

World Duchenne Organization announces Accredited Duchenne Centers Program

Amsterdam, 4 October 2022 – The World Duchenne Organization is pleased to announce the launch of the Accredited Duchenne Centers Program. This global program is part of the unique development of a worldwide accreditation for Duchenne Centers. It consists of an ongoing development of the process of criteria and visitation leading to the right to be named an Accredited Duchenne Center.

This Program will not only accredit Duchenne Care Centers which are providing multidisciplinary care according to the latest Standards of Care and Care recommendations, but will also provide training regarding optimal Duchenne care and support for Duchenne centers which can not –yet– fulfill the criteria for accreditation.

For Accredited Centers, continuing education and training will be provided including modules about latest research insights and gene therapy readiness. A yearly <u>Duchenne Care Conference</u> is part of the program.

The program team consists of Dr Imelda de Groot (program leader), Dr Merel Jansen (program manager), Elizabeth Vroom (World Duchenne Organization) and Suzie-Ann Bakker (program support). The international multidisciplinary Advisory Board is chaired by Prof Nathalie Goemans.

The Accreditation Process itself will consist of site visits after a thorough pre-screening via questionnaires for clinicians, allied therapists and families. The Accredited Duchenne Centers Program aims to open applications to become an Accredited Center by December 2022. The program will be supported by Duchenne Data Foundation.

About World Duchenne Organization

The <u>World Duchenne Organization</u> (WDO) is a global umbrella organization of 52 national patient organizations from 39 countries. WDO is dedicated to finding a cure and viable treatments for Duchenne and Becker Muscular Dystrophy (DMD/BMD), to promoting good standards of care, and to inform parents around the globe. Through international collaboration WDO aims to empower organizations to ensure that wherever they are in the world, the people living with this disease can benefit from a standard of care that is informed by the best practice of the best clinicians from all over the world.

About Duchenne Muscular Dystrophy

Duchenne Muscular Dystrophy is a rare genetic disorder, mainly affecting boys, caused by the absence of dystrophin, a protein needed for stability of the cell wall of muscle cells. Muscles are getting progressively weaker over time, most patients are wheelchair bound by the age of 12 years and ultimately the disease affects the heart, as the heart is a muscle too, and their ability to breath, making it a fatal disease. The same protein is missing in the brain and this can cause behavioral and learning issues. People born with Duchenne and the milder form Becker will require care from many different medical specialists, preferable in a multidisciplinary care team, throughout their lives.

Inquiries

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