

Information about laboratories that perform genetic testing

- Orphanet
www.orpha.net
- GNE Myopathy International
www.gne-myopathy.org/Diagnostic_Centres.html
- The Genetic Alliance UK
www.geneticalliance.org.uk

For further information about GNE myopathy, please visit :

www.musculardystrophyuk.org

www.treat-nmd.eu/gne/overview

Muscular Dystrophy UK

Fighting muscle-wasting conditions



Below you will find a list of patient organisations and support groups that you may find of interest:



Distal Muscular Dystrophy Patients Association (Japan)
www.npopadm.com



Advancement of Research of Myopathies
www.hibm.org

Tara Talks GNE Myopathy

Tara Talks GNE Myopathy (USA)
www.taratalksgnemyopathy.blogspot.co.uk



GNE Myopathy International
www.gne-myopathy.org



Muscular Dystrophy Ireland
www.mdi.ie



Associazione Gli Equilibristi HIBM (Italy)
www.glieequilibristi-hibm.org



Neuromuscular Disease Foundation (USA)
www.ndf-hibm.org

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Muscular Dystrophy UK

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www.musculardystrophyuk.org

Registered Charity No. 205395 and Registered Scottish Charity No. SC039445

Alert card

GNE Myopathy

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Name _____

Date of birth _____ NHS number _____

If presenting at an emergency department, contact the neurology/neuromuscular team and respiratory team at:

as soon as possible on: _____

Contact us today to receive a vital neuromuscular care plan:

info@musculardystrophyuk.org

Freephone helpline 0800 652 6352



Patient information awards
Highly commended

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GNE myopathy

It is also known as hereditary inclusion body myopathy (HIBM), quadriceps-sparing myopathy (QSM), distal myopathy with rimmed vacuoles (DMRV), Nonaka myopathy and IBM Type 2. It is a rare, adult-onset and progressive muscle condition.

Physiotherapy and exercise

Patients diagnosed with GNE myopathy require some supervised physiotherapy sessions and would also benefit from additional sessions of unsupervised exercise. Focus exercise sessions on functional exercises rather than those that target specific muscles. Exercises such as the following will keep you more active and, ultimately, independent:

- partial squats
- walking in the water – in different directions
- for the arms and the core of the body (based on pushing and pulling)

Physiotherapy and exercise (continued)

- rising from the floor
- climbing stairs.

For intensity and load work, avoid overtraining. For strengthening exercises, it is generally recommended to do long series (between 8 and 12 repetitions per set in three set groups).

General aerobic fitness is also important, so activities such as using a stationary exercise bike or Nordic walking also are recommended. It is also important to increase the mobility of the affected muscles, so it is helpful to do stretches on a daily basis. Focus on weaker muscle groups, paying special attention to your calf muscles. For those diagnosed with GNE myopathy, the calf muscles may be more easily shortened.

Find more detailed information about general exercise at:
www.muscular dystrophyuk.org/about-muscle-wasting-conditions/information-factsheets

Genetic testing and GNE myopathy

GNE myopathy affects various muscles, but in most cases the first muscles to be affected are those in the lower parts of the leg. A definitive diagnosis of GNE myopathy can only be achieved through genetic testing. In some circumstances, however, you may need to have a muscle biopsy as well.

Stay connected via a patient registry

- GNE Myopathy Disease Monitoring Programme 'GNEM-DMP' (International): www.gnem-dmp.com
- TREAT-NMD: www.treat-nmd.eu/gne/overview
- Remudy Patient Registry (Japan): www.remudy.jp
- Stay informed about clinical trials: www.clinicaltrials.gov
A registry and results database of publicly- and privately-supported clinical studies of human participants conducted around the world. (Suggested search terms: GNE, HIBM.)