

Genetic Testing: Jnetics

The charity Jnetics was established in order to raise awareness of Jewish genetic disorders and to help anyone affected or at risk to access the best information, services and support possible. Jnetics is a charity not connected to Liberal Judaism. However, we wanted to let you know about the important work that they do.

Why is it so important that I get screened for Jewish genetic disorders (JGDs)?

It is common for Jewish people to be 'healthy carriers' for certain recessive genetic disorders. Though unaffected themselves, 'carriers' are at an increased risk of having children born with these severely debilitating, life-shortening disorders. It is now possible to completely prevent these devastating disorders, as long as one is aware that they are a 'carrier'.

Carrier screening identifies if you are a 'carrier' and are at risk of passing on a severe, recessive JGD. This information enables you and your partner to explore the various options available to ensure that your children do not inherit any of these disorders.

If you have not already had screening, you are strongly advised to get screened before starting a family to help protect the health of your future children.

How likely is it that I am a carrier for one of these Jewish genetic disorders?

1 in 5 Ashkenazi Jews are 'healthy' carriers of at least one severe, recessive JGD. Screening for these disorders is highly advised for people of Ashkenazi Jewish origin – even if only 1 of your 4 grandparents is Ashkenazi Jewish.

Sephardi Jews are at risk of being carriers for a different set of disorders, that vary according to their ancestors' country of origin. For more information click [here](#).

Do both my partner and I need to be screened?

For recessive Jewish genetic disorders, BOTH partners in a couple need to be carriers for the SAME condition for your children to be at risk of being born with that condition. If the results of your screening show that you are not a carrier for any of the disorders being tested, then it is not necessary for your partner to be screened for these conditions. However, if you are found to be a carrier – it is essential that your partner is also screened to check whether they are a carrier for the same condition.

NOTE – even if both you and your partner are carriers for the same disorder, there are options to ensure that your children are not born with that disorder.

What are the options if both my partner and I are carriers for the same condition?

There are several options available for 'carrier couples', couples who are carriers for the same condition.

An increasingly popular option is Pre-implantation Genetic Diagnosis (PGD). This is a process that involves IVF to create embryos that can be screened to check if they will develop into an affected child. Only embryos that will not result in being an affected child are chosen to be implanted back in the mothers' womb.

For information about all the options available, please visit www.jnetics.org or email screening@jnetics.org.

Should I get screened for any other disorders?

If someone in your family is a carrier of, or affected by, a severe genetic condition that is different from those in the standard Ashkenazi panels, then it may be advisable to get screened for that disorder. Where a clear family history is identified, the NHS may provide disorder specific screening. Ask your GP to refer you to your local clinical genetics centre to explore if you have access to screening for a disorder known in your family.

If you have a family history of a dominant condition such as Dystonia or, more commonly, breast, ovarian, prostate or pancreatic cancer associated with the BRCA genes, screening for these may also be advisable and available on the NHS. You can ask your GP to refer you to your local genetics service for a discussion with a genetic counsellor. For more information about hereditary cancers, visit: www.jnetics.org/jewish_genetic_disorders/hereditary_cancers.

Where can I get tested for Jewish genetic disorders (JGDs)?

Jnetics is the only cross-communal provider for carrier screening for Jewish genetic disorders. They run a bi-monthly clinic, in partnership with the NHS, based at Barnet Hospital, with virtual appointments available for those outside of London. Participants meet with a genetic counsellor who will answer any questions and carry out the screening.

Testing is done via a saliva sample and results are returned to you within 3-4 weeks.

The total cost for screening for 9 severe, recessive JGDs, including counselling services, is £240 (subsidised by Jnetics from the real cost of £300).

For more information and to book, click: www.jnetics.org/screening or call 0208 158 5123.