

Reef at sister Payten's fourth birthday party. Payten and Reef have to live in isolation as the slightest infection could be fatal to Reef.

SETBACK FOR BRAVE REEF

He's been through so much already, but now Reef Carneson has skin cancer and the family face deportation from the US By DANÉL BLAAUW

HE TRIES his best to join the rest of the small group gathered around the cake as they sing Happy Birthday to his sister, who's just turned four. But all the plucky six-year-old can manage is a forced phonetic sound. "HA... BI... YOUU...", he belts out excitedly and throws his arms in the air as everyone shouts, "Hooray!"

The video is heartbreaking to watch. Reef Carneson's head is covered in yellow sores and seems too big for his tiny body. His little hands are fused into tight fists and every move he makes takes superhuman effort –

and yet, although he's in constant pain, he's always smiling.

Despite his jollity the party of his sister, Payten, is a low-key affair with only Reef, parents Lydia and Ryan and grandparents Charmeon and Don Carneson in attendance. It would be too much of a risk to invite other children – they could bring in germs that could make the boy even sicker.

Even though Reef and his sister live an almost completely isolated existence in the family apartment in Los Angeles, America, it hasn't stopped word of his incredible story from filtering out. The South African boy, who at the age of 11 months became the youngest cancer patient in the country to

survive a bone marrow transplant, has captured the hearts of people around the world with his brave fighting spirit.

His illness, graft-versus-host disease (GVHD), is so rare it's the inspiration for a proposed episode of popular hospital TV drama series *Grey's Anatomy*.

"Reefie isn't in the episode and it's not about him but the producers had heard about his disease and decided to focus an episode on GVHD to make people aware of it," Ryan tells us via Skype from LA, where the family have been living for three years so Reef can be treated at a children's hospital in the city. "The writers heard about Reefie on the news. It's still only an idea and hasn't been 100 percent confirmed yet."

Actor Jason George, who plays the role of Dr Ben Warren in *Grey's Anatomy*, heard about Reef's struggle shortly after the family arrived in LA and he has visited them a few times.

"Justin Chambers and Sara Ramirez [who play Dr Alex Karev and Dr Callie Torres] have even tweeted about Reef," Ryan says.

Reef has been hailed as a "miracle" child because he's gone through so much and managed to beat the odds. But now he needs another miracle or two because a month ago he was diagnosed with skin cancer.

"It's a major setback," Ryan says. "It means he can no longer use the medication that suppresses the GVHD so he's more susceptible than ever to infections."

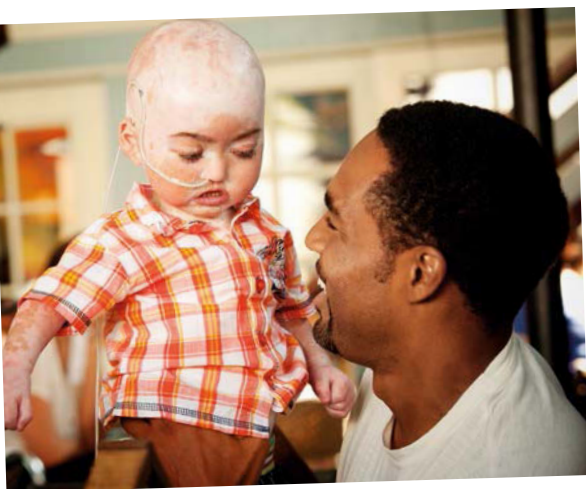
And now on top of everything the family faces possible deportation in February when Ryan's study visa expires. They've hired an immigration lawyer to plead their case but when we spoke to them everything was still up in the air as Ryan applies for a work visa.

"If Reef has to get on a plane back to South Africa it would be as good as a death sentence," Ryan says. "His doctors say he could easily pick up an infection on the flight."

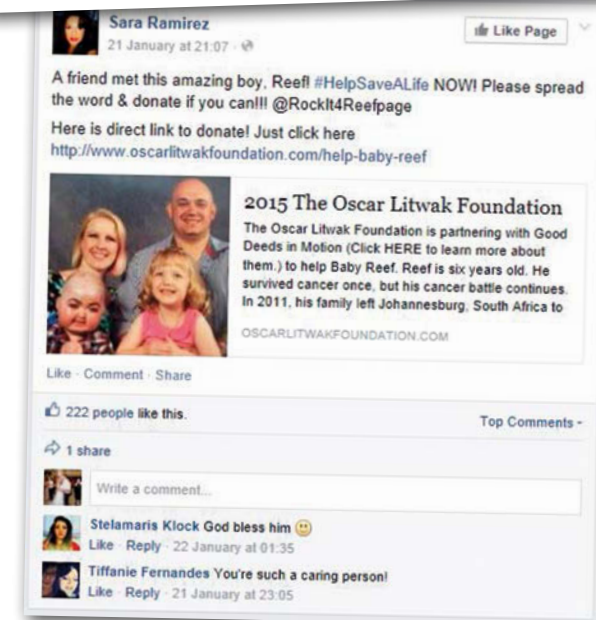
It's just after 11 pm in Los Angeles when we chat to Ryan (35). Lydia (35) and the kids are already in bed. In the background we can see Charmeon (63) walking around the apartment. She's the driving force behind Team Reef, a committee in South Africa that raises funds for Reef's medical costs and the family's daily expenses.

