

## NHSBT Board – Patient Story

July 28 2016



Diane (*above, first from left*), 44 from Tooting, attended the re-opening event for Tooting Donor Centre with her daughter to highlight the need for black blood donors within her community. The story and photo was published in local newspapers and on the NHSBT intranet. Diane was diagnosed with sickle cell disease at 18 months old, a condition which led to her being hospitalised for the majority of her pregnancy. However, with the help of blood transfusions, she was able to have her daughter Chi, now 16 and studying dance and drama. Diane receives regular blood transfusions every 6-8 weeks at St George's Hospital. Without these transfusions, her sickle cell disease would be much less controlled which can lead to a number of serious complications.

Diane originally helped us 15 years ago with one of NHSBT's first sickle cell awareness campaigns for Afro-Caribbean blood donors. Diane was keen to work with us again to raise awareness of the need for more black African and black Caribbean blood donors: "I receive blood regularly to try and keep me as well as possible. It helps me to do the types of things most people take from granted and means I can be there for my daughter would specifically call on members of the local black community who have the ability to help people like me who need regular transfusions. By being a donor, you have the ability to give life."

However not every patient has a positive outcome. A woman with sickle cell disease gave birth to her first baby relatively uneventfully but she required red cell transfusions at delivery. Her second pregnancy was uncomplicated except for two things - firstly at booking the transfusion laboratory identified that she had developed a rare antibody from her transfusion at the end of her first pregnancy and secondly she had an obstetric complication with a

consequent risk of bleeding at delivery. NHSBT arranged to call in donors to support her planned delivery but unfortunately she went into labour early and required an emergency caesarian section. The patient did not require blood at delivery but several days later needed a transfusion, three days after which she was discharged home. A short period later the patient was admitted having developed a wound problem and complications of sickle cell crisis. Four units of blood were ordered but no 'ideal' matched red cells were available in the National Frozen Blood Bank. We defrosted the two most suitable and the patient was given them. However she reacted to the blood, her condition deteriorated and she was put on the Intensive Care Unit. The patients' haemoglobin fell further, another two units were requested and defrosted from the NFBB, but by the time they arrived the patient had sadly died.

It is important to note that no errors were made. The units of blood supplied were done so in a timely manner and NHSBT provided the best match that we had. . With this particular antigen no white donors are negative and only 2% of African Americans are negative so it will always be a difficult situation to manage. With more black donors we have more of a chance of having units such as these available in emergencies.

That is why we are working with patients like Diane and community stakeholders to promote the need for more black donors to give us the best possible chance of helping save and improve as many lives as possible.