

By Mr David Miller



Joshua with his parents, Victor and Peggy.

Joshua's Struggle

Club Rainbow (Singapore) – the adopted charity of the Singapore Medical Association, provides a range of support services catering to the special needs of more than 420 chronically ill children. In this issue, we examine how this charity is helping parents of premature babies.

What was to be a joyous occasion became the start of a long struggle for Victor and Peggy. Seven months into her pregnancy, Peggy suddenly went into labour and was rushed to Mount Elizabeth Hospital where she gave birth to their second child, another son – Joshua.

Born two months premature and weighing just 1,200 grams, the fight for his young innocent life began from his very first breath.

Said Victor, “He was so tiny, so fragile ... not much bigger than the palm of my hand. The doctors told us that there was fluid in his lungs, two of his heart valves had not closed and his liver was swollen. He was on life-support. Peggy and I knew then that our perfect little world had fallen apart and life would never be the same again.”

“Then Joshua’s blood platelets level dropped dangerously low. The doctors told us that there was nothing more that they could do. They advised us to call for a priest. It was one of the darkest days of our lives. We managed to get a

priest who came down and baptised him. The next morning his blood platelet count suddenly went back up. It was a miracle.”

But Joshua’s struggle for life was far from over. Three months after being warded in hospitals with bills running into the tens of thousands (which took the couple several years to pay off), there was an even bigger hurdle ahead.

Recounted Peggy, “When he was about 10 months old, we found out that he had cerebral palsy. He could not move his arms. His fingers were clenched tightly by his chest. He needed almost constant care. We had to be so careful with every little thing. When drinking from a bottle, he would sometimes turn blue and then his body would turn black because he would stop breathing. The same thing would happen if he cried.”

Joshua, now 10, has come a long way. With therapy, he has better control over his arm movements and fingers. He is attending a special school and hopefully one day, he could be taught some useful skills.

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Said Victor, "For a long time, we lived in our own world, taking care of Joshua and worrying about him. But when we joined Club Rainbow, a part of this dark cloud was lifted."

Children who are born premature with low birth weights and chronic complications form the largest illness group within the charity. The other main illness groups supported by Club Rainbow are Thalassaemia Major, Congenital Heart Diseases, Biliary Atresia and Spina Bifida.

To help couples deal with the many issues they will face in raising premature babies, Club Rainbow organises a range of support activities.

It offers individual counselling sessions for parents. The charity also works closely with hospitals to organise talks for parents and other caregivers. It also offers a range of social

activities providing parents with opportunities to meet and bond with other families who are going through the same struggle.

As these children get older, Club Rainbow will be introducing a number of activities for them. Depending on their needs, these could range from offering specific therapy to coping skills.

Said Victor, "Since joining Club Rainbow, we found that there were other families like us. Some of them were worse off."

"In the past, each time we brought Joshua out on our own, people would invariably stare at him and us. But when we took part in some of the outings organised by the charity, there were no stares. Everyone was in the same boat and we felt like a normal family again. The sharing sessions were very helpful. It is good to know that when times are tough, we are not alone." ■

Club Rainbow (Singapore)



**Providing Compassionate Relevant Services
for chronically ill children and their families**

ABOUT CLUB RAINBOW

Formed 14 years ago, Club Rainbow is an independent charity that aims to provide compassionate relevant services for chronically ill children and their families. It is currently helping more than 420 children suffering from a range of chronic and life-threatening illnesses. These include:

- Thalassaemia Major
- Biliary Atresia
- Congenital Heart Diseases
- Spina Bifida
- Premature babies with serious complications such as visual and hearing impairment, chronic lung problems and developmental delay.

Club Rainbow does not receive any grants from the government or other agencies and depends totally on public donations to support these children and their families with the range of free services provided. The charity firmly believes in being transparent in all their dealings. The types of free services provided are:

- Emotional Support
- Educational Help
- Informational Support
- Financial Assistance
- Social Integration

For more information on Club Rainbow, please visit their website www.clubrainbow.org. This charity is also always in need of volunteer doctors to assist in activities or to provide talks for families. If you would like to help, please call 6377 1789 or email contact@clubrainbow.org. ■

