



CCCPS.JO

5 Years & Counting

Who We Are



Achievements



Work in progress



Challenges



To whom it may concern

This is to confirm that the below mentioned Coeliac society
Is a current affiliate member of the Association of European Coeliac Societies (AOECS)

Celiac and non-Celiac care Provider
Amman - Salt Highway street
Al. Saro - Tiebah Neighborhood
Jordan

Tunde Koltai



Chair of the board to AOECS

Board Members:

Tunde Koltai (Hungary)

Katre Trofimov (Estonia)

Izaskun Martin-Cabrejas (Spain)

Hilary Croft (United Kingdom)

Christian Scerri (Malta)

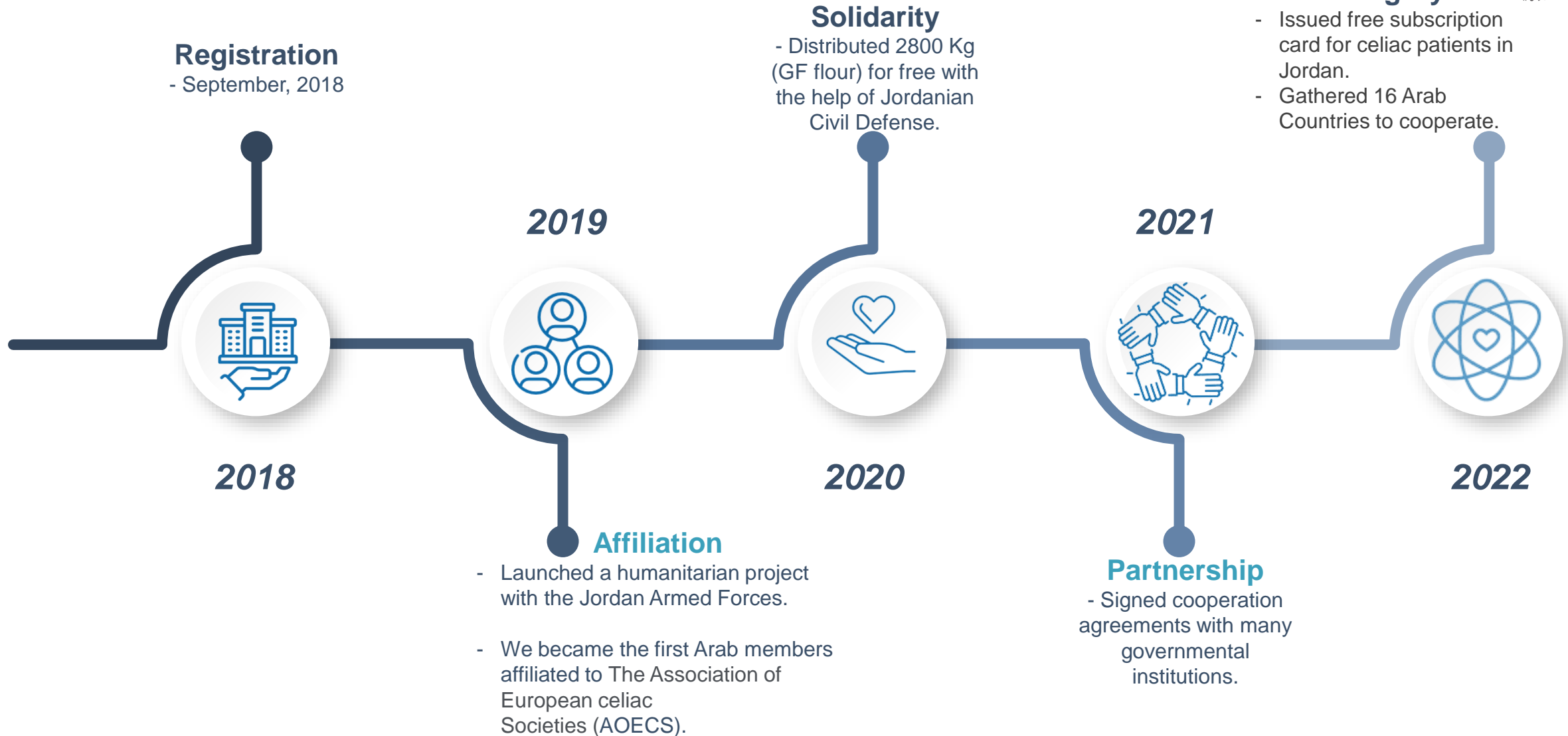
address: 4, Rue de la Presse,
B-1000 Brussels, Belgium



Who We Are?

