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September 2025

DUCHENNE
DATA FOUNDATION

Bringing data to life to improve
the world of dystrophinopathies

Dear Friends, Partners, and Supporters,
We are pleased to share with you our latest updates. We continue to advance our digital tools, support educational programs, strengthen our collaborations, and contribute to the rare disease community at both European and International levels.

Certified with ISO/IEC 27001:2007

Our Information Security Management System is certified (ISO/IEC 27001:2022). This globally recognized certification underlines our commitment to the highest standards of information security, data integrity, and patient trust.

Joining the EPTRI Network

We are delighted to announce that DDF is now a member of the European Paediatric Translational Research Infrastructure (EPTRI). By joining this network, DDF is reinforcing its mission to:

- Advance data-driven research in dystrophinopathies.
- Foster collaboration with European and international partners.
- Promote innovation in the development of therapies for children living with rare neuromuscular conditions.

This new partnership represents a significant step in expanding our role within the European research ecosystem, ensuring that high-quality, accessible data remains at the heart of efforts to accelerate progress for patients and families. Together with EPTRI and its members, we look forward to building stronger bridges between science, clinical research, and patient communities.

👉 Find more about EPTRI

Counting down to WMS Congress 2025!

We will be presenting our poster during **Session 1**:
📍 **Wednesday, 8 October 2025**

Looking forward to sharing insights, exchanging ideas, and connecting with the global neuromuscular community. Your thoughts and feedback will be invaluable!
See you in Vienna!

DDF & EURORDIS Collaboration on Patient Advocates' Training

Applications for the 2026 edition of the Open Academy Schools, are now open offering intensive, face-to-face training in Barcelona from 25-28 May 2026. The Schools on Medicines Research & Development and Scientific Innovation & Translational Research accept applications from patient advocates and researchers that want to make a difference in rare disease research and advocacy.
Don't miss the chance to be part of this unique opportunity! – **APPLY NOW!**

👉 Learn more

What's next?
Coming in 2026: Second Edition of the Data, Ethics & AI Training!
Are you a rare disease advocate eager to deepen your understanding of data management, ethics, and AI in research? We are excited to share that the second edition of the training program ***"Navigating Rare Disease Research: Data, Ethics, and AI in Europe"*** will launch in 2026.

This unique program empowers advocates to confidently engage in data-driven research and influence how ethical and innovative practices shape the future of rare disease research.
Applications open later this year!

Warm regards,
The Duchenne Data Foundation Team

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