



1st CD SKILLS NEWSLETTER

Introduction

Partners of the CD SKILLS project financed by the Interreg Danube Transnational Programme have been very active during the first half of 2021.

Assessment of the current state of the art in the celiac disease management in the region started at the beginning of the period and preliminary results already show the improvement in the diagnostic approach. Further analysis of the data will show the current status of awareness, knowledge and needs about the disease in the Danube region. New diagnostic methods for celiac disease were improved and will be tested in real environment. A possibility to get reliable results of specific coeliac disease testing within the visit time of a patient with a new analytical tool is very promising and first results already show the advantages of this possibility. Despite the limitations in international travel brought by SARS-CoV-2 epidemic, several local and international educational activities were conducted. Interesting patient stories were continually presented and discussed by partnership with the help of communication platform. Another activity focusing on improving the knowledge about coeliac disease was updating of e-learning tools developed in previous project. These tools are being adapted and will be translated in new languages within the next period. Partners were active at international meeting including the World Congress of Paediatric Gastroenterology, Hepatology and Nutrition which was held virtually. Several partners actively participated as speakers at this meeting. Partners also continued their work in the development of pilot services. They were meeting on a monthly basis and established specific stakeholder groups and developed a workplan for each of the seven pilot projects. Some of these projects will start shortly and initial results will be presented within the next period. Achievements of the project and facts about the burden of coeliac disease were widely disseminated during the May to mark the International Coeliac disease day. Two publications which will serve to improve the knowledge of healthcare professionals and patients were finalized during this period, and will be published shortly in partner languages. English versions are already available at our web-site, which also features several other interesting publications and provides interested readers with further information about celiac disease and about the partnership which will hopefully be enlarged by a new partner from Germany before the Summer.

We are kindly inviting you to read this newsletter and visit our web-page and help us in rising the awareness about the celiac disease in the Danube region.

Assessing current state of the art in the management of celiac disease (WPT1)

Main focus of the first work package is the assessment of current state of the art in celiac disease management and assessment of current level of knowledge, awareness and needs among healthcare professionals and patients. Activity is building on the results of the Focus IN CD project and publications in international journals that were published based on the data from Central Europe.

Partners were involved in updating four different questionnaires during the initial phase of the CD SKILLS project. After the introduction of some new questions based on the new knowledge and specific needs of new partners all questionnaires were translated in partner languages and final versions were uploaded on the web platform and distributed among partners who actively promoted the use of questionnaires in their regions.

Data collection focusing on knowledge and awareness of HCPs and patients started in January 2021, and data collection of patient data started after ethical approval of the activity by Slovene national ethics committee and ethical approval in individual countries. About 2000 participants have already participated in this activity.



Preliminary analysis of few cases showed an important improvement regarding the invasiveness of diagnostic approach in the Danube region. Partners will continue to encourage patients and HCPs to participate in the activity until mid-June, whereafter the data will be analysed and reported. Patient data will be collected until May 2022 in order to get the most representative view on the current state of the art in the disease management.

Q1

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Q4

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A new BLItz Technology-based instrument arrived to Heim Pál National Paediatric Institute to assist near-patient quantitative measurement of celiac antibodies



BLItz - a new laboratory instrument utilizing novel biolayer-interferometry technology

The Celiac Disease Center at Heim Pál National Paediatric Institute, Budapest has received with the support of the CD SKILLS project (Interreg DTP) a new laboratory instrument utilizing novel biolayer-interferometry technology. The machine is placed to the outpatient department and will be employed to detect celiac antibodies and serum IgA from a drop of blood. The measurement setting is being developed by the transglutaminase research group of the University of Debrecen, another CD SKILLS partner. The BLItz Technology is based on the optical measurement of antibody binding to a plastic biosensor coated with target molecules, like gliadin or transglutaminase, and is able to give results in few minutes onsite.

