Welsh Blood Service

Hereditary Anaemia Service
Working Together in Wales

Sickle Cell and Thalassaemia Blood Group Genotyping Programme

What are sickle cell and thalassaemia?

Sickle cell disorder and thalassaemia are both genetic disorders of haemoglobin, the oxygen-carrying molecule in blood. In sickle cell disorder, the red blood cells change their shape, become damaged and sticky, blocking blood vessels, causing "crises". In thalassaemia, people cannot produce enough haemoglobin, causing severe anaemia. For both disorders, people often need regular blood transfusions to keep them healthy.

What are blood groups and what is blood group matching?

Red blood cells have labels on their surfaces, known as antigens or blood groups. We inherit our blood groups from our parents and different people have different blood groups. There are over 300 different blood groups, although the most important/well known ones are A, B, O and AB plus RhD positive and RhD negative. These are known as the basic blood groups. There are lots of other bloods groups which are usually of much less importance.

The donor blood selected for transfusion matches the basic blood groups as standard. Blood for people with sickle cell, thalassaemia and, in some cases, rare inherited anaemias is matched for a small number of the more common additional groups but is not matched for the full extended list of blood groups.

How is blood matched now?

Before a person receives a transfusion, they have a blood sample taken, which will be processed by a hospital laboratory to check their basic blood group– this is called a "cross-match". For someone with sickle cell or thalassaemia, they would have their partially extended blood group checked. When the blood laboratory team choose blood for patients, they check that the blood group of the donor matches their blood groups as closely as possible.

How do we find out the blood groups for donors and patients?

We use a technique involving antibodies, known as serology, to detect blood groups. This works well for the basic blood groups, but for testing more of the blood groups (known as extended blood group testing) we need a different technique. This is because serology is time-consuming and expensive, and we do not have the antibodies or resources to test all the different blood groups of patients and donors. Also, we cannot use serology if people have had a recent transfusion.

Why would it help to perform extended blood group testing on our patients and donors?

Each time we transfuse a person, even if we match the basic blood groups, there is a chance that the person can form a new antibody to donor red bloods cells if the extended blood groups are not matched. Antibodies can cause reactions which may be severe and make it difficult to find the right blood for patients in the future. Unfortunately, this happens more often for people with sickle cell and thalassaemia because they get lots of transfusions.

What is the new technology?

Blood groups can also be tested using DNA from blood samples. This is known as blood group genotyping. The blood services in the UK have been using this technology for a while but up until now, it has been a slow and expensive test. Working with an international group of scientists and industry, NHSBT (the English blood service) has developed a new fast and cost-effective test. The Welsh Blood Service (WBS) is supporting this new test alongside for eligible patients in Wales. We have called this the sickle cell thalassaemia and other inherited anaemias blood group genotyping programme.

How would this new technology help patients?

NHSBT is running a similar programme in blood donors and other UK nations are expected to join this in the future. Using the blood group types from donors and patients should allow the NHS, in the future, to provide the best possible blood match for patients, reducing the risk of forming antibodies. For those patients that already have antibodies, it should be easier and quicker to find suitable blood for transfusion.

We can't say when we expect extended matching to be available for those patients who may benefit, but, as more of the patients and the donors have their blood group genotyped, it will be increasingly possible to provide better matched blood.

How can I have my sickle cell and thalassaemia blood group genotyping test done? What is involved?

The blood group genotyping test requires a single sample tube of blood that can be taken at the same time you have a blood test. However, it can only be taken in hospital. The test will be explained to you and, if you agree, they will confirm your consent on the test request form. The samples and request form will be sent to NHSBT for testing. The result will be available to the hospital laboratory team and your clinical team who can share them with you.

Following testing, there is often some of your blood sample left over. The law allows the testing laboratory (NHSBT) to use this, and anonymous information associated with it for quality control (making sure their tests are working correctly), education or training relating to human health, or ethics committee-approved research. Samples may be stored as part of required archiving protocols to enable further investigation for your benefit. This practice helps NHSBT maintain accurate testing procedures and improve its knowledge, and so provide the best possible care for all patients now and in the future. If you do not want your sample to be used for these purposes, you should tell your clinical team so that they can tell NHSBT. We will respect your wishes and dispose of any samples they no longer need.

It is the responsibility of the requester submitting your sample to ensure informed consent has been obtained for all tests, including genetic tests in accordance with current guidance and legislation.

If you are unsure about any aspects of your treatment/care, ask your treating clinical team to explain.

For more information visit:

https://www.nhsbt.nhs.uk/what-we-do/clinical-and-research/blood-group-genotyping/

Acknowledgements to
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Gwasanaeth Gwaed Cymru
Welsh Blood Service
welsh-blood.org.uk