

2nd CD SKILLS NEWSLETTER

Foreword

We are happy to publish our second CD SKILLS newsletter. Partners of the CD SKILLS project financed by the Interreg Danube Transnational Programme have been very active during the second half of 2021.

CD SKILLS partners joined their efforts to improve healthcare services for celiac disease patients in the Danube region. In the third period the project progress was monitored with regular online meetings. Slovene National Ethics Committee approved all project activities. Data collection by four web-based analytical tools developed within the project started and by July 2021 more than 3,000 participants provided their data, which will be analyzed until the end of December. Developed tools will be used by centers outside the Danube region through the network of ESPGHAN.

Medical partners continued with the collection of patient samples for improvement of diagnostic tools including the development of calibrators and report on EMA use. Bio-layer interferometry device was purchased to test new technology for antibodies detection. Literature search for existing celiac disease guidelines was conducted.

Despite the COVID-19 pandemic, several educational events were organized online with active participation of partners. E-learning tools will be updated until the end of this year, new languages will be implemented in spring 2022. An information exchange platform was established, difficult patient cases (cases of the month) are being discussed.

Common pilot methodology was prepared and stakeholder groups were established for later implementation of pilot activities, the mid-term report was completed. Some of the »pilots« are planning to organize pilot events in spring 2022. Hopefully the general situation will improve.

Several communication activities were completed, including the publication of brochures for patients and for HCPs. Brochure for caterers is under preparation, the texts are completed, the publication will be designed in January 2022. Promotion material was disseminated. Partners attended public events.

COVID-19 pandemic influenced our activities. The partnership tried to overcome limitations using IT solutions, however some activities (exchange visits) were postponed. We really hope to meet in person as soon as possible.

WE WISH YOU A MERRY CHRISTMAS AND A HAPPY NEW YEAR,

CD SKILLS project team



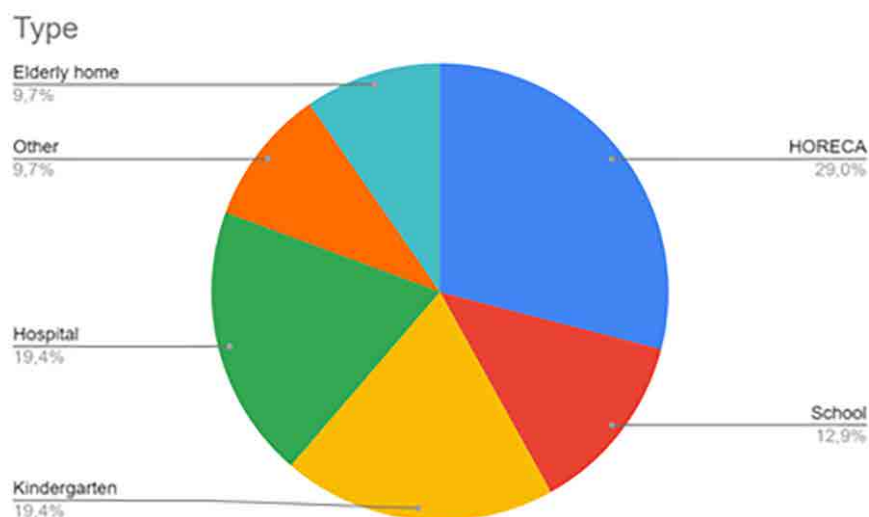


What catering providers need to be able to produce gluten-free meals?

The overall objectives of the Activity.T4.3 „Implementation of quality of life of celiac disease patients“ pilot D.T4.3.2 „Improved capacity of food catering providers to provide safe gluten-free products“ are:

- to raise awareness about celiac disease and a strict gluten-free diet,
- to improve specific stakeholders' (HORECA, hospitals, schools, kindergarten, elderly homes) capacities for preparation of gluten-free food (food labeling as well),
- to protect the physical and mental health of „coeliacs“ and to improve the quality of life of celiac disease patients and their families.