Building knowledge capacities (WPT3)

One of the work packages within CD SKILLS project is WP T3 "Building knowledge capacities". The aim of the project is to improve knowledge, skills and competences of health care professionals, patients and general public in the field of coeliac disease. To achieve that, four activities were planned:



organizing learning interactions, implementation of innovative e-learning tools for HCPs and patients, establishing transnational HCPs information exchange network, organizing cross-disciplinary study visits and participating international professionals and patients' meetings. Responsible partner for WP T3 is PP05 CHZ. During this first year of the project, two regional learning interactions were organized by Romanian and Moldavian partners. Altogether 16 lectures at educational institutions were organized for medical students, students of faculty for agriculture and biosystemic sciences, PhD students of biomedicine and health sciences and of pharmacy and biochemistry, at high schools for nurses, physical therapy technicians, food technicians, for trainee doctors and paediatric residents. We also started to update the e-learning tools for both patients and health care professionals developed within the previous CE Focus IN CD project. The transnational information exchange network for health care professionals was established and up till now 8 cases of the month and one difficult case for discussion were presented. In the next period it is planned to have this platform for information exchange open to other health care professionals in the Danube region beside those already involved in the project as project partners.

Unfortunately, because of restrictions due to COVID-19 pandemic imposed across the world, it was not possible to organise face-to-face learning interactions as planned, and also, cross-disciplinary study visits could not have been arranged. However, LP UKC MB team had presentations on two international meetings held on-line: ESsCD 2020 and UEGW 2020.

These are the first steps in raising awareness about coeliac disease in Danube region and we hope to lay the foundations for further building knowledge and improving skills.

Pilot projects news (WPT4)

Within thematic work package 4 "Pilot projects" partners are designing innovative pilot services based on identified needs and challenges, recorded inequalities, knowledge and management practice gaps, stakeholders' demands, input from partners and lessons learned from previous projects (CE Focus IN CD, SI-HU LQ-CELIAC, FP7 CD-MEDICS). There are seven pilot services aiming to improve public healthcare services and quality of life of celiac disease patients. For each pilot service a preliminary activities list was established.

Testing for Celiac disease in general population, risk groups and elderly

This pilot focuses on the presence of undiagnosed celiac disease (CD) in the general population and especially in the underprivileged groups of the population. Within the pilot, the partners will be screening specific populations with rapid celiac disease tests. We are gathering data from each contributing partner regarding the scale of testing and the populations to be tested. After gathering all these data, we will decide on the rapid test(s) that will be used in this pilot study. Since there is a higher chance of another lockdown in autumn and winter months, there is a sense of urgency for all partners to do their testing before that time.

Testing for Celiac disease related complications

Complications related to CD are extremely important. Undetected or untreated CD patients are exposed to risk for development of serious complications including osteoporosis, thyroid disease, anaemia, infertility, etc. The aim of the pilot is to evaluate the frequency of complications related to celiac disease and to develop recommendations for approach to a newly diagnosed patient with celiac disease in order to diagnose hidden complications and their treatment and follow-up in the management of patients with celiac disease, all in correlation with compliance with gluten-free diet.

ICT supported histopathology analysis of biopsy samples

Inadequate histopathology analysis of small bowel biopsy samples and/or misinterpreted results can lead to wrong diagnoses of celiac disease. One of the methods that could improve and facilitate the biopsy based diagnostic procedure is ICT supported histopathology analysis of biopsy samples that will be compared to traditional methods. In order to improve knowledge and share ideas and experiences, the partners involved in the pilot are preparing a common workshop with clinicians and histopathology experts.



Patient registry set-up

Across the Danube region, there is lack of good quality, standardized data regarding celiac disease patients. In this pilot we aim to develop a common patient registry structure. Patient registries would enable the collection and analysis of data for epidemiology, clinical presentation and characteristics of the disease, diagnostics, associated disease, complications and treatment. It would serve as the basis not only for future medical research programs but also for public health plans and actions. This all together will improve the health care and the quality of life of patients with celiac disease. The partners agreed on the aligned content of the patient registry and are currently analysing the technical approach to be used.

