



Shai-Ann

Shai-Ann Kaela Tam Rong En
15 – 22 February 2004

Joe and Stefanie were already loving parents to 18-month-old Nathan when they conceived Shai-Ann. Their joy turned to dismay and fear when they were told at 20 weeks that she suffered from a rare but very serious heart condition (HLHS) and were advised to consider terminating the pregnancy. After much soul searching, they decided to continue to nurture Shai-Ann in utero and confront her fate, whatever that might be. Baby Shai-Ann fought hard to steal more time with her parents but only lived for one week.

Written by Isabelle Lim and Sonya Szpojnarowicz, from an interview with Joe and Stefanie, Shai-Ann's parents

At an early scan of their pregnancy, Joe and Stef were told that NT (Nuchal Thickening) was beyond the normal range, which was indicative of a possible complication such as Down Syndrome. Although they were advised to go for an amniocentesis test they decided against it, feeling that they would not terminate the pregnancy anyway, and wanted to keep this baby even if she had Down Syndrome.

They knew something was *really* wrong at the 20-week scan, when the ultrasonographer's very serious and silent demeanour confirmed their worst fears. Their doctor explained that Shai-Ann had HLHS (Hypoplastic Left Heart Syndrome). This is a rare and lethal condition where the baby's left heart is not fully developed (the left ventricle is too small to pump blood to the body)—and so is therefore unable efficiently to pump oxygenated blood to the body's major organs, including the brain and limbs.

They were told that serious corrective surgery would have to be done immediately after delivery to give Shai-Ann any chance of life at all, but that chances of survival at

this first-stage surgery were slim—and if they were lucky enough for it to work, she would need further complicated surgeries to be carried out during the first few years of her life.

That day was a whirlwind—they saw four or five advisors, including a medical counsellor and a professor, who drew diagrams of the heart to help explain what HLHS meant. Very little hope was given, and they agreed heavy heartedly to schedule an appointment to terminate the pregnancy—on the advice of the hospital where professionals seemed more inclined towards a “practical decision”.

The following time was a roller-coaster ride of emotions for Joe and Stef. Their parents were at first inclined towards ending the pregnancy, saying that the loss would be greater if they struggled on through the rest of the pregnancy and delivery only to lose their daughter then, or worrying about how difficult it would be if they had to see her strapped with tubes. Stef understood their concern, but explains, “as we gave it more thought and feeling, the answer became a little clearer. We wanted our baby and we wanted a chance at life for her. So we decided to name her ‘Shai-Ann Kaela Tam Rong En’ (Shai-Ann means ‘The Lord God Almighty’, Kaela means ‘Beloved’, the Chinese name Rong means ‘Glory’ and En means ‘Grace’). This was the nicest name we could think of for our little girl, so it was really a precious thing to give to a baby who was doomed not to live. I’d begun to feel her movements, which made the thought of an abortion even harder. We also decided that we wanted to put our faith in God for a miracle of healing—so we prayed that she would be healed despite having the heart condition during pregnancy. We hoped that perhaps at birth or in subsequent days after birth, she would get better and not need any surgery. Our parents, family, friends and church, although they had their own views, were very supportive of our decision, giving us moral, emotional and spiritual support whenever needed. They all knew it was a tough call and were understanding towards what we had to go through just in making a decision.”

Joe and Stef swung from confidence in their faith that somehow Shai-Ann would be healed, to despair over her uncertain fate. They tried to suppress their doubts and fears, holding onto their Christian faith in God’s purpose, believing that there had to be a greater reason why this had happened to them. But they also tried to prepare themselves to accept that Shai-Ann might not be healed and might not be meant to live. Stephanie says, “While we, being human, tend always to want reasons for everything, we had to learn that sometimes some things are just not meant to be understood, but to be accepted gracefully.”

Shai-Ann was born on the afternoon of 15th February 2004, and was immediately taken to the NICU for ventilatory support, tube feeding and sedation. Stef recounts, “We wept when we saw her. Her being born was a miracle in itself....She looked so perfect. And it was painful knowing that she wasn’t perfectly formed inside.”

Things seemed to be going well—on the 3rd day, the oxygen and sedative were reduced and she seemed to be breathing quite well on her own. The following day she was taken off intensive care and moved to the Quiet Room at the Special Care Nursery.

