

**W**hen Lonyo Engele was diagnosed with kidney failure in 2015 after suddenly fainting one day, doctors told him he would need a kidney transplant.

The 44-year-old actor, singer and radio host – who had a top 10 hit with his single “Summer of Love” in 2000 – had suffered from diabetes since he was 18. Although the condition can lead to kidney damage, he had always tried not to let it have an impact on his life.

But his doctors had more bad news: because of his African-Caribbean background, and the lack of kidney donors from similar backgrounds, he could wait three to five years for the transplant – almost double the time it would take for a Caucasian patient. In the meantime, Lonyo was forced to put his life on hold while he underwent five-hour sessions of dialysis three times a week. But, he says he “never felt hard done by. How could I when I wasn’t signed up as a donor myself?”

How to solve the “silent crisis” in donation facing black, Asian and minority ethnic (BAME) communities is the subject of a recent review launched by the MP Eleanor Smith. The problem is one of supply and demand: there are not enough BAME blood, stem cell and organ donors; and BAME groups are more vulnerable to illnesses such as diabetes and some forms of hepatitis, which can lead to organ failure and necessitate transplants. More than a third of those on the waiting list for a kidney transplant are from BAME communities, and they wait, on average, a year longer than their white counterparts.

Lonyo opted to have a dual pancreas and kidney transplant, a more invasive procedure, which would cure his diabetes as well as giving him a healthy kidney. Six months after starting dialysis, he was woken at 5am by his phone. “At first I ignored it. I thought it was one of those PPI calls. And they said: ‘It’s the hospital, we’ve got organs for you. I was very fortunate – I’d been expecting to wait at least two years.’”

After a 13-hour operation and a three-month recovery in hospital, Lonyo met his partner within



**Lonyo Engele had diabetes; after six months of dialysis he received a pancreas and kidney transplant which he says gave him a new life; below, the donor Swanand Patwardhan with Ojas Ranade, the boy he helped**

# ‘Thank you for saving my life’

Lonyo Engele was shocked to learn he needed a kidney transplant. There was more bad news: a shortage of black donors. By **Hannah Partos**

weeks, and not long after that, she was pregnant with their first child. He’s now doing well. He has a one-year-old daughter Isabel, and he often thinks about his donor.

Organ donors are kept anonymous; all Lonyo knows is that his donor was a deceased 18-year-old male. “I just wish I could thank his parents for allowing his organs to be donated, for saving my life. From almost losing my life – I’ve created another.” On his *The Beat* London radio show, Lonyo now encourages listeners from diverse backgrounds to sign up as donors.

The review into BAME donation points to complex reasons behind the shortage of donors. These

include perceptions that certain religions do not permit donation (although none of the major religions objects to organ donation), a lack of culturally sensitive information about donation, and a historic mistrust within some BAME communities of the NHS and government as institutions.

“There’s a general myth among the African-Caribbean community that if you’re signed up as a donor and you have a car accident or something, they won’t try their hardest to save you,” Lonyo says.

When Swanand Patwardhan, a Manchester-based NHS psychia-

trist, signed up to the Anthony Nolan register as a stem cell donor in 2012, his parents, who live near Mumbai, in India, were “very apprehensive. Their first reaction was, why do you want to go through unnecessary pain?”

A few months later, Swanand was told he was a match, and could potentially save the life of a one-year-old boy in the US with leukaemia. In most cases, stem cell donation happens in a process similar to giving blood. Swanand, however, had a general anaesthetic, so doctors could extract a piece of his bone marrow. But he was surprised at how easy the process was. “I thought I’d be sore but I was just a bit tired.” He was discharged the next day.

Swanand says he would not hesitate to donate again. He has since met the recipient of his stem cells, Ojas Ranade, now a healthy

five-year-old and “bundle of joy”, along with his family in Sacramento, California. Ojas’s mother told Swanand of the struggles to find her son a stem cell donor, and her fear that he might die waiting for a match.

In the UK, only 61 per cent of BAME patients in need of a stem cell transplant find a suitably matched donor, compared to 96 per cent of white north European patients. While Anthony Nolan aims to recruit more BAME donors, the charity says that this approach alone is not enough and more needs to be done to grow stem cell registers in regions such as Africa and South Asia, where ethnic groups that are minorities in Western countries are the majority. (Scientists currently use worldwide stem cell registers to find the best match for all patients.) Swanand says that his proud family have now come round to the idea of donation. His parents have signed up as organ donors, and many of his cousins in India have joined the national stem cell register there.

Edith Victoria, founder of the charity Your Blood Helps and a blood donor for almost 20 years, says she often feels frustrated with the “lack of understanding” around donation. Edith has been campaigning to get more BAME people to give blood since her son Gabriel, now aged five, was diagnosed with sickle cell disease shortly after he was born. It’s a blood disorder that mainly affects people of African-Caribbean heritage. He needs blood transfusions when he becomes unwell. “If people hadn’t made time to donate blood, my son would be dead,” she says. African-Caribbean donors with a certain subtype of blood are often the best match for sickle cell patients, but only 5 per cent of blood donors in the last year were from BAME communities, although BAME people make up around 14 per cent of the UK population.

Along with organising donor recruitment drives, Edith posts Instagram selfies when she gives blood, to demystify the process. “I take loads, applying lipstick and singing. I just want to show you don’t feel anything, you’re fine.”

“People say they’re scared of needles, but you have to look at the bigger picture – you’re taking that one second of pain and potentially saving three lives.”

**For more information visit**  
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**There’s a myth that if you’re a donor the NHS won’t try too hard to save you**