



# Hand in hand with Coeliac Disease

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# Focus on Coeliac Disease

**Coeliac disease is an autoimmune systemic disorder caused by ingestion of gluten and related protein components found in wheat, rye, and barley in genetically predisposed individuals. It is one of the most common chronic diseases among children and adults, and affects about 1% of the population in Europe. However, many patients remain undiagnosed.**

Coeliac disease is a complex disorder strongly associated with HLA-DQ2 or DQ8 haplotypes and specific immunological and environmental factors. In patients with coeliac disease, ingestion of gluten triggers chronic damage of the small intestine. The consequence of the morphological changes in the intestinal mucosa is its impaired function with symptoms and signs of malabsorption. Characteristic clinical symptoms of the disease, such as diarrhoea and malabsorption syndrome, are not the most common forms of the disease anymore. Atypical and silent forms of the disease are becoming more and more frequent. Based on the clinical picture, coeliac patients can be divided into two groups: symptomatic and asymptomatic. The symptomatic coeliac disease presents with gastrointestinal or extra-intestinal symptoms and signs. The term asymptomatic or silent coeliac disease is used to refer to patients who are diagnosed based on characteristic changes of intestinal mucosa, although they seem to be clinically asymptomatic. Diagnosis of coeliac

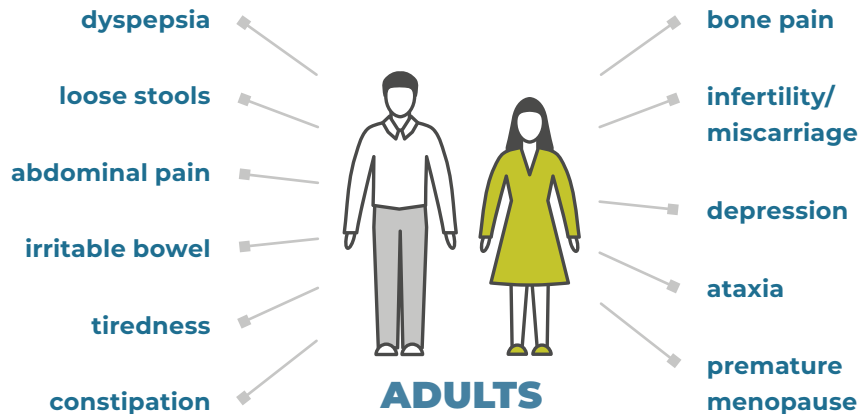
disease is suspected primarily based on the clinical picture. However, the final diagnosis is always based on the presence of a specific reversible immune response and in the majority of patients also on detection of histological changes of the small intestine. In some cases, the diagnosis can be made without intestinal biopsy. It is important, that patients do not start with a gluten-free diet before the final diagnosis is confirmed. The only possible treatment of coeliac disease is a very strict lifelong gluten-free diet, which improves the clinical picture, normalises the level of specific antibodies, and restores the damaged intestinal mucosa. Following a strict diet is also the only way to prevent development of serious long-term effects of the disease. The most significant risk factor for long-term complications is an inadequate gluten-free diet compliance.

*Oat proteins are not related to gluten, but sometimes contamination during the transportation can occur!*



*The coeliac iceberg is large, representing 1% of total population. However, only a small proportion of these patients is detected, corresponding to the tip of the iceberg. Various data show that only 10% of patients are detected due to symptoms and signs, whereas 90% can remain undiagnosed for a longer period of time. The size of the submerged part depends very much on patients' awareness, knowledge of healthcare professionals and availability of reliable diagnostic tools.*

# Symptoms



## HIGHER RISK GROUPS

first-degree relatives of coeliac disease patients

- type 1 diabetes
- immunoglobulin A deficiency

▪ autoimmune thyroiditis

▪ Down syndrome

▪ Turner syndrome

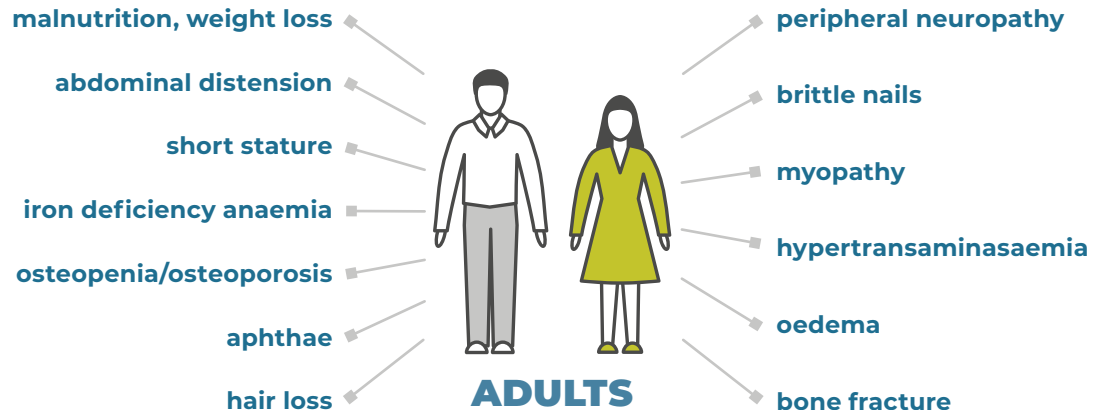
▪ Williams syndrome

QUESTIONNAIRE - if you want to test your knowledge about celiac disease, please contact the lead partner.

# Signs

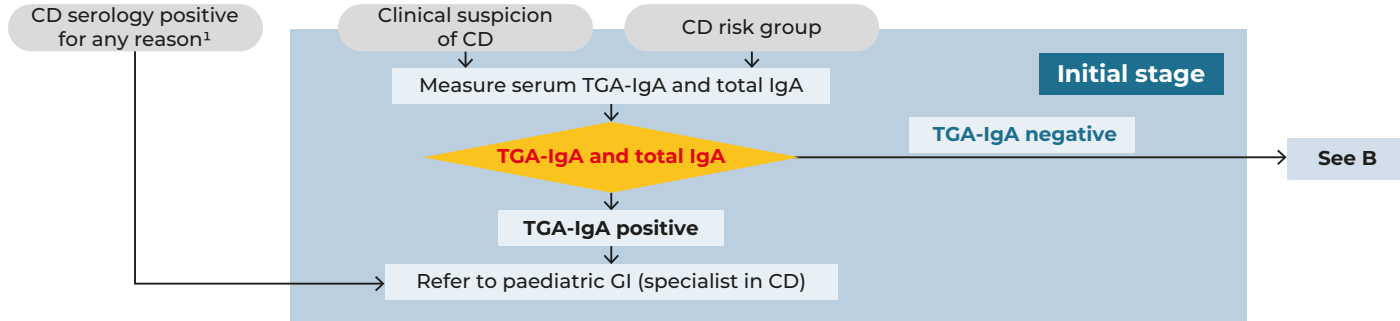
## COMPLICATIONS

- osteoporosis
  -
- autoimmune diseases
  -
- gynaecological disorders
  -
- haematological disorders
  -
- neurological disorders
  -
- psychiatric diseases
  -
- malignant lymphoma of the small intestine



# Diagnosing coeliac disease

A.



B.

