Ten Golden Rules for Navigating Huntington's Disease Research News

Avoid the hype: HDBuzz has Ten Golden Rules for navigating news stories or press releases about Huntington's disease.

By Dr Rachel Harding | April 21, 2025 | Edited by Dr Sarah Hernandez

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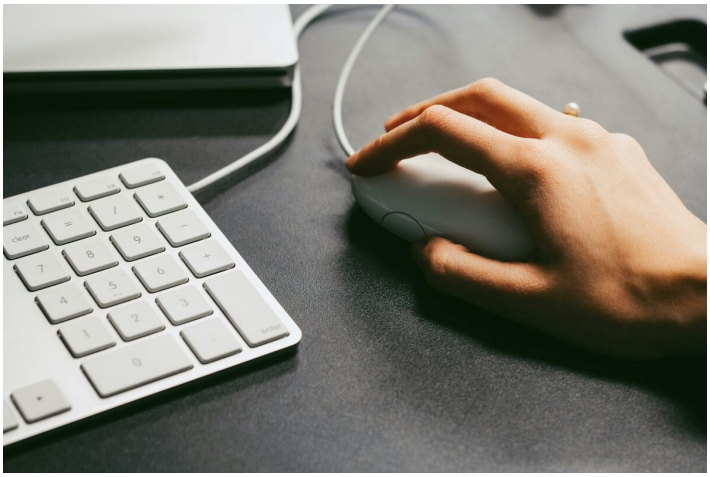
Real progress is being made on the road to Huntington's disease (HD) treatments, but in today's fast-moving digital world, it can be harder than ever to separate genuine breakthroughs from overhyped headlines or flat-out misinformation.

That's why HDBuzz has updated our Ten Golden Rules to help you decide whether a piece of news about HD research offers real promise, or whether its claims should be taken with a healthy pinch of salt.

If this article seems familiar, that's because it is! Ed and Jeff wrote a version of theserules back in 2011. But over the past 14 years, the way we consume news in the age of social media and clickbait-focused news websites has changed a lot. So we hope this updated article provides some clarity and helpful guidelines for navigating research news in 2025.



Clickbait is a headline or link designed to entice people into clicking by being sensationalized, misleading, or intriguing, but providing little in return.

Snowflakes and glaciers

At HDBuzz, we love science. We like to imagine all the world's scientific research as a flurry of snowflakes, gently settling on a mountaintop and gradually, over months, years, and decades, compacting into a huge, unstoppable glacier that can carve entire mountains.

No single snowflake could do that, but combined, over time, the power of science to change the world - and improve the lives of people with HD - is immense.

The search for treatments and cures for HD is exactly like that. Most progress is small, incremental, and takes place behind the scenes. But step-by-step, we're moving closer to therapies that will make a meaningful difference.

How science reaches the public in 2025

Science becomes "official" when it's published in a peer-reviewed journal - but that's rarely how most people first hear about it. In 2025, scientific information spreads across a sprawling ecosystem of platforms: news sites, press releases, blogs, Facebook, YouTube explainers, Reddit threads, and increasingly, short-form video on platforms like TikTok and Instagram.

That's not necessarily a bad thing - more access to information is a win. But it comes with risks. Short videos and viral posts are often created for clicks and engagement, not accuracy. Many creators aren't scientists, and even well-meaning ones can misunderstand or oversimplify complex findings. Sometimes, content is misleading or, worse, just plain false.

At the same time, researchers and institutions are under more pressure than ever to promote their work and secure funding. Teams will often issue press releases that highlight the long-term potential of early-stage research or niche studies, even when those applications are years (or decades) away or only give insight to a narrow aspect of HD research.

One way to excite people about this type of research is to get them to imagine the whole glacier, rather than just the snowflake. When those press releases are subsequently re-written into news articles or turned into social media snippets, nuance can be lost. A promising experiment in cells or mice can easily become "Scientists close to curing Huntington's disease!" - even if human trials are a long way off.

What's the harm?

It's easy to feel hopeful, and we should! But when stories exaggerate the readiness or relevance of early-stage science, people in the HD community can end up misled, confused, or disappointed. And repeated disappointments can erode trust in science altogether. We don't believe this is the fault of individual scientists, journalists, or creators. But in a world where misinformation spreads fast, it's important to stay curious *and* critical.