Monitoring of celiac disease patients with telemedicine solutions

In this pilot the focus will be testing and implementing different telemedicine solutions to improve the quality of regular check-ups for patients with celiac disease during a pandemic, while at the same time minimizing the physical contacts where patients could get infected. The partners involved had an online meeting where we discussed the scope of this pilot and decided on some basic ideas. The pilot leader is already gathering information about the different technical solutions and also a possibility of an additional software support for our pilot (maybe even a specific app for a smartphone).

Development and implementation of gluten-free products registry

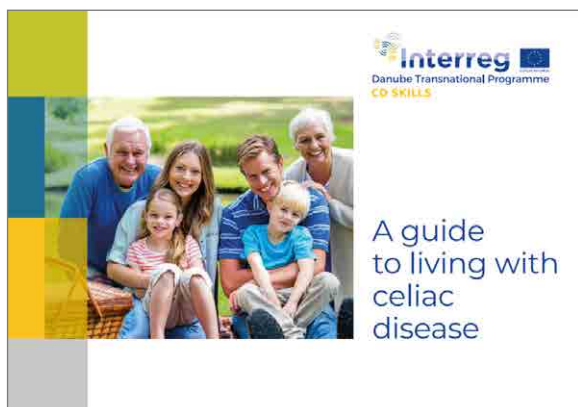
Gluten-free(GF) products registry will be a solution which will serve not only to coeliac patients, but to everybody preparing strict GF food, providing correct and up to date information about gluten free products. GF products registry will be developed as a user friendly and easy to use application. Pilot project will enable us to produce a beta version of the registry which will be easily maintained by societies and used by end users. We expect this pilot to be motivation for the food producers to, more carefully, precisely and at one place, communicate information about food they produce to final consumers, when it comes to presence/absence of gluten in the food.

Improved capacity of food catering providers to provide safe gluten free products

The main aim of this pilot is to develop, implement and test new comprehensive supportive education model including lectures, workshops, education material, gluten-free legislation frame and long-term support to improve capacities of food caterers in a way they will understand basic rules and prerequisites of gluten-free meal preparation. Now, focus in this pilot project is on individual workshops with specific stakeholders. We hope to get information that will help us produce quality content for the end users-caterers and others in charge of food preparation in school and kindergarten kitchens, dormitories, hospitals, elderly homes etc. Inputs from stakeholders will show us where the knowledge and information gaps are, so that we can produce and offer specific and useful materials which will be used for building their capacities. Materials and relevant information in various formats will be placed at a common online platform.

Communication work package news (WPC)

Due to pandemic crisis, we have not been able to organize face to face meetings and events, to participate at conferences and to travel to meetings in this project period, all these activities have been organized online. We have put a lot of efforts to prepare quality publications to support patients and healthcare professionals to gain new knowledge about celiac disease. A transnational campaign to mark International celiac disease day was organized, we have published a press release and organized as well as participated at different events to spread the knowledge and to raise awareness. Project partners designed a general promotion material up to their needs to support newly diagnosed patients, to promote pilot activities, the project and the DTP programme. We have been very active at our website and digital profiles, we regularly published news and attracted as many visitors as possible, namely rising awareness and improving the knowledge as well as the quality of life of celiac disease patients are our main aims. Our patient stories were a real success.



A guide to living with celiac disease

If have been diagnosed with coeliac disease and you have to change to a gluten-free diet, which will enable you to control your health, we have published a “A guide to living with celiac disease” which will provide you with information about coeliac disease, its symptoms, diagnostic methods and treatment, the importance of dietary adherence and regular follow-up as well as the recommended screening of family members. It will offer you guidance about living a gluten-free life, about changes in your lifestyle, where to find necessary information, patient support, and answers to your questions. Using this guide, you

will find that eating, cooking and travelling gluten-free can be easy. Our tips will help you to transform your kitchen into a gluten-free zone or at least into a safe environment where the risk of gluten contamination is minimized. We recommend you to watch our “Gluten-free kitchen” video tutorial, available at our project website <http://www.interreg-danube.eu/approved-projects/cd-skills>. You will find a detailed gluten-free bread recipe and some gluten-free shopping tips.

A guide to living with celiac disease is available at: http://www.interreg-danube.eu/uploads/media/approved_project_output/0001/45/998c62d71d1e3aac4a32e241ca6b43458f49a183.pdf



Hand in hand with celiac disease

Coeliac disease is a lifelong systemic reaction against gluten found in wheat, barley and rye. More than 1% of population (about 1.2 million) in the Danube region could have coeliac disease, with much larger population affected indirectly. It has an impact on families and friends, as well as on childcare institutions, food producers, catering service, and especially on health-care sector. About 80% of patients are diagnosed with long delay or remain undiagnosed, increasing a risk of complications, resulting in high morbidity and mortality, low school performance and high work absenteeism.

The main long-term goals of the project are improvement of the knowledge, skills and competences of health care professionals and patients as well as other stakeholders and increased capacity of healthcare service in the Danube region to better meet the needs of coeliac disease patients and to improve their quality of life. Our brochure to support health care professionals will get us closer to the set-up goals.

Hand in hand with celiac disease is available at: http://www.interreg-danube.eu/uploads/media/approved_project_output/0001/45/d9160462ee259b35e1939c6530b07683eb50d190.pdf

Gluten free day at Medical University in Plovdiv

Gluten Free Day was organized by Department of Peadiatrics and Medical Genetics of Plovdiv Medical University with support of BuSPGHAN and two patients' celiac disease societies. The meeting was organized at Zoom-platform of Plovdiv MedUni. Four main topics were presented: “Gluten free diet - how to prevent obesity” and “Cooking properties of gluten free products” were presented by nutritionist; “How to recognize celiac disease relapse by Pediatric Gastroenterologist” and “Principles of gluten free cuisine” by nutrition instructor and chef. On-line meeting was opened by vice-rector of Plovdiv Medical University and was visited by 68 parents of patients and doctors.

The meeting was recorded and published on Facebook pages of the two patients' celiac disease societies and Plovdiv Medical University and has already attracted more than 5000 visitors.



Training at Medical University Graz




FA Dr. Benno Kohlmaier, a.o.Univ.Prof.Dr. Almuthe Christina Hauer, OA Dr. Sebastian Bauchinger, FA Dr. Helga Christina Stenzel

Pediatrician Dr. Helga Christina Stenzel from Children's Hospital Klagenfurt has been supporting Univ. Prof. Dr. Almuthe Christina Hauer's team since January 2021 as part of her training for an additional subspecialisation in Pediatric Gastroenterology, Hepatology and Nutrition. Dr. Stenzel will stay at the department for more than four months. After completion of her training, she will support the "CD SKILLS" campaign in Southern Austria, thus improving celiac disease management in the Danube region by raising the awareness, improving the knowledge and developing better skills.


