



Baby Reef Carneson was diagnosed with Acute Lymphoblastic Leukemia at the age of 5 months during a routine pediatric check up. He was sent immediately by ambulance from the doctors rooms to Donald Gordon Medical Centre (DGMC) where he was met by an oncologist who did not mince her words and told us the horrible news. She further stated that his chances were not good because a) he had an extremely high white cell count (600,000) and b) he was under the age of 6 months - both of which were against his chances of survival.



A month into the Chemotherapy treatment Reef went into renal failure and had to be rushed to Morningside ICU and put on dialysis ... which he survived ... he then returned to DGMC and continued with an extremely aggressive protocol of chemotherapy. Approximately 3 months into his treatment he started seizing and these seizures could not be brought under control for 3 hours. He was again rushed to ICU at Garden City Clinic and treated for "epilepsy".



Back at DGMC he completed his chemo but as he had not gone into remission after the induction period it was decided that a bone marrow transplant would have to be performed and the search began for a suitable donor. No match was found amongst donors on the SA Bone marrow registry and so the search continued overseas and thankfully a 100% match was found in Germany.



He was transferred to Unitas Hospital, his port removed and a triple Hickman line inserted. His bone marrow was killed off completely with aggressive therapy and he was placed in isolation for 100 days.



It was after this that Reef's problems escalated. His little body swelled up with fluid to the point where he could hardly see out of his eyes and was unable to sit. Fluid also began to fill his lungs. His appetite disappeared and it was a battle to feed him. He was on so many intravenous medications that his liver started to take strain. He also developed graft versus host disease which had been explained could be fatal.

He spent his first birthday in isolation and was very ill indeed.

Having previously thought that he had been through the worst and the actual bone marrow transplant would be a breeze, we were horrified at how ill he became. One morning his blood pressure started to drop severely and he was rushed back to Garden City Clinic - it was discovered that he had gone into septic shock due to an infection in the very lines that were keeping him alive. The Hickman lines were removed from his chest and he was put onto a ventilator. He once again swelled up beyond recognition, developed a Klebsiella virus as well as a fungal infection in his blood. His graft versus host disease became so bad at this time that blisters formed all over his little body which opened into suppurating sores.



Every time they tried to turn him, his little face would get stuck to the pillow and he would start to bleed all over again.

A Professor Modi was called in to see him with regard to this and he diagnosed his skin condition as Steven Johnsons disease (which proved to be wrong at a skin biopsy done later). He started seizing again for 3 hour spells and no amount of "epilepsy" medication brought this under control. It was decided to take Reef to a Neurologist to check up on the seizures. It was then discovered that he did not in fact have epilepsy at all, but had bilateral subdural bleeds on the brain from allowing his platelets to get too low - another huge shock to all concerned. Reef for almost a year has needed platelets every three days to keep his platelets above 50 and to prevent further bleeds on the brain.



Reef at present shows no signs of cancer, but graft versus host disease, lack of appetite and weight loss as well as damage to his liver, lungs and bones present a huge problem. It looks as though Reef's platelets are now finally engrafting and he has not needed platelets for some time now! God knows what we would have done without the hundreds of caring people who donated platelets for him regularly.



Reef is the youngest baby to undergo bone marrow transplant in South Africa. He is unable to straighten his fingers or clench his fists due to skin thickening and tightening from the GVHD, the worst affected being his hands and feet. The itching is severe and he is unable to sleep at night, just screams and scratches.

We thank God daily for the miracle that is Reef as well as for all his caregivers, doctors and the public who unfailingly have donated platelets to keep this brave little boy alive.



Reef had recently been put onto Methotrexate to help with his skin condition - praying this works soon but sadly the Methotrexate bottomed out all of Reef's levels and he got CMV pneumonia and has to be air lifted from Unitas ICU to Garden City ICU via helicopter as they did not expect him to live. He was put on a oscillator in ICU for two days and then transferred to a ventilator for a week. Again we were told that his prognosis was not good, but this little man just will not give up. He was in ICU for 3 weeks and then went to the oncology ward for a further 2 weeks.