During the first year of the project implementation participating partners have had eight (8) internal meetings and twenty-eight (28) workshops with specific stakeholders. We established a specific stakeholder register with the purpose to identify and consult as many various stakeholders as possible: institutions and caterers preparing gluten-free food for their wards or customers. Each partner produced a list of the specific stakeholders that he planned to contact and organize a common workshop, with the main aim to get familiar with problems, challenges, and information gaps these stakeholders face.



Specific stakeholder's type structure

Workshops outputs will be used for the further planning of the education event for caterers and everybody preparing gluten-free food. Among other questions, they were asked what they would find helpful to be able to prepare safe gluten-free meals. Most of the interviewed answered that a list of safe gluten-free products (gluten-free products registry) would be of great help. Some of the other answers were: help in identification of critical points and mitigation measures in the food production chain; menus; instructions on how to prepare a gluten-free meal, changes in public procurement procedures; reliable food traceability; staff education; knowledge, young staff should be aware of severe symptoms; more staff; more space in the kitchen, separate space for preparation of gluten-free food; better equipment.

Partners involved in the pilot project are: PP02 Municipality of Maribor, PP07 Serbian Celiac Society, PP08 National Institute for Mother and Child Health Alessandrescu-Rusescu, and PP09 CeliVita-Living with celiac disease.

The Covid-19 pandemic crisis required our response, so we have adjusted our pilot activities to new circumstances. Our main educational event will be prepared live online and recorded.

We are looking forward to host the online event for all interested target groups which will be organized on March 10th 2022. The programme will be launched In January. You are kindly invited.



Cooperation with one of the biggest food producers in a region on a “gluten-free food registry” pilot

We are happy to present the collaboration between project partner CeliVita and pharmaceutical and food company Podravka, d.d. from Croatia.

Podravka is one of the biggest food producers in Croatia, also present at 60+ other markets, regionally and wider. Podravka promotes the application of socially responsible business norms and the harmonization of the economy with the development goals of the social community and the preservation of the environment for future generations. Podravka's basic business direction is the production of high-quality and healthy products based on good production practice and the principles of food quality and safety management.

As such, we find Podravka one of the most important stakeholder-food producer, companies which can provide us with relevant food information and become one of the information sources for our Gluten free product registry. Podravka has both certified cross grain symbol products, as well as those gluten free labeled, but also those listed as gluten free, as a result of continuous monitoring of food production and possibility of gluten contamination. This information has been shared so far with the consumers on their webpage, but from now on they will be more accessible and structured in the Gluten free food registry, mobile first web application we have been developing within the activity A.T4.3 – Implementation of quality of life of celiac disease patients pilots activities, D.T4.3.1 – Gluten-free products registry. Partners involved in the pilot project are: PP07 Serbian Celiac Society and PP09 CeliVita-Living with celiac disease.



Podravka's Vegeta, one of their most popular products, is gluten-free

Study visit at the celiac disease research center (Celires) of Tampere University



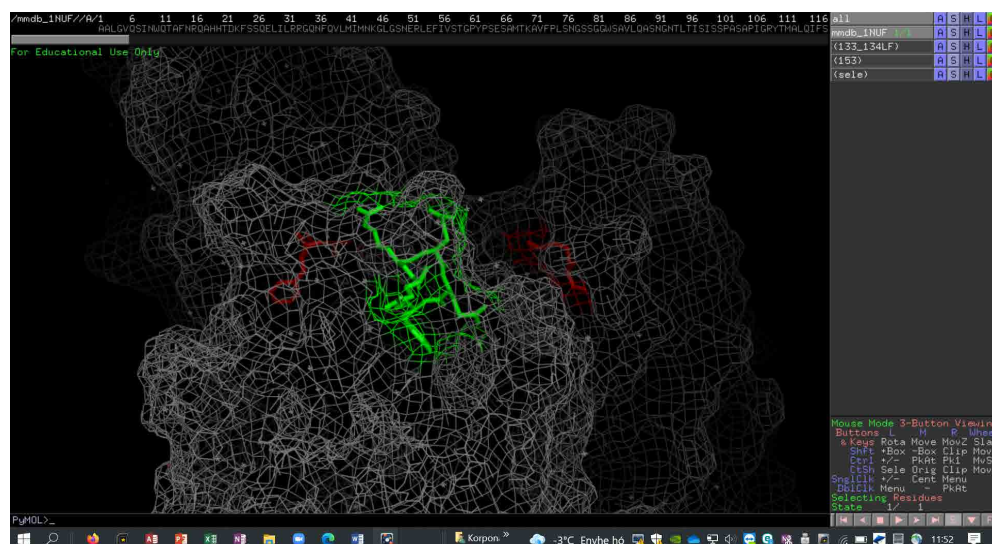
In December 2021 we visited the Celires Center in Tampere, Finland, one of the oldest and most renowned centers for celiac disease care in Europe and discussed their experience with the biopsy-sparing diagnosis of celiac disease in adults as well as further possibilities for research in the field of celiac disease and dermatitis herpetiformis as a collaboration between Tampere University and University of Debrecen, Hungary, a CD SKILLS partner. Finland introduced new diagnostic guidelines in 2018 which first in the world allow the diagnosis of coeliac disease without endoscopy and histological examination regardless of age if serum antibody levels for transglutaminase 2 protein