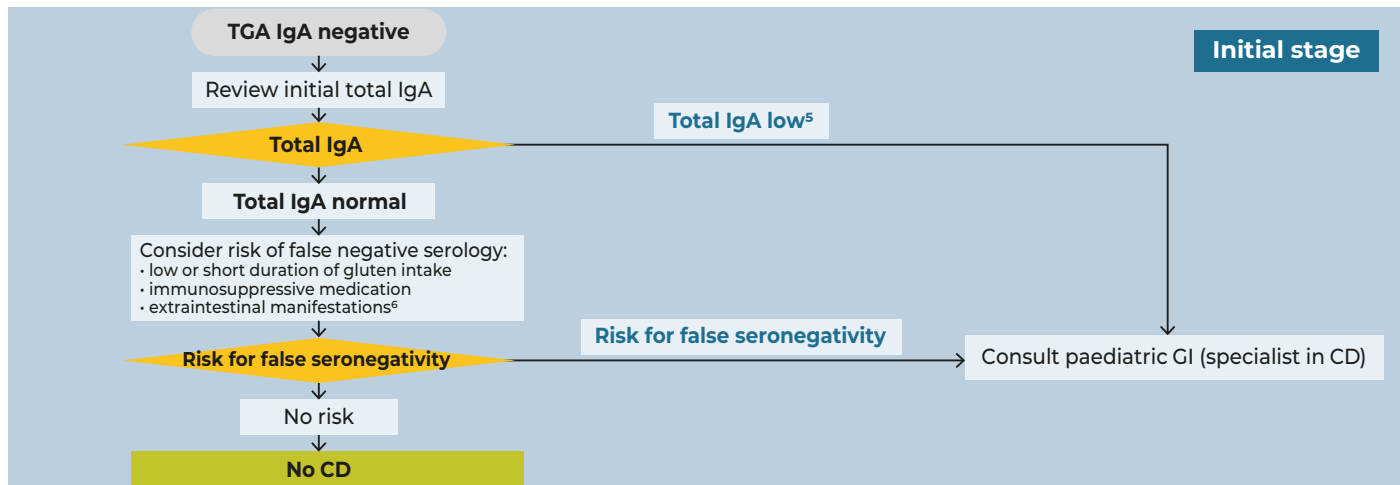
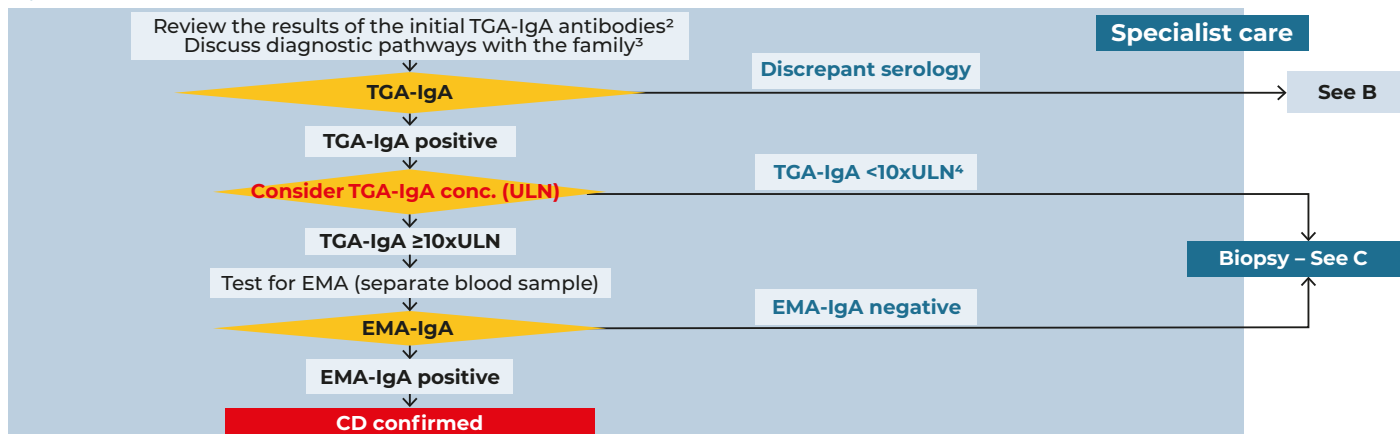
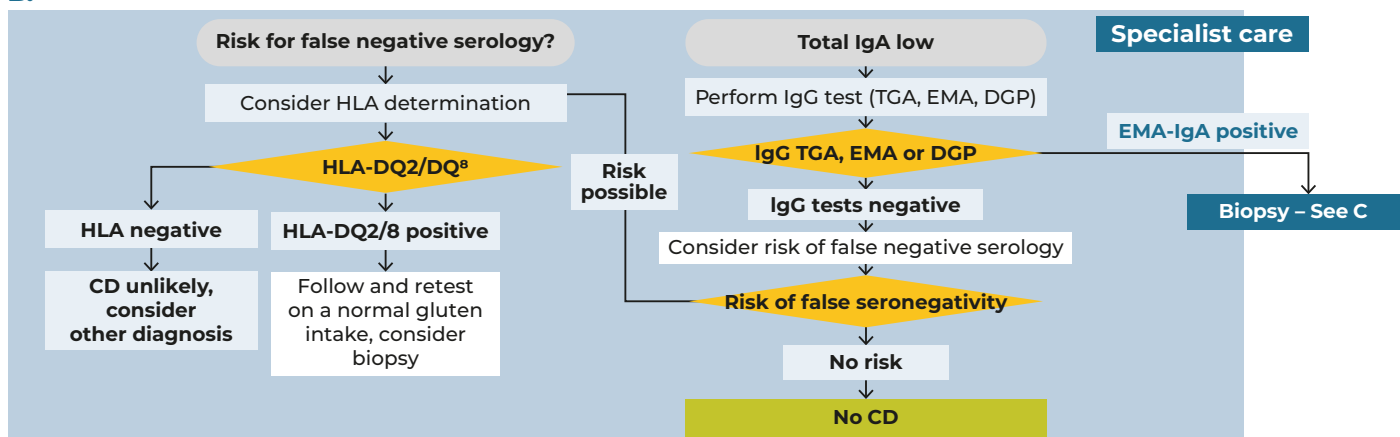


Figure 1. Diagnostic approach in children and adolescents with CD – initial care (A, B) (Husby et al. *J Pediatr Gastroenterol Nutr.* 2020).

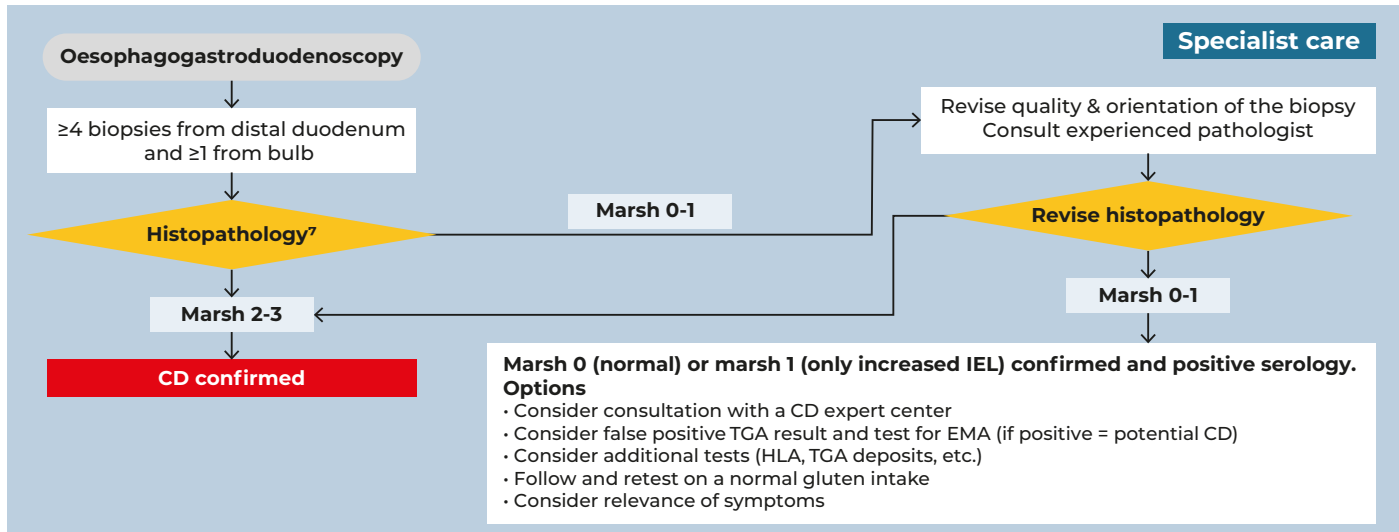
**A.**



**B.**



C.



#### Footnotes

1. Other than TGA-IgA, including point-of-care tests (POCT) and DGP.
2. Check the value also in relation to the cut-off and repeat the test if questionable or borderline. No need to retest if done with validated assay with calibration curve. Test with conventional TGA-IgA test if positive POCT and TGA has not been measured quantitatively.
3. Convey the message that the diagnosis of coeliac disease with or without biopsy confirms the need for a lifelong gluten-free diet and that re-evaluation after introduction of the diet would need prolonged re-exposure to gluten with a series of further investigations.
4. If TGA-IgA is only borderline positive confirm sufficient gluten intake and consider re-testing of TGA-IgA and EMA.
5. Low for age or <0.2 g/l above the age of 3 years.
6. For example, dermatitis herpetiformis, in which serology is frequently negative.
7. The cut-off for normal numbers of IEL is >25 cells/100 enterocytes.

Figure 2. Diagnostic approach in children and adolescents with CD – specialist care (A, B, C) (Husby et al. *J Pediatr Gastroenterol Nutr.* 2020).



# Coeliac disease and diet adherence

**Coeliac disease is treated with a gluten-free diet. This diet restores the damaged intestinal mucosa and improves symptoms in most patients. Since the diet should be followed very strictly and gluten can be present in many kinds of foods and non-foods, referral to a dietician specialized in coeliac disease should be organised at diagnosis.**

The gluten-free diet may be difficult to follow and may lead to social constraints due to the fear of gluten exposure outside one's own household. Dietary adherence is known to differ between individual patients, with non-compliance varying from 25-50% in children and adolescents. Intentional and unintentional gluten exposure can have multiple causes.

Unintentional exposure is mostly due to cross-contamination taking place during food preparation or during meals with other people eating gluten at the same time. It can also be due to insufficient labelling of food products or inadequate reading of these labels. Intentional gluten exposure is more likely to occur in patients who lack symptoms when consuming gluten. It may also occur in adolescence, with peer pressure and risk behaviour causing dietary transgressions. It is also known that transition from childhood to adulthood leads to increased non-compliance, possibly due to lack of medical care since many patients get lost to follow-up.