We know that some folks think of us as "HDBuzzkill", as our articles can be less enthused than other press releases or articles on other platforms. However, for our editorial team, whilst we strive to be peppy and hopeful as much as possible, we also want to prioritise

managing expectations and keeping our reporting as accurate as possible as a matter of the utmost importance.

HDBuzz's Ten Golden Rules for navigating science news

The good news? You don't need to be a scientist to protect yourself from hype and heartbreak. So, HDBuzz has Ten Golden Rules for reading a press release or scientific news article. They're here to help you to draw hope from scientific news where it's warranted - and avoid being let down where it's not.

1. Be skeptical of anyone promising a "cure" for HD now, or in the near future. There are promising leads, but no magic bullets yet.

2. If something sounds too good to be true, it probably is. "Breakthrough," "miracle," and "game-changer" are red flags if not backed by details.

3. Has the research been published in a peer-reviewed scientific journal? If not, it might just be a preliminary result or a publicity push.

4. Is the news about actual research results? Or a new partnership, startup, or funding award? Hope is good, and investment in HD research from different stakeholders is fantastic, but ultimately results from the lab and the clinic matter most.

5. Has the treatment been tested in people with HD? If not, no one really knows if it works in people.

6. Has it been tested in an HD animal model? Even if a treatment seems to have worked in mice, that's a great first step, but a long way from working in people, and many things fail in the path to the clinic.

7. Has it even been tested in an HD model? If the research hasn't yet been tried in a model that mimics HD, it's still at a very early stage.

8. Watch out for clickbait. Articles with headlines like "Scientists Stun the World" or "This CRISPR Discovery Changes Everything" are designed to get attention - not tell the full story. Stick with sources that prioritize facts over flash.

9. Look out for overconfident or definitive language. Be cautious if the language used is absolute - words like "always," "never," "guaranteed," or "proven." Science is careful and cautious for a reason.

10. When in doubt, ask HDBuzz! If you're unsure about something you read or see on social media, drop us a note at editor@hdbuzz.net or use the form at HDBuzz.net. We're pulling double duty with day jobs as HD scientists and researchers, giving us a unique lens to

translate findings from the lab for HD families. And we're happy to investigate and contact our network of experts to help differentiate hope from hype.

Progress is still progress, even when it's slow. Every study, even ones that don't lead directly to a treatment, helps us get closer to our goal. That's the power of the snowflake - glacier model: steady, collective progress over time.

Using the golden rules in practise

Example 1 - "New drugs cross blood-brain barrier to slow progression and even reverse symptoms of Huntington's disease"

In this research paper, we learn that a team of researchers from the Weizmann Institute of Science in Israel have identified two small molecules that can reduce levels of the harmful huntingtin protein that causes HD. These molecules work by interfering with part of the machinery that helps coordinate how genetic message molecules are made.

In a mouse model of HD, direct delivery of these drugs into the brain improved many signs and symptoms of HD in this model. Importantly, the molecules were able to cross the blood-brain barrier, and seemed to slow disease progression without noticeable side effects.

This is a really cool study and suggests that these small molecules that target the genetic root of HD could be a promising path toward new treatments.

Unfortunately, in one of the articles covering this research paper, the story comes across quite differently. The headline alone states that these small molecules are drugs that can slow and even reverse symptoms of HD. Let's go through the rules to see how this article fares. Here is our summary:

Rule 1. Cure claim? ⚠ Caution - Data suggests reversal of symptoms in mice; not a human cure. Reversing HD symptoms is akin to claiming a cure. Whilst the data in mice might support reversal of features of HD mouse models, which we use as a surrogate for HD symptoms, this is a long way from a cure for people.

Rule 2. Too good to be true? ⚠ Caution - Promising results in mice; human applicability uncertain. This article definitely sounds too good to be true in our opinion. These aren't drugs, but tool molecules these folks are using in the lab. There is a long road from a tool molecule being tested in mice in the lab to a drug being tested in people in the clinic.

Rule 3. Peer-reviewed? 𝌆 Pass - Published in EMBO Molecular Medicine.

Rule 4. Actual results? 𝌆 Pass - Reports on experimental findings in mice.

