

# Sickle Cell - Frequently Asked Questions

## Sickle Cell Disease

- Sickle cell disease is the most common and fastest growing genetic disorder in England and the UK
- It is a serious condition which affects the blood and various organs within the body, causing extreme pain, life threatening infections and other complications such as stroke or loss of vision. Blood transfusions can help prevent or relieve these symptoms.
- In the UK, 15,000 people have sickle cell disease and over 300 babies are born each year with the condition. It is most common in black people.
- Advances in the treatment of sickle cell disease mean that patients with sickle cell disease are living longer but the demand for transfusions is higher than ever before.
- To get the best treatment, patients need blood which is closely matched to their own. This is most likely to come from a donor of the same ethnicity. Yet only 1% of current blood donors are black.

## Why do you especially need more black donors?

We urgently need 40,000 new black donors to stop the pain experienced by black patients with sickle cell disease. They need life-saving blood more closely matched than by group alone. This will often come from a donor of the same ethnicity.

## Why are so many fewer people coming forward to donate blood nowadays?

Key barriers to people coming forward to donate that were identified by blood services around the world include:

- Wider and more exotic travel – meaning some are deferred for a period of time
- People having less time to give in an increasingly busy world
- Lack of awareness of the process
- Fear of needles
- Lack of awareness about the need for more diverse blood donors

### **How long does it take?**

In England, giving blood is simple and easy to do and only takes around an hour of your time. The donation itself takes around 5-10 minutes. Each time you donate you can save or improve three lives.

### **How much blood is needed by patients with sickle cell disease?**

Each month hospitals requests between 3,000 and 4,000 units of red cells to meet the needs of sickle cell patients. While we always provide suitable blood for patients, there are certain sub-types that we are not always able to fully match, for example Ro subtype. We need 40,000 new black donors to help meet demand.

### **How many people are affected by Sickle Cell disease?**

It is estimated that around 15,000 patients have Sickle Cell Disorders nationally and an estimated 80% live within M25. 300 babies each year are being born with the condition. It is the most common and fastest growing genetic disorder in the UK.

### **Why is it important for sickle cell patients to get blood from a donor of the same ethnicity?**

Sickle cell patients directly benefit from receiving blood which is as closely matched as possible, and this is achieved by using blood from a donor of a similar ethnicity.

### **What happens if you don't get enough black blood donors to come forward?**

Patients will not receive the best possibly matched blood – this means their treatment is not as effective, increasing the risk of crisis and, in the long term, means it is increasingly difficult to effectively match their blood. Eventually they may become un-transfusable which is a life-threatening circumstance.

### **What difference does closely matched blood make?**

It prevents medical complications in the future for the patient and provides more effective treatment for the patient with each blood donation received.

### **Why has there been such an increase in demand for black donors?**

Sickle Cell Disease is the most common and fastest growing genetic disorder in the UK, meaning more patients requiring treatment. At the same time, treatment advances mean regular blood transfusions are being used more frequently to prevent painful 'crisis' symptoms as well as to relieve symptoms once they have occurred. These advances in treatment, mean that in developed countries like the

UK patients are living longer, but therefore more patients are needing treatment over a longer period of time.

**Can people with Sickle Cell Disease donate?**

No, it is not possible for people with sickle cell to donate, to protect the health of the donor and the recipient. However we would encourage anyone affected by the condition to encourage members of the families and friend circles to donate on their behalf.

**Can people with the sickle cell trait donate?**

Yes, people with the sickle cell trait are able to donate. We just need to know a donor has the trait to avoid giving the donation to sickle cell patients or babies, as it can cause complications.

**I've been told that sickle cell blocks filters – what does that mean?**

To increase the safety of blood, each donation is filtered to remove the white cells. Sometimes blood donated by people with sickle cell trait does not filter properly. If this happens, the donation cannot be used. If it happens more than three times consecutively the donors are informed.