

Screening Tests Information for Potential Gamete Donors, Surrogates and Intended Parents

Introduction

As a potential donor, or where your treatment may involve the use of donor gametes, it is important you are aware of the screening tests we carry out and understand the implications that may follow. We carry out screening to protect the recipient of donor eggs/sperm from acquiring an infection from the donor. This in turn protects donor-conceived people from being born with an infection or acquiring a serious inherited disorder from the donor.

Surrogates and their partners (if applicable) must also undergo screening before being accepted for treatment.

Background

Eggs, sperm and embryos are stored in highly complex and specialised freezers at a temperature of -196°C. Each individual sample is stored in a separate secure container, which is then placed into a freezer alongside samples from other donors. Therefore, there is a theoretical risk that any infectious agents present in a sample from one donor could cross-infect samples from other donors. We should emphasise that there has never been any documented case of this happening in the context of egg, sperm or embryo storage in the UK. However, because of the theoretical risk, the Human Fertilisation and Embryology Authority (HFEA) require all potential donors to be tested for certain important infections prior to storing samples.

This information booklet aims to explain what tests are done and the implications of the results. Please bear in mind that the vast majority of donors we see are not at risk of having these infections, but we feel it is important that you are fully informed before being tested.

What am I tested for?

You will be tested for infections/diseases that can be transmitted via bodily fluids and certain genetic (inherited) diseases. We also carry out a chromosome analysis (karyotype). Potential egg donors will have a blood test to check their AMH level, which is an indicator of ovarian reserve. In addition you will also have a blood test taken to check your blood group.

Infections/diseases transmitted via bodily fluids:

- Human immunodeficiency virus (HIV)*
- Hepatitis B*
- Hepatitis C*
- Human T-lymphotropic virus (HTLV)*
- Cytomegalovirus (CMV)
- Syphilis*
- Chlamydia
- Gonorrhoea

* We are unable to accept you as a donor or surrogate if you test positive for HIV, Hepatitis B, Hepatitis C, HTLV or Syphilis.

Depending on ethnic origin and travel history, additional tests may be required. This will be explained at your consultation.

The main ways in which infections can be transmitted via bodily fluids are:

- By unprotected vaginal, anal or oral sex with someone who is infected; also by sex which draws blood with someone who is infected.
- By sharing contaminated needles or other drug-injecting equipment, non-sterilised equipment for tattooing, acupuncture or body piercing.
- From an infected mother to her baby during delivery, across the placenta or through breast milk.
- Through a blood transfusion in a country where blood is not tested for these infections. All blood for transfusion in the UK is tested.

Genetic (inherited) diseases:

- Cystic fibrosis
- Haemoglobinopathies (eg. sickle cell anaemia, thalassaemia)

Additional screening may be done depending on travel history or if you have a particular ethnic background. This will be discussed before blood samples are taken.

Infectious Diseases

Human Immunodeficiency Virus (HIV)

HIV is a retrovirus that can damage the body's defence system so it cannot fight off certain infections. If someone with HIV goes on to develop certain serious illnesses, this condition is called Acquired Immune Deficiency Syndrome (AIDS).

You may have heard or read about "the AIDS test", but the test does not show if someone has AIDS. The test looks for antibodies to HIV - in other words, if someone has been infected with HIV.

What does a positive result mean?

Antibodies for HIV were found in your blood. You have HIV, BUT this does not tell you if you have AIDS. You will be referred to a specialist for treatment. We are unable to accept you as an egg/sperm donor or surrogate.

What does a negative result mean?

This usually means you do not have HIV and can progress onto the next stage of becoming an egg/sperm donor and can be considered as a surrogate.

Hepatitis B Virus (HBV)

Hepatitis is inflammation of the liver. This can be caused by alcohol and some drugs, but usually it is the result of a viral infection. There are many types of virus which can cause hepatitis. Each of these viruses acts differently. The HBV is very common worldwide and is very infectious.

What does a positive result mean?

It could show:

- Past infection. This means that you have been in contact the HBV and your body has rejected it. You now have natural protection against the virus.
- You are a carrier. This means that you carry HBV and can pass it on to others.

What does a negative result mean?