In most patients, diet adherence is evaluated during follow-up by their medical doctor or dietician. Common opinion is that it is best assessed by a dietary review in combination with laboratory tests measuring the coeliac specific antibodies. These antibodies are known to disappear on a gluten-free diet, usually taking 12-24 months to disappear completely. One should not rely on blood tests alone, since they are not sensitive enough by



itself to detect dietary transgressions in children with coeliac disease. Short dietary questionnaires have been developed instead of the time-consuming dietary reviews, but unfortunately these short questionnaires don't detect all transgressions. A promising new tool is the detection of gliadin immunogenic peptides (the so-called GIPs). If ingested, gluten is excreted through the stool or urine, which can be measured. GIPs could be helpful for example in patients with declining but still positive coeliac antibodies after 2 years or in patients who question their own diet or still have complaints even though they follow the gluten-free diet. However, whether or not GIPs will be useful in daily practice depends on more information about the relationship between the quantity of and time between ingested and excreted gluten in stool/urine.

# Coeliac Disease Secondary Prevention by Early Diagnosis

**Coeliac disease is a common disorder. Research data shows that approximately one percent of the general population has coeliac disease.**

This means that, in the European Union alone, at least 5 million people suffer from coeliac disease. However, this is not reflected in the statistics on the number of diagnoses. Epidemiological data indicate that for every child diagnosed with coeliac disease there are at least seven undiagnosed. In addition, the diagnosis of coeliac disease is often made too late and many patients report a delay in diagnosis that may last for years. This all results in a large number of people with undiagnosed, and thus untreated, coeliac disease.

Untreated coeliac disease results in serious health problems. This has been demonstrated, among other studies, in the analysis of the data from six-year-old children from the general population, participating in the “Generation Rotterdam” project. Undiagnosed, and therefore untreated, coeliac disease in these children resulted in osteopenia, growth retardation, emotional problems, and disturbances in attention and behaviour. In pregnant women, undiagnosed coeliac disease resulted in reduced foetal growth and low new-born weight.

## Why is the Diagnosis of Coeliac Disease Missed?

The problem with the diagnosis is that coeliac patients come to the doctor with a wide array of different symptoms and signs. The clinical picture of coeliac disease is highly variable and often diffi-

cult to recognize. First, the presenting symptoms may be gastrointestinal, such as chronic abdominal pain or diarrhoea, distended abdomen, weight loss, and in children, poor growth. Second, the disease can manifest itself with extra-abdominal symptoms, for example, with joint pain, neurological disorders, osteoporosis or anaemia. Third, there are patients who have non-specific symptoms, such as chronic fatigue. Furthermore, coeliac disease can be asymptomatic. In summary, making a clinical diagnosis of coeliac disease is not easy and physicians must be aware of many symptoms and signs that may be associated with it.

## Diagnosis of Coeliac Disease: Biomarkers in Serum and Blood Tests

The presence of specific antibodies in the blood and serum of people with coeliac disease, such as antibodies against the enzyme tissue-transglutaminase (TGA test) and against endomysium (EMA test) makes the diagnosis possible by means of non-invasive laboratory tests. The reliability of both tests is very high and levels of TGA equal to or greater than 10 times the upper limit of normal levels correlate with severe gluten-dependent alterations of the small bowel mucosa.

Point-of-care (POC) tests offer a promising way to determine TGA quickly and efficiently, however they should not replace more re-

liable serological tests. With these rapid tests, a doctor can determine with high probability if someone has coeliac disease in a droplet of blood in about 10 minutes, without special laboratory facilities. These POC tests thus open the possibility of early detection and treatment of coeliac disease on a large scale, even in entire population groups. That is, the possibility of secondary prevention of coeliac disease through its detection and treatment in early stages.

### **Secondary Prevention by Screening of the General Population**

The most effective form of secondary prevention is general population screening. However, population screening is subject to very strict conditions, the so-called Wilson and Jungner criteria. In addition, scientific evidence on the cost-effectivity of such screening and on its acceptance by the population is scarce. For this reason, a research group from the Netherlands started the project GLUTENSCREEN - Coeliac disease screening in Child Preventive Care Centers in the Netherlands. The intention was to establish a mini-screening for coeliac disease in the general population of children aged 1 to 4 years in the Kennemerland region in North-Holland. However, the project was not approved by the Leiden University Medical Center Ethics Committee, nor by the National Human Research Committee. The arguments referred to were based on the fact that in a general population screening asymptomatic coeliac cases are also detected. According to the committees, this group of people represents an ethical problem. In asymptomatic subjects diagnosed by screening, there would be no balance between the expected health benefits after treatment and the disadvantage of knowing that they are affected by a chronic disease. However, the Leiden University Medical Center Ethics Committee judged that there was sufficient scientific evidence to approve the early detection of coeliac disease in undiagnosed symptomatic children, that is, a “case-finding” project, instead of screening.

### **“Case-finding” as an Alternative to Screening for Secondary Prevention of Coeliac Disease**

The original project was adapted to the current GLUTENSCREEN ([www.glutenscreen.nl](http://www.glutenscreen.nl)). In GLUTENSCREEN, parents and children between 12 months and 4 years of age who visit a Child Preventive Care Center in the Kennemerland region are invited to participate. Participation is simple: Parents answer ten questions about coeliac disease-related symptoms. If the child has one or more of the symptoms a rapid POC test for coeliac disease is done after parental consent. If the test is abnormal, the child is referred to the Leiden University Medical Center for a definitive diagnosis following official guidelines.

The implementation of the GLUTENSCREEN project is above expectations. Since its start in February 2019 till November 2020 (with interruption of 5 months due to the COVID19 pandemic), the rapid coeliac disease test was performed in 1,923 children. The expected detection rate was 1 % of coeliac cases, but the preliminary results show 2 % detection. The purpose of this project is to demonstrate that this form of secondary prevention of coeliac disease is feasible, efficient, cost-effective, and well accepted by the population.



# Other gluten-related medical conditions

**Lately, it has become clear that in addition to patients with coeliac disease and wheat allergy there are also people who react to gluten without proven allergic or autoimmune mechanisms.**

## Wheat allergy

Wheat is one of the most common allergens and wheat allergy is an undesirable immune response to wheat protein (albumin, globulin, gliadin and glutenin) which results in the development of respiratory or gastrointestinal symptoms or sometimes even systemic reactions. The incidence of proven wheat allergy is estimated to be about 0.4-9%.

Wheat allergy is a condition different from coeliac disease. Gluten allergy is actually allergy to wheat since it is a protein specific for wheat. If a person allergic to wheat eats food that contains gluten, following reactions can follow:

- rapid onset reaction: urticaria (hives), angioedema (swelling of the face), breathing difficulty, nausea, and abdominal pain or in some cases anaphylaxis – a life-threatening reaction
- late reactions that occur after 24 hours of ingestion (digestive symptoms, skin changes).

Wheat allergy is treated by avoiding wheat in the diet.

## Non-coeliac gluten sensitivity

Lately, it has become clear that in addition to patients with coeliac disease and wheat allergy there are also people who react to gluten without proven allergic or autoimmune mechanisms. This condition is generally referred to as non-coeliac hypersensitivity to gluten or simply gluten hypersensitivity/ intolerance. It was estimated that the frequency of this disorder in the general population is 0.63-6%.

Clinically, the disease may resemble coeliac disease or wheat allergy and may present with a number of intestinal (diarrhoea, abdominal pain, bloating, etc.) and/or extraintestinal symptoms (weakness, headaches, etc.) that occur shortly after ingestion of food with gluten, and improve with introducing a gluten-free diet. There is no specific test to diagnose gluten intolerance and the diagnosis is made by double-blind placebo-controlled challenge after exclusion of both coeliac disease and wheat allergy.

	<b>Coeliac disease</b>	<b>Non-coeliac gluten sensitivity</b>	<b>Wheat allergy</b>
<b>Definition</b>	Life-long, genetic, autoimmune disease; gluten intake leads to damage of the small intestinal mucosa	Intolerance to gluten or some other component of wheat that does not elicit a specific autoimmune response and does not cause overt damage to the small intestinal mucosa	Immune response to one or more cereal proteins (could be gluten)
<b>Gastrointestinal symptoms</b>	Diarrhoea, bloating, abdominal pain	Diarrhoea, bloating, abdominal pain	Nausea, vomiting, diarrhoea, bloating, mouth and throat irritation
<b>Extraintestinal symptoms</b>	Weight loss, stunted growth, arthritis, osteoporosis, dermatitis, tooth enamel damage, recurrent aphthae, amenorrhoea, infertility, joint pain, neurological disorders	Fatigue, neurological disorders, foggy mind, joint pain	Rash, nasal congestion, eye irritation, shortness of breath
<b>Diagnostics</b>	Clinical picture Serological tests (total IgA and TGA) Small intestinal biopsy	Exclusion of coeliac disease and wheat allergy	Skin prick tests Patch tests Tests to determine the concentration of specific immunoglobulin E Food challenge
<b>Presence of auto-antibodies</b>	Yes	No	No
<b>Small intestinal biopsy</b>	Typical damage of the small intestinal mucosa	NO overt damage of small intestinal mucosa	NO overt damage of small intestinal mucosa
<b>Treatment</b>	A life-long strict gluten-free diet	Gluten-free diet and wheat-free diet (degree of sensitivity is individual)	Strict wheat-free diet

Source: CeliVita – Living with coeliac disease and Children’s Hospital Zagreb.