Rule 5. Tested in HD patients? 𝌆 Fail - Not yet tested in humans. This study has not conducted any experiments in people, not that you would know from the headline, which fails to caveat that this work was conducted in mouse models of HD. The data in the paper is supportive that these molecules might help slow symptoms, or stuff scientists can

measure in HD mouse models which look somewhat like human symptoms of HD. This is an excellent start, but certainly a long way from showing this is a tractable approach to be investigated in people.

Rule 6. Tested in HD animal model? 🟰 Pass - Conducted in mouse models of HD.

Rule 7. Tested in HD model? 🟰 Pass - Yes, in relevant animal models.

Rule 8. Clickbait? ⚠ Caution - Headline may overstate findings. In our opinion, the title of this article is clickbait. The title doesn't tally with the subsequent text which goes into more detail about what really happened in the study.

Rule 9. Definitive language? ⚠ Caution - Language suggests more certainty than warranted. The title of the article and some of the text therein is definitely peppered with overconfident or definitive language. Claiming to reverse symptoms of HD is a very bold statement, which we don't believe the data definitively support.

Example 2 - "AMT-130 slows progression in early Huntington's, 2-year trial data show"

Last July, the HD community had an exciting update from uniQure about their gene therapy drug, AMT-130, currently in clinical trials. The update uniQure provided in their press release was based on data collected from folks treated with the drug over a 2-year time period.

They found that the treatment continued to appear relatively safe, with no new serious side effects since the study was briefly paused in 2022. Most side effects so far are linked to the brain surgery required to deliver the drug. They also reported on a key brain health biomarker, NfL, which typically rises as HD progresses. After an initial spike (likely due to the surgery), people treated with AMT-130 showed a long-term *decrease* in NfL levels, suggesting the drug might be slowing the disease process. This trend was seen in both low- and high-dose groups at 2 years post-treatment, though the number of participants remains small.

On clinical measures, the high-dose group showed about 80% slower progression by cUHDRS, a sensitive scale that tracks HD symptoms, compared to untreated patients in a natural history study. That's a potentially big deal, but with only 9 people in that group, we still need to interpret the results cautiously. Other individual clinical scores showed less obvious effects, and data on huntingtin protein levels or brain imaging weren't shared in this update.

HDBuzz and many others reported on this update. One report from Huntington's Disease News somewhat missed the mark in our opinion. Let's go through the rules to see where this piece falls short. Here is our summary:

Rule 1. Cure claim? 🟰 Pass - No cure claimed.

Rule 2. Too good to be true? ⚠ Caution - Significant claims based on small sample sizes. In our opinion, the article makes claims that are very bold for data from such a small number of trial participants.

Rule 3. Peer-reviewed? ≣ Fail - Data not yet peer-reviewed. Whilst companies typically work to ensure that all of the data they share in updates on clinical trials are accurate and appropriately interpreted, their reports are not peer-reviewed. In fact these "science-by-press release" updates are often geared towards their financial investors, so will often put a positive lens on their findings. Some healthy skepticism is certainly warranted for updates from all companies in this format.

Rule 4. Actual results? ≣ Pass - Interim clinical trial results presented.

Rule 5. Tested in HD patients? ≣ Pass - Yes, in early-stage HD patients.

Rule 6. Tested in HD animal model? ≣ Pass - Preclinical testing conducted.

Rule 7. Tested in HD model? ≣ Pass - Yes, in HD models.

Rule 8. Clickbait? ⚠ Mild Caution - Headline somewhat overstates conclusiveness. For this particular write up, the title clearly overstates the conclusions of the updates released by the company. AMT-130 certainly seems to be moving things in a positive direction, but to write that it absolutely slows HD progression is an overstatement in our opinion.

Rule 9. Definitive language? ⚠ Caution - Some overconfident phrasing present. As laid out with the previous rule, much of the language in the article is too definitive in our opinion. The article claims "Treatment with AMT-130 high dose slowed disease progression 80%". This is in fact based on data from one clinical measure, cUHDRS, with data derived from just 9 people. The data are encouraging, but this phrasing seems to overstate the facts we have so far.