You have most likely never been in contact with HBV and can progress onto the next stage of becoming an egg/sperm donor/surrogate

Hepatitis C Virus (HCV)

In most cases, there are no symptoms until the liver has been significantly damaged. Symptoms are often vague but can include, flu-like symptoms, feeling tired all the time and depression. There is no vaccine.

What does a positive result mean?

You may be a carrier of HCV and can pass it on to others. The first test given is a test for antibodies to HCV. If this is positive, it means that you have been exposed to HCV and your body has responded by producing antibodies. This test does not indicate whether or not you are still infected. You will normally be referred on to a specialist for further tests and to discuss potential treatment. We are unable to accept you as an egg/sperm donor/surrogate.

What does a negative result mean?

You have most likely never been in contact with HCV and can progress onto the next stage of becoming an egg/sperm donor/surrogate.

Human T-Lymphotropic Virus (HTLV)

HTLV type 1 and type 2 (HTLV-I / HTLV-II) infects specific cells in the body known as lymphocytes, a type of white blood cell. White blood cells are involved in the immune response and help the body fight infection. The majority of people infected with HTLV do not develop any related disease and are asymptomatic carriers. A small minority will develop disease, usually after several decades. Although rarely associated with disease, there is a link with the development of adult T-cell leukaemia and HTLV-I-associated myelopathy, also known as tropical spastic paraparesis.

What does a positive result mean?

You are infected with HTLV. This is a lifelong infection, therefore we would not be able to accept you as an egg/sperm donor/surrogate.

What does a negative result mean?

You have most likely not been infected with HTLV and can progress onto the next stage of becoming an egg/sperm donor/surrogate.

Cytomegalovirus Virus (CMV)

CMV is a common virus that infects 50 - 80% of people at some time during their lives but rarely causes obvious illness. It is a member of the herpes virus family. Other members of the herpes virus family cause chickenpox, infectious mononucleosis, fever blisters (herpes simplex type I) and genital herpes (herpes simplex type II). Like other herpes viruses, CMV infection can become dormant for a while and may reactivate later.

What does a positive result mean?

Antibodies for CMV were found in your blood, indicating you have been infected with CMV at some time. You are not necessarily excluded as a donor. Further discussion would be required with medical staff and it is likely that if accepted as a donor, your eggs and sperm would only be used for CMV positive recipients.

What does a negative result mean?

No antibodies to CMV were found in your blood. You have most likely never had CMV and can progress onto the next stage of becoming an egg/sperm donor.

Syphilis

Syphilis is a sexually transmitted infection (STI) caused by the bacterium, *Treponema pallidum*. Symptoms develop in three stages: (1) Single sore marks at the location syphilis entered the body. (2) Skin rash/sores in the mouth, anus or vagina. Treated or untreated, this disappears within a few weeks, after which you experience a latent (hidden) phase with no symptoms. This can last for years. (3) This is the most dangerous stage and can cause serious damage to the body. At this stage Syphilis can be dangerous enough to cause death. Infection during pregnancy usually results in miscarriage, stillbirth or a congenitally infected baby.

What does a positive result mean?

You will be referred for treatment. We cannot accept you to become an egg/sperm donor/surrogate.

What does a negative result mean?

You are not infected with Syphilis and can progress onto the next stage of becoming an egg/sperm donor/surrogate.

Chlamydia

Chlamydia is a STI caused by the bacterium, *Chlamydia trachomatis*, and is one of the most common in the UK. Most people who have Chlamydia are asymptomatic so are unaware they have it. Those who do have symptoms may experience pain when urinating, lower abdominal pain, discharge from the penis/vagina/rectum; also in women, bleeding between periods or after sexual intercourse. If left untreated, infection can lead to serious health problems - in women, pelvic inflammatory disease, ectopic pregnancy and tubal factor infertility; in men, complications are rarer but include epididymitis (pain and swelling around the testicles) and Reiter's syndrome (arthritis). Testing can be done by collecting a urine sample/swab.

What does a positive result mean?

You will be referred for treatment. Chlamydia is easily treated with antibiotics. You will be deferred from donation/surrogacy until treatment has finished and a negative result has been obtained.

What does a negative result mean?

You are not infected with Chlamydia and can progress onto the next stage of becoming an egg/sperm donor/surrogate.

