



## Participate In McArdle Disease Research

### Information for Prospective Participants

#### McArdle Disease and Nutritional Interventions: The Effect of Substrate Ingestion Timing on Management Guideline Effectiveness.

##### **Research team contacts**

**Principal Researcher:** Mr Sam Torrens PhD student, QUT

**Associate Researcher(s):** A/Prof. Robert Robergs, QUT  
Dr Craig McNulty, QUT  
Dr Helen MacLaughlin, QUT  
Dr Lynda Ross, QUT  
Dr Evelyn Parr

##### **What is the purpose of the research?**

We are currently seeking expressions of interest for participants located in Australia to partake in our upcoming early phase experimental research study. This research project is being undertaken as part of a Doctor of Philosophy study by Sam Torrens to better understand whether people with McArdle disease benefit, in terms of their tolerance to exercise, from ingesting sugar at different time intervals before they exercise. .

##### **Are you looking for people like me?**

The research team is inviting individuals with medically confirmed McArdle disease to participate in an early phase experimental research study.

##### **What will you ask me to do?**

The study period will run for four weeks and involves the completion of four lab-based cycling sessions. All exercise sessions will be separated by at least 48 hours and involve one pre-trial fitness assessment (a maximal exercise capacity test) and three separate 20-minute cycling sessions. Before acceptance into the trials, potential participants will undertake a sugar tolerance test to assess how well their body tissues can use sugar. This session will require the participant to come to the lab in a fasted condition and consume 37 g of sugar before being monitored for 60 minutes. Participants will be required to sit still while a series of small finger pricks for blood analysis take place over the course of the 60-minute period. If results show no compromise in blood sugar clearance participants will be accepted into the trial.

Before the commencement of lab-based exercise sessions each participant will be given a low intensity cycling program to be completed at home to accustom them to the movements of cycling (participants will be provided with a stationary exercise bike if they do not have access to one). The lab exercise sessions will consist of participants cycling for twenty-minutes under the supervision of highly qualified and experienced Exercise Scientists and Exercise Physiologists. During the exercise sessions participants will be required to consume either 37 g of sugar or a taste-matched placebo. Breath and blood sampling will also take place during the trials. Six blood samples will be taken during each trial as well as a pre-testing baseline sample and a post testing sample. Blood samples will be retained for future research and consent will be sought by the researchers for future projects that require the use of these samples.

Prior to each exercise session, participants will be provided with a specific nutritionally controlled dinner that they will be required to be consumed the evening prior to the following exercise session. Over the course of the four-week study period, participants will also have their activity and dietary habits monitored and recorded.

***Are there any risks for me in taking part?***

The risks involved in this study are greater than those encountered by the participants during regular daily activities due to blood sampling and the potential occurrence of muscle damage due to unaccustomed exercise sessions. Nevertheless, these risks are minimized by participants undergoing medical screening prior to their involvement, including evaluation of participants current health and fitness levels (e.g. exercise testing, cardiovascular risk factor questionnaire), medical clearance from a General Practitioner before undertaking the trials, having qualified personnel to perform any invasive procedures, and supervision of all exercise sessions. McArdle disease has previously been associated with increased rates of muscle damage (rhabdomyolysis). While the previous studies show this occurrence is rare, participation in this exercise study may put participants at a higher risk of muscle damage.

***Are there any benefits for me in taking part?***

Benefits of participation include supervised exercise sessions with highly qualified and experienced Exercise Scientists and Exercise Physiologists. Exercise Scientists and Exercise Physiologists specialise in knowledge of metabolic pathways and cellular energy production which are the limiting factors that causes the symptoms of McArdle disease. It is envisioned that the outcomes of the study may lead to a change in the general treatment and management protocols for the patients with glycogen storage diseases (GSD) such as the inclusion of exercise prescriptions, assessments and long-term management to include assessment and management by exercise physiologists. Participation will also allow for a greater understanding of the condition of McArdle disease in the pursuit of advances in its management and cure.

***Will I be compensated for my time?***

No payment is made to participants for their participation in this study.

***I am interested – what should I do next?***

If you are interested to know more about this study or wish to participate, please contact Sam Torrens via email [sam.torrens@qut.edu.au](mailto:sam.torrens@qut.edu.au)

***Thank You!***

**QUT Ethics Approval Number: 4763**