News in chronic digestive pathology in children

I. ASPECTUL ENDOSCOPIC SI STRUCTURA MUCOASEI INTESTINALE LA PERSOANE SANATOASE



II. MODIFICARI ENDOSCOPICE, MORFOHISTOLOGICE ALE VILOZITATILOR INTESTINULUI SUBTIRE IN BC (xematoxilin-eozina, x 100)

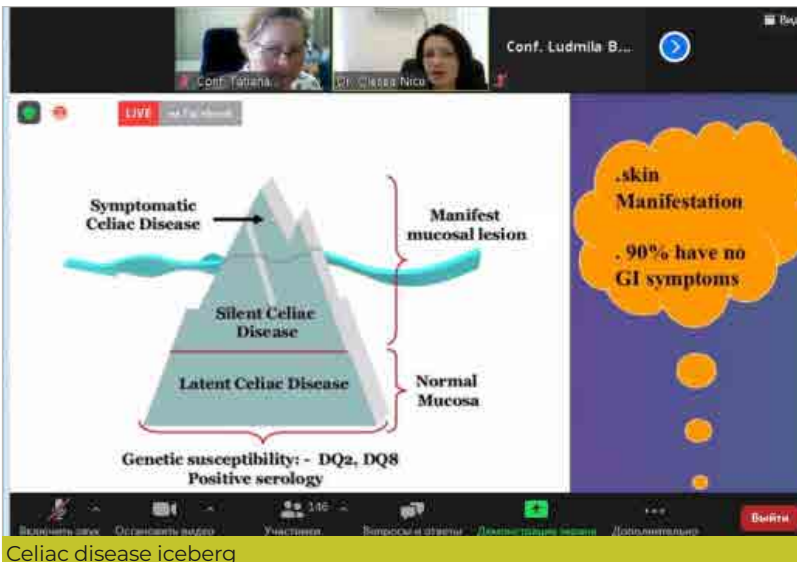
- Infiltratie limfocitara;
- Atrofie vilozitara;
- Hiperplazie de cripte



Typical celiac disease mucosal damage

A national online conference was organized by the Paediatric Society of the Republic of Moldova, on March 26th 2021. CD SKILLS project (Interreg Danube Transnational Program) was presented at the conference by our partner "Nicolae Testemitanu" State University of Medicine and Pharmacy of the Republic of Moldova from Kishinau, represented by prof. Tatiana Raba. 263 participants attended the conference. Two presentations were dedicated to Celiac Disease. Two clinical cases of patients with celiac disease in children were presented. The information regarding the questioning of paediatricians and family doctors focusing on management of celiac disease in children was disseminated. The following issues were addressed: aetiology, pathogenesis, clinical manifestations of celiac disease in children respecting the ESPGHAN 2020 guidelines; cutaneous manifestations of celiac disease in children; presentation of clinical cases of children with celiac disease; findings/conclusions that will contribute to achieving further project results. The conference aimed to familiarize the medical community in the Republic of Moldova with the Project Funded by the European Union and dedicated to improving the management of celiac disease in children in the countries of the Danube Region and in the Republic of Moldova.

dren were presented. The information regarding the questioning of paediatricians and family doctors focusing on management of celiac disease in children was disseminated. The following issues were



Conf. Ludmila B...

Symptomatic Celiac Disease (Manifest mucosal lesion)

Silent Celiac Disease (Normal Mucosa)

Latent Celiac Disease (Normal Mucosa)

Genetic susceptibility: - DQ2, DQ8
Positive serology

skin Manifestation
.90% have no GI symptoms

Celiac disease iceberg



Welcome our new partner Ludwig Maximillian's University



Interreg CENTRAL EUROPE Focus IN CD

deutsch english italiano magyar slovensčina hrvatski

Celiac facts

Online courses on celiac disease



Online Course for Patients

Click here to get extensive and comprehensible information on celiac disease – free of cost, free of ads and without registration!



Online Course for Physicians & Dietitians

Click here to learn more about celiac disease and further improve your skills! The course is already based on the new ESPGHAN guidelines of 2020!



Web-App to Diagnose Celiac Disease

Click here to take advantage of the Web-App which easily guides you through the diagnostic steps. The Web-App is based on the new ESPGHAN guidelines of 2020!

Interactive online courses on celiac disease have previously been established in five different languages: in English, Italian, Hungarian, Slovenian and Croatian and are available at www.celiacfacts-eu

We unfortunately have lost a partner from Bulgaria, but we are happy to welcome new partner Ludwig Maximillian's University form Munich (LMU). Once LMU university hospital will have formally joined as a partner of the CD SKILLS project (which will hopefully happen before summer holidays), it will work closely with other project partners.

The main task of CD SKILLS new partner is to implement patient and health care professionals'

courses in three additional languages: Czech, Romanian; German on the already in Focus IN CD project (Interreg CE) established online platform, available at www.celiacfacts.eu. This will enable an even wider audience in the Danube region to benefit from these learning materials.

