Carrying hereditary persistence of fetal haemoglobin (HPFH)

- A carrier of HPFH is a healthy person.
- Carrying HPFH does not weaken them physically or mentally.

They do not need any medical treatment because they carry HPFH.

What does it mean to carry HPFH?

HPFH is one of many possible variations in the blood called *haemoglobin gene variants*, or *haemoglobin variants*.

Haemoglobin is what makes blood red. At birth babies have mainly haemoglobin F (fetal haemoglobin). Usually this is replaced by haemoglobin A (adult haemoglobin) in the first few months of life. HPFH means that this changeover is not completed, so a carrier of HPFH still has some haemoglobin F.

A carrier will always be a carrier, and no-one can catch it from them. They inherited HPFH from one of their parents, and could pass it on to their children.

Anyone can carry HPFH, but it is uncommon. It is found occasionally among people who originate from Southern Europe, the Mediterranean area, Africa or the Caribbean area. It is rare in other groups.

Can carrying HPFH cause any health problems?

Carrying HPFH is not an illness, and will never turn into an illness. In fact, carriers are less likely than other people to catch malaria. Carriers can eat what they want, and do any kind of work they choose. Carriers can give blood providing they are not anaemic (do not have a lower haemoglobin than usual).

Could a carrier of HPFH have children with a serious haemoglobin disorder?

Carrying HPFH will not affect the health of their children, even if their partner is also a carrier.

What should a carrier do if they are thinking of having children?

They should tell their partner that they carry HPFH and ask him or her to have a blood test “for haemoglobin disorders”. This test should be done before they start a pregnancy, or as soon as possible once a pregnancy has started. Their GP can arrange it.

If their partner is also a carrier, they should ask their GP for an appointment with a specialist counsellor, to confirm that there is nothing to worry about.

Is there anything else that a carrier should do?

If a carrier has brothers or sisters, or already has children, they need to know that they may also carry HPFH. They should ask their GP or practice nurse for a blood test “for haemoglobin disorders”.

Counselling services for haemoglobin gene variants are provided by:

Sickle Cell and Thalassaemia Support Project Paycare House George Street Wolverhampton WV2 4DX www.sctsp.org.uk	Sickle Cell and Thalassaemia Centre (SCaT) First Floor Birmingham City Hospital Dudley Road West Midlands B18 7QH www.swbh.nhs.uk/services/sickle-cell-and-thalassaemia