# Glossary

**Anaemia** – a condition where the levels of haemoglobin (Hb) in blood are less than normal. One of the most frequent types of anaemia is the iron-deficiency anaemia (iron is required for Hb synthesis).

**Antibodies** – protein molecules capable of carrying out certain reactions, which usually have a protective function.

**Antibodies against tissue transglutaminase (TGA)** – antibodies (usually IgA class) directed against the tissue transglutaminase enzyme. These antibodies are usually present in the blood of coeliac disease patients in the active phase of the disease.

**Antiendomysial antibodies (EMA)** – antibodies (usually IgA class) directed against the endomysial tissue. These antibodies are usually present in the blood of coeliac disease patients in the active phase of the disease.

**Antigliadin antibodies (AGA)** – antibodies (IgA and IgG class) directed against gliadin. These antibodies may be present in the blood of coeliac disease patients in the active phase of the disease. In comparison to TGA and EMA their specificity is much lower.

**Biopsy** – removal of a tissue sample in order to examine it in a variety of ways.

**Deamidated gliadin peptide antibodies (dGPA Ab)** – antibodies (usually IgA class) directed against deamidated gliadin peptide. These antibodies are usually present in the blood of coeliac disease patients in the active phase of the disease.

**Dermatitis herpetiformis** – a skin condition characterised by itchy rash on the skin that appear on typical locations (e.g. elbows and knees). It is one of the possible clinical manifestations of coeliac disease.

**Gluten-free diet** – the only way to treat coeliac disease. A strict diet involves a complete avoidance of wheat, barley, rye and, in some coeliac disease patients, even oats.

**Higher-risk group** – a group of people in the community with a higher-than-expected risk for developing a particular disease, which may be defined on a measurable parameter (e.g. an inherited genetic defect, physical attribute, lifestyle habit etc.)

**HLA system** – a complex of genes located on chromosome six, which are responsible for protein synthesis. Proteins play a crucial role in the immunological reaction.

**IgA** – a subclass of antibodies (or immunoglobulins), found in blood and mucosal secretions. In case of IgA deficiency, coeliac disease is more common.

**Intraepithelial lymphocytes** – lymphocytes responsible for immunological protection, found between epithelial cells on the surface of the intestinal lining.

**Lactose** – milk sugar composed of one glucose molecule and one galactose molecule. Lactose intolerance is common in coeliac disease and may disappear completely when a gluten-free diet is adopted.

**Malabsorption** – reduced absorption of nutrients as a consequence of digestive enzymes deficiency or damaged intestinal lining.

**Serological markers** – antibodies, which can be detected in blood. Their presence represents a valuable diagnostic element in the detection of coeliac disease.

**Villi** – anatomical structures in the shape of “glove-fingers” typical for a normal intestinal lining.

**Villous atrophy** – a pathologic defect of the intestinal mucosa. The villi become shorter or even completely flattened (in the case of complete atrophy).

# Patients' stories

## NUŠA AND HER MOM FROM SLOVENIA

The day, when our oldest daughter was diagnosed with coeliac disease was one of the happiest days for our family. The diagnosis of coeliac disease was among the suspicions of doctors for the best and the least harmful disease. We were happy that the marathon from one doctor to another had finished, and that we finally identified what was wrong and how we can help our daughter to live and develop into a healthy and happy woman. Our daughter's health problems did not develop overnight as a rapid deterioration of her health condition. The changes were very gradual, but still not unnoticed. From the early age of two, she had weakened immunity (hypogammaglobulinemia) and was more prone to infections, this is why she was managed by specialists in an allergy outpatient clinic. To avoid diseases, she did not attend organized care (kindergarten). Somehow our happy but quiet girl became even more tired and without appetite after the treatment of her last infection. After consultation with her paediatrician, we did a blood count check, which was fine. Problems with diarrhoea, malaise, pain, constipation, or vomiting were absent. I visited the paediatrician's office several times a month with my moody and tired daughter. No one thought of coeliac disease, we were not referred to a specialist – a gastroenterologist. As we were blessed with a new family member, we thought that maybe it was the lack of



acceptance of her sibling and also visited a psychologist. During the holidays we were hoping for an improvement of her health condition; however, she was rapidly losing weight and her general health was in a bad state. Fortunately, we soon had an appointment with the

*“We were happy that the marathon from one doctor to another had finished.”*

allergist, who referred us to the gastroenterology department. The diagnosis of coeliac disease was confirmed 10 days thereafter. Our girl, a patient with coeliac disease on a strict gluten-free diet, is now growing up and is thriving into a healthy and happy girl. Soon her sister and father, also coeliac patients, joined her in the gluten-free diet.

## **PATIENT STORY FROM SERBIA**

Mihajlo was first diagnosed with coeliac disease when he was five years old. After about twenty days of diarrhoea, he was referred to a gastroenterologist. Based on his symptoms, the doctor immediately suspected coeliac disease and ordered a test for antibodies, which were very high. Endoscopy was also performed which confirmed that it was a case of coeliac disease.

Since coeliac disease is genetically predisposed, the doctor sent other family members for analysis - Mihajlo's sister, mother, and father. The results showed that the mother was the carrier of the gene, which increases the risk of developing coeliac disease, while the father and sister did not carry that gene. After further analysis, the mother was also diagnosed with coeliac disease. She was surprised since, apart from always having anaemia, she believed to be healthy. She did not consider long-term anaemia as a serious health problem. Unlike his mother, Mihajlo had many problems before he was diagnosed. He was listless and without energy, he made little progress, he weighed 15 kg from the third year on, he was a head shorter than his peers were, and he had asthma.

That all changed after the diagnosis and elimination of gluten from their diet. However, it was not easy. The only advice they received from doctors was not to eat gluten and they were given a short brochure about coeliac disease. They had to find out for themselves what to eat, what foods to buy, and how to eat properly. Fortunately, they found out about the Association of Patients with Coeliac Disease, where they received great help and practical advice for everyday life difficulties. It took a long time for Mihajlo to recover. Antibodies dropped fast, but iron values returned to normal only after two years. Today, Mihajlo and his mother are experts in keeping a gluten-free diet. And most importantly - they are healthy.

*“Today, Mihajlo and his mother are experts in keeping a gluten-free diet”.*





## MOTHER FROM HUNGARY

I have a son and a daughter. My son was 11 years old when his swimming trainer suggested taking him to a doctor. He told me that my boy works well, but still, his muscles do not grow, and his track results are not any better. He did not have any gastrointestinal symptoms. We went to see a pediatric gastroenterolo-

*“A swimming trainer suggested taking my son to a doctor”.*

gist and very shortly it became clear that my son has coeliac disease. We started the gluten-free diet and the results were spectacular: in the next two years, he gained 15 cm, 14 kg, and won some trophies in swimming competitions!

On family screening, my daughter also proved positive: she did not have any symptoms either, just a very slight sideropenia. As a brother and sister, they always got along very well, and they are also “sharing” coeliac disease experiences together. We did not ever have any problems with the diet.

Today, my children are 16 and 18 years old and can manage gluten-free shopping and cooking on their own. Needless to say, I am very proud of both of them.

## CHRISTINA, PAEDIATRICIAN FROM GRAZ

I am a paediatrician myself – and years ago, when I once saw my sister-in-law who is a bit younger than me I thought to myself “oh, how pale and irritated her skin looks, certainly she has too much stress and not enough sleep”, and I booked a spa weekend for her to have her pampered with some expensive beauty treatments.

However, before heading for the lovely spa she saw her physician who diagnosed substantial iron deficiency anaemia and sent her upfront for endoscopy: her coeliac disease was diagnosed right then and there!

Soon after that, her first-degree relatives had a blood test done and one brother was found to be positive. He had suffered for years from “irritable bowel syndrome”!

Therefore, please remember: pale and “cracked” skin might not only be a sign of a stressful life but may also be a consequence of iron deficiency, an important sign of coeliac disease!

On a gluten-free diet, my sister-in-law finally has lovely skin again. And she now wants to take on the spa treatments I offered.