exceed ten times of the upper level of normal and patients also show positivity for endomysial antibodies. So far, experience with this new approach is positive - said Professor Katri Kaukinen, the leader of Celires, and it was an important factor that nationwide teaching courses for doctors accompanied the introduction of this new practice. Primary care physicians in Finland have already many years of experience in ordering and evaluating serum antibody results and have open access to endoscopy referrals in case a biopsy is still needed. Currently approximately one-third of adult celiac patients may receive non-invasively the diagnosis in Finland, which resulted in high patient satisfaction.





Researchers at the University of Debrecen work on clarifying the pathomechanism of dermatitis herpetiformis



Some 15% of patients with celiac disease also get an itchy skin disease with the name dermatitis herpetiformis. It is thought that dermatitis herpetiformis results from a separate immune reaction to transglutaminase 3 (TG3), a protein present in the skin. However, it is unclear whether this immune reaction evolves from the immune reaction to transglutaminase 2 (TG2) generally pres-

ent in celiac disease patients or is generated separately from the beginning in susceptible persons. Now researchers at the University of Debrecen produced by recombinant technique hybrid TG2-TG3 proteins to localize the binding site of dermatitis herpetiformis antibodies and test whether these antibodies are also cross-reactive with TG2. TG3 has a degree of homology with TG2 which may explain that some patient antibodies may react with both proteins during the course of the disease.

Screening of family members started at Heim Pál National Pediatric Institute, Budapest

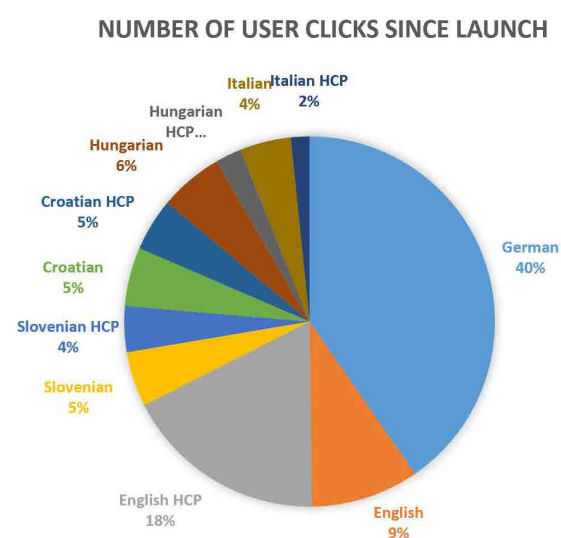
In the scope of pilot projects designed for the screening and early diagnosis of risk groups, Heim Pál is offering autoantibody screening to first-degree relatives of all celiac disease patients newly diagnosed in the years 2020-2021. Second-degree relatives can also be tested if they wish or have suspicious symptoms. Total serum IgA level and antibodies to transglutaminase 2 will be measured by conventional laboratory assays and also by a near-patient rapid method based on biolayer-interferometry using the Blitz machine purchased earlier this year with the help of the CD SKILLS project.

