



Invitational letter to a survey study about McArdle related symptoms, physical activity, quality of life, fatigue, sleep and ketogenic diet 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, you can ignore this invitation, and in that case, we apologize for the inconvenience.

Copenhagen Neuromuscular center is currently conducting a big international survey study, in which we wish to investigate McArdle related symptoms, physical activity, fatigue, quality of life and sleep patterns in people with McArdle disease. These themes are not well investigated in a large cohort of people with McArdle disease.

Furthermore, this survey study will investigate personal experience with a ketogenic diet (high-fat low-carbohydrate diet) or variants of a ketogenic diet. Today we do not have any curative treatment for McArdle disease. Limited research suggests that a ketogenic diet could be a treatment option. However, currently we lack evidence that the diet is effective. Thus, this survey study also aims to report experiences with variants of the ketogenic diet. **It is important and valuable to the study, that you answer all the questions, even if you do not know or have not tried a ketogenic diet.**

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. The survey is anonymous. If you decide to participate, the first question of the survey is a consent form.** The survey is divided in 6 sections (1. General, 2. Diet, 3. Physical activity, 4. Fatigue, 5. Sleep patterns, 6. Quality of life). **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. **We recommend, that you open the survey on a computer.**

Link to the survey: <https://redcap.link/GSDV.English>

Deadline: 31 July 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

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