He was home and doing well for a couple of months when he fell over and broke his arm, a week later he broke his collar bone and sustained a bleed to the brain. We were then told that Reef had osteopaenia of his bones and we had to get a special walker imported that he gets strapped into to walk to prevent further falls.

One morning he woke up with a very swollen face on the one side and it was



discovered that he had an abscess in his tooth and was referred for surgery to remove most of his teeth (only left 6 teeth in his mouth). His front teeth were broken off into the gum from chemo and had to be cut out. A week later, Reef developed fevers and was taken back to hospital where it was discovered that he had an infection in his mouth. Another 2 weeks in hospital and we were praying that now he would be able to eat and get well.



The middle of September this year Reef developed a fever of 40 and started having seizures. He was again rushed to ICU at Garden city clinic and it was found that he had encephalitis - this was caused from a long standing mastoiditis which was ignored. He was having up to 5 seizures a day and this cause some brain injury - he is now unable to use his left arm and leg.

Reef then had grommets put into his ears and was sent home. He was unable to talk, walk, eat (his fed through an N.G. tube), had very brittle bones, a leaking heart valve, a guidewire that was left in his chest by accident (which could also be the cause of repeated infections), he has graft versus host disease of his skin, cannot open his hands at all and his liver is taking strain from all the medications (23 syringes a day).



The problem we faced here in South Africa was that no-one knew how to treat graft versus host disease, as there have never been any children that have survived this long. Also the specialists taking care of Reef are spread far and wide, they do not confer with each other so one will add a medication and another will say no. We needed an oncology hospital where all the specialists were under one roof and worked as a team for the good of the child.

Reef is 3 years old, weighs 9kg and wears baby clothing aged 6 - 12 months. He is incredibly bright and understands EVERYTHING we say to him and has even learnt some sign language. Without the use of his hands and legs, there is very little he can do, mostly he watches DVD's.



With the correct treatment, e.g. REHAB and possibly surgery, Reef could recover fully. His parents Ryan and Lydia sent his Oncologists referral letter to 5 different hospitals in the USA and awaited their reply - they would have to give up their home and car, put all their furniture into storage and move to the USA for as long as it takes to get this incredibly brave little boy healed. It is so very sad that he has fought off cancer and now has to contend with the savage after effects of chemo and steroids. He is not allowed near other children and for fear of getting another infection never leaves the house.



Finally we heard that the Children Hospital in Los Angeles were willing to take on his treatment and the doctors there were very confident that they could help him.

The family left for the USA on the 1<sup>st</sup> of November and Reef was due to start receiving his treatment shortly thereafter – sadly it was more tragic news when he developed a severe blood infection and had to be admitted to the ICU in order to fight this nasty infection. He spent almost a week in ICU and thanks to God's mercy he survived the infection and was discharged into the Bone Marrow Treatment centre for the start of his GVHD treatment. His bank

account is unfortunately not that lucky! The time spent in the ICU has drained the funds that are so vitally important for his GVHD treatment and today, Ryan and Lydia have been told that they have to take him out of the hospital unless they can come up with USD50 000 before the end of this week!!

The current GVHD therapy has been life changing for this little man – he is receiving speech therapy and has already, in such a short space of time, picked up a few words, learnt more sign language. He is also on various other OT programmes to assist with his hands and feet AND he has made some friends – hopefully the first of many!

To see how far he has come since leaving home is phenomenal and he is an inspiration to us all but he still needs around USD400 000 to keep this awesome treatment going – without it he faces life without speech, sight and movement! We are heartbroken at this bad news but remain positive and continue to pray and work tirelessly to raise these funds for our little hero. We are an army of warriors fighting for our most precious warrior but we are struggling and really need your help of a contribution, no matter how small!

I am honored to call this little boy my grandson and attach some photos of Reef's journey with cancer – notice anything? Through all this pain, trauma and agony my grandson is almost always smiling – a true warrior and our hero!

All my love  
CHARMEON CARNESON