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CARE-NMD project for Duchenne muscular dystrophy funded under the EU’s Second Programme of Community Action in the Field of Health with one million Euros

The CARE-NMD project is led by the University Medical Center Freiburg and will help to improve treatment for Duchenne muscular dystrophy patients throughout Europe

Duchenne muscular dystrophy or DMD is the most common of the muscular dystrophies, affecting approximately 1 in every 3,500 newborn boys. As Nick Catlin, father of a son with DMD explains: “DMD is a heartbreaking disease. Children begin to see their muscles waste away and families struggle to cope with the diagnosis and day-to-day management of this condition. Young men with DMD die early, in their late teens, or are left wheelchair-bound and unable to move unaided.”

Although centres for the care of patients with neuromuscular disorders do exist in most European countries, many patients still do not receive treatment according to current guidelines and recommendations. This is particularly the case in Eastern Europe, where lack of information and lack of access to diagnostic and care expertise creates particular inequalities resulting in reduced life quality and life expectancy for DMD patients.

CARE-NMD (Dissemination and Implementation of the Standards of Care for Duchenne Muscular Dystrophy in Europe) was selected for funding by the Executive Agency for Health and Consumers (EAHC) out of 257 applications. The project spans Europe, with partner institutions and patient advocacy groups in Bulgaria, Denmark, Germany, United Kingdom, Poland, Hungary and Czech Republic (funded partners), as well as Croatia, France, Ireland, Macedonia, Netherlands, Belarus, Romania, Russia, Serbia, Slovakia, Sweden and Ukraine (collaborating partners).

Under the leadership of Dr. Janbernd Kirschner (Department of Neuropediatrics and Muscle Disorders at Freiburg University Medical Center, director Prof. Rudolf Korinthenberg), existing treatment standards and availability in these countries will be evaluated and improved through specific training sessions and other measures. “With a secured diagnosis and adequate treatment, children with DMD and their families can be helped to a far higher life expectancy and improved quality of life.” explained Professor Kate Bushby of Newcastle University, United Kingdom. “Better availability of specialist care will also benefit patients with other forms of neuromuscular disease across Europe.”

For more detailed information about the project see www.care-nmd.eu

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