

'OUR LITTLE Fighter'

A ROUTINE check-up revealed Reef Carneson had a deadly disease.

IF you're happy and you know it, clap your hands' booms from the speakers of a small CD player. It's Reef Carneson's favourite song and he's up in a flash, giggling and bouncing around the room. It's moments like this that remind his parents, Lydia and Ryan, just how lucky they are that their son is alive. Oncologists said Reef would be dead within the week after he was diagnosed at the age of five months with high risk infant ALL (acute lymphoblastic leukaemia). The brave little fighter with a love for music and dancing proved experts wrong. Today Reef, now aged four, is the youngest child to undergo a bone marrow transplant in South Africa and the longest survivor of ALL.

The Carneson family is originally from South Africa and took what they term 'a leap of faith', and moved to the United States for Reef's treatment. "Lydia and

Ryan were childhood friends but lost contact for a while before meeting up at the vet where Ryan was practice manager when Lydia brought her dog in for treatment," explains Reef's granny, Charmeon. "They got married a year later, wanted to start a family as soon as possible and were over the moon when Reef finally arrived."

Reef – named after Ben Affleck's character, Rafe, in the movie *Pearl Harbour* (spelt differently but pronounced the same) – was a premature baby, but otherwise normal and healthy in every way until the age of five months. Lydia noticed what looked like a mosquito bite on his forehead, which did not disappear and seemed to be growing. A little worried, she moved his routine six-month

check-up forward by a month. His paediatrician palpated Reef's tummy and must have felt the enlarged liver and spleen and immediately sent Reef

for blood tests and an ultrasound of his abdomen. His white blood cell count was over 200 000 (normal is up to 11 000). A drip was inserted into Reef's foot and he was rushed by ambulance to Donald Gordon Hospital where it was confirmed that he had leukaemia.

Leukaemia is fairly common in children, however, infant acute lymphoblastic leukaemia (Infant ALL) is more rare and severe. Reef started chemotherapy, but the shock to his system caused him to go into renal failure. He was rushed to Morningside Clinic ICU and put onto dialysis. Six months of chemotherapy followed, but the cancer didn't go into remission and a bone marrow transplant was Reef's only hope. He received this incredible gift of life from a young German man, but sadly developed severe chronic graft versus host disease (GVHD) of his skin, eyes,

liver and gut.

"GVHD is a life-threatening disease that causes the new bone marrow to see the body as foreign and try to fight it off," explains Charmeon.

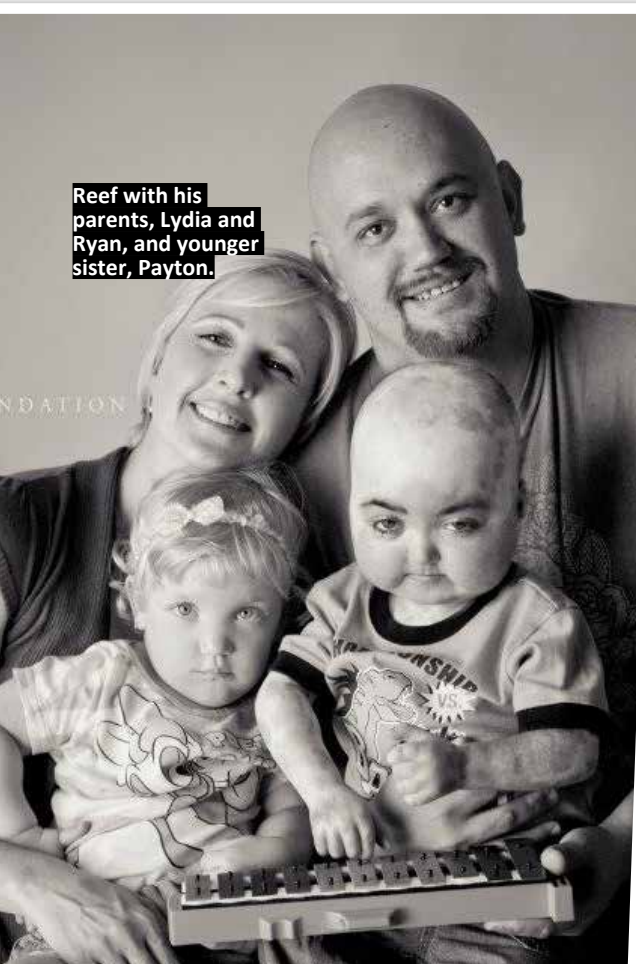
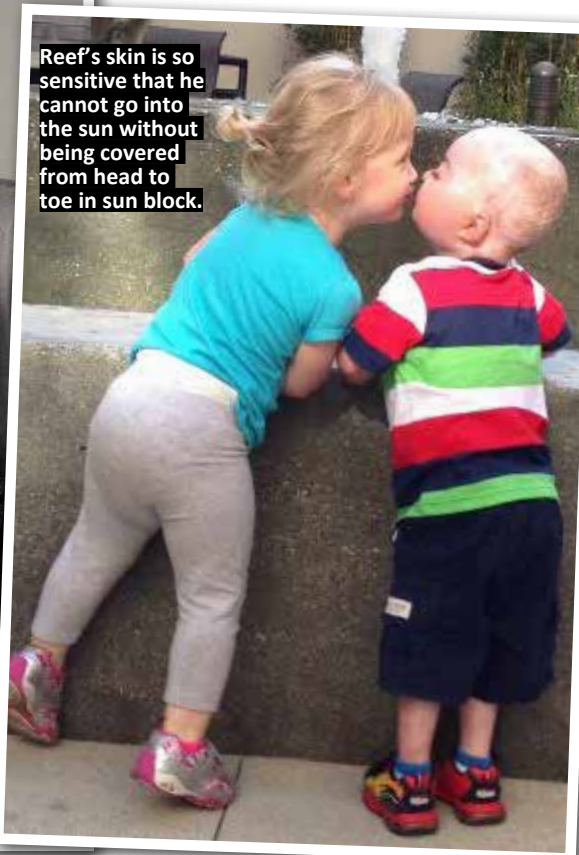
"The disease has left Reef unable to speak, open his hands, straighten his legs, eat or drink on his own. He spent over a year screaming every night from pain and severe itching of his skin. It was then that Lydia and Ryan decided to sell everything they had and move to the US after the Children's Hospital of Los Angeles agreed to help him."

