huntington's victoria®
Hope Dignity Awareness

Family Planning Options

The decision to have a baby can be a life-changing experience for anyone. In Huntington's disease (HD) families, there is the added concern about whether or not any future children will also inherit the condition. The chance of a child inheriting the faulty gene for HD depends on the parent's (mother or father) HD gene status.

DNA Predictive Testing

Should you wish to know your gene status, this can be done through the DNA Predictive Testing Program (See Predictive Testing & Diagnosis information sheet).

1. For those who have had DNA testing and are gene positive (have the faulty HD gene), there is a 50% chance of passing the condition on in each pregnancy.

2. For individuals who have HD symptoms (diagnosed by a specialist neurologist), there is a 50% chance of passing the condition on in each pregnancy.

3. For those who have had DNA testing and are gene negative (do not have the faulty HD gene), there is no chance of passing the condition on to any children

For individuals who are in situation 1 or 2 above, there are options to avoid passing on the faulty HD gene or to find out during a pregnancy whether the baby has the faulty HD gene or not (see below).

If I decide to have children

Deciding to have children is a personal decision and for couples who would like to avoid passing on the faulty HD gene, one or more of the following options may be considered.

• Adoption – This removes the risk of the baby inheriting the faulty HD gene

• Donor sperm (if the father is gene positive) or donor egg (if the mother is gene positive) – This removes the risk of the baby inheriting the faulty HD gene

• Pre-implantation genetic diagnosis (PGD) uses the mother's eggs and father's sperm and involves testing an embryo that has been created using in vitro fertilisation (IVF). Only an embryo that has not inherited the faulty HD gene would be transferred to the mother's uterus in order to develop. - This removes the risk of the baby inheriting the faulty HD gene

• Prenatal Diagnosis involves testing a pregnancy that has been conceived naturally to determine whether the baby has inherited the faulty HD gene. The earliest stage of pregnancy that this testing can be done is around 11 weeks of pregnancy. These tests can cause a miscarriage in a small number of women. – This gives parents information about whether the baby has inherited the faulty HD gene or not.

There is more detailed information about PGD and Prenatal Diagnosis available from: http://www.genetics.edu.au/Publications-and-Resources/Genetics-Fact-Sheets

These information sheets have been compiled in collaboration with the HD community, volunteers and health professionals.