- The Celiac Care Providers Society CCCPS is a young society it was established in September 2018.
- Our administrative board consists of 9 elected members all of whom are either celiac themselves or have a direct family member with celiac.
- Our administrative board include pharmacists, a certified allergy coach, and nutritionists.
- Became an affiliated member of the AOECS in 2019

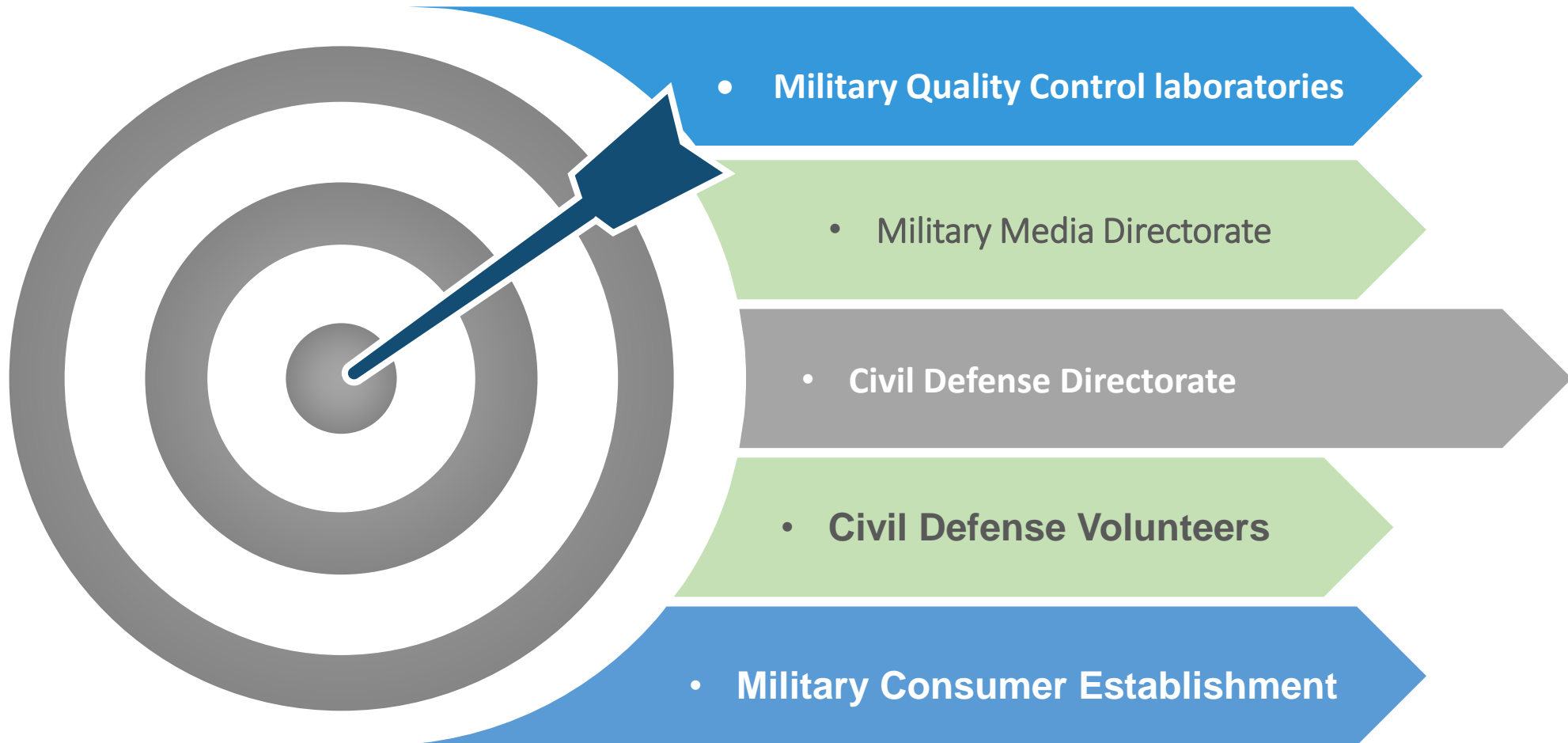
CCCPS.JO Timeline – 5 Years





Our achievements include but are not limited to the following:

❖ Our partnership with the Military Armed Forces





Raising Awareness



- We make regular visits to rural areas where we meet with newly diagnosed patients and their families. We hold awareness workshops and cooking classes to teach them how to bake bread and some traditional sweets.

