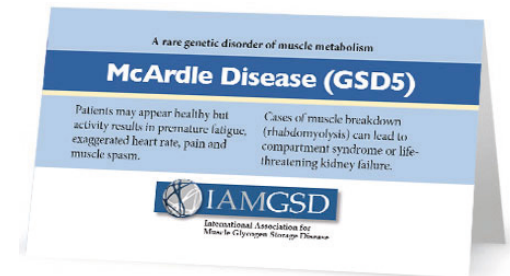



# McArdle Disease information and emergency card

- Print on thick paper or card, double-sided to make two copies.
- Or print two copies and stick together back to back.
- Fill in the emergency doctor details.
- If available, laminate both sides.
- Cut out to form two four-page folding cards.
- Keep copies at home, in your car, in your pocket, wallet or handbag.





International Association for  
Muscle Glycogen Storage Disease

## McArdle Disease (GSD5)

A rare genetic disorder of muscle metabolism

Patients may appear healthy but activity results in premature fatigue, exaggerated heart rate, pain and muscle spasm. Cases of muscle breakdown (rhabdomyolysis) can lead to compartment syndrome or life-threatening acute kidney injury.

McArdle Disease, also known as Glycogen Storage Disease Type 5 (GSD5), is an inherited condition which results in deficiency of an enzyme (myophosphorylase) in muscle cells. This is needed to convert glycogen (fuel stored in the muscle) into energy. The result is a serious energy deficit during the first 10 minutes of any activity, and throughout all *intense* activity.

**People with McArdle Disease may require assistance with:**

- A place to sit down for 10 minutes rest.
- Use of a wheelchair (e.g. at airports)
- In the event of a rhabdomyolysis crisis, to be taken to hospital.

Thanks for your help

[www.iamgsd.org](http://www.iamgsd.org)

## Guidance in event of rhabdomyolysis

- If after strenuous or other unusual activity/exercise† you have any one or more of the following signs:

*Feeling very unwell after activity* - perhaps with flu-like symptoms, can be a sign of rhabdomyolysis (muscle breakdown).

*Low volume of urine* - Producing a very low volume, or no urine at all, constitutes a medical emergency (unless simply caused by dehydration) as the complications can become life threatening.

*Dark coloured urine* - Called myoglobinuria or proteinuria, appears as reddish tea to cola coloured urine. Many factors can affect this including hydration (paler) and strongly coloured food such as beets (darker).

*Tingling, numbness, extreme swelling, discoloured skin* - may indicate compartment syndrome.

†A few people have had these symptoms without significant activity.

- You should:

- Drink plenty of water to help flush your kidneys.
- Go to hospital promptly for medical assessment.
- Take a urine sample with you, if possible.

### TO THE EMERGENCY DOCTOR

For treatment guidelines: [www.iamgsd.org](http://www.iamgsd.org) follow GSD5 and then Medical Emergencies.

McArdle's consultant:

Telephone:

For McArdle physicians by country:  
[www.iamgsd.org](http://www.iamgsd.org) follow 'Useful info'

If in doubt, contact your McArdle's doctor or specialist nurse.