



A new era for HDBuzz

For over a decade HDBuzz has reported unbiased news about Huntington's disease research and trials. As our beloved Ed and Jeff step back, Rachel, Sarah, and Leora look forward to upholding the HDBuzz mission.



By Dr Sarah Hernandez, Dr Leora Fox, and Dr Rachel Harding

May 01, 2024

Edited by Dr Leora Fox and Dr Rachel Harding

HDBuzz strives to be an honest and neutral source of information that Huntington's disease (HD) families can turn to for trusted, unbiased reporting on research and clinical trial news. We're honored to have become a global resource for the HD community over the years (14!) and we look forward to building upon the original mission of HDBuzz as we head into a new era. Read on to learn more about the new editors-in-chief and our plans for the transition.

The need for information

While we know it's hard to fathom at this point, there once was a world before Google. In those dark ages, information was harder to come by. This was especially true for HD.



Then and now: Ed and Jeff in 2011 at one of their first presentations as HDBuzz (left), and later in 2023 presenting at an HDSA convention (right).

Often, the most people heard about HD was restricted to short blurb in a textbook, distilling HD down to a disease passed from generation to generation that one had a 50% chance of inheriting if their parent was affected. This limited picture was particularly disheartening for HD families seeking information. Seeking answers. Wondering what research was being done to find a treatment for this devastating disease.

The broad establishment of the internet changed the way information could be shared. It promised greater accessibility of cutting-edge research. It provided a platform that could be used to immediately share information from one corner of the globe to another – from the lab bench to HD families. But what was out there was often hard to find, full of jargon, and interspersed with misinformation.

The advent of HDBuzz

Two HD researchers saw the gap in getting accurate information from researchers to the people most eager for scientific updates on HD – HD families. In 2010, Dr. Ed Wild and Dr. Jeff Carroll established HDBuzz to rapidly disseminate high-quality HD research news to the global community, written in plain and accessible language, by HD clinicians and scientists.

HDBuzz has gone to great lengths to be impartial in our reporting.

- We don't accept funding from any drug company or organization with a vested interest in a particular treatment or technology
- No funding organization gets any editorial control over HDBuzz content
- Independent external advisors provide input on content to ensure that it is impartial, scientifically accurate, and understandable
- All our authors make disclosure statements, which they review whenever they contribute new content to ensure any possible conflicts are clearly declared

New HDBuzz Editors

As Ed and Jeff advanced in their careers, their research and consulting responsibilities increased. This left them with less time to support the vital mission of HDBuzz. To ensure HD families could continue to rely on HDBuzz as a trusted resource for HD news, the team grew.

A decade after HDBuzz's creation, in 2020, Ed and Jeff folded in 3 new editors: Dr. Rachel Harding, Dr. Sarah Hernandez, and Dr. Leora Fox. If you've been reading HDBuzz articles over the past 4 years, you've likely seen these names in the by-line.

After 4 years of having Rachel, Sarah, and Leora on team HDBuzz, Ed and Jeff are officially passing the baton and stepping back to an emeritus role. This will allow them to focus their efforts on HD research and care, advancing promising ideas and experimental treatments for HD toward the clinic and give the new team the opportunity to grow and develop HDBuzz even further.

Meet your “new” Editors-in-Chief

So who exactly are the new names behind HDBuzz and why should you look forward to hearing their take on HD research in the years to come?

DR. RACHEL HARDING

What got you into HD research?

I have always been interested in understanding the precise molecular details of how biology and disease work; how do different proteins work together to perform a specific biological function and what molecular changes happen in disease for things to stop working

properly? I was intrigued by HD as we know the exact molecular change which causes disease, an increase in the CAG number of the huntingtin gene DNA, but even with this knowledge, unpicking the molecular details or exactly what goes wrong has proved very challenging for the field.

In 2018, I was fortunate enough to be awarded a Huntington's Disease Society of America Berman Topper Family Career Development Fellowship, which helped fund my research looking into the HD protein and how this molecule is changed in disease. I became hooked on trying to answer this question, and it has become the focus of my research ever since.

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It very quickly became apparent just how welcoming and collaborative the HD research community is, and I feel lucky to be able to work with so many fantastic folks. The impressive way HD meetings and conferences span patient viewpoints, clinical trial updates, cutting-edge breakthroughs in the lab and everything in between, is just super.

What's your “real” job?

I am a Principal Investigator at a research institute called the Structural Genomics Consortium (SGC) in Toronto. I wear a second hat as I am also an Assistant Professor in the Department of Pharmacology and Toxicology at the University of Toronto, Canada.

What this all means is that I run a research group who are primarily focussed on studying the HD protein, to better understand how it works, and what goes wrong in disease. As part of the SGC, we are also involved in many early-stage drug discovery research programs, in HD and other diseases.

The work we do is highly collaborative and we have partnerships with lots of different HD labs and other specialists around the world. Open science is a key part of our ethos and we share both our results and the materials we make and study in the lab, including the HD protein, with different labs that span all continents.

Why are you excited about bringing HDBuzz forward?

It has been such an honour to write, edit, present, and report for HDBuzz in the past few years. I have learnt so much about the HD community and it has reinforced my beliefs that science should be for everyone, and that it is critical that everyone has access to the latest research findings in plain language.

In this next phase, I am excited to build upon the great foundation created by Ed and Jeff, and push HDBuzz further. I am especially keen to connect with even more HD communities from around the world and further increase the accessibility of HD research to everyone who needs it.

DR. SARAH HERNANDEZ

What got you into HD research?

