General advice for Haemochromatosis Patients

- Do not take supplemental iron
- Eat less than 350g of unprocessed red meat each week to reduce the risk of heart disease
- Monitor your intake of chicken, turkey and duck white meat
- Avoid raw shellfish, as it can contains bacteria that can cause severe illness in people with high iron levels
- Avoid processed foods and drinks that are fortified with iron (e.g. iron-fortified cereals)
- Drink tea or coffee with iron rich meals as it may decrease iron absorption
- Minimise alcohol consumption
- Have siblings and adolescent children tested

What happens to my blood after a Therapeutic Venesection?

If your liver function is normal and should you wish to donate your blood, any blood taken as part of a therapeutic venesection can be donated for transfusions. This will depend on whether or not you meet NZBS donor eligibility criteria. If you do not meet the donor eligibility criteria then your blood will be disposed of in a safe manner.

Locations for Therapeutic Venesection

North Shore Donor Centre 09 489 8858
441 Lake Road, Takapuna

Epsom Donor Centre 09 523 5733
71 Great South Road, Epsom

Manukau Donor Centre 09 263 4667
Unit B, 116 Cavendish Drive, Manukau

Tauranga Donor Centre 07 578 2194
154-168 Cameron Road, Tauranga

Wellington Donor Centre 04 380 2243
Hospital Road, Newtown

Christchurch Donor Centre 03 343 9040
15 Lester Lane, Addington

Dunedin Donor Centre 03 477 9920
170 Crawford Street, Dunedin

“Early diagnosis and treatment can prevent the known complications of haemochromatosis”

- Barton et al, 1997

Leaflet prepared and provided by the New Zealand Blood Service.
Private Bag 92071, Victoria Street West, Auckland 1142.
71 Great South Road, Epsom, Auckland.
Telephone: 09 523 5733

nzblood.co.nz

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NZBLOOD

Haemochromatosis

INFORMATION

Patient Information

What is Haemochromatosis?

Hereditary Haemochromatosis is a genetic disorder passed down through families resulting in problems controlling iron absorption from your intestine and higher iron levels in your blood and body tissues. This affects about 1 in 200 New Zealanders and is more likely to affect people descended from a common Celtic ancestor, 60-70 generations ago.

Our genes come in pairs, one from each parent. People affected by Hereditary Haemochromatosis inherit two copies of a mutated gene. A person who inherits just one Haemochromatosis gene is considered a carrier and does not have the condition itself. Although clinically significant iron overload develops in some people who have two copies of the abnormal gene, iron stores may still be slightly higher than usual in those who have a single copy.

Individuals with Haemochromatosis have excess iron deposited in their liver, pancreas, heart, endocrine glands, and joints. With early diagnosis and treatment, life expectancy is similar to the rest of the population.

Testing is advised for family members once a person has been diagnosed with Haemochromatosis

Iron is a mineral found in some foods such as red meats. We need iron to make red blood cells. However, an excess of iron in the body can cause organ and tissue damage.

What are the symptoms of Haemochromatosis?

Early symptoms include:

- Fatigue
- Abdominal pain
- Joint pain
- Reduced sex drive
- Unexplained weight loss

Complications may include:

- Liver dysfunction, including cirrhosis andhepatocellular cancer
- Arthritis and arthropathy
- Heart problems, including irregularheartbeats, palpitations, and shortness ofbreath
- Diabetes
- Hormonal changes (loss of libido, irregularmenses, testicular atrophy)

What happens next after a diagnosis?

Your GP (or specialist) may refer you to the local New Zealand Blood Service (NZBS) centre to commence treatment. If there is no centre near you, your local GP practice or some laboratories may carry out the treatment.

How is it treated?

To treat Haemochromatosis, the key goal is to remove the excess iron from the patient's body and avoid any organ damage. The simplest way to do this is through venesection, the removal of blood. Similar to a blood donation, this is done by inserting a needle at the elbow and withdrawing blood directly into a sterile bag.

How long does treatment last?

The treatment for haemochromatosis is lifelong.

A doctor or the Therapeutic Venesection Nurses at NZBS will review your iron test results regularly.

Some patients may need venesection more frequently than others to bring iron levels down to a recommended target range. Once this is reached, a maintenance programme is planned to avoid iron accumulation.