

22-01-2021

Invitational letter to a survey study about ketogenic diet, physical activity, fatigue and sleep in people with McArdle disease.

Copenhagen Neuromuscular center is currently conducting a big international survey study, in which we wish to investigate people with McArdle disease's personal experience with a ketogenic diet. Furthermore, this survey study will investigate physical activity, fatigue, quality of life and sleep patterns in people with McArdle disease.

You are receiving this invitational letter, because you have been diagnosed with McArdle disease. If you do not have McArdle disease, we apologize for the inconvenience.

Today we do not have any curative treatment for McArdle disease. Limited research suggests that a ketogenic diet could be a treatment option. McArdle disease is an inherited disorder leading to blocked utilization of carbohydrate-stores (glycogen) for energy metabolism in skeletal muscle. A ketogenic diet (high-fat, low-carbohydrate diet) induce production of alternative fuel substrates (ketone bodies) and improve fat metabolism in muscle, which should in theory improve muscle function in people with McArdle disease. However, currently we lack evidence to prove the diet's effects. The purpose of this survey is to report patients' experiences with variants of the ketogenic diet in a group of individuals diagnosed with McArdle disease. It is important and valuable to the study, that you answer all the questions, even if you do not know or have tried a ketogenic diet.

The survey is anonymous. In the first section of the survey, there are some general questions about you, including questions regarding McArdle disease. Next, there will be a section on your diet, including a specific section on the ketogenic diet. Finally, there will be some general sections with questions on physical activity, fatigue, sleep, level of functioning, and quality of life. These themes have never been investigated in a large cohort of patients with McArdle disease.

It is important that as many people as possible finish the survey for the results to be reliable. Therefore, this survey study will be distributed internationally. We hope that you want to participate in the study. The survey takes approximately 25-30 minutes to answer. If you decide to participate, the first question of the survey is a consent form. When you start the survey, you will have to finish in one go.

Your survey answers will automatically be saved in our electronic research database at Rigshospitalet, Denmark. The project has been approved by the capital regions data protection agency in Denmark. All data will be kept in regard to Danish data protection laws.

If you wish to participate, click on the link below or copy the link in a browser, and you will enter the online survey.

Link to the survey:

<https://redcap.link/GSDV.English>

Deadline: 1st of April 2021

You are welcome to contact the principal investigator dr. Nicoline Løkken if you have any questions or problems with opening the survey (see contact information below).

Kind regards

Nicoline Løkken
Medical doctor and Ph.d.-student
Principal investigator

Supervisors on the project: professor John Vissing, medical doctor Nicol Voermans

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