It would be a great honour to meet and personally thank the donor of the cord blood unit that saved Stephen. - Daniel

Stephen Oon was barely three months old when he was diagnosed with Chronic Granulomatous Disease (CGD). The three-year-old came a long way, braving through surgeries, multiple infections, Haematopoietic Stem Cell Transplant (HSCT) and isolation from his family.

Although a suitable cord blood unit was found from the Singapore Cord Blood Bank (SCBB) within months, it took over two years before he received the HSCT. During this ordeal, Stephen gathered strength from his family who were determined to pull through with him. For his parents, Daniel and Karen Oon, their source of hope was through the concerned parents.

For more information please visit www.scbb.com.sg
Alternatively, you may call 6394 5011 or email info@scbb.com.sg with your queries and feedback.

Stephen with his mother, Karen

True Grit

While KK Women’s and Children’s Hospital (KKWCH) in Singapore was well-versed in treating CGD, the rare immunodeficiency disorder in which certain immune system cells are unable to kill some types of bacteria and fungi, the condition is often discovered in very early childhood. Daniel explained: “The odds of getting CGD are very small. And the hard truth we found is that many patients with CGD usually do not survive past their early childhood, unless they get a Haematopoietic Stem Cell Transplant (HSCT) as soon as possible. Ideally, it should be done within a year after their birth... Transplant was the only chance of a cure for Stephen’s condition.”

Though shocked by the sudden news, the resilient parents were not in a state of denial but accepted Stephen’s condition readily. Karen said, “(This allowed us to) proceed quickly to the next stage of seeking a cure, acquiring knowledge on treatment and clinical skills in caring for him.”

Stephen with his family

Two months later, a suitable stem cell match for Stephen was found at SCBB. Unfortunately, the joy was short-lived.

Stephen had to be infection-free before he could receive the new stem cells. This time, the wait lasted for over two years. During this trying time, the Oons had to make lifestyle changes to accommodate to Stephen’s health condition.

Daniel shared, “We increased his medical leave period from 12 to 24 months to meet and personally thank the donor of the cord blood unit that saved Stephen.”

With the New Year approaching, both beneficaries share their experiences celebrating New Year through their transplant and their wishes for the New Year.

With each passing day, anxiety increased for the concerned parents...

Test of patience
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During this trying time, the Oons had to make lifestyle changes to accommodate to Stephen’s health condition.

Daniel shared, “We increased our isolation from family and friends, my wife and I would usually be out in the crowd to celebrate New Year, and sometimes even attend countdown parties to soak in the festive mood. However, being in the post-transplant stage, I had to be extra careful. In the end, I stayed home with my wife and Karen to welcome the New Year. I also stuck with my diet of healthy and hygienic food.

“It was post-transplant period for me when I welcomed 2012. The year-end celebration was full of apprehension. I did not want to go out and mix with the huge crowd, for fear of getting an infection. My wife and I would usually be out in the crowd to celebrate New Year, and sometimes even attend countdown parties to soak in the festive mood. However, being in the post-transplant stage, I had to be extra careful. In the end, I stayed home with my wife and Karen to welcome the New Year. I also stuck with my diet of healthy and hygienic food.

“It was still in the midst of my transplant during New Year in 2008. Some of my friends asked me to go for the countdown, but I was unable to. I felt kind of sad that I could not celebrate with my friends. On the other hand, I am thankful my family was around with me to welcome the New Year. I also received words of encouragement from my friends. In the coming year, I wish to continue to stay fit and healthy, and most importantly, wish for a smooth sailing year ahead!”

Goh Koon Wei, 23

Goh Koon Wei, post-transplant

Tan Wei Chuan, 31

Tan Wei Chuan are two of them. Both Singaporeans were diagnosed with Acute Lymphocytic Leukaemia (ALL) and transplant was the only cure for their diagnosis.

Leukaemia (ALL) and transplant was the only cure for their diagnosis. Goh Koon Wei and Tan Wei Chuan are two of them. Both Singaporeans were diagnosed with Acute Lymphocytic Leukaemia (ALL) and transplant was the only cure for their diagnosis.

