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TOGETHER WE ARE STRONGER. THREE EUROPEAN ASSOCIATIONS REPRESENTING THOSE AFFECTED BY LAMA2-CMD CREATE A CONSORTIUM TO JOIN EFFORTS TO PROMOTE RESEARCH AND KNOWLEDGE OF THIS RARE DISEASE

These are Voor Sara, LAMA2 France and ImpulsaT, from Holland, France and Spain respectively. All of them represent people with congenital muscular dystrophy due to merosin deficiency in their countries. They are made up of families who fight so that their sons and daughters who live with this disease have a better future.

LAMA2 CMD, also known as MDC1A, is a very rare congenital (inherited) neuromuscular disease that affects 1 to 4 people in 100,000. The disorder causes weakness and atrophy of the muscles used for movement (skeletal muscles) due to a mutation in a gene called laminin alpha-2 (LAMA2) that contributes to the production of merosin, an essential protein for proper muscle function.

It is a very serious disease that usually manifests before the age of 2. If the muscular damage is very visible by the absence of walking in most of the patients, other problems, such as progressive joint contractures, progressive respiratory weakness, difficulties in eating and speaking, and an important weakness of the upper limbs, are all elements that considerably limit the autonomy of the people affected by LAMA2 CMD.

Through the patient organizations they have created, these families support research into this disease and ensure that they connect with other families, researchers, and physicians in the national and international LAMA2 community.

With this will arises the need to cooperate among them at a European level and they create lama2.com, a website that brings together the Lama2 community and centralizes all the information, educational materials, news, research that is being carried out, as well as the Pharmaceutical Industry Updates.

Another of the milestones that the consortium has marked for 2023 is to organize a European Congress with the aim of promoting networking between researchers, clinicians and patients of the international LAMA2 community in order to accelerate research to find a therapy that guarantees an improvement of the quality of life of those affected by CMD-LAMA2.

For more information:

voorsara.nl
impulsate.org
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