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Duchenne Map & the Duchenne Data Repository

A live demo

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Who we are

Who we are — International, patient-driven, non-profit organisation advancing global data collaboration and patient engagement in DMD/BMD research.

Our vision — Transform the lived experience of people living with Duchenne into actionable knowledge that accelerates discovery, improves care and enables innovation worldwide.

The challenge — After a DMD/BMD diagnosis, families enter a maze of scattered information.

Our answer — Two connected, FAIR-by-design tools built for and by the community — the Duchenne Data Repository and the Duchenne Map.

Duchenne Data Repository

What it is — A global, open-source hub that standardises how dystrophinopathy data is collected, curated, shared and published.

FAIR by design — Makes data Findable, Accessible, Interoperable and Reusable: a standard Dublin Core metadata schema with automated export to a FAIR Data Point.

Secure & governed — Information Security Management System and Data Governance framework in place; sustainability under ISO 27001 verification.

Why it matters — Connects datasets across projects and borders, accelerating research and the development of effective treatments.

Duchenne Map

What it is — An interactive, FAIR-by-design online platform that centralises trusted information for the global DMD/BMD community.

Clinical-trial finder — Helps patients and families discover international DMD/BMD studies and connect with the relevant trial sites.

Who is on it — Patient organisations, care centres, healthcare professionals, researchers, research institutes and companies — mapped worldwide.

Credible & connected — All information is verified and kept up to date, making the community more visible and easier to reach.

Live Demo

Switching to a live walkthrough of both platforms:

Duchenne Data Repository

repository.duchennedatafoundation.org

Home page, user registration, and browsing datasets.

Duchenne Map

duchennemap.org

Interactive map, filters and the clinical-trial finder.

Thank you



Visit DDR

Questions & discussion welcome

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Visit Duchenne Map