

**NHSBT Board Meeting**  
30 January 2020

**Status: Official**

**A Patient Story: Rare blood cells**

Providing the right blood at the right time is central to the mission of NHS Blood and Transplant. For the vast majority of requests, blood can be provided from our stocks for individual patients. However, sometimes the specific requirements require much more detailed searches, sometimes internationally.

Two-year-old Zainab Mughal in America was diagnosed with a neuroblastoma which is one of the most common solid tumors in childhood. It was quite clear that treatment would require many blood transfusions and a bone marrow transplant to treat her condition.

However, Zainab has one of the rarest blood types in the world. Zainab's blood is missing an antigen known as 'Indian B', which most people carry. The only donors likely to be a match are people of exclusively Pakistani, Indian or Iranian descent with the blood type O or A, and fewer than 4 per cent of such people will be missing the Indian B antigen. Indian B is a clinically significant antigen, and so if the patient is Indian B negative, then the donor must be Indian B negative. Also, she had developed antibodies to the Rh E antigen and so E negative units would be required.

Zainab's need for a rare blood type sparked a search for a suitable donor. In a sign of the times, an international search was launched on social media. Over 25,000 people responded, and two compatible donors were identified in the US. The story in NHSBT developed on more traditional lines when the American Rare Donor Programme contacted the International Blood Group Reference Laboratory (IBGRL), our specialist unit based in Filton in Bristol.

The IBGRL carries out world leading testing and research in transfusion medicine – it's a laboratory carrying out specialised testing and holding information on the most complex and rare blood problems. Nicole Thornton, head of Red Cell Reference at the IBGRL, explained the combination of Zainab's unusual blood group and antibodies meant that the type needed would not only have to be Indian B negative but also E negative.

The search of all our NHSBT typed donors found two of our blood donors were a match. The special call-up procedure was initiated. Both donors donated blood within days of being contacted and the red cells were shipped to the US. IBGRL also compiles and maintains the International Rare Donor Panel (IRDP), and stores details of rare donors from 27 countries as well as frozen unit inventories from frozen blood banks around the world and one more donor was found in Australia.

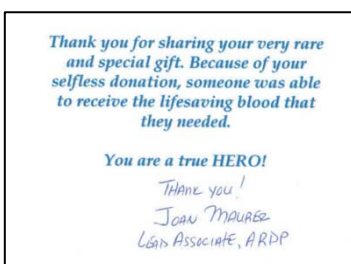
Zainab has subsequently undergone surgery and two bone marrow transplants, with multiple red cell transfusions. One of the NHSBT donors was a 50-year-old British Indian mother of two from Nottingham. She preferred to remain anonymous, but revealingly explained her motivation, “I feel privileged that my blood donation has helped another human being. Having a rare blood type doesn’t tend to be at the forefront of my mind . I didn’t know who the recipient was when I donated but I do know now, having read the coverage. I am very humbled that I have played a small part in aiding someone’s recovery from illness.” She went on to say that, “I do hope the publicity encourages more people to donate, especially from the Asian community, as even a single donation can make a massive difference to someone who needs it. Giving blood is something that most people can do.” It is a wonderful example of the values of our donors.

The logistics of finding the donor, arranging individual appointment for testing and collecting, and processing the units and then sending blood around the world are bespoke and so necessarily complicated. Dr Rekha Anand, the NHSBT Consultant Haematologist who manages the UK’s rare donor panel, has emphasized the team effort from NHS Blood and Transplant and has always urged more British people from minorities to come forward and donate.

As a result of this programme, NHSBT contacted all the UK residents who had registered to participate in America’s OneBlood Drive and new blood donors were recruited in England.

This is great example of how blood donation and specialist testing and logistics can combine to match up donors and recipients in rare cases and make a real difference. It also shows the international, collaborative nature of work in transfusion medicine.

Colleagues working on the America Rare Donor Program sent thank you cards for NHSBT to pass on to the UK donors. Zainab’s smile speaks for itself.



**Authors: Prof David Roberts Associate Medical Director & Dr Rekha Anand Consultant Haematologist**

**Responsible Director  
Dr Gail Mifflin, Medical and Research Director**