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friends. We didn’t want to bring Stephen out of the house for his own safety. This was done to prevent him from picking up new infections from his interaction with other people and environment. In a way, we became very withdrawn from the outside world.

Stephen also underwent a colostomy, due to perianal infections, to make an opening called stoma near his abdomen. This assisted in collecting his stools in a bag attached to him. It took much effort for Daniel and Karen to drain and clean the stoma bag twice a day while remaining a crying and struggling Stephen. At the same time, they had to ensure Stephen does not come in contact with accidental spills and leaks.

Aside to that, the supportive parents were also worried about the change in Stephen’s behaviour after the colostomy. He became reclusive, smiled less, slept more and even lost his appetite. In an attempt to distract the then-two year old from his discomfort and displeasure, the supportive family had to coax and encourage Stephen to take part in his favourite activities such as playing with his toys and watching his favourite television shows.

During this tense period, the already-matched cord blood unit for Stephen was a constant reassurance to Daniel and Karen. This allowed them to divert their efforts on ensuring Stephen is infection-free and prepared for transplant.

Stephen received the transplant in early 2011. By then, Stephen had undergone at least 10 surgeries and many hospitalisation stays.

**Seclusion period**

As Stephen was in an immune-compromised state during the transplant procedure, he had to be in a controlled and sterile environment. This meant Stephen was confined within the vicinity of his bone marrow transplant room in the ward, where only his doctors, nurses and mother were allowed to enter.

The transplant period was a very stressful and turbulent time for Stephen’s parents. Daniel said, “At one stage, Stephen was experiencing fever, hypotension, hyperventilation, high heart rate and low oxygenation in his body all at the same time. Karen would wake up several times in the night to check that he is still breathing.”

Karen had to muster every ounce of her energy to tend to Stephen round-the-clock during this period.

Daniel, on the other hand, travelled between hospital and home, managed the house chores and spent time with their eldest and youngest children on top of juggling his work.

However, the separation from his son was the most difficult. Every day, Daniel would bring a miniature toy car for Stephen just to see his son’s face light up in delight even behind the glass doors that separated them physically or via video calls.

The toy cars became Stephen’s comfort during the isolation period, when he yearned to go to places with his family and play with his older sister.

**Counting blessings**

Stephen reached engraftment two weeks before he turned three years old in March this year, making it the best birthday present for him. This means the new blood-forming stem cells has started to grow and make healthy cells.

Although Stephen was discharged from the hospital and is recovering progressively, he had to be kept in clean environment till his immunity improves. This is because even a seemingly harmless trip to the shopping mall could cause life-threatening illnesses and put him back in hospital.

Stephen used to consume as many as 15 different types of medication. Now with improved health, his daily medicine intake is slowly decreasing. This is a huge relief to his parents who have to keep a close eye on the dosage and timings according to the prescription.

Stephen has now experienced many firsts together with his family – the first stroll in the park, the first meal in a restaurant, the first visit to the supermarket and many more. Daniel shared that Stephen is “like a fish out of the water, who is not familiar with social settings” and is slowly catching up with other kids of his age.

“After three and a half years of living with immunodeficiency, it was priceless to see the look on Stephen’s face when he went shopping for the first time to buy his first pair of sandals. When he walked into a toy shop, he said ‘No! That’s not what I’m cured, I can go everywhere!’” Daniel said.

There are still many things Stephen cannot do just yet, such as building a sandcastle at the beach – an outing he is looking forward to once he gets better.

With his family’s attentive care and the donated cord blood unit, Stephen was given a new lease of life.

Daniel said, "It would be a great honour to meet and personally thank the donor of the cord blood unit that saved Stephen. Your donation has saved my son from another bleak future. He can continue his life like a normal boy now, without fear of the great outdoors."

"To all the other cord blood donors, your little contribution could become the difference between life and death for a person, so thank you for your life-saving gift!"

**SCBB celebrates its 9th anniversary**

Over the past 9 years, SCBB has been fulfilling a social mission of facilitating life-saving transplants by storing donated cord blood predominantly of Asian lineage. This has helped raise the probability of needy Asian patients finding a match.