Reef is currently being treated as an outpatient. As he is severely immune compromised, he is unable to mix with other children, so spends most of his time in the family's small apartment along with his two-year-old sister, Payton.

"A typical day for Reef begins at 07h30," says Charmeon. "He is unable to suck so a liquid formula is squirted into his mouth throughout the day to keep him hydrated. He needs 15 syringes of medicine and is bathed daily with special baby wash and colloidal oats to help with his skin, after which he is creamed from head to toe and both steroid drops and ointment are put into his eyes. He has speech, occupational and physical therapy at hospital and special education at home twice a week. At night, splints

'He spent over a year screaming every night from pain and severe itching of his skin'

Reef's skin is so sensitive that he cannot go into the sun without being covered from head to toe in sun block.



Reef with his parents, Lydia and Ryan, and younger sister, Payton.

are applied to his hands and legs as GVHD causes contractures of all the joints similar to that in severe burn victims. He recently underwent a hearing test and had to be fitted with a hearing aid and the family is saving up so he can undergo dental surgery as the chemotherapy has stripped the enamel off his teeth, which could lead to infection. He recently underwent an ECG and he was found to have a leaking bicuspid valve in his heart and a substantial amount of brain damage."

Reef and his family originally went to the USA on a medical visa, which they were told had to be renewed by him coming back to SA annually. This was not an option both financially and from a health point of view (Reef caught an infection on the plane going to the USA and landed up in ICU, which cost R995 000 which the family paid for from the sale of their possessions). Neither parent is allowed to work in the US, so they are reliant entirely on donations.

As the end of the first year in the US drew near, Lydia and Ryan consulted a pro bono immigration attorney who told them that they only had two options to stay in the US: invest R900 000 in a business, which they did not have, or for Ryan to obtain a study visa, and while he was studying Reef would be allowed to continue his treatment. Ryan found that the cheapest degree course was that of becoming a baking and pastry chef – an 18-month course with an associate science degree at graduation. The family took out loans to pay for his studies and he, in the midst of all the stress, has excelled and

obtained a Presidential Honours roll award for the first two quarters. Sadly, study funds have run out and they are petrified that Reef may have to come back to SA and an uncertain future.

"We have tried appealing to various hotel groups and top restaurants, begging for a bursary for him to complete his studies (graduating in December) with the

promise that he would work for them for a year for free post graduation, but to date have had no success," says Charmeon.

"We continue to pray that Reef can receive more

treatment in the US and that Ryan can graduate, which will enable him to provide for his family in the future."

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Reef was diagnosed at five months old with acute lymphoblastic leukaemia.



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If you are in a position to help the family, Reef has an SMS line. SMS the word REEF to 38771 at a charge of R10, or log onto www.savebabyreef.com for more information, or his Facebook page, 1,000 candles for baby reef official page.

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