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Press release

## **CELIAC DISEASE PATIENTS RAISE AWARENESS ABOUT THE DISEASE AND THE DIFFICULTIES THEY ARE FACING**

**Partners of the CD SKILLS project are developing a new integrated educational model for everyone involved in gluten-free diet**

**May 16<sup>th</sup> is internationally recognized as Celiac Disease Day. On this day, patients raise awareness about celiac disease, which is still widely unknown and alert the general public as well as decision-makers about the difficulties they are facing.**

On this year's International Celiac Disease Day, the Slovene Celiac Society joined forces with the University Medical Centre Maribor and the Municipality of Maribor that are involved in the international project CD SKILLS (Interreg Danube Transnational Programme). The project is addressing the challenges of celiac disease patients with goals to increase knowledge about the disease and develop new services to improve the quality of life of patients.

**Celiac disease is a lifelong systemic autoimmune disease resulting from hypersensitivity to gluten.** Celiac disease patients always have to follow a strict and consistent gluten-free diet. Any intentional or unintentional consumption of gluten can have severe and irreversible consequences to the health of patients. This can lead to higher morbidity and mortality, affect school performance in children, increase absenteeism and has substantial negative impact on healthcare systems and society in general.

Celiac disease can occur at any age, although it is usually diagnosed in childhood. It affects twice as many women than men. More than one percent of the population is affected, which is about 1.2 million people in the Danube region. As much as 80% of patients with celiac disease remain undiagnosed and a lot of patients are diagnosed with delay, up to 10 years in some regions. The reasons for this are low awareness and lack of knowledge about the disease, limited access to diagnostic tools, relatively poor choice of innovative educational methods and inefficient exchange of information.

Celiac disease patients following a strict diet face several difficulties, such as:

- Diagnostic delays due to low awareness;
  - The prices of gluten-free products are 4 to 6 times higher compared to similar products that contain gluten;
  - Public kitchens at workplaces, nurseries, schools, nursing homes, restaurants and even some hospitals lack equipment and knowledge to prepare gluten-free meals. Therefore everyone, from children and students to adults and elderly, is deprived of eating out or getting a warm meal, which can also result in social isolation.
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In CD SKILLS project, the Municipality of Maribor in cooperation with Slovene Celiac Society, the lead partner University Medical Centre Maribor and partners from Romania, Croatia and Serbia will develop a **new integrated educational model**, intended for personnel in nursery, school, hospital and nursing home kitchens.

At this year's occasion of Celiac Disease Day, celiac disease patients appeal to everyone involved in food preparation at their workplace:

“Be socially responsible and a part of inclusive society. Don’t forget about us!”

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## ***MORE ABOUT CELIAC DISEASE***

### ***International Celiac Disease Day***

On the international Celiac Disease Day all European Celiac Disease Patients' Associations connected in the umbrella organisation AOECS (Association of European Coeliac Societies) bring attention to the main issues:

- **Food of celiac disease patients** must contain less than 20 mg of gluten per kg of final product (or less than 20 ppm), which means less than half a grain of wheat per kilogram of rice. The diet is therefore very demanding, as gluten is found in cereals such as wheat, rye, barley, spelt and their cross species. Gluten-free oats is tolerated by most patients, but not all of them. Gluten, which is toxic to celiac disease patients, is often present as a contaminant or additive in many products where it would not be expected.
- **Not following the diet** and unintentional consumption of gluten can have severe and, if repeated, irreversible health consequences: problems with digestion, abdominal pain, nausea and vomiting, weight loss, anemia, chronic fatigue, mouth sores, dermatitis herpetiformis, pathological bone fractures, osteoporosis, abnormal level of liver enzymes, reproductive health disorders, various neurological and psychological problems, growth and developmental delays in children. Often improperly treated celiac disease is associated with other autoimmune diseases, such as thyroid disease, diabetes, neurological diseases and sometimes even cancer. Inadequate nutrition leads to higher morbidity and mortality rates, poor school performance, higher work absenteeism and has a negative impact on healthcare systems and society in general.
- **Gluten-free products are expensive.** Slovenia is one of the few countries where adult patients do not receive any financial support to follow a proper diet. Many patients find it difficult to afford it. Financial support to buy gluten-free products, food on prescription or special tax relief, which are solutions available in some European countries, would reduce irreversible health complications and their consequences and would be quickly reimbursed in savings for treatment.

### ***CD SKILLS project (Interreg Danube Transnational Programme)***

The main objectives of the CD SKILLS project (*Improving celiac disease management in the Danube region by raising the awareness, improving the knowledge and developing better skills*) are increased knowledge about the disease and the development of new services to improve the quality of life of patients in the Danube region. The partnership is composed of hospitals, universities, associations, local communities and food producers from Beograd, Budapest, Debrecen, Graz, Merano, Prague, Kishinev and Zagreb. The project started on 1<sup>st</sup> July 2020 and is a continuation of successful projects CD-MEDICS, LQ-CELIAC and Focus in CD.

By implementing the CD SKILLS project, we would like to overcome the detected difficulties to ensure greater efficiency and sustainability of public healthcare systems that will be able to meet the health and social needs of celiac disease patients and wider society.

An important initial activity of the project is the evaluation of celiac disease management practices in the region, followed by the implementation of a new innovative educational strategy by combining traditional learning methods and modern e-learning tools. A platform for the exchange of knowledge and good practices between healthcare professionals will be developed and implemented, seven pilot solutions will be tested – from new and improved diagnostic methods that will enable effective and early detection of the disease and its complications to pilot solutions that will improve the quality of life of celiac disease patients.

A new educational programme will be developed, tested and implemented in practice. The programme will consist of lectures by various experts, workshops on how to prepare a gluten-free meal, e-learning courses, video presentations and more. A number of educational materials will be available: a guide for patients, a brochure for healthcare professionals, a brochure for caterers, a poster for kitchen personnel with instructions, cards with basic gluten-free recipes, and a script for high-school and college students. All these will be available on a specially designed platform.

The main goal of these activities is to present simple but strict rules on preparing gluten-free meals to kitchen personnel. The rules include:

- Reading labels on food products and checking ingredients for gluten,
- Storing and handling food to avoid contamination with gluten,
- Cleaning and separating kitchen utensils,
- Cleaning and separate use of desks and counters to avoid contamination with gluten,
- Following recipes and rules in food preparation and service.

Our aim is to inform people about basic rules of preparing gluten-free meals and ensure celiac disease patients safe gluten-free meals outside their homes.

**More about the project:**

<http://www.interreg-danube.eu/approved-projects/cd-skills>

**Izobraževalna e-orodja za bolnike in zdravstvene delavce:**

<https://celiacfacts-onlinecourses.eu/?lang=en>