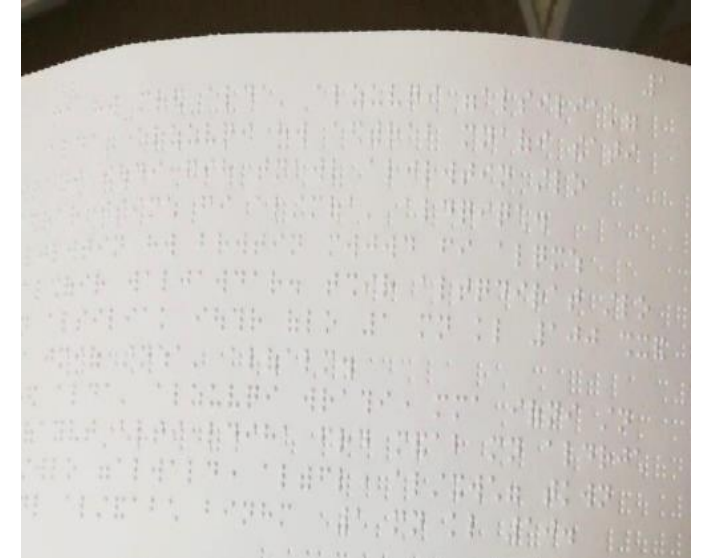


- We hold different fun activities for kids and their families. For example: A movie with gluten free buffet, we hold cooking activities where the kids help in preparing a very famous middle eastern sweet (Kunafah).



- The Royal Academy of Culinary Arts hosted our chef to give gluten free baking courses.





- We recently appointed a representative in some cities around Jordan to facilitate our work such as contacting patients, working with shops in that city to provide gluten free items.
- We hold workshops about celiac disease in universities, hospitals, pharmaceutical factories and schools.
- We hold an awareness campaign for people with disabilities in collaboration with the Higher Council for the Rights of Persons with Disabilities. We produced a video flyer in sign language and translated our leaflet about celiac disease to Braille.

Raising Awareness



- We issued a digital subscription card with a QR code that it sent by SMS. The holder benefits from discounts in labs, hospitals, shops, GF bakeries and restaurants.

amany - abdalraziq



- We have created different cartoon characters to use them in our awareness campaigns with kids.

✦ Raising Awareness



Glutino



Hidden Glutino



NO Glutino



- This is “GLUTINO” our gluten character.

Celiac Disease

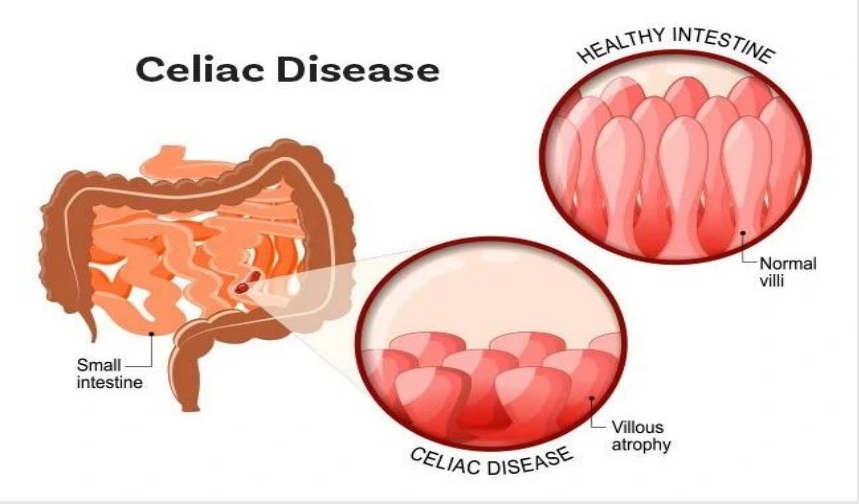
Sometimes called celiac sprue or gluten-sensitive enteropathy, is a serious autoimmune disease that occurs in genetically predisposed people where the ingestion of gluten protein found in wheat, barley and rye.

If you have celiac disease, eating gluten triggers an immune response in your small intestine. Over time, this reaction damages your small intestine's lining and prevents it from absorbing some nutrients (malabsorption).

Definitions

Wheat Allergy

WA is an allergic reaction to foods containing wheat. Allergic reactions can be caused by eating wheat and also, in some cases, by inhaling wheat flour.

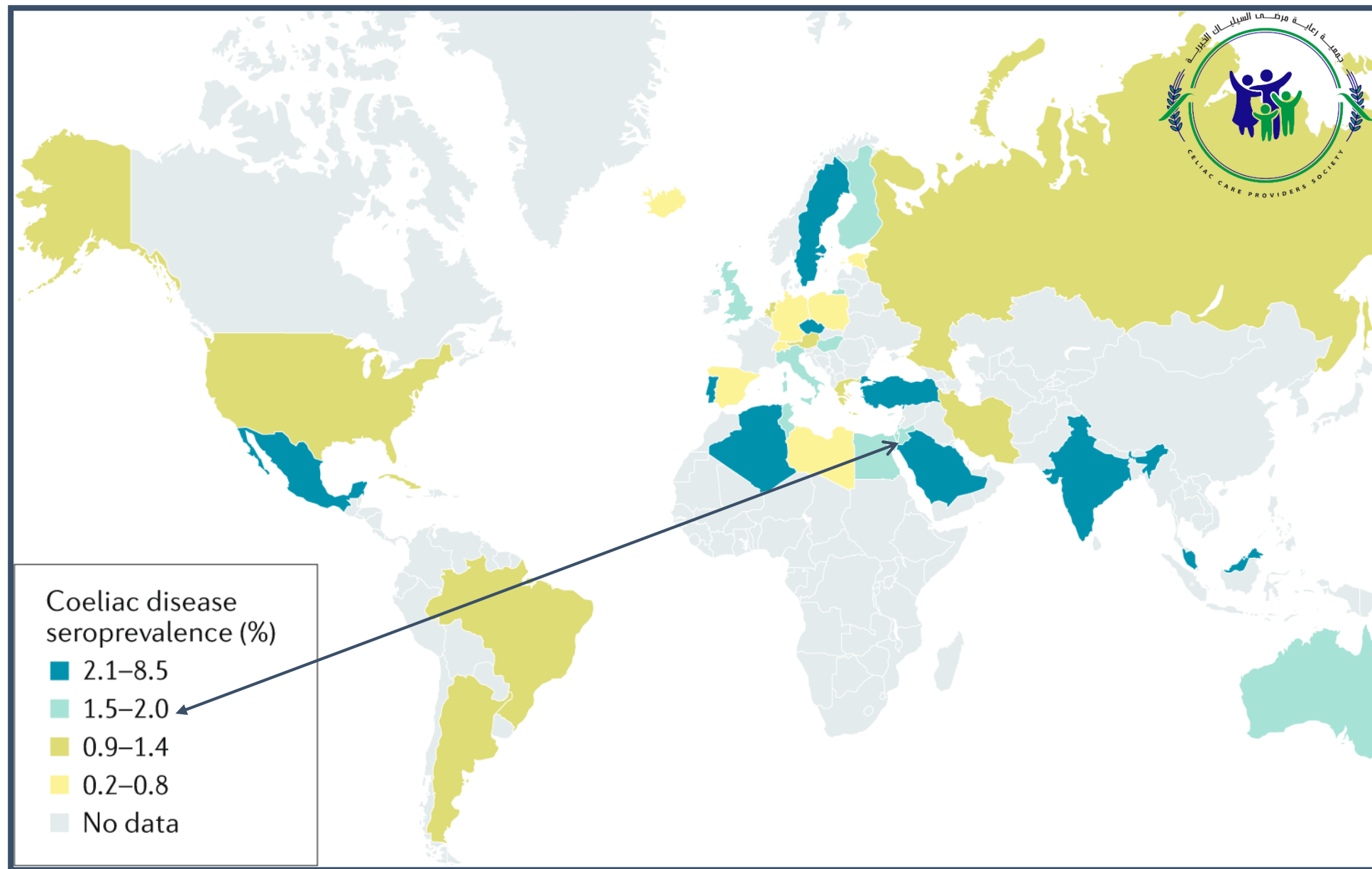


Non Celiac Gluten Sensitivity

NCGS is a condition characterized by intestinal and extra-intestinal symptoms related to the ingestion of gluten-containing foods in the absence of celiac disease and wheat allergy.

The population of Jordan reached 11,310,647 as of the 13th of January 2023 according to the Department of Statistics.

The Seroprevalence shows that in Jordan 1.5- 2.0% of patients have celiac disease which means we have around 226,212.94 celiac patients.



