

## Information about laboratories that perform genetic testing

- Orphanet  
[www.orpha.net](http://www.orpha.net)
- GNE Myopathy International  
[www.gne-myopathy.org/Diagnostic\\_Centres.html](http://www.gne-myopathy.org/Diagnostic_Centres.html)
- The Genetic Alliance UK  
[www.geneticalliance.org.uk](http://www.geneticalliance.org.uk)

For further information about GNE myopathy, please visit :

[www.musculardystrophyuk.org](http://www.musculardystrophyuk.org)

[www.treat-nmd.eu/gne/overview](http://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](http://www.npopadm.com)



Advancement of Research of Myopathies  
[www.hibm.org](http://www.hibm.org)

Tara Talks GNE Myopathy

Tara Talks GNE Myopathy (USA)  
[www.taratalksgnemyopathy.blogspot.co.uk](http://www.taratalksgnemyopathy.blogspot.co.uk)



GNE Myopathy International  
[www.gne-myopathy.org](http://www.gne-myopathy.org)



Muscular Dystrophy Ireland  
[www.mdi.ie](http://www.mdi.ie)



Associazione Gli Equilibristi HIBM (Italy)  
[www.glieequilibristi-hibm.org](http://www.glieequilibristi-hibm.org)



Neuromuscular Disease Foundation (USA)  
[www.ndf-hibm.org](http://www.ndf-hibm.org)

While every reasonable effort is made to ensure this document is useful to clinicians and service users, Muscular Dystrophy UK shall not be liable whatsoever for any damages incurred as a result of its use.

**Muscular Dystrophy UK**

0800 652 6352

[info@musculardystrophyuk.org](mailto:info@musculardystrophyuk.org)

[www.musculardystrophyuk.org](http://www.musculardystrophyuk.org)

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

## Alert card

### GNE Myopathy

**Muscular Dystrophy UK**  
Fighting muscle-wasting conditions



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](mailto:info@musculardystrophyuk.org)

Freephone helpline 0800 652 6352



Patient information awards  
Highly commended

Publication date: September 2014 (reviewed annually)

## 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](http://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](http://www.gnem-dmp.com)
- TREAT-NMD: [www.treat-nmd.eu/gne/overview](http://www.treat-nmd.eu/gne/overview)
- Remudy Patient Registry (Japan): [www.remudy.jp](http://www.remudy.jp)
- Stay informed about clinical trials: [www.clinicaltrials.gov](http://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.)