

Why join the registry?

The Myotubular and Centronuclear Myopathy Patient Registry covers every country in the world. It aims to help researchers locate suitable patients for clinical trials and research studies, improve our understanding of the conditions and their prevalence, and encourage new research.

This in turn will help to develop better standards of care for patients, families, and the medical community, and will help geneticists to better prepare and advise families affected by these conditions in the future.

Patients can register to:

- ✓ **Support** research projects by providing MTM and CNM data.
- ✓ **Be visible** for recruitment to research studies or clinical trials.
- ✓ **Encourage** further research through the existence and availability of the data.
- ✓ **Provide** information on living with MTM and CNM, to help develop better standards of care.
- ✓ **Stay informed** about relevant news, research, or clinical trials.

SCAN ME!



Strength in Numbers

Join today by registering online

www.mtmcnmregistry.org

Or email us at:

mtmcnmregistry@newcastle.ac.uk



www.mtmcnmregistry.org

The Myotubular and Centronuclear Myopathy Patient Registry



Reaching clinical trials

Research to find a treatment or cure for myotubular and centronuclear myopathies is underway, however, there is currently no cure or effective treatment. Several natural history and observational studies have been completed or are in progress, and the first clinical trials have also begun.

The main purpose of the Myotubular and Centronuclear Myopathy Patient Registry is to offer clinicians and researchers an easier path to treatment development by providing disease-specific data, helping with recruitment, and informing patients and families about relevant research or new treatments.

If you are not eligible to join the registry but would like to receive updates and newsletters, please email us and we will add you to our mailing list.

Who can register?

We welcome registrations of:

- ✓ People with a myotubular or centronuclear myopathy diagnosis (ideally confirmed by genetic testing or muscle biopsy)
- ✓ Female carriers of X-linked myotubular myopathy
- ✓ Deceased patients who had a confirmed diagnosis.

What information is collected?

- ✓ Personal details such as name, gender, date of birth and contact details
- ✓ Genetic report or biopsy report
- ✓ Clinical information such as diagnosis and symptoms.

How do I register?

Register on our website and create a login so you can view or update your information at any time.

If a patient is under 18, a parent or guardian can register on their behalf.

Is my data safe?

Yes. Your information will be stored on a secure server and looked after by the Registry Curator at Newcastle University, UK. Researchers can apply for an anonymised data report from the Registry or ask the Curator to send information about their project to the relevant patients.

The registry steering committee (a panel of expert doctors, researchers, and patient representatives) assess each request to make sure it is suitable and ethical.

Patients' identifiable information or contact details will never be shared.

Visit our website for more information

