                                                                                      OCTOBER 2024

DUCHENNE
DATA FOUNDATION

Bringing data to life to improve
the world of dystrophinopathies

DDF joins the ERDERA partnership

We are thrilled to partner with the European Rare Disease Research Alliance (ERDERA). Over 170 organizations are joining forces with a bold vision to make Europe a global leader in rare diseases (RD) research and innovation, supported by the European Union and member states. ERDERA aims to build on past EU-funded projects by developing a robust infrastructure for data and expertise, funding new research, providing training, and translating findings into practical solutions for RD patients. It will also work to align research strategies internationally and nationally.

Duchenne Data Foundation with its extensive expertise in patient empowerment activities, data management, implementation of FAIR data principles and AI-based data modeling and analysis, will contribute in several components of the ERDERA activities, including:

- Data management
- Real word data
- Data sharing and analysis services
- Education and training on RD research

the website.

Funding to continue deep phenotyping of the DMD and BMD brain

We are proud to continue our collaboration with Leiden University Medical Center (LUMC) on a joint effort to perform deep phenotyping of the brain in people living with Duchenne and Becker Muscular Dystrophy (DMD and BMD). This new project, builds on previous work by the BIND project (2020–2024), and aims to:
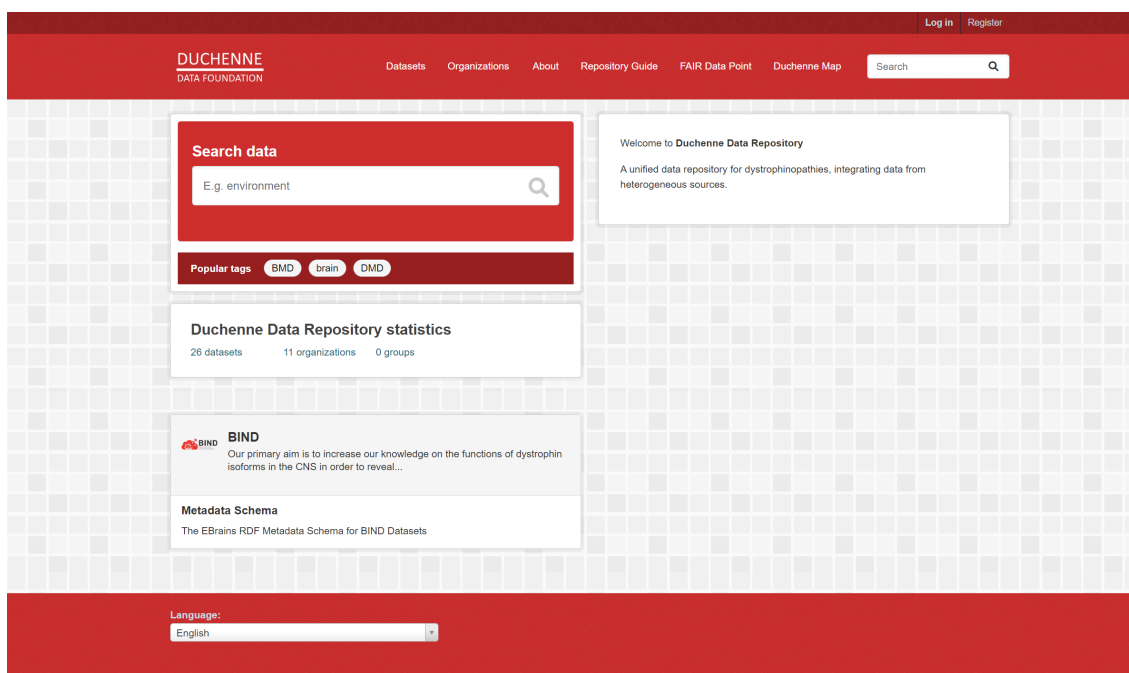
- Deepen the understanding of DMD/BMD cognitive profiles through advanced analysis of neuropsychological, emotional, and behavioral data.
- Explore the structural and functional brain basis of these profiles through cross-correlation with imaging data.

This collaborative research work has started on October 1st 2024, and promises to significantly expand insights into the brain's involvement in dystrophinopathies. The project has received funding from several national

financially to the implementation of the project with a total of €102,000 in funding.

Dr. Hermien Kan, principal investigator and vice director at the CJ Gorter MRI Center of the department of Radiology at LUMC is looking forward to starting the project. *"We are excited to be able to continue our collaboration with DDF to further our understanding of brain involvement in DMD and BMD and make these data available."*

Duchenne Data Repository

We are excited to announce the release of the new **version** of our data repository! This update comes with enhanced security features, including two-factor authentication, brute force protection, stronger password tokens and file type checker ensuring that your data remains safe and compliant with the latest standards. Additionally, the user interface has been redesigned for a more intuitive and streamlined experience, making it easier than ever to access, manage, and share data. To help you get the most out of the new system, we've created comprehensive **training materials**, including video tutorials and step-by-step guides, which are now available on our website. Explore the new features and improve your workflow!

Visit Duchenne Data Repository

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