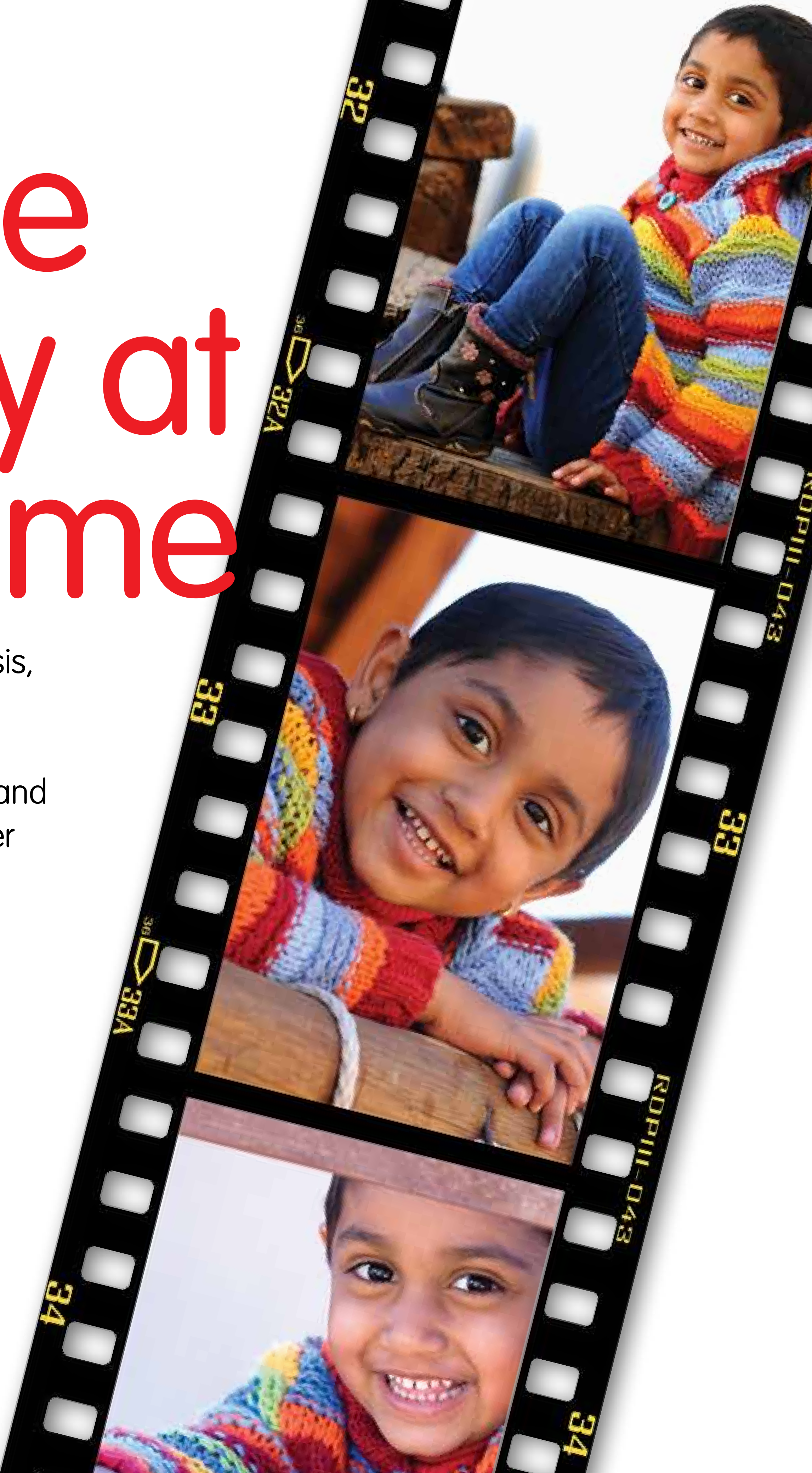
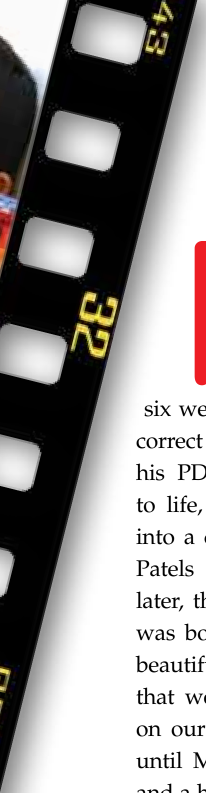
One day at a time

A scary diagnosis, and one every parent dreads, sent this mom, and family, into super strength mode

BY **CAMILLA RANKIN**





Ferhana Patel's first child, Tawseen, was born with Down Syndrome. He was immediately taken into ICU where he stayed for six weeks. He had open heart surgery to correct two holes in his tiny heart and close his PDA valve. Despite this scary start to life, Tawseen thrived and has grown into a characteristically loving child. The Patels were delighted when, four years later, their second child, Abdur Rhaman, was born, followed two years later by a beautiful daughter, Ayaana. "We thought that we had survived the biggest bump on our parenting journey with Tawseen, until May 2010 when Ayaana, then two and a half, woke up complaining of a sore tummy." Here is her story.

The unimaginable diagnosis

"Ayaana did not have a fever, but was grunting strangely so I took her to our GP who sent her for a chest X-ray. She had pneumonia. At the hospital, Ayaana was taken (alone) into a procedure room where they poked and prodded her for over an hour. She became hysterical – completely traumatised – so much so that now, over a year later, she still screams blue murder when a nurse dressed in blue comes near her. Ayaana was admitted for two days, but given the all clear for her blood count, and again a week later at a check-up we got the same results.

