



Association Of European Coeliac Societies

Association of European Coeliac Societies, AOECS, celebrates the International Coeliac Day on 16 – 17, May 2009

“Who is coeliac”

The most important aim of the day is to make coeliac disease better known in Europe. AOECS represent more than 250000 diagnosed coeliacs from the 5 millions (1 % of the population).

Who is coeliac?

In the past coeliac disease was regarded as a very rare childhood condition, but recent studies have shown that it is more common than previously thought. The incidence rate amongst the European population estimated around 1:100, in some countries (Finland, Hungary) even higher. Nowadays more adults are diagnosed than children and many of whom had no health problems during childhood, but develop symptoms only when adults.

Around 10 % of all first degree relatives (parents, brothers and sisters and children) of known coeliacs are also at risk of developing the disease.

What is coeliac disease?

Coeliac disease (known also as gluten-sensitivity or gluten intolerance) is an autoimmune disease, a permanent intolerance to dietary gluten of genetically predisposed persons. Unless it is related to food proteins, it should not be confused with food allergy.

Coeliac disease can be diagnosed at any age of life and the symptoms can vary from mild to severe, but many cases are asymptomatic or misdiagnosed, and remain often undiagnosed because of the common complications and the numerous associated diseases, like anaemia, early osteoporosis, secondary lactose-intolerance etc.

Nowadays the average rate of diagnosed cases in Europe only in few countries is higher than 1:5. The period between the first symptoms and the diagnosis of coeliac disease in many cases is longer than 10 years.

The gold standard of the diagnosis is a blood test (examining serological markers), confirmed by a small bowel biopsy. Coeliac disease can not be diagnosed based on any other methodologies and examinations (like magneto-resonance, allergy tests, homeopathy, etc.)

The treatment of coeliac disease is based on the avoidance of the trigger factor: the wheat gluten.

Only treatment = glutenfree diet

Gluten is a protein, found in certain cereals (wheat, rye, barley and their crossbreed varieties), and is the trigger factor of the disease. Coeliac patients must keep strict gluten-free diet, lifelong.

The glutenfree diet sounds simple but it is not easy to follow. Gluten containing cereals are commonly used as ingredients of bread, pasta, cakes, etc.

On 20th January 2009 a new COMMISSION REGULATION (EC) No 41/2009 was published concerning the composition and labelling of foodstuffs suitable for people intolerant to gluten. AOECS welcomes this regulation helping coeliacs to identify more easily suitable food .

The Regulation is based on the new Codex Standard for Foods for Special Dietary Use for Persons Intolerant to Gluten.

The International Coeliac Day

The Association of European Coeliac Societies (AOECS) has been promoting the International Coeliac Day since 2006. This day is conceived to increase awareness of condition both amongst the general public as well as the medical professionals.

With a large variety of activities and events in several countries the national and local patients' associations want to make coeliac disease better known in Europe and hope to improve the lives of coeliacs still ignoring their condition.

More information

AOECS is an independent European non-governmental umbrella organisation, in 2008 had the 20th anniversary of founding in Rome, in 1988 and since that time represents the specific interests and needs of coeliacs living all over in Europe. AOECS has 33 member-associations in 29 European countries, and apart from representing coeliac patients' specific interests is very active in scientific research on coeliac disease.

AOECS is a partner in two medical and scientific EU funded research-projects on coeliac disease: PreventCD and CDMEDICS .

AOECS launched in 2007 the Action of "Coeliacs for Coeliacs", with the aim of helping coeliac patients of Eastern-European countries, where the awareness of the disease is very low and coeliac patient are not treated properly.

For more information about the programs and the disease, the treatment, please contact the AOECS Board of Directors:

Jean-Louis Kieffer
ALIG of Luxembourg

Christian Scerri
Coeliac Association Malta
e-mail: board@aoecs.org
www.aoecs.org

Tunde Koltai
Hungarian Coeliac Society