

Accelerating the discovery of diagnostics and treatments for neurodegenerative diseases.



# EPND's mission is to change the future of neurodegenerative disease by removing barriers to data and sample sharing, and fostering collaboration.

Critical progress in the diagnosis, treatment, and prevention of neurodegenerative diseases is challenged by longstanding barriers to collaboration across the research process:



Insufficient visibility and access to high-quality, longitudinal, and well-characterised samples and data for research Complex requirements for safe, legal, and ethical data sharing adds burden to individual researchers



Need for sustainable infrastructure and processes for durable support



Collaboration and data sharing efforts are siloed, with few one-to-many or cross-disciplinary opportunities

## **Building Novel Solutions**

EPND is building a data- and sample-sharing platform to accelerate the identification and validation of biomarkers for neurodegenerative diseases. EPND enables discovery of studies and facilitates research and analysis with existing data and biosample collections. EPND's case study research feeds back into the platform for further reuse and accessibility of the data. Our goals:

Establish a **data-and sample-sharing platform** to enable discovery and analysis Accelerate research in biomarker discovery through **large-scale** analysis and innovation Build **long-term sustainability** of infrastructure and processes to ensure data access and reuse Facilitate connection and **multidisciplinary collaboration** for a global community of users

## Together, we can change the future of neurodegenerative diseases.

Visit www.epnd.org or contact info@epnd.org to become a part of the movement.



This project has received funding from the IMI 2 Joint Undertaking (JU) under grant agreement No. 101034344. The IMI JU receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA.





## **Explore EPND's Technical Hub**

## The EPND Hub: a unified portal for data and biosample sharing

Expanding a first-of-its-kind, open, accessible database enabling discoverability and access to more than 100 neurodegenerative disease research studies from 25+ countries across Europe. Designed to facilitate collaborative research, the EPND Hub includes a wealth of metadata about studies, datasets and biosample collections, covering 12 disease areas and representing over 800,000 research participants.

#### **Registered users can:**

- Search for and request biosamples from neurodegeneration research studies.
- Discover, access and analyse datasets within cloud-based workspaces on the AD Data Initiative's AD Workbench, which provides permissioned users with compute power and statistical tools.
- Contribute metadata on studies, biosample collections and datasets to the Catalogue, making research discoverable to increase potential for collaborations, funding, and grants.

## **Upcoming EPND milestones**

#### EPND is developing new Hub functionalities including:

- Processes for permissioned data access requests to support analysis of individual patient data within secure workspaces.
- Federated data analysis allowing permissioned researchers to analyse data that remains at source.

### **New at EPND!**

**The ATN dataset** was released by EPND in May 2025, drawing on contributions from 10 cohorts across Europe as part of the project's ATN biomarker case study.

Accessible via the Hub, the dataset includes biomarker measurements, demographic, clinical and genetic variables from **350 participants** with **AD**, **PD or DLB**.

## Tools, services & resources

EPND also works to develop tools, services and resources for the research community. Deliverables include SOPs for aligning protocols for collection of key research materials to reduce variation between cohorts and results in multicentre studies. Access our resources, services and tools at www.epnd.org/resources

- ELSI Support Desk: providing guidance and support to help researchers navigate legal obligations and institutional requirements for GDPR compliance
- Biobanking Best Practices and Webinar: a standard set of operating procedures for the harmonisation and standardisation of biospecimens, with an expert-led webinar providing best practice guidance
- SOP for Body Materials Collection: Protocols for collection, processing and storage of samples for use in high-throughput, high-sensitivity and other assays

This project has received funding from the IMI 2 Joint Undertaking (JU) under grant agreement No. 101034344. The IMI JU receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA.