

SCREENING FOR COELIAC DISEASE IN THE MALTESE POPULATION

Information Sheet

Dear parent/guardian,

We would like to inform you that we will be studying coeliac disease in **3 to 18 year olds** in Malta with the intent of profiling the disease and developing a reliable way of diagnosing this disease at an early stage, even before the full symptoms develop. We hereby ask for your cooperation by participating in this research which will benefit your child and future generations to come. The results of the research will be confidential, and we will abide by the ethics and medical committee's regulations in conducting such research.

What does the research consist of?

Specially trained personnel will be carrying out the test. The test takes a couple of seconds to complete and only involves taking a small drop of blood from your child's finger. We shall be using a special device to prick your child and obtain a drop of blood. The test will give a positive or negative result. You will be informed of the result via email and, if the result is positive, you will be offered further testing at the hospital as an out-patient. You may at any point opt out of this exercise.

What is coeliac disease?

Coeliac disease is a condition which occurs when people become sensitive to a protein called gluten in their diet. Gluten is found in wheat and other cereals, and is normally a harmless part of the food we eat. However, if you have coeliac disease, gluten damages the lining of the small intestine causing problems with the absorption of nutrients and vitamins. Coeliac disease can be diagnosed at any age, from infancy to old age, but it is most commonly seen in children and young adults. The treatment, which is usually very successful, is to remove all sources of gluten from the diet. It is estimated that the disease affects about 1 in 100 individuals; however, in the vast majority of cases, it is misdiagnosed.

What symptoms might I expect with coeliac disease?

Coeliac disease typically presents with diarrhoea, poor weight gain, vomiting, abdominal bloating and decreased appetite. Atypical presentations may also occur such as skin rashes, thyroid disease, diabetes, movement disorders, anaemia and possibly signs of nutrient malabsorption. In an older age

group, it might also present with certain types of intestinal tumours. Besides this, it is known that an untreated coeliac has higher morbidity and mortality when compared to a healthy individual.

How is coeliac disease managed?

Up to now, the only effective way of managing coeliac disease is to start and remain on a gluten free diet. This will promote intestinal recovery and prevent the possible complications which are associated with the disease. The State will also help affected individuals by sponsoring gluten free food and flour. Besides this, there are a number of associations that help individuals cope with the disease.

What are the benefits of this study?

The participants in this study will have the opportunity to be tested for coeliac disease free of charge. If an individual is found to have the disease, early diagnosis would mean that treatment can be started earlier, at a point when the damage to the intestines may still be limited and hence avoid possible complications associated with the disease.

Finally, this study will help us understand the disease within the context of the Maltese population so as to be able to set up a screening program for future generations. This will reduce morbidity, improve resource distribution and improve the quality of life of the Maltese population. You may find more information about this project on www.itamaproject.eu.

For this reason, we kindly ask you to give your consent for your child to participate in this study by filling in the online application that can be found at the following web address: app.itamaproject.eu/register. A few days after registering you will be contacted by MUMN staff who will inform you when and where the test will take place. On the day of the test you are to bring the email you received when you registered your child as it contains his/her candidate number and is to be handed over to the personnel concerned. If you have any queries or concerns, please send an email to jacqueline@acrosslimits.com or call 79476744.

Yours sincerely,

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