

Research

Scientists around the world are looking into ways to slow down or prevent the advance of Huntington's disease (HD) and, as a result, there are several studies taking place.

People are often excited about such studies and may hope to become a part of one of these. However it is an ever changing landscape due to ongoing developments, and what may look positive today can appear less so tomorrow

There can be disappointment if drug trials are stopped or you find out that you don't meet the eligibility criteria for a specific study. Nevertheless, it is reassuring to note that vast amounts of money and time are being invested in research and any suspended or discontinued trials will have made inroads for future work. This is only the beginning for researchers. There is much to hope for in Huntington's disease community.

1. How do I find out about the latest research?

[HD Buzz](#) shares the latest information and news about Huntington's disease research. It is written by scientists and clinicians involved in such studies and is easy to understand. This is a reliable source of information if you are looking for up to the minute developments in the search for effective treatments for Huntington's disease.

2. Can I become involved in research?

When it comes to research studies, participating in [Enroll-HD](#) is probably the most important thing that you can do right now, especially if you are asymptomatic or at risk of Huntington's disease. Enroll-HD is an observational study set up in order to collect information from you. It would involve you attending an appointment so that your information can be entered on to a confidential database. Researchers and scientists will analyse this data in the hope that they can develop new treatments. This

database is a helpful register to identify specific groups of people for specific trials, for example it may be that a certain functional or motor score is required.

Now worldwide, Enroll-HD is helping to gather knowledge about how Huntington's disease works. Your input could help researchers accelerate the development of therapeutics and help them understand what treatments may work in the future. If this is something you would be interested in, you would be invited to attend an annual two-hour appointment to undergo a series of small tests/assessments and answer questions about your lifestyle.

The first step is to ask your HD Specialist who to contact. A number of the Scottish Huntington's Association specialist services conduct Enroll-HD Clinics and may recruit people out of area. Or, if you prefer, visit www.enroll-hd.org/participate/clinic-locations to get in touch with your nearest Enroll-HD site.

3. Will I meet the Enroll-HD requirements?

Any family member impacted by Huntington's disease can take part in the study, including:

- People who know they carry the faulty gene that causes HD, symptomatic or not
- People at risk of developing Huntington's disease
- People who have had a negative test result for the disease
- Spouses/partners of a family member with Huntington's disease
- Children under 18 (with parental consent) with clinically diagnosed Juvenile Huntington's disease

As time goes on, more trials and studies will be developed. It is important to know which studies are underway in your area. Keep in touch with your HD Specialist for up-to-date information.

Useful links

[Visit HD Buzz for latest research news](#)

[Find out more about Enroll-HD](#)

[Contact a Scottish Huntington's Association HD Specialist](#)

[Scottish Huntington's Association Financial Wellbeing Service](#)

[National and Regional Care Frameworks for Huntington's disease](#)

[Scottish Huntington's Association Youth Service](#)

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