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July 2025

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DUCHENNE

DATA FOUNDATION

Bringing data to life to improve
the world of dystrophinopathies

Dear Friends, Partners, and Supporters,

New on the Duchenne Map: Register Accredited Care Centers!

We are excited to announce a major update to the [Duchenne Map](#):
You can now register accredited care centers directly on the platform!

What's the benefits?

- ✓ Submit accredited care centers for inclusion on the global interactive map.
- 🌐 Promote visibility and access to high-quality care worldwide.
- 🔍 Help families, clinicians, and researchers find trusted care providers.

👉 [Watch the training videos](#)

Call to Action: Share Your Data or Metadata with the Duchenne Data Repository

🔍 Why contribute?

- Increase visibility and reuse of your data.
- Connect with international collaborators.
- Help build a smarter, more connected future for the dystrophinopathy community.

👉 [Further details here](#)

Thrilled to Collaborate with EURORDIS!

We are truly grateful to collaborate with EURORDIS on the development of an exciting new online training program: 🎓 "Navigating Rare Disease Research: Data, Ethics, and AI in Europe"

This initiative, part of the ERDERA Project, is a pilot program designed to support patient advocates and junior researchers in understanding the

delivered two dedicated webinars, offering foundational insights and sparking important conversations around data initiatives driven for and by patients, as well as strategies and best practices for handling multimodal data.

 [Find more information here](#)

EURORDIS Open Academy 2-5 June Barcelona

We are truly grateful to be co-organisers of the EURORDIS Open Academy 2025 this year- a landmark initiative that empowers patient advocates with the knowledge, skills, and confidence to shape the future of rare disease research, policy, and care.

What truly stood out during the School on Medicines Research & Development was the exceptionally high-level of participants' knowledge and expertise, and their continuous, active engagement throughout the entire program.

From thought-provoking questions to collaborative discussions, the energy and dedication of the attendees created an inspiring learning environment. We look forward to seeing how this empowered community will continue to shape the future of rare disease research.



👉 [Find more information here](#)

Save the Date!

DDF will be presenting a poster at the upcoming WMS 2025.

📍 World Muscle Society Congress | 7–11 October 2025 | Vienna, Austria

Our poster title: "Integrating Digital Tools for Clinical Trial Discovery in Dystrophinopathies: The Role of the Duchenne Data Repository and Duchenne Map".

Stop by our poster to learn how digital infrastructures are transforming patient access to critical information, supporting research, and improving care.

Stay tuned for more details—we look forward to seeing you in Vienna!

Register & Contribute Your Data/Metadata Now



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