The Global Seroprevalence of Celiac Disease

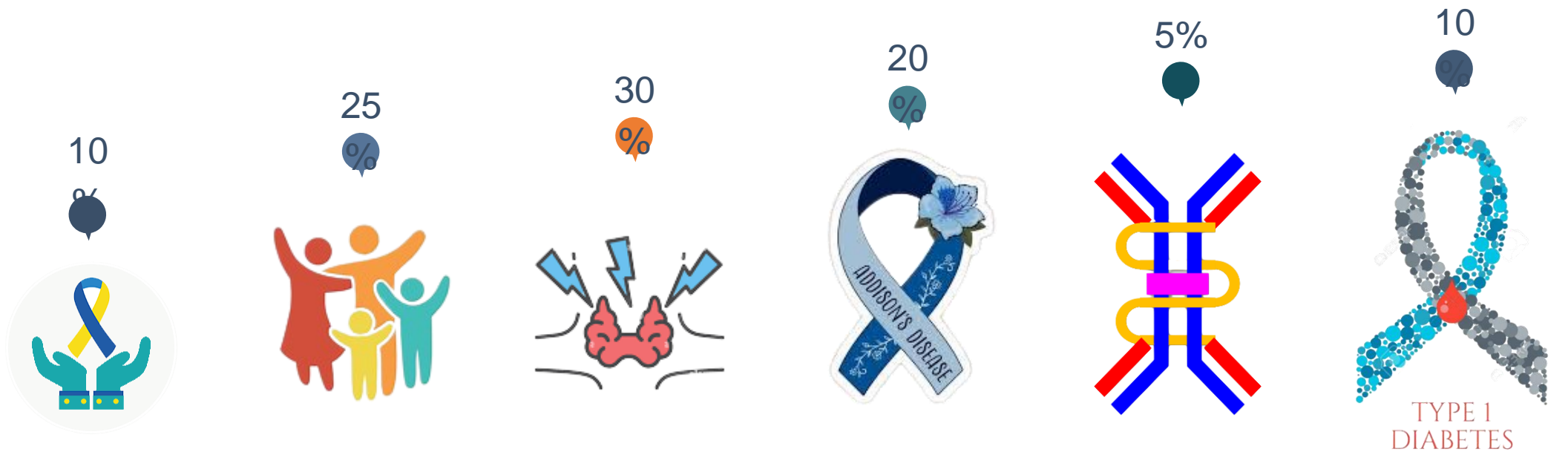
Signs



Symptoms



RISK FACTORS



DOWN SYNDROME
TURNER
SYNDROME
WILLIAMS
SYNDROME

FIRST-DEGREE
RELATIVES OF
CELIAC DISEASE
PATIENTS

AUTOIMMUNE
THYROIDITIS

ADDISON'S
DISEASE

IMMUNOGLOBULIN
DEFICIENCY

TYPE 1
DIABETES

Complications



Cancer

People with celiac disease who don't maintain a gluten-free diet have a greater risk of developing several forms of cancer, including upper digestive tract, hepatocellular carcinoma, lymphoma.



Malnutrition

This occurs if your small intestine can't absorb enough nutrients. Malnutrition can lead to anemia and weight loss. In children, malnutrition can cause slow growth and short stature.



Nervous system problems

Some people with celiac disease can develop problems such as seizures or a disease of the nerves to the hands and feet (peripheral neuropathy).



Infertility and miscarriage

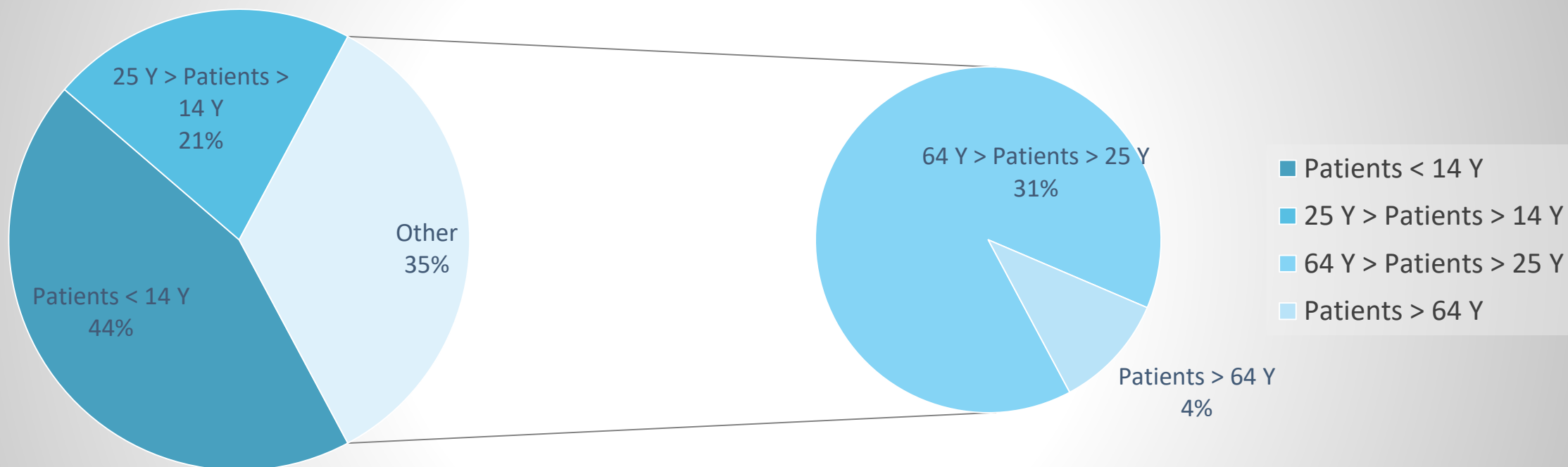
Malabsorption of calcium and vitamin D can contribute to reproductive issues.



