

DUCHENNE

DATA FOUNDATION

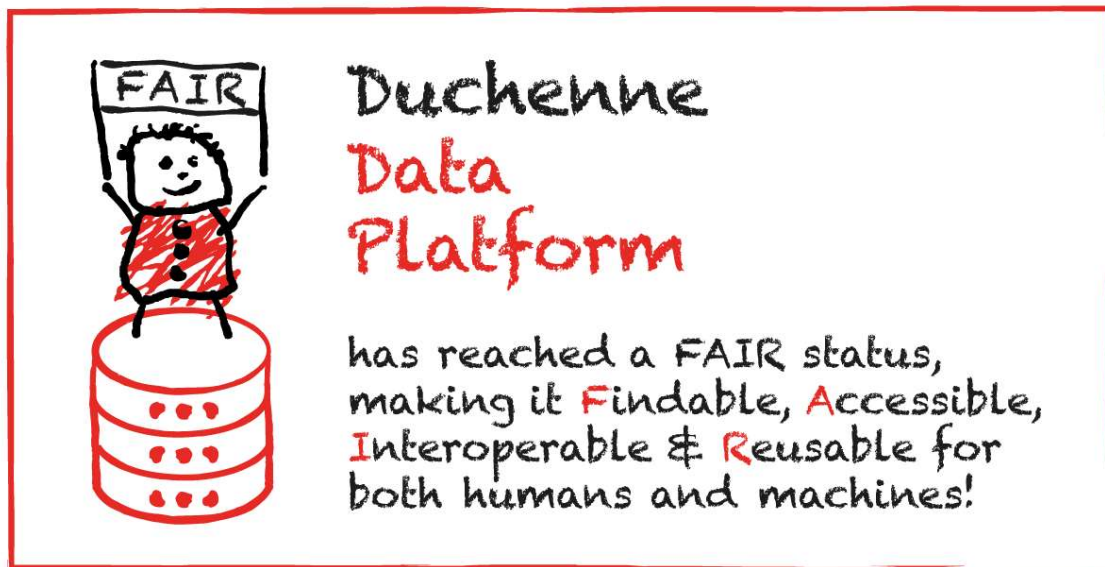
Our Actions in 2021

In 2021, the Duchenne Data Foundation continued the important work for the Duchenne and Becker Patient community. This year:

- The new clinical trial filter has been deployed and is active on the [Duchenne Map](#)
- [Duchenne and Becker digital](#) program started this year and completed 4 successful webinars
- [Duchenne Data Repository](#) is the central storage for datasets generated from the [BIND project](#) following the FAIR principles
- [Social Duchenne](#), the survey on the main social issues that DMD patients and their families are dealing with was completed
- [Duchenne Emergency and Capacity Building program](#) started this year with the contribution of WDO and the first aid was directed to Lebanon after the Beirut Explosion
- 13 meetings with multiple companies have been held for the [Duchenne CAB](#)
- We welcomed [3 new Board members](#), Dr. BS Ajaikumar, Rob Schreur and Klair Bayley
- Two new members joined the [DDF team](#), Katerina Tzima, Administration and Communication Coordinator and Sergiu Siminiuc, Technical Officer

In the new year, we will continue to work on these activities and more, to improve the lives of people living with Duchenne and Becker Muscular Dystrophy.

registry to deploy an innovative and sustainable FAIR solution



The Duchenne Parent Project in the Netherlands announced that their patient-led online registry (The [Duchenne Data Platform](#)) has successfully deployed an innovative and sustainable FAIR solution, achieving a FAIR status.

- **Findability** – machines can find DDP
- **Accessibility** – machines can read that access is open for metadata
- **Interoperability** – a FAIR transformation solution has been implemented (called CDE-in-a-Box) making DDP ready to be linked to other registries
- **Reusability** – once our FAIR transformation workflow is on, machines will know which licenses we have for reuse of our data.

[READ MORE](#)

Duchenne Patient Academy 2021: Successfully completed



This year's Duchenne Patient Academy was completed successfully with over 75 patients and patient organizations from 40 different countries following this 5-day training.

Each day was dedicated on a different need expressed from the community. This year the sessions were focused on improving care, on capacity building and how to influence policy, on therapies development, data and scientific information.

MORE INFORMATION



**On behalf of the Board and team members of the
Duchenne Data Foundation, we would like to wish
you a happy and fruitful New Year!**

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