Results are generated in the Blitz by an optical tool in 5 minutes upon binding of serum antibodies to the transglutaminase antigen. Subjects with positive rapid results will receive endomysial antibody testing and further clinical evaluation to confirm the presence of celiac disease.





Almost 80.000 users visited the Focus IN CD/CD SKILLS e-tools since the launch



The content of the E-learning tools has been developed during the Interreg CE Focus IN CD project. The goal is to improve competences of employees working in healthcare sector as well as empower patients and increase their self-management capacities. The e-tools are divided in two main sections; for patients and for the health care professionals (HCP). The e-tools are currently available in six different languages (English, German, Croatian, Hungarian, Italian, and Slovenian) and additional two/three new languages (Czech, Romanian and probably Bulgarian) will be added during the CD

SKILLS project. The LMU Children's Hospital team will implement the new languages on the Moodle platform during the upcoming weeks and is intensively working on the German translation of the HCP e-learning course. We are very proud to share the user statistics, which shows that almost 80.000 users visited the e-tools since the launch.

Visit our e-tools: <https://celiacfacts-onlinecourses.eu/?lang=en>



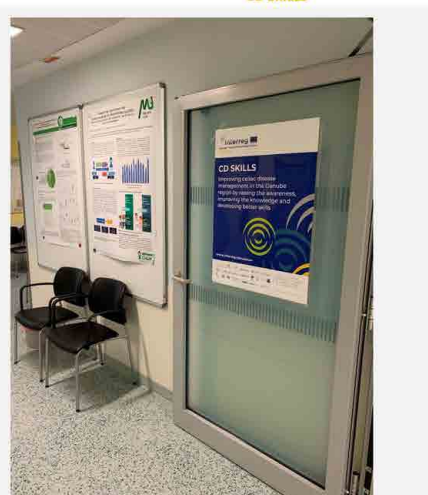
A part of LMU project team

Annual meeting of the pediatric gastroenterology, hepatology and nutrition working group of the Austrian society for pediatrics and adolescent medicine

Due to the problematic situation with the COVID-19 pandemic, the meeting had to be held as a virtual meeting. However, we succeeded in having all Austrian Ped GI heads as the audience. Presentations on various projects, in particular on Pediatric Celiac Disease (CD SKILLS) were held. The national and international networking of the working group regarding committees, studies, registers and the EU project "CD SKILLS", were presented.

Detailed information about the Interreg Danube Transnational Programme project »CD SKILLS«, for the improvement celiac disease management,

WP COMMUNICATION



Project co-funded by the European Union (ERDF, IPA, ENI)

were disseminated. Specifically, our aim was to encourage the colleagues to take part in the analysis of health data of patients who were newly diagnosed with celiac disease in all Austrian regions.

Vorsitz nachmittags: Ass.-Prof. Dr. Wolf-Dietrich Huber

- 13.20 - 13.30 **Zöliakie-EU-Projekt „CD Skills“**
A.C. Hauer, MedUni Graz
- 13.30 - 14.00 **CED-Therapie off label**
A. Moschen, JK Universität Linz
- 14.00 - 14.20 **Fallpräsentation 6: „Verkalkt und fibrotisch - eine seltene Präsentation von CHF“**
Ch. Dalus, UniKlinikum Salzburg
- 14.20 - 14.40 **Fallpräsentation 7: Der spannende Fall aus Wien**
Team MedUni Wien

Ab 14.40

Ausklang mit „Abschiedsjause“



Step by step to a gluten-free meal



A safe gluten free meal can be prepared anytime:)

As a part of a pilot activity »Improved capacity of food catering providers to provide safe gluten-free products« with the main aim to empower kitchen staff of the hospitals, kindergartens, schools, nursing homes, as well as restaurants and hotels, to be able to prepare safe gluten-free meals, a publication »Korak za korakom do obroka brez glutena« has been designed and printed. With the help of the publication ”Step by step to a gluten-free meal”, which offers simple recipes and instructions, some kind of »first aid«, the caterers will make it easier to prepare a safe gluten-free meal for a celiac patient.

Slovenian Ministry of Health recognized our publication as a valuable contribution to the improvement of the quality of life of celiac disease patients and decided to finance reprinting of the brochure. Every celiac disease patient will receive a brochure accompanied to Slovenian Celiac Disease journal ”Celiakija” in December.

We are proud to announce that a new publication ”Step by step to a gluten free meal” was published in the frame of CD SKILLS pilot project activity in cooperation of Slovenian celiac disease society and Municipality of Maribor.

Photos: CD SKILLS project

The brochure can be found here: http://www.interreg-danube.eu/uploads/media/approved_project_output/0001/46/bc1499acf98e02c8194f5b54c28209031d-f3135c.pdf



The preparation of a gluten-free meal in a public kitchen or restaurant

Gluten-free foods are, by law, strictly foods for which the total gluten content does not exceed 20 mg/kg (20ppm); including “non-prepacked” foods. In patients with celiac disease, traces of unintentional gluten can cause serious complications.

Therefore, we prepared a poster with detailed steps that should be considered when preparing gluten-free food, which is at the moment available in Slovenian, but will be very soon designed also in English.

The instructions have been prepared in cooperation of Slovenian celiac society, Croatian celiac society CeliVita and Municipality of Maribor and are available here: http://www.interreg-danube.eu/uploads/media/approved_project_public/0001/48/8c8a7abc326ac29c01e5ea037fd90363872f82f3.pdf

Photo: CD SKILLS project

Patient story from Romania – missing safe gluten free restaurants

I have been diagnosed with celiac disease when I was more than 30 years old. So, part of my life I was able to enjoy the <normal> lifestyle, going out and eating in restaurants without any concerns regarding gluten. I was able to go anywhere, anytime.

After my diagnosis, my social life changed drastically. There are no safe gluten free eating out options in the city where I live. Meetings with friends and colleagues have changed; they are much shorter and less spontaneous. I definitely cannot go anymore anywhere I want, anytime. Going out in the evening is not something that I can do spontaneously. I have to go home, eat something, and then go out and enjoy time with friends. It is uncomfortable to watch others eat and one not be able to participate, to share the moment. My friends are very nice and supportive and they rarely eat in front of me, as they understand that it is not something I fully enjoy, nor do they. Nevertheless, the time I spend out has reduced significantly and the type of interactions changed since I need to follow a gluten free diet.

When I meet new people, we cannot just go out for a lunch or dinner and get to know better as other people do, as there are no safe gluten-free options. So, I might be perceived as less open and less willing to spend time with friends, even though I am not.

There have been moments when I needed to choose something from the menu that was closest to a safe gluten free option. I often had the feeling that the personnel from the restaurants does not fully understand what is gluten and what are the requirements of a gluten free diet, why it is important to avoid cross-contamination and how this can be achieved.

I strongly believe that there is need to increase awareness about celiac disease and gluten free diet. More knowledge, experiences, good practices are needed to be shared with stakeholders from restaurants, café, catering in order to create the premises of safe gluten-free options for persons with celiac disease, and thus to improve their quality of life and allow them to have a satisfactory social life. Food is never just food, it is an important part of building social ties, enduring relationships, and not being able to share it has a strong negative impact.

Photo: Unsplash, Priscilla du Preez





Dr. Pavel Frühauf participated as a speaker in specialization course **Basics of Paediatrics**, which took place 11th – 15th October 2021 in Prague.

*The course was organised by **Institute of Postgraduate Education in Medicine**, which is an organisation in charge of specialization and long-life education of physicians, pharmacists, stomatologists and other medical professions. The course was designed for **physicians preparing for certification in pediatrics**.*

*On 13th October, Dr. Frühauf held a lecture **“Paediatric Gastroenterology”**, his lecture included also a presentation of CD SKILLS project, its goals, current state of activities and achievements. The participants of the lecture were **22 young physicians** from hospitals across the Czech Republic.*

General University Hospital in Prague



*Dr. Peter Szitanyi participated at international medical event **SunWave Pharma Scientific Conference**, which took place 14th – 17th October 2021 in Prague.*

On 16th October, Dr. Szitanyi held a lecture **“Coeliac disease and CD Skills project”**, which was focused on specifics and up-to-date medical achievements in treatment and diagnostics of CD and it also included a presentation of CD SKILLS project, its goals, current state of activities and achievements. The participants of the lecture were 22 physicians from Romania.