Bone weakening

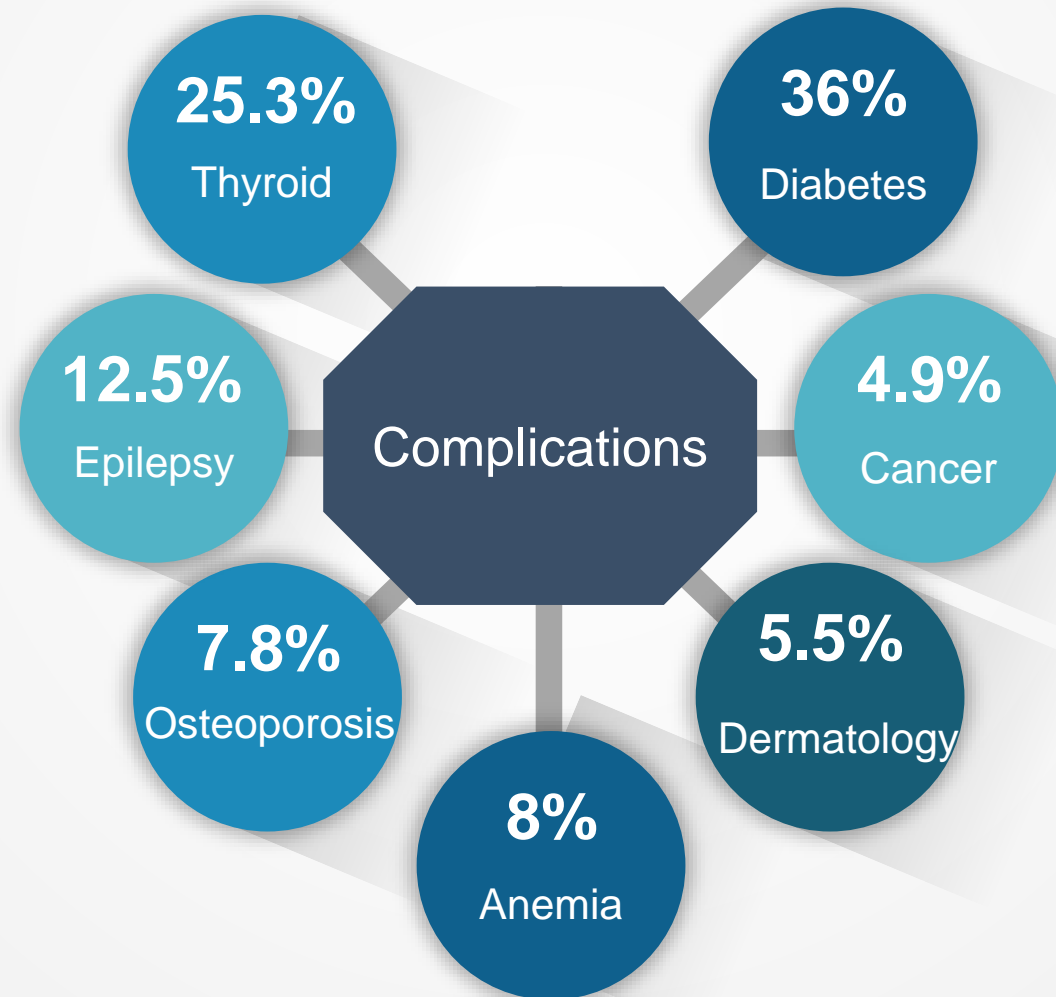
Malabsorption of calcium and vitamin D can lead to a softening of the bone (Osteomalacia or rickets) in children and a loss of bone density (Osteopenia or osteoporosis) in adults.

Distribution of patients by age group



We have around 4518 registered patients in our society

According to our data 26.4% of patients suffer from other autoimmune diseases and complications of celiac disease



Treatment:



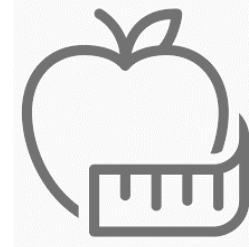
Long life



**Gluten
Free**

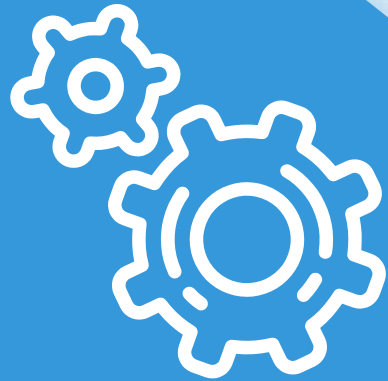


Strict



Diet

Less than 20 ppm is allowed for celiac patients, so any cross-contamination will trigger the antibodies.



Work in Progress

1

- We are currently a member in the Codex technical committee in Jordan working on “Standard for Gluten Free Foods.”

2

- The JFDA approached us to provide them with scientific material for a comprehensive booklet about Celiac disease.

3

- We are pushing to make Celiac screening tests mandatory and free for children between ages 2-11.

4

- We have an agreement with the AIC (Italy) to translate the Italian Celiac Project for schools and incorporate it in our local schools to raise awareness between students and teachers.

5

- We are working on our website.

6

- Collaboration with the society in Aqaba

7



- We are currently meeting with governmental and private entities to come up with a guideline for the gluten free certification for restaurants and products.



8

- We have initiated a collaboration between celiac societies from 17 Arab countries.



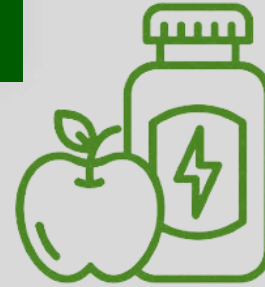
Challenges:

1



- No official records and statistics regarding celiac disease.

2



- Very high taxes on gluten free items as they are considered food supplements.

3



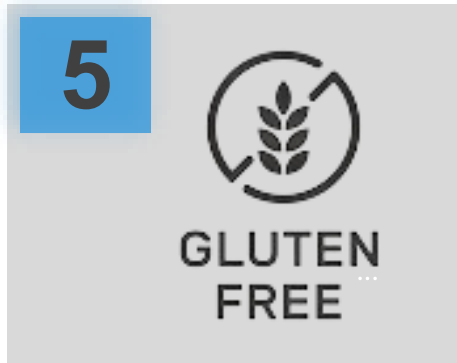
- No financial aid from the government to the society or to the patients.

4

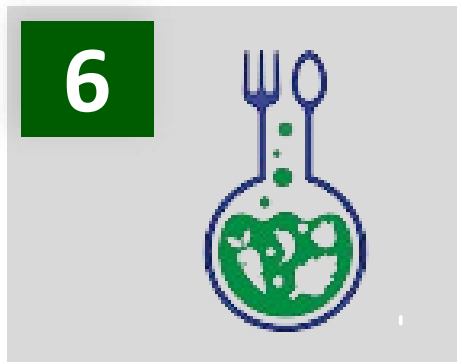


- Lack of awareness about celiac disease in the medical field.
- Not differentiating between Celiac Disease and Wheat Allergy.

Challenges:



- Misuse of the GF logo



- The presence of laboratories without accreditation for testing GF products.



- Lack of commitment by some companies to gluten-free product standards:

المذكورة اعلاه تعاني من مرض حساسية القمح (celiac disease) وهي بحاجة الى المتابعة والعلاج في عيادة الجهاز الهضمي وتحتاج الى حميه خاصة خالية من الجلوتين

يعاني المريض المذكور اعلاه من حساسية القمح وسوء الامتصاص الناتج عنها وهشاشة العظام

Extra universal flour concentrate gluten free
Ingredients: gluten free wheat starch, corn starch, corn flour, glucose, thickeners: guar gum, E 464; potato fibre, acidity regulator: E 575; raising agent: sodium carbonate.
Suitable for people intolerant to gluten.

خليط دقيق ناعم خالي من الجلوتين (AR)
المكونات: نشاء القمح خالي من الجلوتين، نشاء الذرة، دقيق الذرة، الجلوكوز، مواد مغلضة (صمغ الغار)، E464، ألياف غذائية، منظم حموضة (E 575)، مواد رافعة (كربونات الصوديوم).
صمم خصيصا للأشخاص الذين يعانون من حساسية الجلوتين.

Nutrition Facts	
الحقائق التغذوية	
Serving size / حجم الحصة (100 g)	
Calories / السعرات الحرارية	350 KCAL
* نسبة الإحتياج اليومي / 18% Daily Value	
Total Fat / الدهون الكلية 0,4 g	1%
Saturated Fat / الدهون المشبعة 0,1 g	1%
Trans Fat / الدهون المتحولة 0 g	
Cholesterol / كوليسترول 0 mg	0%
Sodium / الصوديوم 52 mg	2%
Total Carbohydrate / الكربوهيدرات الكلية 88 g	33%
Dietary Fiber / الألياف الغذائية 0 g	0%
Total Sugars / السكريات الكلية 5,9 g	7%
Added Sugars / السكر المضاف 0,5 g	
Protein / البروتين 0,6 g	1%
* تدل على نسبة الإحتياج اليومي للمغذيات في الحصة الواحدة مبنية على نظام غذائي يحتوي على 2000 سعرة حرارية	



Net weight: /
الوزن الصافي:

1 kg / كغ

Cooking Instructions:
Ingredients:
• 300 g extra universal mix Bezgluten
• 1 teaspoon of salt (9 g)
• 1 teaspoon of sugar (7 g)
• 10 g of yeast in powder or 25 g crushed fresh yeast
• 50 ml of water (temp. about 30 °C)
• 2 spoons of oil (20 g) + oil to grease
Preparation method:
Ingredients, place in a bowl and blend at high speed for 2 minutes until smooth mass. Pour the mass into 2 molds with oil 30 x 12 cm and level the surface with a damp cloth and leave to rise for about 45 minutes. After this time, brush with oil and place in preheated oven to bake. Bake about 20 minutes.

