



Selbsthilfegruppe Glykogenose Deutschland e.V.
www.glykogenose.de

Guidance on emergencies:

Urine is reddish to cola coloured – myoglobinuria or proteinuria.

Flu-like symptoms can be a sign of rhabdomyolysis.

Producing a very low volume or no urine at all (unless simply caused by dehydration) constitutes a life-threatening emergency.

If after strenuous activity (possibly after muscle tension in anger/excitement) you have one or more of these signs you should:

➔ Go to hospital promptly. ➔ Drink plenty of water to help clear your urine. ➔ Take a urine sample with you, if possible.

The holder of this certificate suffers from

Glycogen Storage Disease Type V – McArdle

A rare genetic disorder of muscle metabolism.

- Patients appear healthy, but activity can result in **premature fatigue, exaggerated heart rate, pain and muscle spasm.**
- Cases of muscle breakdown (rhabdomyolysis) can lead to **life threatening kidney failure.**

To the emergency doctor:

- Treatment of rhabdomyolysis (very high CK level)
- Monitor renal function
- Compartment syndrome?
- Risk of malignant hyperthermia during general anaesthesia