



HD & Family Planning

Information & Services

The Northern Ireland Regional Genetics Service is based at Belfast City Hospital but also has clinics throughout Northern Ireland. You can seek a referral to the RGS from your GP or specialist doctor to discuss family planning options or genetic testing for HD.

HD Buzz, a journal written by scientists especially for patients and families, has a great article explaining family planning options

<https://en.hdbuzz.net/036>

Couples from Northern Ireland are currently referred to Guys Hospital in London for treatment once they meet their eligibility criteria. Generally, they will need to attend 5-6 appointments in London per round of PGD, then if successful the pregnant person will be cared for locally during their pregnancy.

<https://www.guysandstthomas.nhs.uk/our-services/pgd/about-us/welcome.aspx>

Funding:

Couples from Northern Ireland, may seek funding for PGD via the Regional Genetics Service and certain eligibility criteria will apply but the genetics counsellor will discuss these.

The criteria for accessing PGD from Guys Hospital, whether paid for by the NHS or by yourself privately, requires the female to be 39 or younger to engage in treatment.

If funding is approved, it is done so for one cycle of PGD and you may be considered for future cycles at a later stage.

At present the majority of appointments will take place at Guys in London, though there are efforts to partner with the NI Regional Fertility Service so that some appointments could take place locally.

Couples required to travel to London will be assisted to book essential flights and accommodation which will be funded by the NHS. Other out of pocket expenses may or may not be covered. This will be explained at the outset.

Other issues raised:

You may wish to speak to your friends, family or church leader to discuss your questions or concerns about religious or ethical issues and then balance the information you receive with what you and your partner feel is best for your situation.

It may be possible to have PGD even if the at-risk partner does not want to be tested but this will require blood samples from the at-risk partner and their parents. The process becomes more difficult if it is not possible to obtain blood samples.

Same-sex couples may also seek funding and avail of PGD with the added issue of having to secure donor eggs/sperm.

Whilst it is generally not permitted to test children under 18 for HD, it may be possible, in certain circumstances to test a fetus for HD during pregnancy but this will depend on the individual case.

The process of first referral to Guys until a potential pregnancy usually takes approximately 12 months however factors such as COVID may impact time frames.

Embryos that are found to be HD positive are left to perish. Embryos which do not have HD will be implanted, one at a time, and the remainder stored by Guys subject to certain timeframes and potential costs.

If a partner is already symptomatic with HD, Guys will, along with other factors take into consideration the welfare of any potential child when deciding whether to proceed with PGD.

Local Support:

HDANI have a number of women who have gone through PGD and would be willing to share their experiences with anyone considering the process.

Contact info@hdani.org.uk

In addition to the Regional Genetics Service, you can also seek support from the Fertility Network who have a range of peer support, counselling and information services including fertility nursing.

<https://fertilitynetworkuk.org/support-for-those-in-northern-ireland/>
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To view our information session on PGD

https://youtu.be/K61zd6S-g_c or visit our Facebook page [HDANorthernIreland](#)