Example 3 - "AAN 2025: Pridopidine Shows Sustained Benefits on Progression, Cognition, and Motor Function in Patients With HD"

Recently, at the prestigious 2025 American Academy of Neurology Annual Meeting in San Diego, there was a presentation about pridopidine, a drug that activates a brain-protective protein called the sigma-1 receptor. Often, the abstract from talks at meetings like this are published in journals so that there is a record of the meeting and folks can see what research was presented.

From this abstract, we learnt that researchers studying pridopidine had scrutinised over 100 weeks of data to see how pridopidine might affect everyday function (TFC), disease progression (cUHDRS), movement, cognition, and quality of life. They found that for people *not* taking antidopaminergic medications (like VMAT2 inhibitors or antipsychotics), pridopidine seemed to outperform placebo across all measures, with some benefits lasting over a year. Based on this, the authors suggest that pridopidine could be a promising and safe, long-term treatment for HD.

This abstract was picked up and written about in this article. The HDBuzz team thinks this article falls short of conveying the complete picture. Let's use the rules to help us work through where this article misses the mark. Here is our summary:

Rule 1. Cure claim? 𝌆 Pass - No claim of a cure.

Rule 2. Too good to be true? ⚠ Partial fail - Subtle overhyping. This article provides little context of the long and complicated journey the drug pridopidine has taken in clinical trials in HD. In its most recent trial, PROOF-HD, pridopidine failed to show benefit in people with HD and did not meet its endpoints. The news article does not provide this historical context and the title of the abstract does not accurately portray the facts of the study.

Rule 3. Peer-reviewed? 𝌆 Fail - Conference data only. The conference abstract, although published in the esteemed journal Neurology, is not peer reviewed. This is stated in the abstract itself, but not the news article. This means that no external scientists have scrutinised the study to see if the claims made in the abstract are really supported by the underlying data and should be interpreted with caution until they are.

Rule 4. Actual results? 𝌆 Pass - Real clinical data, though limited to a subgroup.

Rule 5. Tested in HD patients? 𝌆 Pass - Phase 3 trial.

Rule 6. Tested in HD animal model? 𝌆 Pass - Not mentioned but detailed in published literature.

Rule 7. Tested in HD model at all? 𝌆 Pass - Preclinical work exists.

Rule 8. Clickbait? ⚠ Borderline - Sensational phrasing in the absence of context. The article uses phrases such as "Sustained benefits" and "Significant benefits on progression, cognition, and motor function" that imply more certainty than the subgroup analysis supports, and could be deemed clickbait by omission.

Rule 9. Definitive language? 𝌆 Fail - Overstated benefits not clearly qualified. There are examples in this article of overconfident or definitive language which lack in our opinion appropriate qualifiers such as "suggests," "trended toward," or "needs further validation," which are standard in cautious scientific reporting.

Final thoughts

In a world flooded with content, from traditional news stories to snappy TikToks, it's more important than ever to know how to spot good science. At HDBuzz, we're here to help. We believe in sharing clear, accurate, and hopeful information with the HD community.

With that in mind, don't forget **Rule 10** - if you're unsure about something you read or see on social media, drop us a note at editor@hdbuzz.net or use the form at HDBuzz.net. We're happy to investigate!

Science is slow, but it's moving. And we're moving with it. Let's keep learning, questioning, and pushing forward - together.

Sarah Hernandez is an employee of the Hereditary Disease Foundation, who has provided financial support to researchers who have work described in this article. For more information about our disclosure policy see our FAQ...

GLOSSARY

blood-brain barrier A natural barrier, made from reinforcements to blood vessels, that prevents many chemicals from getting into the brain from the bloodstream

huntingtin protein The protein produced by the HD gene.

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

differentiate differentiation is the process of one cell type turning into another cell type.

biomarker a test of any kind - including blood tests, thinking tests and brain scans - that can measure or predict the progression of a disease like HD. Biomarkers may make clinical trials of new drugs quicker and more reliable.

Receptor a molecule on the surface of a cell that signalling chemicals attach to

placebo A placebo is a dummy medicine containing no active ingredients. The placebo effect is a psychological effect that causes people to feel better even if they're taking a pill that doesn't work.

CRISPR A system for editing DNA in precise ways

Total Functional Capacity A standardized rating scale for function in HD, used to assess capacity to work, handle finances, perform domestic chores and self-care tasks

NfL biomarker of brain health