*“Pale and “cracked” skin might be a sign of coeliac disease”.*



## MARINA FROM CROATIA

I was diagnosed with coeliac disease at the age of 30, and I can say that it was one of the happiest days of my life. If you are wondering why, continue reading to get introduced to that quiet, changing, cocooned, and above all painful coeliac disease! For as long as I can remember, I have been listening to my parents' stories about how by the age of 7 I didn't have any appetite and the only thing I would eat was fruit. In that period of my life, while running around carelessly with friends I fainted, and in the hospital, I was later diagnosed with epilepsy. I was given anti-epileptic drugs to keep the illness under control. I also remember the pain in my lower limbs. The doctor explained that I grew quickly and that was completely normal. The problem was that the pain was so strong that I could not sleep at night. I was doing many sports and was very active, almost hyperactive. There was not a month during the year when I did not have aphthae in my mouth, I was losing my hair, and after childbirth, I was experiencing enormous mood swings and lack of concentration. Revolution caused by genetic tests for coeliac disease. The biggest problem was the leg pain I was experiencing. In my twenties, I begged the doctors to find the cause of the pain and the weakness that I was experiencing daily. The pain was getting stronger, my knees were shaking, I could barely walk up the stairs, even just

walking was exhausting. Sometimes I just couldn't get out of the bed, even if my baby was crying in need of his mother. All the hospitals and medical examinations were not able to determine the nature of my problem. I was told to check with a clinic in the USA to improve my health. I decided to stay brave and to believe that I was young enough to get through everything, even though that period of my life when I was taking painkillers daily just to get through the day. I also decided to completely ignore the comments of my friends and colleagues that maybe I was suffering from multiple sclerosis. In the second decade of my life, I gave birth to

*“Finally, I was calm...”*

two children, both diagnosed with coeliac disease (in infancy). While the genetic testing for coeliac disease was non-existent in my country at that time, my husband and I both underwent testing for coeliac disease-specific antibodies to maybe discover the coeliac disease, but we were both negative. One day we received an invitation for genetic testing which we gladly accepted hoping to find answers to our questions. My results came in positive (the presence of HLA-DQ2 and DQ8

was established). I repeated the serology, which also came positive at this time, as well as the small intestine biopsy, to round up the whole story. I immediately started with the gluten-free diet. The antibodies decreased over the years. The pain started to fade slowly. It was only 5 years after the strict and persistent gluten-free diet that my results came in negative. For so many years I lived my life in pain, got the wrong diagnosis, and took the wrong therapy. After starting the gluten-free diet the pain in my muscles and joints disappeared, along with long and painful menstrual bleeding and aphthae. Finally, I was calm enough to continue my life. My diet consists of groceries, which do not contain gluten naturally, and my mission became to raise the quality of life of people suffering from coeliac disease! In the end, I would like to say that coeliac disease wasn't even considered a possibility in the adult population at the end of the last and the start of this century if it wasn't manifested with clear symptoms: stomach ache, diarrhoea, vomiting. Today, I can say that genetic testing contributed a lot to discovering coeliac disease in family members and first relatives of the diseased, as well as to many people whose coeliac disease was completely asymptomatic. We cannot give up on educating patients and medical staff and raising awareness about coeliac disease as a quiet epidemic that carries a lot more diseases and weak states of our organism.





## THE STORY OF ANNA (CZECH REPUBLIC)

My daughter Anna was diagnosed with coeliac disease in October 2020, two months before her tenth birthday. I felt desperate, realizing that she has probably suffered from the disease since she was born and that none of the physicians, who have seen her in the past ten years, including a fair number of gastroenterologists, could ever identify her health problem. Although the symptoms she had could give the doctors the idea, no one thought of coeliac disease.

When I complained to the paediatrician that I did not like the look of Anna's stools, light in colour, sometimes greenish, with mucus and residues of undigested food, she just waved it away. She claimed it was just slow digestion. My daughter's conspicuous paleness made the doctor check for possible anaemia, but that was all.

Similarly, no one noticed her distended abdomen even when she was a baby. She had been diagnosed with low muscle tone and Vojta therapy was applied on her, but no one searched for the underlying condition. Even for the paediatric gastroenterologist that we used to see, coeliac disease was completely out of focus, even when he examined her stools for the presence of pathogens.

Anna often had hiccups as a newborn

baby, and then belching and bad breath, especially after she woke up, and finally, gastroesophageal reflux (GER) was diagnosed when she was nine years old. However, no one investigated whether this problem is due to coeliac disease, which often happens.

Coeliac disease was identified by chance. We were looking for a new paediatric gastroenterologist and chose the facility at the General University Hospital in Prague, where we got a friendly welcome. Luckily, we were in the capable hands of a real expert, dr. Peter Sztányi, who after having just a glance at Anna suspected she might suffer from coeliac disease. We made an appointment with him as we wanted to confirm the diagnosis of GER because in the summer of 2020 she experienced nausea and vomiting. Doctor Sztányi referred us for a gastroscopy to exclude esophagitis. In addition, he ordered blood tests as well, and these "unfortunately" revealed the presence of a low titre of antibodies against coeliac disease (TGA). The diagnosis, in that case, should only be confirmed by endoscopy. Immediately after histological confirmation of the diagnosis, we put Anna on a strict gluten-free diet, and now we are trying to adapt to this new situation in our life.

It never crossed my mind that Anna might suffer from this disease, and I have difficulties accepting that no one would

*"It never crossed my mind that my daughter might suffer from coeliac disease."*

discover that, although it might have happened very easily. I keep thinking about why the government has not included coeliac disease in the obligatory neonatal screening, which detects a lot of diseases, including some much rarer than this severe autoimmune disease.

I keep thinking why paediatricians who see babies and children at regular preventive follow-ups do not focus on coeliac disease more, as they miss hundreds of cases of coeliac children, which is sad and alarming, considering how a serious disease it is. For us, the diagnosis was a blessing in disguise but, sadly, many families will not receive the appropriate medical care in time. The authorities should definitely think about how to improve this ugly situation.



## MAJA FROM ZAGREB (CROATIA)

I was born in the 1970s in Zagreb, Croatia, and one of my first memories, among playing and having fun, were serious digestive issues and complications. My family got rid of all the carpets from our apartment, as my vomiting was frequent and often unpredictable. I also remember that I attended numerous different medical examinations. I was told by my parents that doctors were taking my blood to regularly check it since I was an anaemic little child. Although many different examinations were made, doctors concluded that I was physically healthy but under a lot of stress, because my parents were in the middle of a divorce and that their separation was the main issue of my digestive problems.

During my childhood and adolescence, I often felt nauseous, tired, and frequent vomiting was still part of my life. I adored playing sports and was good at karate, but when training for more serious competitions began, I could not keep the pace - mornings after intense training sessions, I could not get out of bed, but the good thing is that I did not quit karate until late college years.

When I started working, at least once every few weeks I was so sick and vom-


iting that I could not come to work. I still remember my first boss telling me "Hey, you should seriously check your health". I was 27 years old at that time.

As I was getting older, I began to have ataxia and a lot of pain in my joints, the big ones and the small ones, too. I remember my ankles used to hurt so much and I had awful pain in my finger joints, so I could not walk. I had a Waaler-Rose test, which turned out negative. Besides frequent vomiting, constant nausea, and joint pain my blood work indicated smaller than normal MCV and low thrombocytes. When I complained to my doctor, I got the explanation that I am genetically different from others and that I should visit a mental therapist to help me with my hypochondria. The good thing was that I was exercising regularly and I tried to stay physically active. At that time, other areas of my life were more than fine; I had a good job and I met a wonderful guy who has, later on, become my beloved husband.

At the end of 2011, just as I accepted that I will live forever with vomiting and pain, a solution for my trouble arose, and it was in the form of a food intolerance test. Because of the candida overgrowth in my body, a homeopathic doctor prescribed a very strict diet, which I had to follow for 6 months: I had to cut out gluten, sugar, dairy, beans, and fruits. And after a few weeks of that diet, a miracle

happened - for the first time in my life, I felt really good. I had no pain, no vomiting, no nausea, and had lots of energy and my strength in sports (especially in windsurfing) became obvious. My skin cleared up; my bloating disappeared... I was happy, optimistic and enjoyed being in my body.

Soon after stopping with the diet and starting to eat normally, all of my symptoms came back, worse than ever. During 3 weeks I lost 7kg, I looked pale and felt so weak I could not go to work or even walk my dog. I was tested for parasites and bacterial infections and everything was fine, except I was feeling awful.



*"I have a positive outlook on life."*

The good thing was I was curious about what was happening to me and I started reading about coeliac disease and reading the symptoms. It was the year 2012 and coeliac disease in adults in



Croatia was something unfamiliar to most of the family doctors and general population. Encouraged with a period of feeling good I was persistent and went to take a screening test for coeliac disease in Croatia and after that, I was examined at the University Hospital Centre Zagreb and finally got a diagnosis and confirmation that vomiting and nausea weren't only in my head and that this is a real, but manageable disease.

