



GNE Myopathy is known by different names such as Hereditary Inclusion Body Myopathy (HIBM), Nonaka Myopathy, Distal Myopathy with Rimmed Vacuoles (DMRV) Quadriceps Sparing Myopathy and other names. The disease manifests itself in early adulthood. It begins with muscle weakness and ultimately makes the person totally disabled. It is a recessive genetic disease which means that a person gets one defective copy of the GNE gene from each parent. The normal GNE gene helps the body to make a sugar (sialic acid) important for muscle function and other activities.

We at GNE Myopathy International (GMI) are dedicated to helping patients with this disease, those who are recently diagnosed, or ones who are yet to be correctly diagnosed, and assist them with finding the necessary resources to make their lives productive and fulfilling. **It is very important to get diagnosed early as there are two medicines on trial for this disease.** For further details please visit our website (gne-myopathy.org).

Some early signs and symptoms of GNE Myopathy:

- *Foot drop with toes stubbing the ground
- *Loss of balance and frequent falls
- *Weakness in legs, arms, hands, hips, and shoulders
- *Cramps in legs, weakness in the hamstrings
- *Inability to run or climb stairs
- *Difficulty standing on toes or heels

Please contact specialists in your country, or mail us at gne.myopathy@gmail.com. You can also visit our website www.gne-myopathy.org for further information. Please feel free to **translate** this page to your language and share with doctors and anyone with these symptoms.