For further information about GNE myopathy, please visit:

www.musculardystrophyuk.org
www.treat-nmd.eu/gne/overview

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

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

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- www.musculardystrophyuk.org
- www.harmonisation-of-myopathies.org
- www.musculardystrophyuk.org
- www.ndf-hibm.org
- www.gniequilibristi-hbhm.org
- www.glieequilibristi-hibm.org
- www.taratalksgneamyopathy.blogspot.co.uk
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Alert card

GNE Myopathy

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

Publication date: September 2014 (reviewed annually)
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.musculardystrophyuk.org/about-muscle-wasting-conditions/information-factsheets

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)

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.remydujp.com
• 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.)