

## Earlier Diagnosis for Better Lifelong Health: *A Manifesto for Change*

ESPGHAN and the AOECS are calling on the EU and its Member States to employ effective detection programmes to achieve early diagnosis of coeliac disease in children.

Paediatric coeliac disease is common; affecting 1 in 100 children in the majority of European countries and in some countries, as many as 3 in 100. Most children, however, have not been diagnosed.

In children, diagnosing coeliac disease as early as possible is essential for ensuring optimal growth, development and symptom management.

There are many serious associated health complications if coeliac disease is left undiagnosed, including impaired weight gain and growth problems, delayed puberty, iron-deficiency anaemia, chronic fatigue, osteoporosis

and an increased risk of additional autoimmune diseases. The lack of awareness of coeliac disease, in both members of the public and healthcare professionals, means that the diagnosed cases of the disease only represent a small fraction of the total number of people affected.

A significant challenge in recognising coeliac disease is the variation in the presentation and intensity of symptoms. In many cases, coeliac disease may even occur without any symptoms. As well as encompassing children that present common coeliac disease symptoms, programmes must therefore facilitate effective diagnoses in children with a less clear clinical picture.

## Achieving Early Diagnosis of Paediatric Coeliac Disease

### Common Symptoms

- Diarrhoea
- Failure to thrive
- Weight loss
- Stunted growth
- Delayed puberty
- Iron-deficiency anaemia
- Nausea or vomiting
- Abdominal pain
- Chronic constipation
- Recurrent mouth ulcers
- Abnormal liver biochemistry
- Chronic fatigue
- Dental defects

### High-Risk Groups

- First-degree relative with coeliac disease
- Type 1 diabetes
- Turner syndrome
- Down's syndrome
- Autoimmune thyroid disease
- Williams syndrome
- Autoimmune liver disease

## Three Steps to Promote Earlier Diagnosis

By providing early detection programmes, we can achieve earlier diagnosis and treatment, reduce the risk of future associated health complications and give children the opportunity to thrive.

Greater public awareness of paediatric coeliac disease

Greater healthcare professional awareness of coeliac disease, its symptoms and the high-risk groups

Establishment of national detection programmes for early identification of paediatric coeliac disease

# Paediatric Coeliac Disease Across Europe

## What is Coeliac Disease?

Coeliac disease is a frequent and lifelong autoimmune condition, caused by an abnormal reaction to gluten – a protein found in wheat, barley and rye – grains that are common in the European diet. It can occur at any age, including in babies when weaning once gluten has been introduced to their diet, in children and in adolescence. When a child with coeliac disease eats gluten, his or her immune system reacts by damaging the lining of the small intestine.



The most common food-related chronic disease among children in Europe



Up to 80% of cases remain undiagnosed in children



One of the most common chronic diseases among children, affecting 1 in every 100



Despite being easy to detect and treat, diagnostic delays can reach 8 years



Prevalence in paediatric population has risen in recent decades



Early diagnosis and treatment prevents complications

### Diagnosis

Achieving early diagnosis of coeliac disease is critical to ensuring good lifelong health and providing children with the ability to thrive.

All children with suspected coeliac disease should have their diagnosis and follow-up appointments established by a paediatrician or paediatric gastroenterologist, with continued access to appropriately skilled paediatric dietetic services.

### Treatment

The only current treatment for coeliac disease is a strict, lifelong compliance to a gluten-free diet, which achieves remission of the symptoms and prevents further complications.

With 52% of paediatric coeliac disease patients experiencing problems with dietary adherence, healthcare professionals must monitor and advise patients about the benefits of following a gluten-free diet.

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