"Then two days later, she started to grunt and cough again. An X-ray showed the pneumonia was back and this time much worse. The pulmonologist was able to treat Ayaana with antibiotics, clearing the pneumonia, but was really concerned that an infection in her groin – like a festering blister – that she picked up in hospital was not healing. Her body should have been able to fight the infection, especially as she was on a course of antibiotics. It was rare for Ayaana not to be screaming when a doctor examined her, so when she was next asleep and the doctor did his checks, he was able to hear her heart and picked up a heart murmur. She, like Tawseen, had an open PDA valve and would need surgery to correct it. Thinking we had finally got to the bottom of all her medical woes, we booked her in for surgery.

"We were wrong. Two weeks before her scheduled operation, Ayaana got a severe ear infection and I noticed lumps on her neck. The doctor did a needle prick test and her blood looked like water it was so thin. He ordered a full blood count and told us not to go home but wait for the results at the hospital. At 6pm that night, he told us that Ayaana had Acute Lymphoblastic Leukaemia (ALL). Cancer. I was stunned. Although the doctor explained it all to us: treatments, success rates, in all the shock and confusion, I heard none of it."

And so the journey begins, again

"The next morning Ayaana was admitted to the Charlotte Maxeke Johannesburg Academic Hospital, which has the best paediatric oncology ward in Africa, under the care of Professor Janet Poole. At government hospitals children under six are treated for free and we were told that the costs of private treatment could reach the millions for the same level of care offered by this hospital.

"Ayaana was admitted immediately for the initial phase of treatment, due to last 33 days. My husband, still in denial, asked if we could go home and start treatment after Ramadaan. When they told us that treatment could not wait, the practical realities began to sink in. I could not leave Ayaana alone in the hospital – her trauma was still so great – but my other children were still at school, Tawseen needed to go to his therapies (at that stage he was seeing a physio, speech and occupational therapist once a week), so on some level our home life had to go on.

"My parents moved in, and I started a detailed diary to keep track of Ayaana's treatments, medications and procedures. With this type of cancer there are no stages of disease, you either have it or you don't.

"The cancer Ayaana has (ALL) accounts for 27 percent of all childhood cancers. Doctors do not know what causes it, or why one child gets it and another does not. It is not infectious or inherited. And left untreated it is fatal. Painfully fatal."

Hospital life

There are five stages of treatment for ALL: the initial phase, a second and third phase, which we chose to combine into a six-month high-risk chemo, then a fourth out-patient phase, followed by the fifth phase, which is maintenance. The doctors only explain the next phase when you get there – all the focus is on this phase, this month, this point: it's one day at a time.

"During the initial phase, Ayaana was in total isolation; not even her siblings were allowed to visit in case they brought some kind of infection with them. She received chemo via a drip until she was well enough to have the – totally unrelated – heart surgery, after which she would be eligible for a portacath (a catheter that is inserted under the skin in order to deliver medication directly into a vein).

"While we began our religious fast, my mother cooked all Ayaana's favourite meals, we brought trinkets, bedding, a kettle and a microwave to her hospital room and made as much of home out of it as we could.

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"The community of mothers in the ward we were in was incredible, as were the CHOC staff. Complete strangers whose children had gone through the same thing would come and talk to you, counsel you, tell you what to expect, giving you hope and support. We have made many new and deep friendships this way."

Wise beyond her years

"Ayaana seems to understand on some deeper level what is needed from her. When visitors come over unexpectedly, she takes herself off into her bedroom (to avoid infection) and says, 'My counts are too low,' or when the boys are swimming

CHILDHOOD CANCER IN SOUTH AFRICA

According to the CHOC Parent Handbook (2010) by Leandra Visser: "Childhood cancer is rare. Worldwide, 150 children per million are diagnosed with cancer each year. In South Africa, accurate figures have not yet been published, but some data suggests that only 70 to 80 children per million are diagnosed a year – a total of between 500 and 600 children each year. It is estimated that a further 500 children die of childhood cancers a year in South Africa before it is diagnosed or treated.

"Why? Sometimes people don't have access to the specialised medical services they need – this is especially true for rural areas and poor communities where people do not have the means (finances or transport) to seek medical help.

"Lack of awareness is another reason for this. Many parents don't recognise the early warning signs and symptoms and because it is actually such a rare disease, some doctors have never come across it in their practices."

See CHOC's early warning signs poster on our website: www.yourparenting.co.za. The good news is that the cure rates for childhood cancers are much higher than those for adults and today, the majority of childhood cancers can be treated very effectively and 60 to 75 percent can be completely cured. Visit CHOC's webite at www.choc.org.za for more.

LIttle survivor **Despite living with cancer, Ayaana's strength shines through**

and she is not well enough to, she will by choice dangle her feet in the pool and say, 'I am only a little of better. When I get lots of better I can go in.'

"It has been really hard explaining all the treatments to her, but she adores Barney and her brothers love the Transformers, so each of her medications has been given a name from these shows: "Barney and BJ are going in to fight the baddies!" which helps her to swallow the many – sometimes 12 at a time – bitter pills she has to take.

"Some of the medication has a profound effect on her personality, making her cranky, aggressive and very moody: there were days I could not tell when it was my daughter and when it was the meds talking. Even Ayaana will say on these days: 'The chemo is making me crazy.'"

A life on hold

"Ayaana has just reached stage five of her treatment: the maintenance phase. We have just had our first family holiday to the beach since her diagnosis and for now we only need to be in the hospital once a week for treatment. We have a bit of breathing space now. The road ahead is still long and full of the unknown, but at least now we can see the light at the end of it: Ayaana's light. "