

## **How BAME patients, carers and family members can be involved in campaigning**

If you are reading this guidance, it is more than likely you have been affected in some way by the shortage of organ, bone marrow and stem cell donors.

Do you want to do something to help change this? We need your support to raise awareness and encourage more people to pledge their support to become donors.

### **Background**

There is a real shortage of donors generally, but particularly those from Black Asian and Minority Ethnic backgrounds. As a result, patients from these communities have to wait much longer for a transplant than those from the general population.

One in four people waiting for a kidney transplant is Black or Asian and will have to wait on average five years or more for a kidney transplant, twice as long as the rest of the population. Yet less than 2% of people who have registered their wish to be a donor on the NHS Organ Donor Register are Black or Asian.

Black and Asian people are more likely to need a kidney transplant because they are more susceptible to developing diabetes, high blood pressure and other illnesses which can lead to kidney failure.

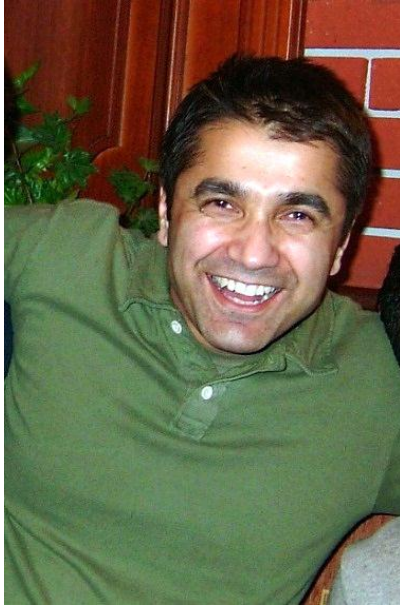
In bone marrow transplantation, a Black or Asian person with blood cancer is much more likely to have a successful bone marrow or stem cell transplant if the donor is from the same ethnic / racial background. Unfortunately, most ethnic communities continue to be under represented on the bone marrow register. This means it is more difficult to find suitable donors for members of these communities who require a transplant. Only 8% of people on the Anthony Nolan register are non-Caucasian.

If more people registered, more lives could be saved and the NBTA aims to tackle this shortage.

Take inspiration from the amazing people below and see how you can get involved!

## Case studies

### *Rik's story*



In December 2011, Rik had a lifesaving stem cell transplant following an extensive search; thankfully a donor was eventually found in Germany. There is a real shortage of stem cell donors in the UK and to make matters worse Asian donors make up only 4.8% of those on the register. Rik, along with his family and friends, have set up the Rik Basra Leukaemia Campaign to raise awareness of the shortage of Asian donors on the Anthony Nolan register and encourage people between the ages of 16-30 to register with the charity - potentially saving someone's life. Rik and his supporters have been highlighting the cause at cultural events such as Leicester's busy Diwali celebrations and at educational establishments such as De Montfort University and Regent College in Leicester. A key aim is to encourage younger people to think and register, as younger people provide the best possible outcomes for patients. Rik's campaign to recruit more young Asian donors has helped boost the number of people that have registered by an incredible 150%.

## *Naomi's story*



Naomi heard about the bone marrow register after hearing an appeal from The African-Caribbean Leukaemia Trust (ACLT). As she arrived at the Notting Hill Carnival the ACLT were recruiting people to sign up. Naomi was with one of her friends who suffers from sickle cell anaemia so she was aware how important it was.

In 2007 Naomi received a call saying she was a potential match for a patient. Naomi donated Peripheral Blood Stem Cells (PBSC). This involved a nurse visiting her at home in the three days leading up to the donation date to give her injections that increase the rate at which her body produces stem cells in her blood. On the day before her donation, Naomi went to the hospital in London for a check up and stayed in a nearby hotel ready for the donation the next day. During the donation, the nurses were very friendly and welcoming, and her partner was allowed to accompany her the whole time too which helped Naomi to relax. The process lasted approximately the length of two movies, which Naomi watched on the portable DVD player provided by the hospital!

Since 2010, Naomi has been volunteering for the ACLT and campaigning to raise awareness by attending events, fundraising through bucket donations, giving speeches at events and volunteered at recruitment drives. The recruitment drives allow potential donors to ask Naomi questions, as she has first hand experience of the procedure.

Naomi says “joining the register and donating was one of the easiest decisions I have had to make - with the greatest of outcomes. Knowing that by taking a few hours out of my life I have potentially saved someone’s life feels surreal, but that is exactly what being a bone marrow donor does. Looking back, I feel privileged to have been somebody else's lottery numbers and encourage anybody eligible to register to do so. Believe me that is one decision you can always be proud of”

## Wendell's story



Wendell, known as Raph, donated a kidney to a friend in 2007 and hasn't looked back - his principle after donating a kidney was to "try everything"! He set up his own charity website [www.Minus1Kidney.com](http://www.Minus1Kidney.com) to raise awareness of donation and is also a regular blood donor. He is well-known in some parts of London for carrying around a toy 'Thor' hammer emblazoned with his website address as well as logos for the ACLT, the Anthony Nolan Trust and Kidney Research UK!

Raph made it his mission to undertake a special event every year on the anniversary of his kidney donation to demonstrate how active a person can be following donation. So far these have included a tandem skydive and running the London Marathon!

And finally, Raph sums up his charity work nicely "the charities I support are the real heroes."

**We need many more people like Rik, Naomi and Raph. Could you be like them? Are you feeling inspired and want to help? Find out below about the support that is already out there and how you can be empowered to get involved!**

There is a wealth of information, support and expertise to help you achieve your goal of raising awareness, and encouraging people to make their donation wishes known.

*Useful existing resources*

For further information please see the partners page of the NBTA website, which gives the links to NBTA members' websites which contain a wealth of useful resources:

<http://www.nbta-uk.org.uk/partners/>