“Huntington’s disease” has been a household phrase for me since I was about 12 years old. That’s when I found out my maternal grandmother died from HD. I grew up watching family members suffer with HD, knowing what it meant for the next generations if something wasn’t done. That really lit my curiosity. From then on, I wanted to learn as much as possible about HD and how we could solve this problem so that we could get a treatment.

It turns out I had a whole lot more questions than there were answers! Ultimately this led to me getting a PhD in Biology with the hopes of helping to find a treatment. I did my postdoc with Dr. Leslie Thompson at the University of California, Irvine. She’s a pioneer in HD research – she was a member of the team that went to Venezuela to identify the gene that causes HD.

With Leslie, I used stem cells to model HD. We’re able to turn those cells into brain cells and ask and answer all sorts of questions about how the gene that causes HD is specifically affecting brain cells. I also worked with fruit flies that carried the HD gene to do genetic experiments.

What’s your “real” job?



Rachel, Sarah, and Leora have been bringing you content as HDBuzz since 2020 and are excited to take up the mantle as the new Editors-in-Chief to continue the mission of HDBuzz.

About 2 years ago I started working at the Hereditary Disease Foundation (HDF) as the Director of Research Programs. The HDF was started by the Wexler Family, who is also affected by HD. Dr. Nancy Wexler has really changed the face of HD research, instilling collaboration into the field that has moved mountains. She led the missions to Venezuela to find the gene that causes HD.

At the HDF, I coordinate our scientific programming through webinars, workshops, and conferences. I also manage the grants program. Finding a treatment for HD is the primary mission of the HDF, and we believe that will happen through research. In 2023 we spent 85% of all donations on research. In 7 years, we’ve given over \$13M in grants and fellowships to over 100 recipients!

I love the work that I get to do at HDF because I get to help support amazing researchers and see all the latest HD research as scientists are coming up with it. It's the perfect job for me! My 12-year-old self would be pumped to see where I am.

Why are you excited about bringing HDBuzz forward?

The mission of HDBuzz really speaks to how I felt when I first found out HD runs in my family. When I was a kid, I just wanted answers about HD. I wanted to know about the latest research. I wanted to know what people were doing out there to get us closer to a treatment. If HDBuzz had been around back then, it could have saved me a lot of time (like, a whole PhD's worth!).

I'm excited to bring HDBuzz forward because I know how HD families feel that just want to know what's going on. I feel like scientists have a duty to get the information they find to the people that are affected by that information. The research project isn't over until information gets where it needs to go. HDBuzz has been a fantastic resource for the HD community in ensuring that happens.

I spent 22 years in classrooms and at the lab bench developing the tools and skills that enable me to help people understand the science behind what's going on in HD. I'm honored to be the conduit to get information about the research to the HD families who need it most.

DR. LEORA FOX

What got you into HD research?

I grew up volunteering (singing and dancing, actually!) in long-term care facilities where I became aware of a lot of neurodegenerative diseases, including HD. I was also one of those high school science nerds who started working in a lab as soon as someone would let me. This combo led me to study neuroscience in college, work in an Alzheimer's lab afterwards, and eventually to pursue a PhD in neuroscience at Columbia University in New York City.

I was lucky enough to land in the lab of Ai Yamamoto, who was one of the first scientists to show that "turning off" the HD gene could lead to improvements in HD mice. She introduced me to the HD research community and gave me opportunities to write and speak in addition to designing experiments.

What's your "real" job?

I've been at HDSA since 2016, and since 2021 I've overseen research and patient engagement programs. HDSA funds research, communicates about research, and helps to bring family voices into the drug development process. We are the largest family-facing HD organization, and we primarily serve the US.

In addition to research we support more than 60 multidisciplinary HD care centers around the USA, and we have a variety of advocacy initiatives, educational programming at the local and national level including our yearly HDSA Convention, the largest global gathering

of HD families. We provide many different types of social services through our network of 100+ social workers, support groups, disability services, and other national and local programs.

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Research plays into many aspects of support and care and vice versa, and I am constantly learning from the community members I speak to and from my colleagues in social services.

Why are you excited about bringing HDBuzz forward?

I like to say that my passion is helping people understand science, and helping scientists understand people. Bridging community needs with stellar research and presenting it in a way that everyone can understand is key to perpetuating the search for treatments.

I did not enter this field with a personal connection to HD, but this community, the families and the scientists, have become very dear to me. I love to write and edit, to engage with all sorts of people, to enable cross-talk and access and inquiry, to see research progress and to communicate its importance.

To be able to apply a hard-won skillset to help make HD science accessible, even entertaining, within a global community I care about - what a dream!!

What we're dreaming of doing

HDBuzz has a solid foundation thanks to Ed and Jeff, and we are building upon their efforts to strengthen and expand upon the HDBuzz mission. Here are some of the steps we are taking towards that goal:

- Get feedback from the global HD community about information needs, perceptions, and ideas for HDBuzz
- Increase our pool of scientist-writers to include a diversity of voices
- Integrate AI translation for global accessibility by having all articles available in as many languages as possible
- Plan site updates and ongoing content based on community feedback

Thank you to Ed and Jeff!

As the new editors-in-chief of HDBuzz, we give our warmest, most heartfelt thank you to Ed and Jeff for what they created in HDBuzz. You've created an invaluable resource for the community that has shaped the way HD families receive news about ongoing research and trials. We look forward to continuing your mission as we usher HDBuzz into the future!

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

GLOSSARY

neurodegenerative A disease caused by progressive malfunctioning and death of brain cells (neurons)

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

stem cells Cells that can divide into cells of different types

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