Ryan's dark brown eyes look sad and exhausted. The medical terms and names of medications and diseases roll off his tongue as if he's a doctor. And little wonder – Reef was just five months old when he was diagnosed with an aggressive form of leukaemia (YOU, 19 January 2012). YOU has interviewed his parents several times over the years and followed his often traumatic journey.

At 11 months Reef survived a bone marrow transplant, but then complications set in – his body rejected the bone marrow and he developed the rare GVHD, which means



BELOW LEFT: Sara Ramirez, Dr Callie Torres in TV series Grey's Anatomy, shared this Facebook message about Reef, encouraging her fans to support him. LEFT: Reef melted the heart of actor Jason George. BELOW: A scene from the show. A possible new episode inspired by Reef will deal with a case of GVHD (graft-versus-host disease).



Reef's medical costs are anything from \$100 (R1 150) to \$2 500 (R28 750) a month, depending on his condition.

An American organisation, Good Deeds In Motion, is trying to raise funds for them. "It's very difficult in America," Ryan says. "The American attitude is different. People don't realise what a generous and friendly nation South Africa is."

REEF'S skin cancer diagnosis came as a huge shock to the family.

"He was doing so well. He can walk, put on his slippers by himself and

tries hard to dress himself. He struggles to put on a shirt because he can't open his hands, but he tries."

His vocabulary has improved so much he no longer uses gestures to communicate and Ryan is often surprised by the words that come out of his son's mouth.

"His latest is, 'Daddy, behave yourself' and 'You're rude'."

But now because of the latest setback they feel they're back at square one.

"The cancer isn't that dangerous but because of Reef's history and because he's been taken off his medication the cancer could spread to his liver and other organs. There's also the danger that the GVHD could return," Ryan explains.

Under normal conditions the skin cancer could be burnt off or cut out but because Reef is so susceptible to infections doctors don't want to remove it surgically. Instead he's getting chemotherapy for the skin cancer in the form of a cream that's applied to his head.

"The cancer is on the side of his face and

on his head. He cries terribly when we apply the cream because it burns."

His skin doesn't heal so that's why he has lots of open sores, making him more susceptible to infection.

It's not only Reef who's suffering because of his rare disease.

"Payten can't go to school because if she comes into contact with other kids it poses a risk of infection to Reef," Ryan says. "She's being held back to some extent, which is very sad. She just wants to be a normal child, but Reef also just wants to be a normal child."

Reef and Payten are home-schooled three times a week.

"Payten is very sharp – she's actually at the level of six-year-old because she's being home-schooled along with Reef."

When the teacher comes to the apartment she must wear gloves, a coat and a mask to avoid exposing the children to germs.

Meanwhile the family anxiously count down the days to when they'll hear whether they're going to be deported. "It can go either way. We pray and hope for a miracle."

Just before we went to print Reef was rushed to hospital again, apparently because the sores on his head caused by his skin cancer became infected.

"His white blood count was 33 000 which is very high [a normal count is about 4 500 to 10 000]," his grandmother Charneon Carneson wrote in an email from L.A.

"Reef has a high fever, headache and diarrhoea."

For more about Reef go to savebabyreef.com. To make a donation of R10, SMS Reef to 38771. To make a monthly donation of R20, SMS Reef to 31222.

'The cancer could spread to his liver and other organs'

he has no immune system and the slightest infection could kill him.

The GVHD left him totally dehydrated and his skin was as hard as parchment and would tear with the slightest movement. Despite the pain he couldn't shed a single tear and at times he had continuous convulsions for up to three hours. Lydia had to carry him everywhere and at age three he still couldn't walk.

Eventually Ryan and Lydia sold their Johannesburg home and all their possessions and moved to America, where they've lived ever since.

"In South Africa he was in hospital every two weeks with an infection. In two-and-a-half years in America he's been admitted only once, and that was just after we arrived here – he'd picked up an infection on the flight," Ryan says.

But it's a struggle to keep their heads above water. The family live on donations and Ryan doesn't have a work permit and had to quit his job.

"I was studying which meant we could stay for another year. Then I was doing practicals which meant we could stay for a further year. But when Reef was diagnosed with skin cancer the doctors said I should rather spend as much time as possible with him."