmine getting stronger and healthier each day.

After post-BMT, she received blood transfusions twice when her HB dropped below 8 gm% and platelet transfusions thrice when her platelet count fell below 30,000. Jasmine is now a happy girl and growing well. As a family we have gone through feelings of shock, frustration and despair but we have had hope and lots of support, encouragement and care from friends, doctors and relatives. I am grateful to the doctors and nurses in UMMC and Penang General Hospital, the blood donors and the Penang Thalassaemia Society for all their help in ensuring that Jasmine received the best possible care for her Thalassaemia.

