

C-Path Roundtable: Help4HD Unites to Discuss Advancements in Huntington's Disease Treatments

“My husband passed away with no therapies, no treatments that worked for him, and it took away his quality of life. I am going to continue to fight so that does not happen to my children, and thousands of friends across the world. That’s what pushed my advocacy movement in the beginning. I couldn’t believe that my new community had nothing, no options. So, if I stood back and did nothing, what was that going to do?”

This quote, from Help4HD CEO Katie Jackson, is one of many powerful anecdotes included in the video below that displays C-Path and Help4HD coming together for an impassioned, podcast-style discussion surrounding Huntington’s disease. Thomas Hart, Director of Outreach for C-Path’s Rare and Orphan Disease Programs, as well as Critical Path for Rare Neurodegenerative Diseases (CP-RND), and Huntington’s Disease Regulatory Science Consortium (HD-RSC) Executive Director Terina Martinez were joined by Jackson and Lauren Holder, Help4HD Radio’s producer and host, on Huntington’s Disease Awareness Day. In the time the four spent together, the vigor, drive, compassion, and desire were on full display from four people who spend their lives advocating for people living with HD, researching better treatments, living with the disease, and/or caring for loved ones affected by the disease.

Help4HD and HD-RSC were both founded with a mission to find better treatments and improve the lives of those living with HD.

“Our latest focus is trying to fill the toolbox of more sensitive measures assessments that can be used in earlier stages of HD, so that drug developers don’t have impossible puzzles in front of them with a need to enroll large trials for long durations that use incomplete measures, and don’t give a complete picture of what is going on within the heterogeneity and individual experience of the disease,” Terina explained.

With open dialogue and collaboration between organizations displayed in this roundtable, by listening to the patient voice, and utilizing the power of clinical trials, we can work to give people living with Huntington’s what they need the most: Time.

Learn more about HD-RSC at c-path.org/program/huntingtons-disease-regulatory-science-consortium/.

Learn more about Help4HD at help4hd.org/.