



## Start here!

Huntington's disease research news. In plain language. Written by scientists. For the global HD community.



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**W**elcome to HDBuzz! This special page is for people who are new to Huntington's disease, or new to the world of HD research.

Reading the articles linked here will help you pick up the basics of what Huntington's disease is, and get up to speed with some of the most promising things scientists are doing to come up with effective treatments for HD.

## Huntington's disease - the bare essentials

- Our [Science FAQ](#) covers the very basics of HD and introduces some ideas about why we need research to find treatments.

## About HDBuzz

- Our [HDBuzz FAQ](#) and [People Page](#) explain what HDBuzz is, and the people behind it.
- And our [Funding](#) page explains where we get our money from and how we make sure HDBuzz is neutral and reliable.

## The most promising possible treatments

Some of the world's top scientists are working round the clock to develop treatments for Huntington's disease - and real progress is being made. Dozens of possible treatments are being worked on, and every day a successful treatment gets one day closer. Here are some leading approaches being tested in the clinic.

**Huntingtin lowering** Huntington's disease is caused by a faulty protein, and huntingtin lowering drugs tell cells to make less of that protein. Huntingtin lowering is sometimes called "gene silencing". Right now many scientists believe it is our best hope for an effective treatment. Read about it in our [Gene Silencing Primer](#).

- The [first successful huntingtin-lowering trial](#) was announced in December 2017; this

was followed by [a larger, longer trial called Generation-HD1](#) that tested whether the drug, renamed tominersen, could slow the progression of HD. Unfortunately [this trial was halted early](#) because it did not have the expected benefit and may not have been safe for some participants. However, tominersen [will be re-tested in an upcoming trial](#).

- [Several other approaches to huntingtin-lowering are being developed and tested](#), including other ASO drugs, viruses containing instructions to make less of the huntingtin protein, and even “small molecules” that could be taken by mouth.

**Other approaches** to addressing HD biology and HD symptoms include preserving the connections between nerve cells, enhancing certain types of signals in the brain, stopping CAG repeats from lengthening, and treating problems with thinking and movement. [Read more about these approaches here.](#)

## Living with HD

Some of our most popular articles offer the latest information about day-to-day issues faced by Huntington’s disease family members.

- [‘Making Babies’](#) explains how people at risk of HD can use assisted fertility methods to have HD-free kids - even if the would-be parents don’t want to be tested themselves.
- Our article on the [‘Genetic Gray Area’](#) of HD sheds light on the often confusing topic of people whose HD genetic test result isn’t quite positive or negative, but somewhere in the middle.
- Many HD-affected people are frustrated by a lack of interest or expertise from care professionals. Take a look at our article on [Closing the Care Gap](#) to find out about the expert guidance available to professionals - why not show it to the professionals looking after you?

## Taking action

Successful treatments to prevent, slow, reverse or cure Huntington’s disease will arrive more quickly if more people help out. Here’s what we recommend:

- Sign up for [Enroll-HD](#), the largest global study of HD family members. Anyone from an HD family can sign up and you don’t need to have had a genetic test to do so. A short annual assessment involving questionnaires, thinking tests and a blood sample is all it takes to help us understand HD and put you in pole position for clinical trials.
- In the USA, look at the [HDSA’s TrialFinder](#), which will tell you what drug trials and other research studies are going on near you.
- In Canada, look at the [HSC’s Clinical Trial Locations](#) page.
- In Europe, check out the [EHA](#) and the [Euro-HD Network](#).
- In Australia, check out the [HDNA’s Map-HD Registry](#).
- If you are affected by Juvenile HD, Check out HDYO’s [JOIN-HD Registry](#).
- Elsewhere, the [International Huntington Association](#) will help you get involved.

# Getting behind the headlines

A key mission of HDBuzz is to help our readers sort out the hope from the hype. News and blog stories can sometimes give a false impression of how promising a particular treatment is, or how soon it could deliver for HD-affected people.

- Our [Ten Golden Rules](#) article suggests ten simple steps to help you draw hope from a science news story, without being disappointed by impossible promises.

Meanwhile, there are many areas of science being explored as part of the larger “HD research pipeline” which are not yet ready to pursue in humans. Sometimes these are interesting and potentially useful, but sometimes they generate headlines that aren’t necessarily able to live up to the hype. Here are some examples of recent articles about broad topics, “basic science,” and techniques that are moving HD research forward.

- Our [Stem Cell Primer](#) explains the real value of stem cells, right now - as tools to help us understand Huntington’s disease.
- [New systems for classifying stages of HD](#) and [new technologies](#) are being applied to large human datasets made possible by those from HD families who participate in observational studies. These have the potential to speed up or design better clinical trials, and to improve care.
- New tools, like [tracers for visualizing huntingtin](#) in the brain, and [novel animal models of HD](#), are making it easier for researchers to more accurately study HD biology in different systems. HD scientists are constantly innovating, by [putting a new spin on gene editing](#), [uncovering new mechanisms](#) for existing drugs, or identifying [new ways](#) to track the effects of HD on the brain and body.

## The very latest

We regularly produce reports from major scientific meetings and conferences. They’re a great way to get an overview of all the hottest Huntington’s disease research. [Catch up on the latest conference news here.](#)

## Make yourself at home!

HDBuzz is designed so that each article makes sense on its own and gives you all the background info you need. So don’t be afraid to explore.

- Each article has a **learn more** box, containing links to original sources and background information.
- Every article has a **topics** box so you can easily find content on a particular subject.

If there’s something about HD research you’d like explained but can’t find here, feel free to use the ‘Suggest an article’ box on the front page.

And to make sure you don't miss anything exciting, follow us on [Twitter](#) or [Facebook](#), or sign up for [Email updates](#)

Welcome aboard. We're glad you found us.

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*The authors have no conflicts of interest to declare. [For more information about our disclosure policy see our FAQ...](#)*

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## GLOSSARY

**huntingtin protein** The protein produced by the HD gene.

**gene silencing** An approach to treating HD that uses targeted molecules to tell cells not to produce the harmful huntingtin protein

**clinical trial** Very carefully planned experiments designed to answer specific questions about how a drug affects human beings

**observational** A study in which measurements are made in human volunteers but no experimental drug or treatment is given

**juvenile HD** Huntington's disease where symptoms begin before the age of 20.

**stem cells** Cells that can divide into cells of different types

**ASOs** A type of gene silencing treatment in which specially designed DNA molecules are used to switch off a gene

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