We are very much looking forward to a close and successful cooperation and to possible face-to-face meetings in the coming months.

National Institute for Mother and Child Health Alessandrescu-Rusescu news

In order to raise awareness and educate about celiac disease, National Institute for Mother and Child Health Alessandrescu-Rusescu Bucharest, Romania is regularly posting on its Facebook page educational materials addressed to patients. The topics covered so far are related to celiac disease and other gluten related disorders, symptoms of celiac disease, diagnostic, IgA deficiency, gluten identification in food, gluten in medicines.

Interactive online events are organized regularly, one took place in December 2020 regarding celiac disease and gluten contamination, and another one in May 2021, as live Q&A session about celiac disease. The events are still available online and can be accessed by those interested (<https://www.facebook.com/boalaceliaca/>).



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Stran · Bolnišnica

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insmc.ro/compartimente/centrul-regional-pentru-managementul-bolii-celiace

Centrul de Management pentru Boala Celiacă
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Vă anunțăm că am finalizat prima publicație în cadrul proiectului CD Skills, un ghid pentru <Viața cu boala celiacă>.

Ghidul este acum disponibil în format electronic, în limba engleză, iar în curând va fi disponibil în limba română. Il puteți găsi la: <http://www.interreg-danube.eu/.../project-publications>

CD Skills Interreg DTP proiect este un proiect transnațional european care urmărește creșterea diagnosticării timpurii a bolii celiace, îm...
Prikaži već

Prikaži prevod

Fotografije Prikaži vse fotografije

Interreg Danube Transnational Programme CD SKILLS

A guide to living with celiac disease

FB news to inform general public about a new CELIAC DISEASE publication "A guide to living with celiac disease" for patients



A lecture on celiac disease for future kindergarten teachers



Future health care professionals learning about celiac disease

A lecture on celiac disease was held on May 7th 2021 at the College for Vocational Studies in Healthcare for students who are being educated as kindergarten teachers. It was organized in cooperation of the University Children's Hospital and Serbian Coeliac Society.

As one of the goals of the CD SKILLS project is to increase the awareness of the general population about celiac disease, we considered this target group as very important. We think that it was of great importance for future educators in kindergartens to be

informed about celiac disease, to know how to recognize it, but also to be aware of the importance of a gluten-free diet.

Initially dr.Nataša Dragutinović (University Children's Hospital) had a lecture about celiac disease, talking about the symptoms, about how to confirm the diagnose it how to treat celiac disease. The nutritionist of the University Children's Hospital, Snežana Živkovic, presented a balanced gluten-free diet. Vesna Pavkov and Mirela Markovic, representatives of the Serbian Coeliac Society, explained the importance of carefully reading the labels in process of choosing gluten-free foods, they presented the obstacles that patients with celiac disease are faced in everyday life and the role of the society in the fight to improve the quality of life of people living with celiac disease.

The lectures were interactive, 17 students attended them. Future educators have shown great interest in this topic, especially in improving the respect of the rights of people with celiac disease.

Lecture on celiac disease

A lecture on celiac disease and gluten-free diet for third-year students within the subject Nutrition was held at the High Medical School in Belgrade on Friday May 7th 2021. It was organized by a partner from the University Children's Clinic in Belgrade. The representatives of the University Children's Clinic Tiršova, Dr. Nataša Dragutinović, pediatric gastroenterologist and Snežana Živković, specialist professional nutritionist dietitian, and the representatives from the Serbian celiac society Vesna Pavkov and Mirela Marković were the speakers.



A cooperation between health care professionals and a celiac patient society representatives

Students were introduced to joint activities within the European project of the Danube countries CD SKILLS whose goal is to improve medical procedures on diagnosing and treating celiac disease as well as improving the availability of gluten-free food in stores and restaurants.

