

**PRESS RELEASE**

**EMBARGOED UNTIL: 00.01 MONDAY 26<sup>TH</sup> JULY 2010**

**60% OF PEOPLE WITH COELIAC DISEASE HAVE BEEN PREVIOUSLY MISDIAGNOSED WITH IBS**

Coeliac UK, the national charity for people with coeliac disease, surveyed over 1,600 members and found that nearly 60% of them had previously been incorrectly diagnosed with irritable bowel syndrome (IBS) instead of being tested and diagnosed with coeliac disease.

1 in 100 people in the UK have coeliac disease, an autoimmune disease caused by intolerance to gluten. There is no cure and no medication for condition and the only treatment is a strict lifelong gluten-free diet. Left untreated by the diet it can lead to osteoporosis, infertility and bowel cancer.

The survey also highlighted that nearly 60% of people had also been diagnosed with anaemia without testing for the cause. Other conditions that had been diagnosed by doctors included: anxiety and depression; 'holiday tummy'; gastroenteritis, gallstones; duodenal ulcer; ME or chronic fatigue syndrome; appendicitis and even hypochondria.

Coeliac UK launched the survey in 2009 at the same time that NICE (National Institute of Health and Clinical Excellence) issued a guideline on coeliac disease in order to provide a benchmark on the then current situation surrounding diagnosis.

The NICE guideline on the recognition and diagnosis of coeliac disease identified specific symptoms and associated conditions such as Type 1 diabetes, which are linked to the coeliac disease. As a result, more people should be tested for the condition driving up diagnosis rates. See website [www.nice.org.uk/CG86](http://www.nice.org.uk/CG86) for full details of the guidelines.

Sarah Sleet, Chief Executive of Coeliac UK said: 'It is too early to tell if the NICE guidelines are improving diagnosis rates but as a charity we are receiving around 1,000 new member requests a month from people who have just been diagnosed. But with around 500,000 people currently undiagnosed in the UK there is still a long way to go and it will be another 30 years at the current rate of progress before we crack the problem.'

"The NICE guideline is an important first step but we need a sea change in practice among GPs. In order to prevent years of misery for patients and needless waste of hard pressed NHS resources, we need a target for diagnosis of the disease in the Quality and Outcomes Framework (QOF) of the GP contract which has been recognised as an important lever in changing GP practice. The idea was recently rejected by NICE but if we do not see a significant improvement in the current rates of diagnosis, Coeliac UK will be pressing again for its inclusion."

The survey also asked how long they had visited the GP with symptoms related to coeliac disease before they were diagnosed. 23% had visited for 11 years or more and a further 11% of patients having symptoms and visiting their doctor for over 20 years before finally being diagnosed. Nearly a third (32%) of respondents said that they thought GP knowledge about coeliac disease was poor or very poor.

Although the condition is genetic and the prevalence increases from 1 in 100 in the general population, to 1 in 10 for close family members, worryingly the survey found that 79% of respondents' family members had not been offered a test for coeliac disease despite a recommendation to do so within the NICE guideline.

Awareness amongst the medical profession is increasing and in addition to the NICE guideline, a coeliac disease module has recently been published on the British Medical Journal Learning website. Written by Peter and Helen Gillett, Peter is a Consultant Paediatric Gastroenterologist at the Royal Hospital for Sick Children in Edinburgh and Consultant Adult Gastroenterologist and Helen works at St John's Hospital in Livingston, near Edinburgh, the module is aimed at medical students, general practitioners and hospital doctors, allowing them to work through a series of exercises to recognise, diagnose and investigate suspected coeliac disease patients.

- Ends -

For further information, please contact:

Kate Newman at [kate.newman@coeliac.org.uk](mailto:kate.newman@coeliac.org.uk) 07952 071014 / 0208 399 7478  
or Jo Archer [jo.archer@coeliac.org.uk](mailto:jo.archer@coeliac.org.uk) 01494 796131.

#### **Notes to editors:**

Statistics taken from a survey of over 1600 Coeliac UK Members, May 2009 – May 2010

- A range of case studies of men, women and children are available on request from Coeliac UK.
- Coeliac disease is a serious illness where the body's immune system reacts to gluten found in food, making the body attack itself.
- 1 in 100 people in the UK has coeliac disease, however only 12.5% of these have been diagnosed and average length of diagnosis is 13 years.
- Gluten is a protein found in wheat (including spelt), rye and barley. Some people are also sensitive to oats. Obvious sources of gluten include breads, pastas, flours, cereals, cakes and biscuits. It is often used as an ingredient in many favourite foods such as fish fingers, sausages, gravies, sauces and soy sauce.
- The symptoms of coeliac disease range from mild to severe and can vary between individuals. Not everyone with coeliac disease experiences gut related symptoms; any area of the body can be affected.
- Symptoms can include bloating, abdominal pain, nausea, constipation, diarrhoea, wind, tiredness, anaemia, headaches, mouth ulcers, recurrent miscarriages, weight loss (but not in all cases), skin problems, depression, joint or bone pain and nerve problems.
- Around 1000 newly diagnosed people are joining Coeliac UK every month. For further details on Membership please call the Helpline on 0845 305 2060 further information can be found at [www.coeliac.org.uk](http://www.coeliac.org.uk).