

PRESS RELEASE

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A new platform and many new features for the Duchenne and Becker Patient Registry

BlueCompanion is Parent Project's new technical partner

The DMD/BMD Italy Patient Registry, promoted and managed by the patients' organization Parent Project, is undergoing a phase of important renewal.

This database, which collects demographic and clinical information on patients with Duchenne and Becker muscular dystrophy, in fact, has recently moved to a new, even more functional platform and its technical management has been taken over by BlueCompanion, a company specialized in providing digital services for the health sector.

What is the Patient Registry

The Patient Registry is a tool that essentially facilitates a fundamental process of mutual information between the worlds of patients and research. It also allows patients to know if it is possible for them to access a clinical trial starting in Italy and to stay informed on the progress of scientific research and on aspects of clinical management, precious for health in daily life. To all intents and purposes it is a means of making patients' voices heard in a clear and increasingly structured way.

Created in 2008, over time the Registry has grown to the point where it now collects data from around 1000 patients. It has evolved in its structure, becoming part of the network of international registries connected by the global Treat-NMD network, harmonizing with the internationally defined dataset.

More information about the Patient Registry (in Italian)

What's new

Parent Project needed a more easily usable and implementable database, capable of adapting flexibly over time. Clinical management and new treatments, in fact, often require adapting and varying the types, quantity and quality of collected data.

Meeting BlueCompanion allowed the organization to make this leap in quality. The team of experts, made up of different professionals, will allow, in an open dialogue, to make all the desired



changes in the most optimal way. The new platform is already operational.

An important innovation concerns the transition to internationally standardized nomenclatures to classify comorbidities and drugs. Furthermore, a quality system has been implemented that meets the standards required by regulatory bodies. The coming months and years will see the creation of many innovations, always in the direction of encouraging trials, research and patient care.

Filippo Buccella, founder of Parent Project, explained: *«We are happy to have undertaken a collaboration with BlueCompanion. The significant skills put into play in this phase will certainly allow us to further relaunch the role of the Patient Registry, which has been very useful so far but which will become extraordinary in the years to come. The world of clinical trials is changing, collaboration between patients, research and regulatory bodies is increasing, and this tool will, in the coming years, be even more of a key to accelerating the path towards a therapy for DMD and BMD.»*

Susanna Del Signore, BlueCompanion CEO, commented: *«BlueCompanion is really proud starting this partnership with Parent Project. The realization of the new Parent Project e-registry is in total harmony with the founding mission of BlueCompanion: to make structured clinical data available to patients and parents, doctors and, where required, regulatory agencies. The new e-registry makes the follow-up of the individual state of health operational on the one hand and on the other allows the longitudinal study of the populations with Duchenne or Becker disease, also in relation to clinical trials and pharmacological and/or support treatments that gradually become available.»*

Gianluca Zia, BlueCompanion COO, added: *«The migration of the legacy database towards a CleanWeb® core and the construction of a web platform capable of capturing data from different sources are the first tangible result of the collaboration of the two Teams! And all this was inspired by the Parent Project meeting in February 2024, a moment of precious exchange between families and professional figures who share the objectives of the association.»*

About PARENT PROJECT:

Parent Project aps is an association of patients and parents with children affected by Duchenne or Becker muscular dystrophy. Since 1996, it has worked to improve the treatment, quality of life and long-term prospects of children and young people through research, education, training and awareness. The basic objectives that have made the association grow to date are to support the families of children living with these pathologies through a network of Listening Centres, to promote and finance scientific research in this field, and to develop a collaborative network enabling to share and disseminate key information.





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About BLUECOMPANION:

BlueCompanion LTD (London, UK) and **BlueCompanion France sas** (Jambville, France) are SMEs specialized in creating and managing integrated digital platforms and CRO services for studying health, implementing clinical trials and regulatory compliant clinical data registries.

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