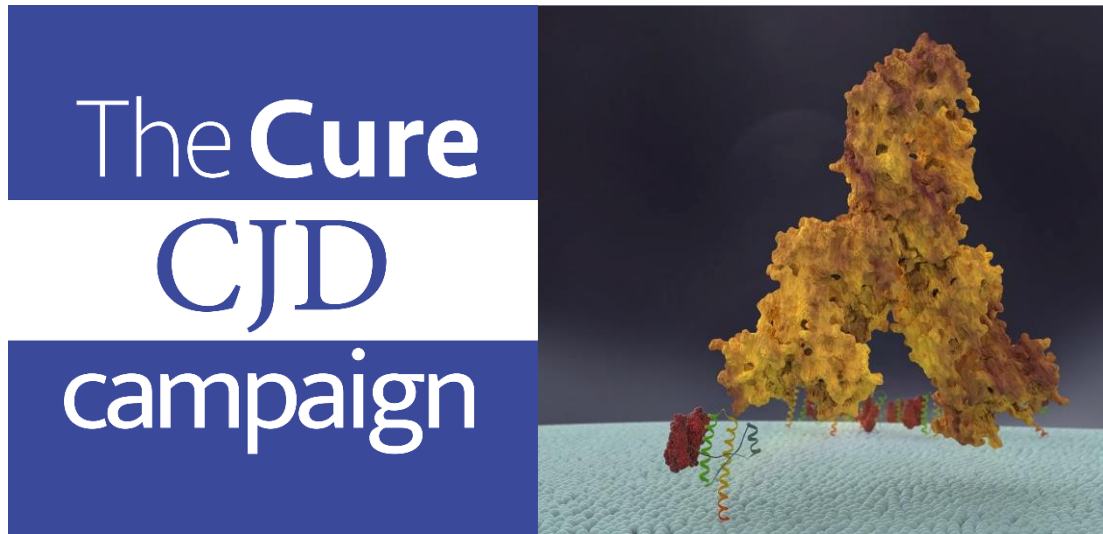


PRESS RELEASE



London / Paris / Barcelona – 6 November 2025

“Cure CJD Campaign” charity launches campaign to raise £9 million to progress treatment for fatal prion diseases

To mark **International Prion Disease Awareness Day** on **12 November**, the non-profit Cure CJD Campaign is launching an international fundraising effort to raise **£9 million** (€10.2 million) to fund the **Phase II clinical trial of PRN100** — the most promising treatment ever developed for prion diseases, a group of rare, fatal and currently incurable neurodegenerative disorders.

The charity aims to mobilise the **public, foundations and major donors** to enable this treatment to reach the decisive stage of clinical validation building on 30 years of research and encouraging experimental treatment.

This trial could finally lead to an effective therapy for patients affected by **prion diseases** (Creutzfeldt-Jakob, GSS, FFI), while also paving the way for advances benefiting conditions such as **Alzheimer’s and Parkinson’s disease**.

Prion diseases: still invariably fatal

Although little-known to the public, prion diseases account for roughly **one in every 5,000 deaths** and one in 2,000 UK citizens may be carriers of the disease.

They are rare but invariably fatal neurodegenerative disorders of the brain, which can remain silent for years before causing rapid and irreversible physical and mental decline, inevitably leading to death. These diseases include Creutzfeldt-Jakob disease (CJD), Gerstmann-



Sträussler-Scheinker syndrome (GSS) and Fatal Familial Insomnia (FFI), and can be sporadic, genetic or acquired.

They are also starting to attract attention in popular culture — notably in the TV series *Chicago Med* (Season 11, soon to air on Sky Witness and NOW), in which one storyline focuses on the devastating diagnosis of GSS.

Promising early results: three decades of research confirm PRN100's potential

PRN100 is the result of **three decades of ground-breaking research** conducted by the **MRC Prion Unit** at University College London and its linked hospitals (UCLH). A small treatment program administered PRN100 to six patients with CJD.

The results, published in the world's leading neurology journal *The Lancet Neurology* (2022), were described as **very encouraging** and concluded: “These findings justify the need for formal efficacy trials [...]” and that “**It will be important to now evaluate PRN100 in a regulated phase 2 study** [...]”.

The next crucial step is the **Phase II clinical trial**, which aims to demonstrate the treatment's efficacy in patients with CJD.

After 30 years of dedicated research, just a few final steps remain to turn hope into reality — to transform the lives of patients, at-risk populations, families, carers and society as a whole.

It is hoped that PRN100 could also be used to completely prevent onset of disease in healthy individuals who carry one of the many genetic mutations that cause prion disease during adult life or those who have been accidentally exposed to prions during past medical treatments.

Benefits beyond prion diseases: possible future role for Alzheimer's and other neurodegenerative diseases

The Lancet article also suggests a future role of PRN100 for treatment of Alzheimer's disease and possibly other common neurodegenerative diseases. The article remarked that “The interaction between PrPC and synaptotoxic amyloid β assemblies can be efficiently **blocked by PRN100**, suggesting a **possible future role** for anti-PrP antibodies in treating **Alzheimer's disease and, possibly, other common neurodegenerative diseases.**”


This Phase II clinical trial will also generate valuable scientific data likely to benefit other conditions such as **Alzheimer's** and **Parkinson's**, which share certain “**prion-like**” disease mechanisms.

Charlotte Saigne, Chair of Cure CJD Campaign, said:

“As a charity formed by individuals personally affected by the disease, we are filled with hope to see such a promising treatment within reach — one that could halt these terrifying and fatal diseases and contribute to the broader fight against Alzheimer’s and other neurodegenerative conditions.”

Leckie, currently going through GSS (genetic prion disease):

“Every day presents a new challenge be it mental, physical, or emotional and I feel privileged and truly humbled by the support from colleagues, clients, family, and friends. It gives me the motivation I need to keep a positive mental attitude given the very stark reality of this rare, critical, and untreatable illness.”

 Watch Leckie’s full testimony at curecjd.org

Link to *The Lancet’s* article: [Prion protein monoclonal antibody \(PRN100\) therapy for Creutzfeldt-Jakob disease: evaluation of a first-in-human treatment programme](#)

- *This image represents antibody drug PRN100 (yellow) binding to normal prion protein (multi-coloured) on the surface of a cell (white) and blocking its incorporation into growing prions.*

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Notes to the Editors

About Cure CJD Campaign

Cure CJD Campaign is a volunteer-led charity formed by people personally affected by prion disease. Its mission is to raise funds to support the work of the MRC Prion Unit (Medical Research Council) at University College London (UCL) to develop treatments or a cure such as PRN100, and to raise awareness of prion diseases and the crucial importance of prion research for other prion-like conditions, including Alzheimer’s and Parkinson’s.

For more information: curecjd.org

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