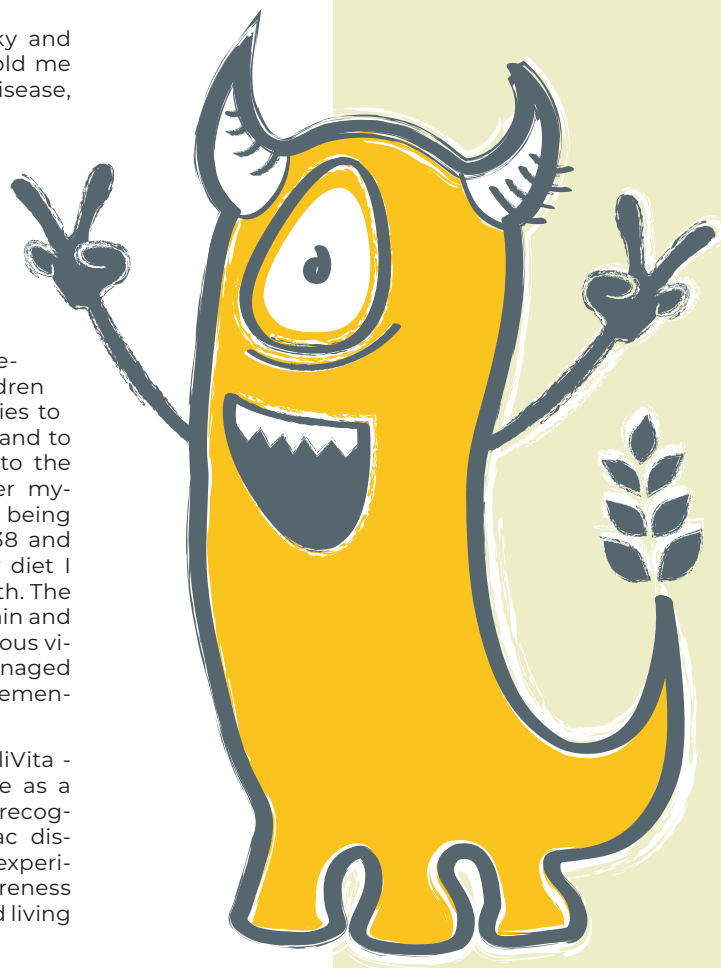
Following a strict gluten-free diet, since 2012 resulted in improving my overall health, my pain and nausea went away and life became much better without regular vomiting. I feel much stronger and I have a positive outlook on life. A year or two after starting a gluten-free diet I was able to drink yogurt again :), and nowadays I can even drink a glass of milk without getting diarrhoea.

Living with coeliac disease and following a strict gluten-free diet is not easy, as it may seem at a first glance. The way we eat affects our family and friends and dictates many activities - almost every social event includes food and we have to plan our every meal. Some people in our lives are caring and understanding

and others see us as picky and demanding. One doctor told me "You can't have coeliac disease, you look fit and strong", "Yes, I do, but I am following a gluten-free diet, it wasn't always like that", I replied.

There is a lot of misinformation about coeliac disease out there and there is a huge amount of space for raising awareness and helping children and adults and their families to get the diagnosis on time and to encourage them to stick to the gluten-free diet. I consider myself lucky because after being diagnosed at the age of 38 and removing gluten from my diet I regained good overall health. The major problem is weight gain and I was diagnosed with a serious vitamin D deficit, which I managed to cure with proper supplementation.

To help others, I joined CeliVita - Living with coeliac disease as a volunteer. I hope that unrecognized patients with coeliac disease can benefit from my experience and I can spread awareness about being diagnosed and living on a strict gluten-free diet.





## IGOR, PEDIATRICIAN FROM MARIBOR

I was diagnosed with coeliac disease at the age of 44. For many years, I had numerous symptoms typical of coeliac disease, from unbearable abdominal pain, diarrhoea, constant bloating, anaemia, fatigue, and infections all the time. Since I have had insulin-dependent diabetes for thirty years, this diagnosis of coeliac disease should be slightly more expected. The condition was staring me in the face, I just did not see it. As I am a paediatrician who knows about the symptoms I should have got it sorted out sooner. In addition, I know some eminent experts, who are treating the disease in their daily work. A few years before my diagnosis, I was traveling to a gastroenterological congress with a colleague expert in the field of coeliac disease. I suffered from severe pain, cramping, bloating, and diarrhoea at the time, especially when I had eaten a good breakfast of fresh rolls, but we did not see the obvious. In defense of my expert friend, my coeliac test had been repeatedly reported as negative. Afterward, additional problems developed. Both of my ankles were swollen, my anaemia was severe, and iron supplements did not help. Then another colleague of mine saved me and made the diagnosis. My serological tests were negative before

because I also have an IgA deficiency. Now, I am on a gluten-free diet, I am 15 kg heavier than when I first started. I feel good, without any medical problems. It is hard when I pass the bakery and there is a delicious smell of freshly baked bread, though. It is also hard when I am in the hotel where they have breakfast with 15 types of delicious bread and bread rolls. Reading labels can be difficult, especially if you need glasses for small print like me. However, it is worth it. I accepted the diagnosis of coeliac disease relatively easily, and I am now accustomed to my chron-

*“The condition was staring me in the face, I just didn’t see it.”*

ic condition. This is also probably true because my health is incomparable to that of five years ago. I make gluten-free bread myself. I miss an occasional doughnut for carnival and I miss the Bled cream cake. Nowadays, there is a better variety of gluten-free products available on the market. Unfortunately, gluten-free products are relatively expensive, which can be a big problem.

# About the CD SKILLS project

**CD SKILLS project is addressing existing challenges of healthcare sector in coeliac disease management in the Danube region.**

Coeliac disease is a lifelong systemic reaction against gluten found in wheat, barley and rye. It can occur at any age, but usually starts in early childhood. Women are affected twice as common as men. Without a very strict exclusion diet severe complications can develop. 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 healthcare 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. This has important negative impact on sustainability of healthcare sector and society. Possible reasons are low awareness and knowledge about the disease, limited access to diagnostic tools, limited opportunities for innovative learning and inefficient information exchange.

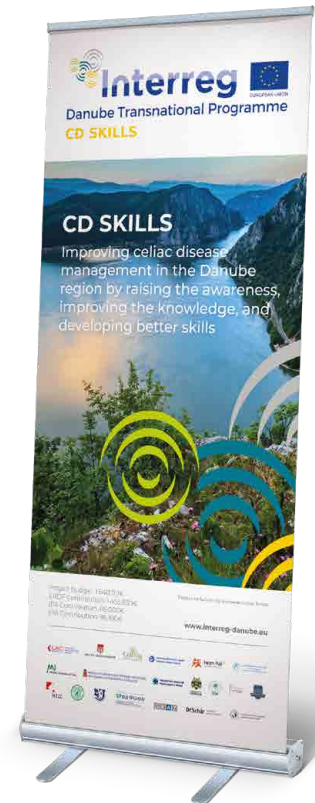
CD SKILLS project aims to overcome these shortcomings to ensure sustainable public healthcare

sector, which will efficiently meet health related and social needs of patients and general public affected by coeliac disease.

Important initial activity of the project is the assessment of regional practices in CD management, which will be followed by introduction of innovative learning strategy combining traditional lectures and modern e-tools, supported by the new information exchange platform, development of efficient disease detection strategies, and testing of innovative pilot services focusing on early detection and improved diagnosis of the disease and its complications and improvement of patients' quality of life.

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.

More about the project:  
<http://www.interreg-danube.eu/approved-projects/cd-skills>



# About the partnership

**Transnational multidisciplinary partnership of the CD SKILLS project is composed of highly competent partners with different competences and roles, including healthcare service providers, such as university hospitals, which also serve as research, education and training institutions, patient support organisations (NGOs), public authorities, gluten-free producers/suppliers, and professional associations ensuring exchange of different perspectives addressing common challenges of coeliac disease.**

Partners are coming from eight Danube region countries: Romania (National Institute for Mother and Child Health Alessandrescu-Rusescu ), Czech Republic (General University Hospital in Prague), Croatia (Children's Hospital Zagreb and CeliVita - Living with Celiac Disease), Serbia (University Children's Hospital and Serbian Coeliac Society), Moldova ("Nicolae Testemitanu" State University of Medicine and Pharmacy of the Republic of Moldova, Kishinau), Slovenia (University Medical Center Maribor and Municipality of Maribor), Hungary (Heim Pal National Paediatric Institute and University of Debrecen), Austria (Medical University of Graz) and Germany (Ludwig Maximilian's University Munich). Interested Associated Strategic partners of the project are coming from Austria, Bulgaria, Croatia, Hungary, Italy and Romania, and are composed of patient organisations, gluten-free food products producer, medical societies, healthcare policy makers and public authorities.

Many partners have successfully collaborated in international initiatives and are known internationally for their work in the field of coeliac disease. Partnership has been involved in many projects addressing public service including coeliac disease related projects: Interreg CE Focus IN CD, bilateral SI-HU LQ CELIAC, FP7 CD MEDICS, FP6 PREVENTCD, MediCel, ProCeDE, Trans-2-Care, and many others.



