

Thursday's spotlight: Each day brought new bone marrow donors but also despair as

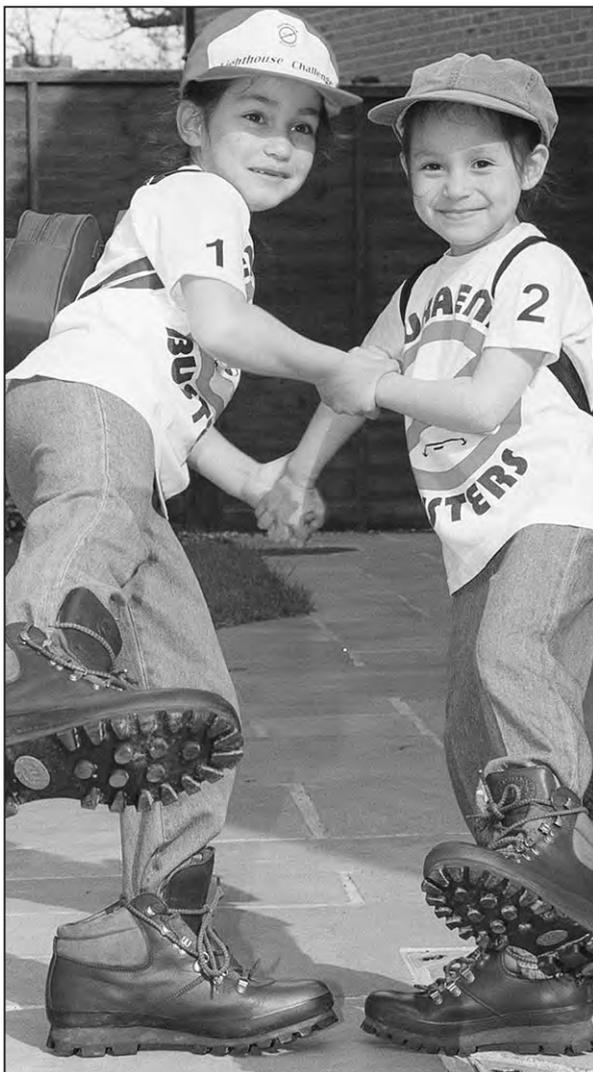
Charity of change:



ON CALL: David Flavell at the call centre in Poole.



PUBLIC EYE: The Leukaemia Busters logo was soon instantly recognisable.



FUNDRAISING: Serena and Sapphira Flavell help the fundraising efforts.

The fight

PART FOUR

Today we continue the story of Doctors David and Bee Flavell as they worked tirelessly to save their son. Tragically, their monumental efforts prove to be in vain.

I WAS really unprepared for the mayhem that followed after Simon's story broke on *South Today*.

The news team, headed by anchorman Bruce Parker, had put together a moving piece appealing for Eurasian donors.

They even interviewed Simon in his hospital bed, who touchingly told viewers he wanted to be a doctor like his mum and dad.

It was powerful stuff and we sat breathless after it was screened, hoping that it would elicit the right response.

Next morning the single telephone on my desk became hot as call after call came through from individuals and media organisations.

At the end of the previous night's item on Simon the BBC had asked viewers not to dial its switchboard, fearing it would be swamped with calls.

As a result, the following day all the calls arrived on my desk.

I was totally overwhelmed and attempted to cope the best I could, as did the general hospital switchboard, with its extensions all manually connected through an operator in those days.

It was obvious we had attracted a large number of potential bone marrow donors.

The big question now was how to administer this task and arrange for all the blood samples to be tested for compatibility with Simon's tissue type.

Initially we had anticipated all the blood samples would be tested by the Wessex Blood Transfusion Service but it quickly became obvious it wouldn't be able to cope with the numbers that started coming through.

Salvation came that same day in two different guises.



DEDICATED: Drs Bee and David Flavell worked tirelessly in their

Our first saviour came in the form of a call from the Anthony Nolan Research Centre at the Royal Free Hospital, an organisation taking its name from little Anthony, who had died in 1979 from aplastic anaemia.

At that time this organisation was the biggest bone marrow donor registry in the world with laboratory facilities that enabled it to offer to tissue-type all the blood samples from our potential donors.

The second came in the form of a telephone call from then *Daily Echo* health reporter Jacqui Goddard, wanting to interview myself, Bee and Simon.

At first Bee was reluctant to have

our space invaded once again, wanting to protect Simon from media glare and retain our privacy.

She was soon persuaded, however, that we couldn't run an effective campaign to find a donor for Simon by shying away from coverage.

A single phone call later and Jacqui had grabbed her coat and rushed to the general hospital, pen and notepad in hand.

Her entry into the picture was to change everything and prove instrumental, not just in our quest to find Simon a donor, but also in launching Leukaemia Busters in the years ahead, allowing it to become what it is today.

Postal strike hindered donor search

Slowly but surely we began to cope with the large number of inquiries and started to feel that we really were on track to finding Simon a donor.

Then, out of the blue, disaster struck.

Over 400 blood samples that we had arranged to have sent to The Anthony Nolan Labs got caught up in a postal strike and were stuck in mailbags at sorting offices throughout the country.

The blood only had a life expectancy of 48 hours; if it wasn't delivered to the Nolan lab within this time it was unusable.

