epnd
European Platform for Neurodegenerative Diseases

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.

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 110 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 14 disease areas and representing over 900,000 research participants.

Registered users can:

— Search for and request datasets and 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 Hub, making research discoverable to increase potential for collaborations, funding, and grants.

Upcoming EPND milestones

EPND is developing new Hub functionalities including:

— A federated brokerage interface that can route access requests to remote data holders, ensuring coordinated review while data remains locally governed.

— Federated data analysis allowing permissioned researchers to analyse data that remains at source.

New at EPND!

Five datasets from our **ATN and Complement Biomarker Study** have now been released, drawing on biosample and data contributions from 10 cohorts across Europe.

Accessible via the Hub, the datasets includes ATN and complement biomarker measurements from CSF & plasma; 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