# Project partners

## University Medical Centre Maribor, Slovenia

The University Medical Centre (UMC) Maribor is a public healthcare institution providing secondary and tertiary healthcare services in north-eastern Slovenia. It is a research organization that also serves as an educational and training institution for future healthcare professionals. The UMC Maribor employs approximately 3,500 people, of which around 600 are medical doctors and around 1,800 associated healthcare professionals. Annually, about 60,000 patients are treated as inpatients and almost 400,000 as outpatients in different sub-specialty units. Its Medical Emergency Unit is a professionally and organizationally homogeneous unit providing non-stop 24-hour medical care. In addition to healthcare services, the UMC Maribor is included in research projects and cooperates with major research centres at the national and international levels. It employs a multi-disciplinary team of experts in different fields including the Medical Research Department with the Project Office experienced in project management. UMC professionals are members of the ESPGHAN Celiac Disease Working Group. Paediatric Department UMC MB has been involved in many national and international coeliac disease-related projects LQ CELIAC, Focus IN CD, CD-MEDICS, PreventCD, ProCeDe, and others. <https://www.ukc-mb.si/>

## Municipality of Maribor, Slovenia

City Municipality of Maribor (MOM) is a self-governing local community consisting of the city of Maribor and 33 other settlements. It is the second biggest city in Slovenia. In the field of health, we are responsible for social security, health protection, and family matters, for elderly care, health insurance for citizens without insurance, awarding scholarships, for awarding concessions in the field of health and

pharmacy services. The city municipality is also the founder of many public institutions. In the last few years, we have been actively involved in mainly soft-measure European projects in the field of preventive health care. We have been a lead partner in bilateral Slovenian – Hungarian project LQ – CELIAC as well as in Focus IN CD project (Interreg Central Europe programme) with the main aim to increase the quality of life of celiac disease patients and to raise awareness among professionals and the general public. The Office of project development is focused on the preparation of project applications, management, implementation, and reporting of European projects. <https://www.maribor.si/>

## Medical University of Graz, Austria

The Medical University of Graz (MUG) was founded in 2004, originating from the previous Medical Faculty of centuries-old Karl-Franzen's-Universität: Approximately 2,500 employees are working here in academic and non-academic areas and over 4,300 students are enrolled in diploma (medicine, dentistry, nursing science) and doctoral programs (medical science), with PhD-programs as a hub of innovative and high-end medicine. The MUG research community bundles its innovative capacity in four research fields and the general approach of sustainable health research. The Centres for "Medical Research" and "Knowledge and Technology Transfer in Medicine", the Biobank Graz (with > 20 million biological samples), and many other facilities provide a perfect research infrastructure. Students, instructors, and staff learn and work together according to the principles of the biopsychosocial model, which places the person with all his or her needs at the centre of attention. Not only do students gain from expert knowledge, so does the whole population, thus taking

advantage of a great range of knowledge, also in the context of media coverage and a great number of events. Postgraduate education for doctors and other target groups completes this broad range of services. <https://www.medunigraz.at/en/>

### **University Children's Hospital Belgrade, Serbia**

One of the most important medical institutions not only in Serbia but also in the region, the University Children's Hospital in Belgrade was founded in 1924 under the leadership of Professor Franz Groer, an eminent associate of Vienna's School of Paediatrics. Later, in 1926, Professor Matija Ambrožič, also from the Vienna School, was appointed head. The first Department of Paediatric Surgery was founded by MD Dimitrije Jovičić, who had trained in France and was the first qualified paediatric surgeon in Serbia. In its first three years, the Children's Clinic was located in a private building in Kneza Milosa Street and had four rooms. Construction began on a new building on 4th October 1936 by Royal Decree of King Petar Karadjordjević and under the highest protection of Her Majesty Queen Marija. Today, the building is classified as a cultural monument. For more than 90 years, the University Children's Hospital has been a centre for the provision of specialized care and treatment in all areas of paediatrics and paediatric surgery, for the education and training of students from the University of Belgrade's School of Medicine, and scientific research.

<http://tirsova.rs/>

### **Children's Hospital Zagreb, Croatia**

Children's Hospital Zagreb is a unique tertiary healthcare institution for children in Croatia. Since 1997, its Department for paediatric gastroenterology and nutrition has been the Referral Centre of the Croatian Ministry of Health for children with gastrointestinal disorders and specific nutritional requirements. The team includes paediatric gastroenterologists, dietitians, psychologists, working therapists, and nurse specialists. The centre is fully equipped for all necessary diagnostic procedures and various treatment modalities, including enteral and parenteral nutrition. Concerning celiac disease, this de-

partment runs the Croatian largest clinic for paediatric celiac disease patients with about 20–30 newly diagnosed patients per year. The team members have participated in the work of the ESPGHAN Celiac disease Working Group and in several national (Screening for celiac disease in first-grade school children) and international projects on celiac disease (PreventCD, ProCeDe, MediCel). <https://www.kdb.hr/>

### **General University Hospital in Prague, Czech Republic**

General University Hospital in Prague (GUHP) is one of the largest hospitals in the Czech Republic. Together with the 1st Faculty of Medicine of Charles University, it creates a broad base not only for diagnostic, therapeutic, and nursing care but also for teaching, science, and research. The Department of Paediatrics and Inherited Metabolic Disorders represents the Centre of excellence for children with metabolic, rheumatologic, inflammatory bowel disease, and other gastrointestinal disorders, and for children with specific nutritional requirements. A multidisciplinary approach is a part of daily routine. The team includes paediatric gastroenterologists, dietitians, and nurse specialists. The centre fully covers all diagnostic and therapeutic procedures, including endoscopy, enteral and parenteral nutrition. Concerning Celiac disease, this department runs the country's largest clinic for paediatric Celiac disease patients, with about 100 newly diagnosed patients each year. The employees are members of the ESPGHAN and actively participate in different international projects. <https://www.vfn.cz/>

### **Serbian Coeliac Society, Serbia**

Serbian Coeliac Society was founded in 2005 by a group of mothers with coeliac children. The main motive was lack of knowledge about the disease, educational material, counseling about the gluten-free diet, and difficulties in finding safe gluten-free food products. Since then, the association has grown into a national organization that works closely with associations in the region and Europe, doctors, scientists, and other experts as well as the institutions and organizations in the field of food production. The Serbian Coeliac Society has been an AO ECS member since 2008. Our goal is to ensure that we



live in an educated, well-aware society where early detection and diagnosis of coeliac disease is possible, followed by labeled, safe food, at a price available for our patients.

[www.celijakija.rs](http://www.celijakija.rs)

### **National Institute for Mother and Child Health Alessandrescu-Rusescu, Romania**

The National Institute for Mother and Child Health “Alessandrescu Rusescu” Bucharest (INSMC) is one of the institutes of the Ministry of Health in Romania with expertise in population research in the field of maternal and child health status. In the field of population research, INSMC collaborates with international institutions (United Nations Children’s Fund, United Nations Population Fund, Center for Celiac Disease (CD) Control USA, US Agency for International Development). INSMC research led to health policies by the Ministry of Health in Romania and the research results were used as reference data by international organizations (WHO). INSMC includes 2 University Clinical Departments (Gynaecology and Paediatrics) as part of the University of Medicine and Pharmacy “Carol Davila” Bucharest and 4 National and Regional Centres focused on specific medical fields: Materno-Foetal Medicine Centre, Cystic Fibrosis Centre, CD Centre, and Clinical Genetics Centre. The CD Centre is a tertiary centre focused on CD diagnosis, management, providing medical care, educational programs for professionals and the general population, and running clinical research in collaborative national and international networks.

<https://www.insmc.ro/>

### **CeliVita - Living with Celiac Disease, Croatia**

CeliVita is a patient association founded in 2014, to protect health and improve the overall life quality of people who suffer from Celiac disease, wheat allergy, and gluten sensitivity. CeliVita has members from all over Croatia, as well as a branch office in the Slavonia region. Its activities are focused on raising awareness about CD, as a general health problem, but also on providing practical help to the

patients and family members. Its volunteers provide comprehensive support and tools, necessary for successfully overcoming everyday challenges and maintaining a proper gluten-free diet. Preserving the overall physical and mental health of those affected, including family members is one of CeliVita’s missions. Support provided by the association includes counseling about gluten-free diet implementation and legal rights, educating about CD and risk factors for complications, cooking classes, nutritional and psychological workshops and lectures, manuals, and brochures, raising awareness programs in nurseries and schools, members meetings, and gatherings and many other activities. CeliVita’s members enjoy many benefits from various partnerships.

