



Jakob

Jakob Ajani Wu Shao
2 October 2003 – 5 July 2004

Jakob was born prematurely at 33 weeks of pregnancy. His parents Walter and Monique loved and supported him through his struggles to deal with endless problems and complications—and after 9 months and 3 days he gave up the battle and died of multiple organ failure. Jakob's father Walter has written a letter from his beloved son to tell his story, and adds his own personal letter to Jakob.

Written by Walter Wu, Jakob's father

Dear Uncles and Aunties

My name is Jakob Ajani Wu Shao, son of Walter and Monique. I was born on 2nd Oct 2003 (six weeks early) and weighed 1.43 kg. When I came, the doctor told my Dad that I would have to stay in hospital for at least one to two months. He also said that I would have some problems and that he would do his best to make me well.

Since my lungs were weak, the doctor used an ETT tube to help me breathe. After three days, he said that I had an open blood vessel near my heart. Most people call this condition a hole in the heart. So I was given medicine to close the hole. He also ran tests on my liver as my jaundice level was very high. I also suffered from fits and even choked on my milk several times. A nurse taking care of me said that I scared her as I did not breathe at all. The doctor also said that my body could not absorb the milk coming into my stomach.

A month later, the oxygen tube had been removed but I still needed to breathe with a box around my head, providing me with extra oxygen as my lungs were still weak. I also had a tube that sent a little milk through my nose to my stomach continuously as I couldn't stomach too much milk at one time. The doctor was also waiting for results from tests on my liver as he suspected I had liver disease. The nurses at the hospital thought that I might need to stay in the ICU for about three months or more.

After just over one month, I was transferred to another hospital. A few weeks later, the doctor told Daddy and Mummy that I had Lissencephaly. Daddy had already suspected this and was not very surprised. Worried about my condition, Mummy and Daddy cried. Then came another shock for them in January 2004 when the doctors discovered that I had Hiatus Hernia.

At this point, I was still breathing with a box around my head. Several times, my brain stopped sending messages to breathe and frightened everyone extremely. I even had a Code Blue announced once by a nurse aunty. Wow!

The next big thing was a double procedure on my stomach. A doctor used keyhole surgery to repair the Hiatus Hernia, perform a Fundoplication, and put a Bard button into the stomach. This meant that my stomach was finally in the correct position and I could also drink milk without vomiting so easily. The button let my parents pour milk through a tube directly into my stomach. I still couldn't swallow without choking. This would aspirate milk into my lungs and would cause pneumonia. The Fundoplication reduced this greatly and I was able to retain my feeds.

In May 2004, the doctors advised Mummy and Daddy that I needed a tracheotomy to help me breathe easily. The surgery was faster and shorter than the previous one. I was then transferred to the Children's Intensive Care Unit (CICU) where I would stay for a week. Then, I was transferred again. This time, to Ward 65, a stepped-down ward, different from the CICU.

I didn't like this place very much. Many visitors did not respect that my neighbours and I needed quiet rest to recover well. I remembered one particularly rude visitor (a mummy) who even sneezed in my direction—how inconsiderate! I also remembered Daddy being very upset about that. I spent a very uncomfortable two weeks in that ward.

In the week leading up to 11th June (my date of discharge) my parents were busy getting everything ready for me. I was very quiet due to some changes in my body. But the doctors thought that I was fine. On 7th June 2004, one of the consultants wanted to increase my feeds over a longer stretch instead of giving me less over a shorter period of time. Daddy didn't think it was a good idea. I started breathing very hard and my tummy was full with milk spilling out of my button. Daddy stopped them from feeding me and wanted the feeds to be reverted to the original volume. That night, he and Mummy stayed back late to make sure that my breathing was ok before they went home.

Unfortunately, the next day, my father received a call from the hospital. I couldn't breathe well and my heart rate was very slow. The staff took a long time to resuscitate me. They took blood to do ABG's and other tests. My potassium was very high and my sodium was very low. The doctors told Daddy that my glands were not functioning well. This was why my heart rate, blood pressure and temperature were all very erratic. They had to give me steroids to help me get better.

Over the next few weeks, I became swollen and nothing the doctors did worked. They ran tests and put me back on a glucose drip because I could not retain my milk. My pores were getting so big due to the swelling that I was leaking fluids through the pores on my back. My lungs were also flooding with fluids. The doctors had to insert a needle (chest tap) to draw out the fluid. They drew out 150 ml of fluid—the same amount as a small mineral water bottle. They wanted to repeat the chest tap the next day but I stopped breathing just before they began the procedure. This time, it was bad. Daddy thought I was gone and he nearly broke down. The doctors revived me and I was sent down to CICU.

Based on the tests and my condition, a new name was taught to Daddy—Nephrotic Syndrome. My kidneys were leaking protein and not washing my blood properly. The only treatment was to give me lots of steroids. Not to build muscles but to help my organs work better. Don't forget, I also had adrenal gland failure.

Daddy and Mummy were told a week later that my condition was not improving and the doctors were now in "palliative" mode. That big word meant to make sure I was comfortable because no medicine was going to save my life. Daddy and Mummy wanted to bring me home and a doctor said he would try to stabilise me.

On 3rd July, Mummy was happy because I tried so hard and I looked much better but I was gasping for breath all of the next day. My breathing only stabilised at night. My heartbeat was erratic and the doctors told Daddy and Mummy to prepare for the worst—yet again.

Then, 5th July came and my heartbeat slowed drastically. Daddy and Mummy were called at 7.40 am and told to come immediately. Thanks to the peak hour traffic, they only reached me about 8.35 am. They held me as my heart stopped and I slipped away.

Dear Jakob,

I want to say that I love you. I know that the nine months you spent in hospital weren't fun. But you were very brave. Every time you smiled, you brought so much joy to us. Your moments of pain were painful to us too. And yet, you fought on. You fought when the doctors gave up hope. You showed us all how strong you were.

Daddy wants you to know that Mummy and I will be strong, so don't worry about us. You're with Jesus now and there is no more pain. Daddy will take care of Mummy so you can go in peace.

Dear dear Jakob. We will really miss you so much. And yet we know that this is all for the best. I love you so much that each time I had to do something I knew might be painful for you, it hurt. Please forgive me.

Love

Daddy

Walt

We Will Remember

They shall not grow old, as we that are left grow old:
Age shall not weary them nor the years condemn.
At the going down of the sun, and in the morning,
We will remember them.

– Laurence Binyon