

May 17, 2023

Dear Friends,

I am happy to announce that HDSA is embarking on a new and exciting partnership with RARE-X, the patient-driven data collection platform of Global Genes, to harness the power of your voice and lived experience to speed the development of therapeutics for HD.

The new HD Data Collection Initiative will create a high-quality natural history study to accelerate knowledge development through effective patient-owned data collection, data connection and community pooling of data. Simply put, your health data – owned by you and shared by you – will help doctors and scientists better understand HD so that care – and a cure – come faster.

Right now, researchers have access to an amazing amount of clinician-reported data, through the ENROLL-HD platform and learnings from other observational studies like PREDICT-HD and COHORT. Your doctor's observations and medical assessments are extremely important and over the last ten years ENROLL-HD has transformed drug development for HD. (We cannot overstate the importance of being in ENROLL-HD. Visit www.hdtrialfinder.org to enroll today!)

However, there's more to life with HD than what doctor's see in their office.

At HDSA we know that people with HD and their caregivers are the real HD experts. Your lived experiences with HD, either personally or as a family member caring for someone, provide vital insights into what families need now.

Through this new partnership with RARE-X, HDSA is inviting you to share your firsthand experience as someone in an HD family in a structured and secure manner. Anyone will be able to participate, all you will need is access to the website which will launch at the HDSA Convention on Saturday, June 3rd. Over time you will answer surveys about your health or that of your loved one with HD.

The data is de-identified and will be collected through validated surveys, which means that they have been studied to make sure they are in formats that are proven to be reliable ways for people to share their own health journeys. Overtime, by adding your "HDID" (a unique number assigned to everyone who participates in ENROLL-HD) this dataset will complement the clinician reported information of ENROLL-HD and build a three-dimensional picture of life with HD with clinician, patient and caregiver data.

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The HD DCI aligns perfectly with HDSA's three Strategic Goals that are critical to the accomplishment of our mission to improve the lives of people with Huntington's disease and their families:

1. Care: Ensure access to the highest quality care for all those affected by Huntington's disease.
2. Cure: Accelerate the development of treatments for Huntington's disease.
3. Community: Support and empower the HD Family.

The goal of this project is to create a robust dataset that provides a multifaceted picture of the lived experience of HD which will serve as a natural history study to help pharmaceutical and biotechnology companies have comparative data for their drug trials. Additionally, the data collected in this initiative will help inform the way doctors treat people living with HD leading to the highest quality best care practices. And finally – and most importantly – the HD Data Collection Initiative will give you the power to share your HD experience.

RARE-X has the experience to build this platform, but in order for us to get the data that will speed drug development, we need you – members of the HD community – to participate! This will be a truly collective experience, and like all HDSA projects, our goal is to work with everyone who shares our mission. That's why we will be building several committees to support its launch, including forums for HD Community Advocacy Organizations and opportunities for community feedback through an HD Family Voices Committee. Importantly, because this is a large-scale data collection project, there will also be a Governance & Data Steering Committee.

This is just the beginning and we know you have a lot of questions.

- First, please tune in to the Research Forum on Saturday, June 3rd at the 38th Annual HDSA Convention for the launch presentation. (Live streamed but also on-demand at www.HDSA.org.)
- As the HD Data Collection Initiative rolls out, we'll be sure to keep you informed through our website, social media channels and webinars as appropriate, but we invite you to add your name to our HDVoices email list so that we can contact you with more information about how to get involved in the HD Data Collection Initiative. Simply visit www.hdsa.org/HDVoices
- Or send us a note at HDVoices@hdsa.org.

Building a robust natural history platform for HD that harnesses the power of the community to accelerate care and cures is a huge undertaking and it will take all of us. I look forward to sharing and learning with you as we launch this HD Data Collection Initiative and take another huge step forward in our journey to improve the lives of everyone affected by HD.

Yours,

A handwritten signature in black ink, appearing to read "Louise Vetter", written over a light blue horizontal line.

Louise Vetter
President & CEO

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The HD Data Collection Initiative
- A partnership between HDSA and RARE-X –

Frequently Asked Questions

What is the HD Data Collection Initiative?

The HD Data Collection Initiative is a project of the Huntington's Disease Society of America to build a high-quality natural history study to accelerate knowledge development through effective patient-owned data collection, data connection and community pooling of data. Simply put, your health data – owned by you and shared by you – will help doctors and scientists better understand HD so that care – and a cure – come faster.

Who is running the HD Data Collection Initiative?

The Huntington's Disease Society of America is working with RARE-X, the patient driven data collection platform of Global Genes (Global Genes is a patient advocacy organization like HDSA, but it is for all rare diseases) to launch the HD Data Collection Initiative. But – the HD DCI is for the entire HD community, so all HD family advocacy organizations are invited to get involved and we will be hosting a committee for HD families to get involved in making the most of this study. A formal process to sign up for the committees will be launched in June, but to express your interest beforehand email HDVoices@hdsa.org.

Why is the HD Data Collection Initiative important?

Right now, researchers have access to an amazing amount of clinician-reported data, through the ENROLL-HD platform and learnings from other observational studies like PREDICT-HD and COHORT. However, there's more to life with HD than what doctor's see in their office. At HDSA we know that people with HD and their caregivers are the real HD experts. Your lived experiences with HD, either personally or as a family member caring for someone, provide vital insights into what families need now.

How will I be able to participate in the HD Data Collection Initiative?

The HD Data Collection Initiative will be an online project. Once launched, all you will need is access to a website to log-in and start answering surveys about your health or that of your loved one who is affected by HD. RARE-X will manage the online data in compliance with the highest standards of privacy and personal data protection, and you will always be in control of your data.

Where can I learn more about the HD Data Collection Initiative?

Tune into the Research Forum on Saturday, June 3rd at the 38th Annual HDSA Convention for the unveiling. (Live streamed but also on-demand at www.HDSA.org.) As the HD Data Collection Initiative rolls out, we'll be sure to keep you informed through our website, social media challenges and webinars as appropriate.

Additionally, we invite you to add your name to our HDVoices email list so that we can contact you with more information about how to get involved in the HD Data Collection Initiative. Simply visit www.hdsa.org/HDVoices

Thank you!