

## Press Release

Issue date Monday 19 September 2016

# CHARITY DRIVES DIAGNOSIS AS 50,000 PEOPLE COMPLETE THE UK'S FIRST COELIAC DISEASE ONLINE ASSESSMENT

With around half a million people in the UK still to be diagnosed with coeliac disease, the UK's first ever online assessment for coeliac disease, developed by Coeliac UK and launched by patron Caroline Quentin in May 2015, has been completed by over 50,000 people searching for an explanation to their symptoms.

The online assessment, [www.isitcoeliacdisease.org.uk](http://www.isitcoeliacdisease.org.uk) is a key initiative of the Charity's campaign, '**Is it coeliac disease?**' which is driving improvements in diagnosis of the serious autoimmune disease caused by a reaction to gluten. Currently the average period from onset of symptoms to diagnosis of coeliac disease is a staggering 13 years, and the campaign aims to reduce the years of unnecessary suffering and endless visits to the GP.

Based on National Institute for Health and Care Excellence (NICE) guidelines, the online assessment gives people more confidence to seek further medical advice from their GP. Upon completion of the assessment, people receive an email with the results which will indicate whether their symptoms are potentially linked to coeliac disease.

Since the launch around 87%\* of people who have completed the online assessment have been advised to go to their GP for a blood test that looks for the antibodies produced in undiagnosed coeliac disease and given essential information on the testing process – not to remove gluten from the diet until all medical tests are completed otherwise it can lead to false negative results.

One in 100 people in the UK has coeliac disease, with the prevalence rising to one in ten for close family members. However, current statistics show only 24% of those with the condition are diagnosed, leaving an estimated half a million people in the UK undiagnosed.

Coeliac disease is not an allergy or an intolerance but an autoimmune disease where the body's immune system damages the lining of the small bowel when gluten, a protein found in wheat, barley and rye, is eaten. There is no cure and no medication; the only treatment is a strict gluten-free diet for life. Left untreated, coeliac disease can lead to a number of complications including osteoporosis, infertility and in rare cases small bowel cancer.

Symptoms vary from person to person and can range from very mild to severe. Key symptoms caused by coeliac disease include: frequent bouts of diarrhoea, stomach pain and cramping, regular mouth ulcers, ongoing fatigue, lots of gas and bloating, nausea and vomiting, and unexplained anaemia.

Sarah Sleet, chief executive of Coeliac UK, said: “We are very pleased that so many have already taken the assessment, but there is still a long way to go to find the missing half a million undiagnosed people! So I urge everyone to check their symptoms through our online assessment tool, and if the symptoms are related to coeliac disease, go to your doctor and ask for a blood test but don’t stop eating gluten until you are tested otherwise critical blood tests may give a false negative result.”

A confirmed medical diagnosis of coeliac disease enables people to receive appropriate follow up care and support, as well as providing evidence for close family members to also be tested.

The charity also held pop up events across the UK in seven cities (London, Leeds, Cardiff, Manchester, Glasgow, Birmingham and Newcastle) over the past 15 months. During that time 25,000 leaflets were given out. Whilst almost 500 people were tested using a point of care test indicating coeliac disease, 17% tested positive and were referred to their GP for further investigation.

Ends

For more information or interviews please contact  
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\* Those completing the assessment are likely to be experiencing symptoms having seen and responded to the charity’s awareness campaign which highlights the symptoms of coeliac disease, and so not a pure screening of the UK population. Coeliac UK is now surveying those referred for testing for outcomes, which will inform future development of the assessment.

#### **Notes to the Editor**

- Coeliac disease is a serious illness where the body’s immune system reacts to gluten found in food, making the body attack itself.
- A wide range of case studies are available on request from Coeliac UK.
- 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.
- Average time to diagnosis is 13 years
- 1 in 4 people diagnosed with coeliac disease had previously been diagnosed with IBS
- Coeliac UK has a Helpline on 0845 305 2060 and further information can be found at [www.coeliac.org.uk](http://www.coeliac.org.uk)