Who is at Risk?

The defective gene may be passed from parent to child at conception. If a parent has the abnormal gene, each son or daughter has a one in two (50%) chance of inheriting HD.

If a person does not inherit the abnormal gene from the affected parent they cannot pass it on to their own children.

Huntington's Disease does not appear in one generation, skip the next, then reappear in a third or subsequent generation. However it may appear to skip a generation where a person dies of an unrelated cause after having children but before they develop symptoms of HD.

It is estimated that the prevalence of HD in NSW is 8 per 100,000 population. The number of people with a 50% risk of inheriting the HD gene was estimated at 32 per 100,000 population. These estimates are conservative and the true prevalence is probably somewhat greater.

The Impact of HD

Huntington's Disease creates a ripple effect throughout families and their communities. Within the family, multiple generations may have inherited the disease, thus overwhelming family resources. Within the community, lack of information about the disease can isolate members of HD families and/or affect their medical care.

The unsteady gait, slurred speech and confusion associated with HD can result in people being mistaken for someone under the influence of alcohol or drugs.

The presence of HD affects decisions about careers, marriage and having children. The emotional, social and economic challenge to everyone involved, whether they have the disease or not, cannot be underestimated.

Effective support and services can improve the quality of life for all those touched by HD.

Genetic Testing for HD

The gene responsible for HD was identified in 1993. It is now possible for those at risk to learn whether or not they have inherited the HD gene before symptoms appear.

Deciding whether to have the predictive test is a very personal choice. It needs to be considered carefully because the implications vary for each person. However, you won't have to make the decision without support, as counselling is a major part of the testing program.

NSW Health Clinical Genetics Services are staffed by clinical geneticists, genetics counsellors and social workers and can provide more detailed information and arrange counselling or testing if required.

An End to HD?

The rapid development of medical research and genetic science in recent decades offers the best chance for a treatment or cure for HD. There is an active international collaboration of scientists and medical professionals working on both the fundamental science of HD and treatment options.

What is Huntington's Disease?

About Huntington's Disease?

- Huntington's Disease (HD) is an inherited brain disorder which affects individuals of either sex.
- It is degenerative: symptoms gradually worsen as the disease progresses.
- Symptoms usually begin to appear between 30 and 45 years of age, sometimes after the gene has already been passed on to a new generation.
- Less commonly, HD may develop in young children or as late as 70 years.
- HD is most commonly characterised by involuntary movement and lack of co-ordination. People with HD have often been falsely accused of drunkenness.
- As the disease progresses the jerking and twisting movements are more likely to increase and slurred speech and swallowing difficulties can develop.
- People with HD usually experience short-term memory loss and reduced ability to plan and organise. Depression and personality changes are not uncommon.
- Life expectancy is about 15 to 20 years after symptoms appear.
- If a person does inherit the abnormal gene, symptoms of HD will eventually show, providing the person lives long enough.
- The HD gene was isolated in 1993 but there is still no cure for the disease.
- A predictive test now enables people who are at risk to learn whether or not they have inherited the HD gene before symptoms appear.

Huntington's NSW

The Australian Huntington's Disease Association (NSW) Inc. was established in 1975.
Its objectives are to develop support and educational programs to help people affected by HD; to assist their families to understand and cope; and to give HD families in NSW and the ACT a strong single voice.

The Association is an incorporated body, managed by a board elected by its members, and is authorised to fundraise in NSW and the ACT.

Services We Provide

- Enquiries and referrals
- Information (publications & website)
- Carer support
- Rural outreach service
- Holiday camps and social activities
- Research funding
- System advocacy

How You Can Help?

We are funded by a combination of government grants, charitable donations and our own fundraising. Donations from the public assist us to maintain and expand our services. Donations of more than $2.00 are tax-deductible.

Need Help?

We provide a range of services, and refer people to other agencies as necessary. These include the following services of NSW Health:

- The NSW Huntington Disease Service located at Westmead Hospital. The service provides clinical, allied health and other services.

- Clinical Genetics Services throughout NSW for genetic counselling and predictive testing.

Contact Us

We are located in West Ryde in Sydney.
We are open Mon-Wed and Friday but it is best to telephone before visiting to ensure that the person you need to see is available.

Street Address: 21 Chatham Rd
West Ryde NSW 2114

Mailing Address: PO Box 178
West Ryde NSW 1685

Telephone: (02) 9874 9777

STD Freecall: 1800 244 735 (rural NSW only)

Email: info@huntingtonsnsw.org.au

Website: www.huntingtonsnsw.org.au