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SCREENING GĦALL-MARDA TAS-COELIAC FIL-POPOLAZZJONI MALTIJA

Dan il-fuljett fih żewġ partijiet:

- **Ittra ta' informazzjoni li tispjega dwar il-proġett**
- **Ċertifikat ta' kunsens (li inti bħala ġenitur/gwardjan tiffirma jekk taqbel li tipparteċipa)**

PARTI I: Ittra ta' informazzjoni

Għażiż ġenitur/gwardjan,

Nixtieq ninfurmak li bħalissa qed isir studju fuq il-marda tas-Coeliac fost it-tfal u l-adoloxxenti Maltin. Dan qed isir sabiex din il-marda tkun magħrufa iktar u tinqabad f'perjodu fejn l-individwu jkun għadu ma żviluppax is-sintomi. B'hekk inkunu nistgħu nitrattaw il-marda b'mod iktar effettiv u mingħajr ħafna tbatija min-naħa tal-pazjent. Minn hawn nitolbu l-għajnuna u l-kooperazzjoni tagħkom sabiex tieħdu sehem f'dan l-eżerċizzju li jwassal għall-benefiċċju, sew għat-tifel jew tifla tagħkom, kif ukoll għall-ġenerazzjonijiet futuri. L-informazzjoni li se tkun qed tingħabar ħa tkun miżmuma b'mod kunfidenzjali u inwiegħdu li ħa nkunu qed inżommu mal-linji gwida hekk kif maħruġa mill-bord tal-etika.

Fiex tikkonsisti din ir-riċerka?

Dalwaqt, fl'iskola fejn jattendi/tattendi t-tifel/tifla tiegħek, ser issir sessjoni mmexxija minn persuna kwalifikata. F'din l-attività, din il-persuna ser tkun qed tieħu qatra demm mit-tifel jew tifla tiegħek permezz ta' labra apposta biex isir test fuqha. Waqt li jkun qed isir it-test, ser jinġabar il-kwestjonarju li int tkun imlejt. It-test jagħti indikazzjoni jekk it-tifel jew it-tifla jistax ikollhom il-marda tas-coeliac. Jekk jiġi riżultat pożittiv, int se tkun infurmat/a u tiġi offrut biex isiru iktar testijiet l-isptar bħala out-patients. Inti tirriserva d-dritt li tieqaf tieħu sehem f'dan l-istudju fi kwalunkwe fażi tiegħu.

X'inhi l-marda coeliac?

Din hija kundizzjoni fejn persuna ssir sensittiva għal proteina magħrufa bħala gluten. Din hija proteina li tinsab f'ikel bħal qamħ u ċereali u li soltu ma tagħmilx ħsara. F'persuna li tbati bis-coeliac, din il-proteina twassal għal infjammazzjoni fil-musrana, li ma tibqax tassorbi l-minerali u n-nutrijenti li jittieklu. Din il-marda tista' taffettwa individwi mit-tfulija sa ma jsiru adulti. Madanakollu, is-coeliac toħrog l-aktar fit-tfal u fl-adolexxenti. Sal-lum il-ġurnata, l-aktar mod effettiv biex tikkontrolla din il-kundizzjoni huwa billi tieqaf milli tieħu gluten fid-dieta tiegħek. Huwa stmat li 1 minn kull 100 individwu huwa effettwat minn din il-marda, pero ħafna minnhom ma jkollhomx djanjożi korretta.

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X'inhuma s-sintomi ta' din il-marda?

L-iktar sintomi komuni ta' din il-marda huma dijarrea, dardir u remettar, uġigħ ta' żaqq u nefħa fiż-żaqq, nuqqas ta' aptit u diffikultà biex iżżid il-piż. Tista', madanakollu, ma jkollok xejn minn dan, imma jkollok sintomi oħra bħal anemija, mard fit-tirojde, problemi ta' mobbilta', dijabete u xi sinjali ta' nuqqas ta' vitamini u minerali. Fl-adulti, din il-kundizzjoni tista' twassal għal żvilupp ta' ċerti tumuri fil-musrana. Meta mhux trattata, din il-kundizzjoni twassal għal iktar mard u kumplikazzjonijiet.

Kif nista' nikkura din l-kundizzjoni?

Il-marda tas-coeliac tista' tiġi kkontrollata billi ma tiħux iktar gluten fl-ikel li tiekol. Dan iwassal sabiex il-musrana tirkupra u terġa' tibda sservi l-funzjonijiet tagħha. Dan iwassal biex jiġu evitati kumplikazzjonijiet li huma assoċjati ma' din il-kundizzjoni. Persuni li jbatu mis-coeliac huma eliġibbli għall-għajnuna mill-istat biex jixtru prodotti mingħajr gluten. Hemm ukoll ħafna għajnuna minn għaqdiet tas-coeliac.

