



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

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

Date of Birth: _____