GB Extra universal flour concentrate gluten free
Ingredients: gluten free wheat starch, corn starch, corn flour, glucose, thickeners: guar gum, E 464; potato fibre, acidity regulator: E 575; raising agent: sodium carbonate.
Suitable for people intolerant to gluten.

AR خليط دقيق ناعم خالي من الجلوتين
المكونات: نشاء القمح خالي من الجلوتين، نشاء الذرة، دقيق الذرة، الجلوكوز، مواد مغلضة (صمغ الغار)، E464، ألياف غذائية، منظم حموضة (E 575)، مواد رافعة (كربونات الصوديوم).



• Proposed Solutions for Celiac Disease Challenges in Jordan as Presented by the Society :

1

- Enhance Awareness and Education:
 - Conduct extensive awareness campaigns
 - Target specific groups
 - Develop educational materials

2

- Improve Accessibility to Gluten-Free Products:
 - Encourage the establishment of specialized gluten-free stores
 - Support local producers
 - Collaborate with supermarkets and grocery stores

3

- Strengthen Regulations and Enforcement:
 - Advocate for stricter regulations
 - Establish a robust certification system
 - Enhance enforcement mechanisms

4

- Promote Research and Capacity Building:
 - Support research initiatives
 - Organize workshops and training programs
 - Encourage collaboration

5

- Advocate for Policy Changes and Support:
 - We urge Jordan to integrate celiac disease into national healthcare, guaranteeing diagnosis, treatment, and care.
 - Advocate for financial support
 - Seek partnerships

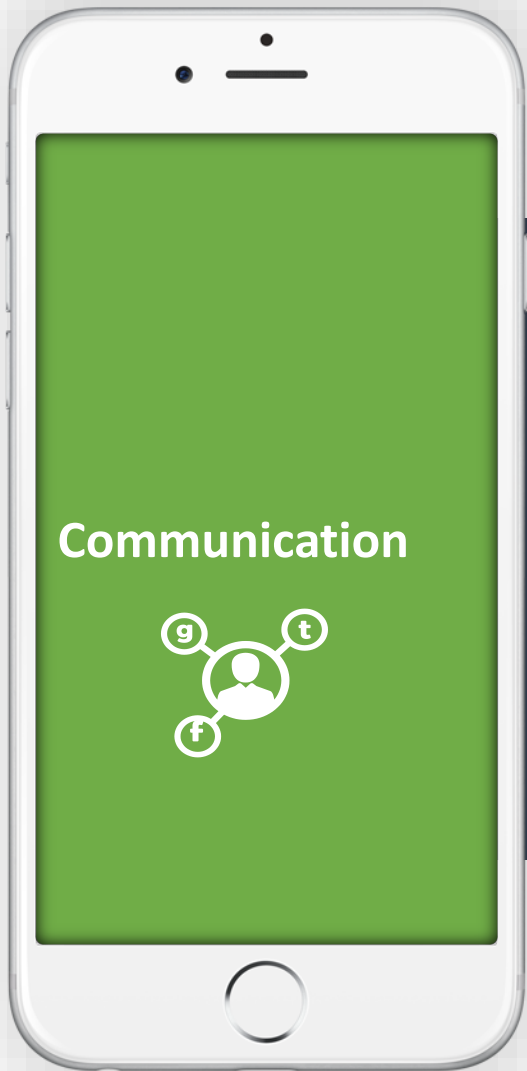
6

- Empower Celiac Patient Organizations:
 - Provide ongoing support
 - Encourage collaboration
 - Facilitate networking opportunities

References:

- <https://www.mayoclinic.org>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8767653/> (The Progression of Celiac Disease, Diagnostic Modalities, and Treatment Options)
- <https://pubmed.ncbi.nlm.nih.gov/29551598/> (Global Prevalence of Celiac Disease: Systematic Review and Meta-analysis)
- <https://www.nhs.uk/conditions/coeliac-disease/>
- <https://surgpathcriteria.stanford.edu/gi/celiac-disease/marsh.html>
- <https://www.nice.org.uk/guidance/ng20/chapter/Recommendations#serological-testing-for-coeliac-disease>





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Celiac Care Providers Society



Thank you for listening