<https://www.celivita.hr/>

### **Heim Pál National Paediatric Institute, Hungary**

Heim Pál National Institute of Paediatrics, Budapest is a multidisciplinary children’s hospital for specialist care, which is also responsible for the coordination of clinical guidelines and specialized post-gradual teaching. The Coeliac Disease Centre is an independent department in the hospital for the integrative care of celiac disease patients and families regardless of age, which includes diagnosis, regular follow-up, dietetic counselling, and screening of family members at risk. The team consists of paediatric gastroenterologists, clinical and research nurses, full-time dietitians, and laboratory technicians. We operate an open-access outpatient facility for the direct referral of cases from primary care and we closely collaborate with the Department of Gastroenterology and Nephrology and with the Department of Pathology. The Coeliac Disease Centre has its own diagnostic laboratory providing transglutaminase and endomysial antibody testing for 19 other institutions in the central and western parts of the country. It also provides a second opinion on all celiac-related questions at the national level, develops management strategies, and disseminates knowledge among all medical professionals. <http://heimpalkorhaz.hu/>

## **University of Debrecen, Hungary**

The University of Debrecen is a leading teaching institution with approximately 30,000 students, 12,000 of them coming from abroad. This represents a very good possibility for the dissemination of knowledge and new findings. The University of Debrecen is responsible for tertiary-level medical care for the whole of North-Eastern Hungary (approx. 1.8 million inhabitants). The Coeliac Disease Study group was founded in 2002 and consists of clinical staff at the Department of Paediatrics (paediatricians, paediatric gastroenterologists, nurses, social workers) and basic researchers (biochemists, molecular biologists), and closely cooperates with the transglutaminase research group at the Institute of Biochemistry and Molecular Biology. Transglutaminase is the most important autoantigen in celiac disease and also plays an important role in modern diagnosis. Further, the group is currently investigating innovative diagnostic tools, standardization of antibody testing, and disease features at the cellular level. <https://www.edu.unideb.hu/>

## **Ludwig Maximilian University of Munich, Germany**

Ludwig-Maximilians-Universität (LMU) München is a public corporation with the right to self-governance. It is one of the leading research universities in Europe, with a more than 500-year-long tradition. LMU Klinikum is a centre of high-tech medicine, innovation, and medical and technical progress, at the same time has the sense of individual care, security, and trust. The Children's Hospital was founded in 1846 by August Hauner and is named after him. With 15 paediatric subspecialties and paediatric surgery, it is one of the largest tertiary academic paediatric centres in Germany. The division of paediatric gastroenterology has high experience in Celiac Disease (CD), and was leading and participating in several national and international research projects on CD, e. g. the ProCeDE study, PreventCD, TEDDY, the German Celiac Registry. Together with the Child Health Foundation, it was a partner of the Interreg program Focus In CD, leading the work package on different online tools. <https://www.lmu.de/en/>

## **“Nicolae Testemitanu” State University of Medicine and Pharmacy of the Republic of Moldova**

The State University of Medicine and Pharmacy "Nicolae Testemitanu" in Moldova is the only institution for the education of doctors and pharmacologists in the country. It includes many departments with 23 laboratories, 2 scientific centres, and 1200 specialists (8 academics, 5 corresponding members of the Academy of Sciences of Moldova, full and honorary members of academies from other states, 172 doctors habilitated in the medical sciences, 528 doctors in medical sciences, 15 laureates of the state award in the field of science and technology). It offers specialized pre-university higher education integrated into the cycle I, II, doctoral higher studies (cycle III), postdoctoral programs in Romanian, Russian, French, and English (ISO 9001: 2008; since 2016 applies the ISO 9001: 2015 standard). The University is a member of the Association of International Universities for European Medical Education (2013). Since 2019, it is internationally accredited by the World Federation of Medical Education, an independent accreditation and evaluation agency. It collaborates with over 90 international universities.

<https://www.usmf.md/ro>



## Associated strategic partners

### **Health Service, Youth and Family Office, City of Graz, Austria**

The city of Graz is the second-largest city in Austria. The city is divided into 28 urban districts and is the fastest-growing region in Austria. Graz is a statutory city (that is, a city with statutory privileges). This is an important characteristic, as it implies that the city itself bears full administrative responsibility for all social services. The administrative core of all preventive measures in child- and youth welfare in Graz is the Youth and Family Office in the city's administrative body. Health service is integrated into this structure. It also provides services for public schools, kindergartens, nurseries, and day-care. The team amongst other paediatricians includes general practitioners and one nutritionist. The Health Service mainly provides preventive medical check-up and medical advice services. When signing up for nurseries, kindergarten, day-care, etc., parents have to fill in a health form; coeliac disease is one of the interrogated points. Accompanied by their parents, all pupils, attending a public school in Graz, undergo a medical check-up in their first year (age about six to seven). At this time, parents are asked again about chronic diseases, such as coeliac disease. A further medical check-up is provided until the end of compulsory school attendance.

[https://www.graz.at/cms/beitrag/10015960/7751496/Amt\\_fuer\\_Jugend\\_und\\_Familie.html](https://www.graz.at/cms/beitrag/10015960/7751496/Amt_fuer_Jugend_und_Familie.html)

### **Romanian Association for Gluten Intolerance, Romania**

Romanian Association for Gluten Intolerance (ARIG) is the national coeliac patient's association, a non-governmental, independent organization and its main mission is to improve the quality of life for coeliac patients in Romania. Romanian Association for Gluten Intolerance is a member of the Association of European Coeliac Societies since 2018 and is running the ELS scheme for gluten-free products since 2019 with over 600 Romanian certified gluten-free products. ARIG focuses its activities on four main pillars: legislation and patients' rights, patient education and coeliac disease aware-

ness for the general public, coeliac community support, coeliac disease awareness gluten-free business sector development support. The association's activity is based exclusively on volunteer work since 2017. The activity of the association is supported by active coeliac community members. <https://celiac.org/eat-gluten-free/gf-services/celiac-association-of-romania/>

### **Bulgarian Coeliac Association, Bulgaria**

Bulgarian Coeliac Association was established on 31. 3. 2009 by a diverse group of volunteers with coeliac disease from Bulgaria. At that time there were only a few specialists who knew about the disease. The association was dedicated from the very beginning to helping people with coeliac disease and other gluten-related conditions, get support and understanding from the community, have an easier life, have access to gluten-free food. We are striving for people with gluten-related conditions to get independent, trustworthy advice and support from the medical specialist, have more rights from the state, and not only manage the impact of gluten, but also find all answers to how to live well and happy with coeliac disease. The main activities are fulfilled with the Facebook group, where people ask questions and get answers. We regularly update it with recent information materials for gluten-free nutrition, Celiac Disease, and the life and obstacles for people with this entity in Europe.

We are trying to help the availability of gluten-free products and food in more and more places. In a collaboration with municipalities and medical specialists, we helped the introduction of a gluten-free diet in nurseries and kindergartens in some areas in Bulgaria.

### **Bulgarian Society for Paediatric Gastroenterology, Hepatology and Nutrition, Bulgaria**

The Bulgarian Society for Paediatric Gastroenterology, Hepatology and Nutrition is a voluntary, politically and socially independent non-profit association of individual and legal entities who meet the conditions set out in this statute, acting by the principles of the Constitution of the Republic of Bulgaria and the regulation of the Law

on non-profit legal entities and the current Bulgarian legislation. The aim of the Society to spread awareness in the area of paediatric gastroenterology, hepatology, and nutrition, to stimulate the research in the same field, and to disseminate this knowledge through meetings and in other ways. The Society fulfills its goals through the development and participation in programs, projects, and other activities related to the activities of the society in Bulgaria and abroad provides scholarships for training on issues of the paediatric gastroenterology, hepatology and nutrition, organizes congresses, symposia, workshops and provides dissemination and assistance for implementation in the country of new methods in the field of paediatric gastroenterology, hepatology, and nutrition.

<http://bulspghan.org/za-nas/>

### **Croatian Institute of Public Health, Croatia**

Croatian Institute of Public Health (CIPH) is a central public health institute in the Republic of Croatia, founded in 1893 to promote the health and welfare of the population. CIPH deals with public health, health promotion and education, disease prevention, microbiology, environmental health, school medicine, mental health care, and addiction prevention. CIPH's main tasks are to plan, promote and implement measures for the enhancement of population health and reduction of health problems. It prepares and implements prevention programs and other health care measures aimed at promoting a healthy lifestyle. The Institute functions as a statistical authority, which maintains national public health registries, supervises data storage, and coordinates the work of other health registers. It coordinates the network of regional public health institutes, actively participates in the creation of health policy and public health regulations, and engages in international cooperation to improve public health and welfare.

<https://www.hzjz.hr/>

### **Hungarian Paediatric Gastroenterology Society, Hungary**

The organization is an umbrella society for all medical professionals in the field of paediatric gastroenterology in Hungary (specialist physicians taking care of patients with celiac disease, primary care doctors, and other HCPs, like specialized nurses and dieticians) with significant teaching activity and dissemination potential. Furthermore, society plays important role in health care policymaking and maintains relationships with health authorities and various industrial partners, as well as with gastroenterologists looking after adults. The society disseminates European guidelines and regularly comments on new directives and various planned changes in medical practice. Therefore, society is interested in contributing to the improvement of diagnostic tools and diagnostic strategies for celiac disease, particularly in professional aspects. These activities and results will be incorporated into the annual teaching activities and postgraduate courses for HCPs and young doctors. Society is committed to promoting high-quality medical care and reducing the invasiveness of diagnostic procedures and costs.

### **Dr. Schär - Innovating special nutrition, Italy**

Our story began in 1922 in South Tyrol, the heart of the Italian Alps, with a vision to improve the lives of people with special nutritional needs. Ever since the company was founded, proximity to the consumer has been our guiding commitment. Our core competence combines the specific, complex requirements placed on nutrition with dedication and joie de vivre. Responsibility, progress, and proximity are the values that give us our stability and reliability. We are a family-run company with a global reach, with 18 sites in 11 countries and more than 1,300 employees worldwide. We are the market leader in Gluten-Free nutrition and leverage our expertise to develop new, pioneering nutrition solutions. Our products are available in about 100 countries.

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