

Name	Supporting organization	Web address	Estimated time to complete	Description
Congenital Muscle Disease International Registry (CMDIR)	CMDIR is supported by a consortium of CM groups and sponsoring families	www.cmdir.org	30-45 minutes	The Congenital Muscle Disease International Registry (CMDIR), includes demographic, disease specific and diagnostic questions. You do not have to be diagnosed with a specific muscle disorder to register. For this registry, please only register as a carrier if you are symptomatic. For questions contact: at counselor@cmdir.org
International Family Registry for Centronuclear and Myotubular Myopathies	Joshua Frase Foundation	www.joshuafrase.org	5 minutes	The International Family Registry for Centronuclear and Myotubular Myopathies is a simple patient registry that includes demographic and genetic information. It allows a visual representation of our community using geotagging. Once your registration is complete, your de-identified pin will be added to our global map. A picture is worth a thousand words; lets show the world how strong we are. For questions contact: connect@joshuafrase.org
Myotubular and Centronuclear Myopathy Patient Registry	Myotubular Trust	www.mtmcnmregistry.org	10 minutes	The Myotubular and Centronuclear Myopathy Patient Registry provides researchers with a snapshot of the motor function, cardiac function, heart function, eating/swallowing function and breathing function, as well as information about your treating hospital and whether you have had a genetic confirmation. For questions contact: contact@mtmcnmregistry.org