X'inhuma l-benefiċċji li joħorġu minn dan l-istudju?

Qed noffru li nagħmlu dan it-test b'xejn biex ngħinukom tindunaw bil-marda u b'hekk tieħdu l-kura li hemm bżonn fi stadju fejn forsi l-ħsara fil-musrana tkun għadha fil-bidu. B'hekk, ikollkom iċ-ċans tevitaw kumplikazzjonijiet għal uliedkom.

L-għan aħħari huwa li dan l-istudju ser jgħinna nifhmu aktar din il-marda fil-kuntest tal-popolazzjoni Maltija. Dan ħa jgħin biex jitfassal pjan ta' 'screening' għal din il-marda biex fil-ġejjieni nnaqqsu l-impatt ta' din il-marda fuq is-saħħa tat-tfal u l-adulti, u b'hekk intejbu l-kwalità tal-ħajja tal-poplu Malti. Tistgħu ssibu iktar informazzjoni dwar dan il-proġett fuq is-sit elettroniku tagħna **www.itamaproject.eu.**

Għalhekk nixtiequ nitolbukom ġentilment li tagħtu l-kunsens tagħkom biex it-tifel/tifla tagħkom jipparteċipa/tipparteċipa f'dan l-istudju billi timlew iċ-ċertifikat ta' kunsens u l-kwestjonarju li jinsabu fil-paġna tan-nofs ta' dan il-fuljett, taqilgħuha u tibagħtuha lura l-iskola. Jekk għandkom xi dubji jew domandi, tistgħu tibagħtu ittra elettronika fuq **info@itamaproject.eu.**

Dejjem tagħkom,

Dr. Christopher Barbara
Dr. Ramon Bondin
Dr. Samuel Aquilina
L-Isptar Mater Dei, Malta
Il-Ministeru tas-Saħħa ta' Malta

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PARTI II: Ċertifikat tal-Kunsens u Kwestjonarju biex jimtlew mill-ġenituri/gwardjani tat-tfal u jiġu rritornati l-iskola.

Ċertifikat tal-Kunsens

Jien ġejt mistieden/mistiedna biex nawtorizza lil ibni/binti jieħu/tieħu sehem fir-riċerka fuq il-marda tas-coeliac. Jiena qrajt, jew qrawli, l-informazzjoni li ġiet ipprovduta lili u ngħatali ċ-ċans li nistaqsi l-mistoqsijiet li kelli fejn dawn twieġbu b'mod sodisfaċenti. Jiena volontarjament nagħti l-kunsens tiegħi biex ibni/binti jipparteċipa/tipparteċipa f'dan l-istudju.

Isem l-iskola ______________________________

Isem it-tifel/tifla ______________________________

Isem il-ġenitur/gwardjan ______________________________

Firma tal-ġenitur/gwardjan ______________________________

Data ________________

Jum/Xahar/Sena

PARTI GĦALL-UŻU UFFIĊJALI
DATA TAL-EŻAMI: ________________
WAĦĦAL L-ISTIKER HAWN TAĦT

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Kwestjonarju

Isem u Kunjom it-tifel/tifla						
Numru tal-Identità		**Sess**	Tifel ◯	Tifla ◯		
Skola						
Klassi (Sena)		**Data tat-twelid**				
Villaġġ/Belt ta' Residenza		**Numru tal-mowbajl/telefown**				
Etniċità Immarka l-kaxxa t-tajba ✓	Ewropew ◯	Afrikan ◯	Asjatiku ◯	Oħrajn: ___________________		

Immarka ✓ jekk it-tifel/tifla jbati/tbati (issa jew fil-passat) minn dawn il-kundizzjonijiet:

	IVA	LE	MA NAFX
1. Għaja u nuqqas ta' enerġija			
2. Problemi ta' immunità			
3. Episodji ta' rimettar (iktar minn darba fix-xahar fl-aħħar 3 xhur)			
4. Problemi fil-fwied			
5. Dijabete tat-Tip 1			
6. Anemija (pallidu/a, demm baxx)			
7. Rewmatiżmu			
8. Problemi bil-kliewi			
9. Epilessija			
10. Ħsara konsiderevoli fis-snien			
11. Bdil fil-burdata			
12. Dijarea			

