



NEWS RELEASE

## Prilenia Donates Clinical Trial Datasets to CHDI Foundation to Advance Huntington's Disease Research

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NAARDEN, The Netherlands & WALTHAM, Mass.--(BUSINESS WIRE)-- **Prilenia Therapeutics B.V.** today announced a Data Use Agreement (DUA) under which Prilenia will provide CHDI with clinical data from the placebo arms of its PRIDE and PROOF studies for the purpose of advancing research into treatments for Huntington's disease (HD).

"Collaboration which balances scientific rigor with data openness is an ethical and scientific imperative. Sharing data is key to accelerating and advancing knowledge and understanding and accelerates progress aimed at the development of much needed treatments capable of diminishing the effect of intractable diseases such as HD," said Dr. Michael R. Hayden, Prilenia's Chief Executive Officer. "Patients are at the center of this initiative; it is vital to foster an ecosystem where we can all work together to fully utilize high-quality data to enable future innovation for the benefit of people living with HD."

Robi Blumenstein, the president of CHDI Management, the company that manages the scientific activities of CHDI Foundation, remarked: "Prilenia's gifting of these data will help us better understand how placebo-related effects influence clinical trial outcomes, which could improve the design and interpretation of future trials and ultimately support the development of more effective approaches to slow the progression of this devastating disease. A better understanding of placebo effects could also help strengthen the validation of external comparator approaches, including those derived from the Enroll-HD dataset."

Under the terms of the agreement, CHDI receives a worldwide, non-exclusive license to use the individual patient level data for the placebo patients from the two studies, full ownership of any research results it generates using the data, and the option to also make the data available to qualified third-party research institutions and companies. Prilenia retains ownership of the underlying data itself, and all data remains securely coded and anonymized to protect the identity of study participants. Any publications arising from the research may include a Prilenia author and will acknowledge Prilenia as the source of the data.

## About Huntington's Disease

Huntington's disease (HD) is a rare, inherited, autosomal dominant, neurodegenerative disease that results in functional, motor, cognitive and behavioral symptoms, and ultimately leads to death. HD is caused by a mutation in the huntingtin gene<sup>i</sup>, and each child of a parent with HD has a 50 percent chance of developing the disease<sup>ii</sup>.

Across the world an estimated 100,000 people have HD<sup>iii,iv</sup>, with an additional 300,000 people at risk of developing HD<sup>v,vi</sup>. It is usually diagnosed between the ages of 30 and 50, although HD can occur at any age, including in children and young adults (known as juvenile onset HD or JHD). The disease progresses slowly over 15 to 20 years, with patients slowly losing their ability to work, communicate, manage day-to-day life and take care of themselves. This increasing disability leads to full reliance on a caregiver and, ultimately, death.

The only currently available treatments for HD focus on symptomatic relief and palliative care, with nothing impacting measures of overall progression. A potential registrational Phase 3 study of pridopidine in early to mid-stage HD is planned to commence in the second quarter of 2026.

## About Prilenia

Prilenia is a private biopharmaceutical company driven by an unwavering commitment to scientific excellence and accelerating progress for people affected by Huntington's disease (HD), amyotrophic lateral sclerosis (ALS) and other neurodegenerative disorders. Our mission is simple but urgent: to develop and provide sustainable access to transformative medicines for people affected by devastating neurodegenerative diseases.

Prilenia is partnered with Ferrer for the commercialization and co-development of pridopidine.

The company is incorporated in the Netherlands and backed by leading life sciences investors.

For more information, please visit [www.prilenia.com](http://www.prilenia.com), and connect with us on [LinkedIn](#) or [X \(Twitter\)](#).

## About CHDI Foundation, Inc.

CHDI Foundation is a privately-funded, nonprofit biomedical research organization devoted to a single disease – Huntington’s disease (HD). Its mission is to collaboratively develop therapeutics that will provide meaningful clinical benefit to patients as quickly as possible. To achieve this CHDI manages a diverse portfolio of research projects through a novel virtual model that encourages scientific collaboration to more directly connect innovative research, drug discovery, and clinical development. This helps bridge the translational gap that often exists between academic and industrial research pursuits, and which adds costly delays to therapeutic development. CHDI’s activities extend from exploratory biology to the identification and validation of therapeutic targets, and from drug discovery and development to clinical studies and trials.

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<sup>i</sup> Eddings, C. R., Arbez, N., Akimov, S., Geva, M., Hayden, M. R., & Ross, C. A. (2019). Pridopidine protects neurons from mutant-huntingtin toxicity via the sigma-1 receptor. *Neurobiology of disease*, 129, 118–129. <https://doi.org/10.1016/j.nbd.2019.05.009>

<sup>ii</sup> Myers RH. Huntington's disease genetics. *NeuroRx*. 2004 Apr;1(2):255-62. doi: 10.1602/neurorx.1.2.255. PMID: 15717026; PMCID: PMC534940.)

<sup>iii</sup> <https://medically.roche.com/global/en/medical-material/HSG-2019-poster-yohrling-prevalence-of-huntington-s-disease-in-the-US-pdf.html>

<sup>iv</sup> Pringsheim T, Wiltshire K, Day L, Dykeman J, Steeves T, Jette N. The incidence and prevalence of Huntington's disease: a systematic review and meta-analysis. *Mov Disord*. 2012 Aug;27(9):1083-91. doi: 10.1002/mds.25075. Epub 2012 Jun 12. PMID: 22692795.

<sup>v</sup> Medina et al., Prevalence and Incidence of Huntington's Disease: An Updated Systematic Review and Meta-Analysis. *Mov Disord*. 2022 Dec;37(12):2327-2335.

<sup>vi</sup> Jiang, A., Handley, R. R., Lehnert, K., & Snell, R. G. (2023). From Pathogenesis to Therapeutics: A Review of 150 Years of Huntington's Disease Research. *International Journal of Molecular Sciences*, 24(16), 13021. <https://doi.org/10.3390/ijms241613021>

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