This was not an overnight achievement. The past nine years set the scene for SCBB to widen its recognition in Singapore and across the world. Take a look at key statistics and sharing from SCBB staff.

As part of my job, I receive collected cord blood from participating hospitals for processing and banking. Through my work, I realise that utmost care must be observed when handling the cord blood from the moment it is collected. What amazes me is the meticulous process that is required to adhere to the international standard. I perceive that SCBB lives up to its purpose of banking and preserving high safety and quality cord blood units.

- Sabariah Adam, Nurse Coordinator

Over the seven years of my working at SCBB, I have seen more parents coming forward to donate their baby’s cord blood, especially through walk-in interests from expectant parents and referrals from delivering doctors. Minorities such as Indians are also more willing to donate now after finding out about the benefits of cord blood donation.

- Michelle Enrica Sibalai Kaindoy, Clinical Coordinator

I would choose ‘courage’ to describe SCBB in one word. The essence of the character has been displayed by everyone who helped SCBB since its establishment.

Chairman Prof Tan See Kirat had the courage to start the public cord blood bank and has been the central figure to shape SCBB to become world class and successful.

The delivering doctors dare to introduce the concept of cord blood donation to expectant parents. They take the time to educate expectant parents on the significance of their donation to patients in need of cord blood transplant. They continuously dare themselves to collect as much cord blood as possible after ensuring the safety of the mother and newborn, so that the collected cord blood unit will be usable for future use.

The cord blood donors have the courage to be selfless and donate cord blood to help those who are in need. Our nurse coordinators have the courage to approach expectant mothers and tell them about the importance of cord blood donation. Last but not the least, transplant physicians have the courage to use cord blood to treat new conditions.

Without the courage from all these helping hands and other supporters, SCBB would not have been able to facilitate transplants in Singapore and around the world.

- Cecilia Tan, Nurse Coordinator
Stephen's parents, Daniel and Karen, were having a very stressful time for a number of reasons. They were being treated by doctors and nurses to ensure that Stephen was confined within a controlled and sterile environment. By then, Stephen had undergone at least 10 surgical procedures aligned with his care plan. Stephen received the transplant in early 2013. Although Stephen was discharged from the hospital and is recovering progressively, he had to be kept in clean environment till his immunity improves. This is because even a seemingly harmless trip to the shopping mall could cause life-threatening illnesses and put him back in hospital. Stephen used to consume as many as 15 different types of medication. Now with improved health, his daily medicine intake is slowly decreasing. This is a huge relief to his parents who have to keep a close eye on the dosage and timings according to the prescription.

Stephen is infection-free and prepared for his return home. This has helped raise the probability of needy Asian patients finding a match. This was not an overnight achievement. The past nine years set the scene for SCBB to widen its recognition in Singapore and across the world. Take a look at key statistics and sharing from SCBB staff.

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Cecilia Tan, Nurse Coordinator

### Categorisation of transplants

Local paediatrics

Local adults

International paediatrics

International adults

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*All statistics are correct as of 31 Oct 2013

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*Includes cord blood units for clinical, research and quality assurance

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It would be a great honour to meet and personally thank the donor of the cord blood unit that saved Stephen. - Daniel

While KKH - the hospital Stephen was admitted to – searched for a suitable stem cell match, Stephen had to go through a second surgery to remove another swelling caused by the abscess and Stephen was immediately wheeled for an emergency surgery. He was also diagnosed with CGD.

CGD is a rare type of immunodeficiency disorder in which certain immune system cells are unable to kill some types of bacteria and fungi. This leads to long-term and recurrent life-threatening infections. The condition is often discovered in very early childhood.

Daniel explained, “The odds of getting CGD are very small. And the hard truth we found is that many patients with CGD usually do not survive past their early childhood, unless they get a Haematopoietic Stem Cell Transplant (HSCT) as soon as possible. Ideally, it should be done within a year after their birth…” Transplant was the only chance of a cure for Stephen's condition.”

Though shocked by the sudden news, the resilient parents were not in a state of denial but accepted Stephen's condition readily. Karen said, “This allowed us to proceed quickly to the next stage of seeking a cure, acquiring knowledge on treatment and clinical skills in caring for him.”