General University Hospital in Prague



Celiac disease patient registry (Moldavia)

Within the CD SKILLS project, the unique Registry of patients with celiac disease is being developed in electronic format and structured based on a software purchased by the project. Data about patients with celiac disease is based on the questions stipulated in the Q1 questionnaire developed as one of the tasks of the State-of-the-art analysis work package of the project.



Activity was coordinated with the Minister of Health of the Republic of Moldova and on the basis of this unique electronic Registry the procedure for elaboration of the National Program for combating celiac disease with the elaboration of the Single National Registry of celiac disease patients will be initiated.

The National Program will be initiated based on the results of our project and based on the proposal of the CD SKILLS team from the Republic of Moldova and needs the approval of the Ministry of Health and the Parliament of the Republic of Moldova. Therefore we included this activity in our plan and we will propose it to the Ministry of Health.

By November 2021 we purchased required software and worked on developing the necessary fields to include patient information. All activities are organized within the project and according to the legislation of the Republic of Moldova.

Photo by Tatiana Raba

Lecture for nurses at the University medical center Maribor



A lecture to educate nurses and to raise the awareness about celiac disease among health care professionals of Pediatric department of University Medical Center Maribor was designed and presented.

Martina Klemenak explained facts about celiac disease: incidence, pathophysiology, clinical picture, diagnostic workup and treatment with special attention to gluten-free diet and how non-adherence to the diet leads to serious complications of the disease. Moreover, cases of patients with celiac disease were described.

CD SKILL project was promoted.



Training for teachers of secondary schools for cooks

In November 2021, we implemented our program (training) named “Health problems caused by gluten, gluten-free diet and production of gluten-free foods”, accredited by the Republic of Serbia Ministry of Education for secondary vocational school teachers.

The program was implemented in cooperation with the Association “Limitless” within the cross-border project Healthy and safe gastro-nomic products as a potential for new employment in two secondary vocational schools.



At two schools: at the Public Secondary School Center “Petar Kocić” from Zvornik (Bosnia and Herzegovina) and at the Secondary Vocational School “Branko Rđicević” (Ruma, Serbia), a program of healthy nutrition without allergens was launched to develop of new skills in young chefs.

The first step towards the ultimate goal to transfer the knowledge about celiac disease and gluten-free diet to the new generation of high school students was done. The teachers play a crucial role in the process.

We took the opportunity to present the CD SKILLS project, its specific objectives, and the work of the Serbian celiac disease association. A brochure for patients was presented.



While the lecture lasted, we also prepared gluten-free bread in the bakery, so that the participants had the opportunity to follow the preparation of gluten-free bread. At the end of the training, everyone tried gluten-free bread.



A total of 22 teachers from both schools attended the lecture.

We wish a lot of success to the young chefs and their teachers!



Nurses and technicians' symposium



At the Hotel Omorika, Mount Tara in Serbia, a traditional Symposium for nurses, technicians, and professors was held from 24th to 28th November. Participants presented experiences and good practice examples of the treatment, care, and health care

of patients in the field of surgery, emergency medicine, gynaecology and obstetrics, internal medicine, paediatrics, psychiatry, and other health care fields. The plenary session was dedicated to Covid-19.