	IVA	LE	MA NAFX
13. Ta' spiss jilmenta/tilmenta b'uġigħ ta' żaqq			
14. Problemi tat-tirojde			
15. Nefħa żejda fiż-żaqq			
16. Ippurgar irregolari			
17. Alopeċja (telf ta' xagħar)			
18. Vitiligo (tbajja ċari fil-ġilda)			
19. Sindromu ta' Down, Williams jew Turner's			
20. Pustumetti fil-ħalq frekwenti			
21. Diffikultà bil-bilanċ u l-mixi			
22. Nuqqas ta' piż, anoressija			
23. Jikber/Tikber bil-mod, Statura qasira			
24. Għadam dgħajjef			
25. Konstipazjoni/Stitikezza			

Hemm xi ħadd fil-familja li jbati mill-marda tas-coeliac?

IVA ◯ LE ◯ MA NAFX ◯

Jekk weġibt iva, speċifika kif jiġi/tiġi mit-tifel/tifla?

Missier ◯ Omm ◯ Aħwa ◯ Nannu min-naħa tal-omm ◯ Nanna min-naħa tal-omm ◯

Nannu min-naħa tal-missier ◯ Nanna min-naħa tal-missier ◯ Oħrajn: ___________________

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SCREENING FOR COELIAC DISEASE IN THE MALTESE POPULATION

This Informative Consent Form has two parts:

- **Information Sheet (to share information about the study with you)**
- **Certificate of Consent (to sign if you agree that your child may participate)**

PART I: Information Sheet

Dear parent/guardian,

We would like to inform you that we will be studying coeliac disease in the Maltese paediatric population 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 help 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 visiting the school your child attends. They will collect the attached questionnaire and consent forms and if you give us your consent, will perform the test. The test 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. If, the result is positive, you shall be informed and offered further testing at hospital. 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.

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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 foods 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 and signing the consent certificate and questionnaire found in the middle of this leaflet. The completed document is to be returned to the school. If you have any doubts or questions, please send an email to info@itamaproject.eu

Yours sincerely,

Dr Christopher Barbara
Dr Ramon Bondin
Dr Samuel Aquilina
Mater Dei Hospital Malta
Ministry for Health, Malta

www.itamaproject.eu
info@itamaproject.eu

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PART II: Certificate of Consent and Questionnaire to be filled in by parent/legal guardian of child and returned to school

Certificate of Consent

I have been invited to allow my child to participate in a research on coeliac disease. I have read the foregoing information, or it has been read to me. I had the opportunity to ask questions about it, which have been answered to my satisfaction. I consent voluntarily for my child to participate in this study.

Name of School ____________________________________

Name of Boy/Girl ____________________________________

Name of Parent/Guardian ____________________________________

Signature of Parent/Guardian ____________________________________

Date ____________________

Day/month/year

FOR OFFICIAL USE ONLY
DATE OF TEST: ____________________________
ATTACH THE STICKER BELOW:

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Questionnaire

Child Name & Surname			
Child ID number		**Gender**	Male ◯ Female ◯
School			
Class (Grade/Year)		**Date of Birth**	
Town/Village of Residence		**Contact number**	
Ethnicity Tick as appropriate ✓	European/Caucasian ◯ African ◯ Asian ◯ Other: ______		

Tick ✓ if your child has or ever had any of the following medical conditions:

	YES	NO	DON'T KNOW
1. Persistently tired/ weak/low energy			
2. Immunodeficiency			
3. Vomiting (more than 1 episode per month in last 3 months)			
4. Liver problems			
5. Diabetes type 1			
6. Anaemia (pallor, low blood level)			
7. Rheumatoid Arthritis			
8. Renal problems			
9. Epilepsy			
10. Severe dental decay			
11. Mood changes			
12. Persistent loose stools			

	YES	NO	DON'T KNOW
13. Repeatedly complains of abdominal pain			
14. Thyroid problems			
15. Abdominal distention / bloating, flatulence			
16. Irregular bowel habits			
17. Alopecia (hair loss)			
18. Vitiligo (white skin patches)			
19. Down's, Williams or Turner's syndrome			
20. Recurrent mouth ulcers			
21. Difficulty with balance/walking			
22. Poor weight gain, anorexia, weight loss			
23. Short stature/growth failure			
24. Weak bones			
25. Constipation			

Does any family relative suffer from Coeliac Disease?

YES ◯ NO ◯ DON'T KNOW ◯

If yes, please specify the relationship to the child:

Father ◯ Mother ◯ Sister/brother ◯ Maternal Grandfather ◯ Maternal Grandmother ◯
Paternal Grandfather ◯ Paternal Grandmother ◯ Other:______________________