Gonorrhoea

Gonorrhoea is a STI caused by the bacterium, *Neisseria gonorrhoeae*. An infected person may have no symptoms but can still transmit the infection without knowing. Symptoms can include pain while urinating, discharge from the penis/vagina. Men can also experience inflammation of the foreskin and pain/tenderness in the testicles or prostate gland (this is rare). It occasionally causes serious complications.

What does a positive result mean?

You will be referred for treatment. Gonorrhoea is treated with antibiotics (often a single dose). However, there are many strains of Gonorrhoea that are resistant to the commonly used antibiotics, therefore it is important to investigate any suspected infection. You will be deferred from donation/surrogacy until treatment has finished and a negative result has been obtained.

What does a negative result mean?

You are not infected with Gonorrhoea and can progress onto the next stage of becoming an egg/sperm donor/surrogate.

Genetic (inherited) Diseases

Cystic Fibrosis

Cystic fibrosis (CF) is a life-shortening genetic condition and affects almost 10,000 people in the UK. It causes the lungs and digestive system to become clogged with thick, sticky mucus and life expectancy is shortened.

Four percent of the Caucasian population carries this gene. If you carry one of these genes, we will inform you of the test result and provide a medical explanation of the next step.

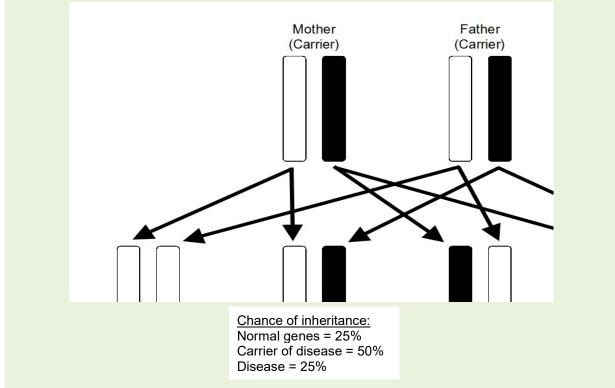
Sickle Cell Anaemia

Sickle cell anaemia is a genetic blood disorder that affects red blood cells, which carry oxygen around the body. Red blood cells are normally disc-shaped and flexible so move easily through the blood vessels. Sickle red blood cells are shaped like a crescent and are stiff and sticky, so block blood flow in the blood vessels, which can cause pain and damage organs. These abnormal blood cells have a shorter life-span than a normal blood cell and the body is unable to make new blood cells fast enough to replace the dying ones.

Thalassaemia

Thalassaemia is the name given to a group of inherited blood disorders that affect the body's ability to make haemoglobin, the protein in red blood cells that carry oxygen. There are different types of thalassaemia, depending on the haemoglobin abnormality, and the severity depends on the number of gene abnormalities.

For these particular diseases, the child needs a pair of abnormal genes to be born with the disease. For each pair of genes, each parent passes on one copy to the child. The possible outcomes if both parents are carriers are shown below:



Frequently Asked Questions

Can I choose not to be tested?

No, the HFEA requires all egg/sperm donors, surrogates and their partners, to be tested.

Will I be told the results of the tests?

Yes, everyone who has these tests will be told the results. You cannot opt out of being told the result.

Why do I need to be retested after 6 months?

Tests used are to either detect the DNA of the virus/bacteria or to detect specific antibodies which your body produces in response to an infection. The infections/diseases we screen for have a "window period". This means that when you are initially screened, levels of the virus or bacteria in your body may be lower than the level that is detectable. It can take some weeks or months for levels to become detectable or for antibodies to develop. Six months is considered a sufficient time for the window period between contracting the infection/disease and for detectable levels to develop.

What are some of the practical effects on being tested?

Looking after yourself - if your test result is positive, knowing that you have a particular infection or disease can allow you to get treatment, advice and counselling about your own future health.

Can I still be a donor/surrogate if I am deferred because of a positive test?

If you are deferred from donation/surrogacy after testing positive for Chlamydia or Gonorrhoea, you will be referred for treatment and retested after the course of treatment has finished. If results are negative, you may still be considered to become an egg/sperm donor/surrogate.

For further information

- □ Ioth.edindonor@nhs.scot
- 0131 242 2440 (answer machine)
- https://services.nhslothian.scot/edinburghfertilitycentre/