The next day, Friday, Joe and Stef were overjoyed to see their tiny daughter drink some milk from a bottle, although she panted a little, and to see her open her eyes and look at them. They began to hope for a miracle, and there was even talk of going home over the weekend.

But on Saturday morning everything started to go downhill. Shai-Ann's oxygen levels fell and she had to be sedated again. Family and friends came to the hospital to be with them all as everyone thought that this was "it". But her condition stabilised and she slept for most of the day. Joe and Stef couldn't bear to leave her and decided to spend the night at the hospital. She was panting breathlessly, and at about 4.00 in the morning the staff told them that Shai-Ann was unlikely to live until daybreak.

Shai-Ann died peacefully as her parents cradled her, kissed her, talked and sang to her. Stef says, "We were grateful that she had given us a 'warning'—her deteriorating condition on Saturday made us decide to stay overnight, which gave us the opportunity to be with her at 4.00 am when she was in distress. And we were grateful that we could be alone with her in the quiet of the night during her last hours. I had the chance to talk to her and share my dreams with her, to take time to kiss her goodbye and just hold her and touch her. I do think that she hung on to her life and fought for that one extra day of time, for us."

As Joe and Stef drove home that morning, Stef recounts, "I saw a sunrise that I will never forget. It was beautiful—the clouds, the skies. It gave me a sense of peace. For some reason, I saw the heaven that my little girl had gone to and I was happy for her. Happy and relieved that her pain and suffering was over. It was really a bittersweet moment. And I told my husband that we should take a morning drive on her death anniversary just to remember this peace."

Stef tells the story, "We missed her a lot and for a couple of weeks, I think I cried almost every day. I'd write letters to her telling her how I felt, or what her brother was up to, and even what I wish I could have done. It was especially difficult during my son's afternoon naptime, because the house would be so quiet and I could imagine that if Shai-Ann was home, she'd be crying for milk or something. Her cot was still not dismantled, the toys and little pillows—everything we'd prepared in faith that she would come home, was left untouched for a few weeks.

I would also drop by the shop in hospital mall where we bought the dress that she wore for her wake/funeral. I'd look for a dress of the same design just to remember how it looked on her and the feel of it. Maybe the sales staff think I'm loony as I do go there fairly often just to do that!

It helped that we agreed to talk openly about her and the loss, to share our feelings with each other, and never to condemn anything felt or said by each other, especially if one of us took longer to "get over it". It also helped that we gave each other the space to grieve on our own as well. Crying openly was NEVER taboo. Just lots of hugs and understanding. The key thing was never to bottle up or hide any feelings about our loss.

Our journey with Shai-Ann brought us closer as a couple. Her life brought healing

to some parts of our marriage, which I thought would take a miracle to mend. But they did. I do regret that it took our baby's life to mend her parents' relationship. I am eternally grateful to her.

And of course, it was a joy to know we were pregnant again. A church friend was concerned that we would see this third child as a replacement of Shai-Ann, but it is never so. In our hearts, we are parents of three children (how can I go through three full-term pregnancies and not remember how many!) even though (for convenience) sometimes, we just say that we have two. And we can't wait for the day we can tell Shai-Ann's story to her brothers, so that they can receive her into the family as we did, and be proud of her spirit and her life as well.

Joe and I talk a lot about what Shai-Ann might be like if she had lived, whether she'd be like her brothers or not, how old she would be today, what life would be like if she had survived etc. We do talk about that one week as well, but not really in detail. There is a song by 3 Doors Down ("Here Without You") that Joe reserves specially for her, and I tear up when I hear Sarah McLachlan's "Answer". (I heard this on CD one morning on our way to visit Shai-Ann in SCN. It couldn't have been a more painful moment in the car.) We mention her quite a bit in our conversations with other people (those who knew and went through the time with us). My Dad recently said she was the prettiest baby out of the three (I thought, "Of course lah, she's a girl!") And because her Birthday (15th February) is almost exactly one month after my 3rd child's Birthday (14th January), we had a time of remembrance with family and close friends, together with Jed's first-month celebration. We plan to tell the boys about their sister when they are old enough to understand, and to place her urn at a niche as a family occasion. She is very much part of the family and we keep her very much alive in memory.

Our pastor asked if we have "let her go"—yes, we have definitely let her go. But it doesn't change the fact that she is our child and we're her parents. It's just like having a daughter marry and move abroad. You let her go but you don't love her any less at all. And our way of loving her is to share her life and her courage with others, because we're so proud of her.