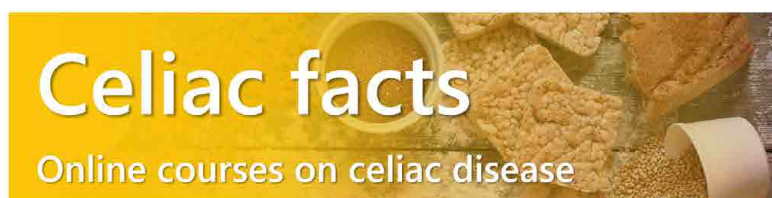
On Friday, November 26th, an EDUCATIONAL SEMINAR ON CELIAC DISEASE IN CHILDREN was held. The moderator was dr. Natasa Dragutinovic, from the University Children Hospital "Tiršova" from Belgrade. Dr. Dragutinovic gave a lecture about the novel approach in the diagnostic process and treatment of this disease. Nurse Žaklina Stanković prepared an overview of practical cases in working with patients at the gastroenterology department. Snezana Živkovic, a nutritionist and dietitian, also employed at University Children Hospital "Tiršova", spoke about the important role of a nutritionist related to the support during the implementation of a gluten-free diet. Representatives of Serbian celiac associations Vesna Pavkov and Mirela Markovic presented celiac disease and a gluten-free diet from a patient perspective. The daily challenges of both, patients and their families, were presented. It was emphasized that patients need greater support from society in ensuring a safe meal not only in their household but also outside the home, in kindergartens and schools, student canteens, restaurants. The cooperation of CD SKILLS partners in the Danube Region and the role of the Serbian celiac association was presented.





Implementation of innovative e-learning tools for health care professionals and patients

Within CD SKILLS project, two innovative e-learning tools will be implemented, one for health care professionals and one for patients. Implementation of these tools will contribute to reaching the objectives of CD SKILLS project, to improve and harmonize existing celiac disease management practices in the Danube region and to increase patients' self-management capacities.



The e-learning tools are being built on the existing tools developed within the CE Focus IN CD project and updated based on the new ESPGHAN (European Society of Paediatric Gastroenterology, Hepatology and Nutrition) celiac disease management guidelines published in 2020 and on the lessons learned from CE Focus IN CD project. It was shown in Focus IN CD project that the knowledge about celiac disease among HCPs and CD patients is not satisfactory and that further awareness-raising and learning activities are needed, in order to improve knowledge and to minimize the number of unrecognized patients and unnecessary diagnostic delays. In addition, patients should be informed better about their disease to reach higher compliance with the gluten-free diet. The use of tools will be promoted through the networks of medical partners, professional societies and patient support organisations and public authorities.

The e-learning tools available in English, German, Slovenian, Hungarian and Croatian language will be further updated and versions in new languages of CD SKILLS partners (Romanian, Czech and Bulgarian) will be added.

The aim of the e-learning tool focusing on healthcare professionals is to increase awareness, knowledge, skills and competences of different profiles of healthcare professionals. It is an open on-line course that can be accessed without the need to register. It is comprised of two units, covering basic information on celiac disease, clinical manifestations, diagnosing, treating and monitoring of celiac disease. Each unit offers also a self-assessment and several lessons including interactive elements.

The aim of the second e-learning tool focusing on patients is to increase awareness, knowledge and competences of patients and to improve capacity for their self-management. This online course is open to public and includes four units covering background, diagnosis, treatment and living with celiac disease and explaining the medical background in lay terms. It also offers self-tests, graphic illustrations interactive elements, videos and a dictionary.



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!



Online Course for Patients

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



CD SKILLS transnational information exchange platform for health care professionals

A transnational information exchange platform for health care professionals was established within CD SKILLS thematic work package three „Building knowledge capacities”. This web-based platform is designed for health care professionals to share problems in the field of celiac disease with other members of the network who will provide counseling, guidance or simple exchange of experience.

Each month an interesting and instructional clinical case will be presented as a „case-of-the month »presentation. Up till now each project partner presented at least one case, having in total eleven case presentations at the platform. The platform also gives health care professionals the opportunity to share questions/problems and to discuss challenging celiac disease clinical cases. We are inviting health care professionals, especially gastroenterologists who are dealing with celiac disease to join as na strengthen the community and cooperation among European specialists. Please, visit the platform, which is available here: <https://cdskills.eu/>



Case of the month from Hungary

“A 12 years old boy was referred to our center for a second opinion. He was diagnosed with new-onset type-1 diabetes mellitus in November of 2020. Routine screening for coeliac disease serum antibodies yielded positive results in a University Hospital on the 1st of December 2020 as follows.... Read more: <https://cdskills.eu/>

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