



## What is Euromac?

A registry of people diagnosed with McArdle Disease and other very rare muscle disorders.

## Which conditions are included?

McArdle Disease and other rare neuromuscular glycogenoses, including: Glycogen Storage Disease (GSD) Types 0, IV, VII, IX, X, XIII; Phosphoglycerate Kinase 1 Deficiency; and Muscle Lactate Dehydrogenase Deficiency.

## What are the aims of Euromac?

- Obtain epidemiology data on the conditions.
- Improve the data available on diagnosis and treatment.
- Inform patients, citizens and society about the conditions.
- Assess clinical and cost effectiveness of standard and novel therapeutic interventions.
- Perform data analysis on the conditions.

## What long term impacts are expected?

- Improved access to specialised care.
- Increased knowledge of the conditions.
- Reduced delay in diagnosis.
- Eliminated incorrect advice which leads to debilitating symptoms.
- Reduced risk of life-threatening crises necessitating admission to critical care.

## Who can join the Euromac registry?

Anyone in the world who has a genetically confirmed diagnosis of one of the conditions. Those who have not had DNA analysis can be guided to appropriate testing services.

## Why should I join the Euromac registry?

- You will contribute to the shared knowledge of the conditions.
- You may be invited to join future studies or trials on a pan-European basis.
- You will receive news of Euromac's work and reports of any studies and trials which use the registry.
- You will receive details of any other information that Euromac disseminates on behalf of partners or patient groups; for example, news of events or publications.

## What is the application process?

You can complete an initial expression of interest, including details of your neuromuscular consultant. This can be done on-line via a link on our web site, or on a form which you can download and print. Euromac will then contact your consultant to advise them of the procedure. If you do not have a consultant, Euromac will put you in touch with the nearest suitable consultant.

## When will the registry open?

Euromac plans to start accepting applications for entry to the registry during 2014. The date will be announced on our web site, in our newsletter and through social media.

## Who supports Euromac?

Euromac has 15 partner institutes from eight countries in Europe plus the US – see web site for details. It has funding from the European Union Directorate General for Health and Consumers.

## How can I get more information?

There is more information on our web site. If you have further questions you can contact us by email. See details below. If you wish you can sign up to our website (and in future subscribe to our newsletter), but this is not a requirement of acceptance into the registry.



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