To their credit, postal workers instigated a hand search at sorting offices throughout Britain, but it

was like searching for a needle in a haystack and consequently we never found more than 200 of the samples.

We will never know whether one of those lost samples would have been a suitable match for Simon, something we prefer not to think about.

Despite this setback, more than 2,000 individuals, many of them Eurasian, were tested and added to the Anthony Nolan panel.

We were to learn later that at least two people we'd recruited through Simon's appeal were suitable donors for patients in the US, one for a Cherokee woman in Oklahoma whose life was consequently saved.

a match could not be found and slowly they watched as their son slipped away

to save Simon



efforts to find a cure for their son Simon, pictured inset, before the illness took hold.

The very next day, the *Echo* ran Simon's story on the front page under the banner headline Can you save Simon?

Knowing the difficulties we faced with collecting names and addresses of potential donors calling into my office, the then editor Pat Fleming sanctioned Jacqui to set up two hotlines on her desk, each with high-capacity answering machines running 24 hours a day.

Day after day the calls came in continuously as the story went out on television and radio, as well as in newspapers.

The appeal rapidly took on a life of its own as the national and foreign press began to publish articles in London, New York, Sydney, Los Angeles, Bangkok and Gibraltar and it seemed the world was definitely on Simon's side.

A new complication arose when we realised we would have to pay for tests on blood samples from potential donors living in France and the US.

We simply didn't have the money – but were prepared to remortgage our house – but then the *Echo* came through again and launched an appeal to raise money for this purpose.

Through the generosity of kind-hearted readers, we were able to pay for the tests and shall be eternally grateful to them.

Time went by and Simon began to feel progressively better.

Bee spent most of her time with him on the ward while I worked up to 20 hours a day co-ordinating the appeal.

Jacqui would arrive at her desk in the *Echo* newsroom each morning and take all

the details off the answering-machines, copy them out longhand on to sheets and fax them to me at the general hospital.

I then arranged for the callers to be contacted to organise blood samples and ascertain their eligibility as a donor.

It was a daunting task for a lab office poorly prepared for such work, particularly as most possible donors worked during the day.

To solve this problem we arranged to bring in teams of volunteers at night who began the task in earnest – time was running out. Eventually we had to set up a call centre in Poole courtesy of British Telecom, manned by members of Ferndown Round Table and their families.

A handful of donors came very close to a match for Simon, but none was sufficiently close enough to allow a bone marrow transplant to go ahead.

For Simon the appeal had failed and as April approached we saw the first hint that his leukaemia was returning as the haematology department began reporting the "occasional leukaemia cell" in his blood.

It was with dignified acceptance that we sadly faced up to what we knew was inevitable, Simon taking strength from his Buddhist belief that his life was but one of many he would enjoy in the future.

True or not, it was his clinging to this notion that helped ease him from this world into the next.

As he lay dying we frankly discussed his

pending death. He was unafraid and totally accepting of his plight, concerned only that we should continue our research work after he was gone to improve things for future leukaemia sufferers.

It was during those last special days together that a sacred pledge was made between us.

We promised him two things: first that we'd do all we could through our work to seek cures for other children that came after him and, second, that we would have more children ourselves.

We had chosen to have only the one child in the past because of our commitment to our work.

Now that position had shifted and it became of burning importance to us to have more children after he'd gone.

These two pledges seemed to give him a sense of peace and inner tranquillity as,

day by day, his life slipped away until eventually he was no more and we were suddenly left childless.

At his funeral, or rather, the celebration of his life as we preferred to call it, I read out the following poem written for him by me for the occasion:

Freed spirit of ours

In time you shall return

Like the ebbing and flowing of ocean tides
On moon's rise we so often watched, you and I.

Such words befitted his love and understanding of the sea, a love we all shared as a sailing family, married to his belief that one day he'd be returning, just as does the tide daily.

Shortly after his death the *Echo* ran moving tributes to Simon and hints began to appear in its coverage that something had to be done for children who had drug-resistant leukaemia – roughly one-third of all childhood leukaemia patients at that time.

Editor Pat Fleming suggested the newspaper should run an appeal for Leukaemia Busters to raise funds for our work, work that we would conduct in earnest in future years as a memorial to Simon and all other children who had lost their lives to this disease.

Pat wanted to know what sort of amount we needed and how we'd use any money raised.

The answer was already in my head – if we were to take our ideas forward and develop antibodies for the treatment of children with leukaemia then we would certainly need a new laboratory facility dedicated to this task.

So it was agreed on that fateful day that we would appeal to the same *Echo* readership who had been so very supportive during Simon's bone marrow appeal, to help raise £150,000 to build and equip a new lab at the general hospital.

Jacqui Goddard was to be in charge of writing the articles and keeping the appeal alive and well for however long it took.

To our absolute delight, though through sorrowful eyes, we saw how the scene had been set for a new appeal, realising that this and the work it eventually led to would become a living memorial to Simon and the work his bravery inspired.

This was, and will for ever be, very important to us, as any bereaved parent knows there is the lingering and dreaded feeling that their child will be for ever forgotten by this world.

So plans began to fall in place to build the first children's leukaemia research laboratory dedicated to the task of finding new treatments.

In our minds we knew that there could only be one fitting name for this new laboratory. It had to be The Simon Flavell Leukaemia Research Laboratory.

All that remained now was to raise the money and to persuade the hospital and university authorities to allow us to build it.

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