



Haemochromatosis

The role of the South African National Blood Service

What is Haemochromatosis?

Haemochromatosis (HH) is a genetic iron overload disorder. It is estimated that one in 115 South Africans of Caucasian descent have this disorder, which can cause the body to accumulate excessive levels of iron. If left untreated, the excess iron is deposited in the liver, the pancreas, the heart and other organs and this will eventually severely impair the function of these organs.

What is the treatment?

The *reduction phase* of treatment aims to aggressively remove blood (as often as once a week initially) and thereby reduce stored iron levels, to the lower end of normal, by the removal of some 450ml of blood at a time (known as therapeutic venesections). Once stored iron levels are so reduced, venesections should take place less frequently (usually at 2 -3 monthly intervals) to maintain iron levels at appropriately low levels. This is known as the *maintenance phase*.

How can the SA National Blood Service (SANBS) help in treatment?

SANBS is available as an important partner in the treatment of HH. It is able to provide services during both the reduction and the maintenance phases.

REDUCTION PHASE

- SANBS is usually able to remove blood weekly (or as often as requested by the patient's own doctor) at any of its Blood Donor Centres.
- The 'Reduction phase' service will apply whenever the period between therapeutic venesections is less than 56 days (which is the period that regular blood donors have to wait between blood donations).
- All venesections will only be undertaken on instruction from the patient's own medical advisor.
- This service will be provided whether or not the blood is of use to SANBS and whether or not the patient conforms to all of the normal criteria used for blood donation. Whole blood which is donated at intervals of less than 56 days cannot, by regulation, be transfused to a patient.
- A charge will be made by SANBS for this therapeutic venesection service at a level that covers the direct costs of providing the service.

MAINTENANCE PHASE

- SANBS will venesect any person who is in the maintenance phase and requires venesection at intervals of 56 days or more
- This person must comply with all the criteria for normal blood donation.
- There will be no charge for blood donated in the maintenance phase.

For information on haemochromatosis, its diagnosis and its treatment, go to the web site of the South African Haemochromatosis Society:

www.haemochromatosisza.org