Belfast Health and Social Care Trust
caring supporting improving together

FOI/33085

03 March 2025

Reproductive genetic counselling for MHD and Huntington's Disease

1. **How many individuals with or at-risk of a causal variant in an MND gene (presymptomatic or clinically affected with MND) have been seen for reproductive genetic counselling (ie to discuss recurrence risk and options such as PGT or PNT) in the last 12 months?**

   <10

   2. How many individuals with or at risk of a causal variant in an MND gene (presymptomatic or clinically affected with MND) have proceeded with preimplantation genetic testing (PGT) in the last 12 months?

   0

   3. How many individuals with or at risk of a causal variant in an MND gene (presymptomatic or clinically affected with MND) have proceeded with prenatal testing (PNT) in the last 12 months?

   0

   4. How many individuals with or at risk of a CAG repeat in the huntingtin gene (HTT) (presymptomatic or clinically affected with Huntington Disease) have been seen for reproductive genetic counselling (ie to discuss recurrence risk and options such as PGT or PNT) in the last 12 months?

   <10

   5. How many individuals with or at risk of a CAG repeat in the huntingtin gene (HTT) (presymptomatic or clinically affected with Huntington Disease) have proceeded with PGT in the last 12 months?

   <10

   6. How many individuals with or at risk of a CAG repeat in the huntingtin gene (HTT) (presymptomatic or clinically affected with Huntington Disease) have proceeded with PNT in the last 12 months?

   0

7. On behalf of which organisation and department are you answering this request?

Belfast HSC Trust, NI Regional Genetics Service

8. Optional free text –

To prevent potential identification (and to be consistent with NISRA advice) due to small patient numbers involved, the response <10 is used.