



Patient Information Form

In our effort to collect information from and suggest resources to GNE Myopathy patients, we ask that you kindly provide us with any information that you are comfortable sharing with us.

Name: _____

Email address: _____

Phone Number: _____

Do you have GNE Myopathy? YES / NO

Date of Birth: _____

Ethnicity/Nationality: _____

When and at what age did you notice symptoms? _____

What were your first symptoms? _____

Who diagnosed you with GNEM? _____

Name and contact information of doctor who diagnosed you: _____

Are any of your siblings or relatives affected? YES / NO

If so, please list their names: _____ Do

you know your mutations? If so, please list: _____

Would you like us to contact you as more information becomes available for GNEM? YES / NO

Would you like to receive our quarterly newsletter? YES / NO