



Congenital Muscular Dystrophy

CureCMD is an international advocacy group launched in 2008 by three parents whose children have CMD. Their mission is to target research into finding effective therapies and eventually a cure. CureCMD.org offers disease specific information, up-to-date news on ongoing research, stories, resources and information for doctors, scientists and clinicians. There is also growing online community of families and individuals united by their diagnosis of CMD.

www.cureCMD.org



SAM is a registered charity that aims to increase awareness of CMD through media, educational and fundraising campaigns and to finance key research projects and drug trials that will significantly increase scientific understanding of CMD. The charity's ultimate objective is to bring potential life enhancing drugs to this generation of Muscular Dystrophy sufferers.

www.helpsam.info

Congenital Muscular Dystrophy International Registry

Help us lead the way to a treatment and cure



Please register today

The Congenital Muscular Dystrophy International Registry (CMDIR) has been created to identify the global CMD population – to raise awareness, improve standards of care, facilitate clinical trials and ultimately to find a treatment or cure.

With your help, we have a much better chance of achieving our goals. The fact is we are more likely to succeed in finding a treatment or cure if we know who is affected by CMD, what their diagnosis is and how the disease is affecting that individual. We need to gather this information for all CMD cases.

The registry includes disease specific and diagnostic questions and has online help and access to genetic counsellors if you have questions. Even if you do not have genetic confirmation of a particular disease (i.e. a diagnosis made by muscle biopsy or clinical observation), you should still register with CMDIR.

www.cmdir.org

What is Congenital Muscular Dystrophy (CMD)?

The CMDs are a group of diseases causing muscle weakness, usually evident from birth, with several defined genetic mutations.

The condition causes muscles to break down quicker than they can repair or grow. CMD is a progressive disease, and an affected individual may have various physical and neurological impairments. Some children never gain the ability to walk, whilst others lose the ability as they grow older.

There is currently no treatment or cure for the CMDs, **but there is hope!**

The CMDIR is funded and has been made possible through the support of Northern Ireland based charity Struggle Against Muscular Dystrophy (SAM) and international advocacy group CureCMD.

CMD subtypes included in the CMDIR:

- Ullrich CMD
- Merosin Deficient CMD (MDC1A)
- Dystroglycanopathy (WWS, MEB, Fukuyama)
- Integrin Alpha 7 Deficiency
- Integrin Alpha 9 Deficiency
- Laminopathy (Lamin A/C)
- Rigid Spine MD (SEPN1)
- Undiagnosed CMD (including merosin positive)

LGMD subtypes included in the CMDIR:

- Bethlem Myopathy
- Dystroglycanopathies (LGMD2K, LGMD2I, LGMD 2L, LGMD2N)