Although the measures of the epidemic coronavirus were still in effect, they managed to organize a lecture like this and to point out the need for a timely diagnosis and proper implementation of the gluten free diet.

We are thankful to the organizer and to the students for the warm reception, attention and encouraging questions.



CD SKILLS participation at world congress of paediatric gastroenterology, hepatology and nutrition

Members of the CD SKILLS partnership participated at the WCPGHAN (World Congress of Paediatric Gastroenterology, Hepatology and Nutrition) which was held virtually in the beginning of the June. A congress that should have taken place in Vienna was organised by our partner Christina Almuthe Hauer from the Medical University Graz. Despite the limitations brought by epidemic the meeting attracted about 4,500 participants from around the World. Several other partners were also actively participating at the meeting.

Jernej Dolinšek from the University Medical Centre Maribor presented a lecture on the diagnostic challenges in celiac disease at the postgraduate course and led a Meet the Expert session about the coeliac disease. Ilma Korponay-Szabo from Debrecen presented a talk on genetically negative coeliac disease patients. Alina Popp from National Institute for Mother and Child Health in Bucharest chaired a coeliac disease symposium and Zrinjka Mišak from Children Hospital Zagreb was chairing a session on Acute gastroenteritis. Together with her colleague Mario Mašić she presented a poster on screening for coeliac disease in school children.

Several partners also participated at the Coeliac disease Special interest group of ESPGHAN (European Society for Paediatric Gastroenterology, Hepatology and Nutrition), where it was decided that one of the activities of the CD SKILLS project aiming at the assessment of current management practices of coeliac disease will be disseminated across the Europe and beyond and about 30 participating centres have already expressed their willingness to participate.

We wish to congratulate the organiser of the meeting for a great success of the meeting and all the participants from our partnership for their contribution.

CeliVita lectures for students in Petrinja, which was affected by a damaging earthquake



It was with our great pleasure that we CeliVita visited High School Petrinja, at the moment relocated to small village Jabukovac, some 12 km north of Petrinja, and gave a lecture to 4th grade students of the Food Technicians programme. Petrinja (Croatia) has been hit with an devastating earthquake in December 2020, with smaller earthquakes repeatedly happening ever since... life of people changed dramatically, most of them moved from their homes to safer place, same as high school and its students who moved to this idyllic village, eager to continue with their education and normal life.

One of six educational programmes that take place in a school is the one for Food Technicians who are being educated to become professionals in the food industry. Food Technicians organize the receipt, handling, storage of food raw materials and products, manage food production processes and work in appropriate control-analytical and development laboratories. They can work in the production of various food products where they primarily take care of the acceptance and storage of raw materials or they can lead and supervise individual technological processes.

CeliVita gave a lecture about celiac disease and life on a strict gluten free diet, as part of CD SKILLS 3rd thematic work package "Building knowledge capacities". Organisation of learning interactions is



City ruins

part of this work package. We've also talked about gluten, its characteristics and use in the food and cosmetic industry; legal requirements related to food labelling, when it comes to gluten; cross contamination and its management.

Few days after our visit, we had two more lectures for 2nd and 3rd grade students attending the school online.

We want to thank students and teachers for the interest they've shown for the topic and to the school principal for understanding the importance of such lectures.

We expect this lecture helped to raise a new generation of professionals in the food industry who will understand specific needs of celiac disease patients and all the others on a gluten free diet.

First meeting in person

Last Thursday of April 2021 General University Hospital in Prague members of CD SKILLS project had their first meeting in person. We discussed all the important points including promotion materials, final quantities for brochure prints and so on.

We are excited that COVID restrictions had finally let us meet in person and can't wait to meet with other participating member countries of CD SKILLS project some time in the future.



CD SKILLS members from General University Hospital in Prague

Visit CD SKILLS (Danube Transnational Programme) website and stay informed:
<http://www.interreg-danube.eu/approved-projects/cd-skills>

Our e-learning tools for patients and health care professionals are available at: www.celiacfacts.eu