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DUCHENNE
DATA FOUNDATION

Bringing data to life to improve
the world of dystrophinopathies

Dear Friends, Partners, and Supporters,

As we are approaching towards the end of 2024, we reflect on the journey we have taken together and all that we have accomplished. This year has been one of growth and innovation from exciting milestones to new concepts and collaborations. We are incredibly grateful for your continuous support and partnership.

Highlights of 2024:
This year, we reached several significant milestones that have been years in the making. Whether through new projects, strengthened partnerships, or our advanced data tools and services, we have committed to delivering excellence, and we've seen remarkable success as a result.

1. Collaborations

We are proud to be part of the ERDERA (European Research & Development in Rare Diseases) partnership. This initiative brings together a diverse group of experts, researchers, and organizations dedicated to tackling the challenges faced by those affected by rare diseases. By working together, we aim to enhance knowledge, improve patient care, and drive forward impactful medical advancements.

https://www.duchennedatafoundation.org/launch-of-the-ddf-erdera-partnership/

We are also 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 collaborative research work has started with the BIND project, on October 1st 2024, and promises to significantly expand insights into the brain's involvement in dystrophinopathies.

https://www.duchennedatafoundation.org/bind-project-secures-funding-to-continue-genotype-phenotype-correlation-of-dmd-bmd-brain/

Innovation has been at the core of our strategy in 2024 catering for the evolving needs of our community's end users. We have developed and implemented creative solutions and followeding new paths to stay ahead and create value for everyone involved.

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.

https://repository.duchennedatafoundation.org/

3. Community Education & Empowerment
In collaboration with World Duchenne Organization, we are proud of the emergency, educational and capacity-related programs we run. Our commitment to community engagement and empowerment continues to guide our decisions as we strive for a better future for all.

https://www.duchennedatafoundation.org/projects-with-wdo/

Looking Ahead to 2025:

As we turn the page on this year and step into the new one, we are excited for what lies ahead. 2025 will be a year of even greater opportunities, challenges, and successes. We are setting ambitious goals, and we know that with your continued support, we will reach new heights. We look forward to all the possibilities that 2025 holds, and we can't wait to share this journey with you.

Wishing you a joyous holiday season and a prosperous New Year ahead.

All the best,
The DDF team

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