

**Press Release**

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**Funding awarded to investigate how common clinically diagnosed coeliac disease and dermatitis herpetiformis is in the UK today**

Coeliac UK, the national charity for people with coeliac disease along with Core, the national UK charity that funds research into diseases of the gut, liver and pancreas announces that Dr Joe West of the University of Nottingham, has been awarded £80,000 to investigate how many people are clinically diagnosed with coeliac disease and dermatitis herpetiformis (DH) in the UK today and the health consequences of having the condition in the diagnosed population.

Statistically 1 in 100 people in the UK have coeliac disease, an autoimmune disease caused by intolerance to gluten. It is estimated that currently only 10-15% of those with the condition have been clinically diagnosed however, with no official register by the NHS of the number of people diagnosed, the exact diagnosis levels are unknown.

There is no cure and no medication for coeliac disease and the only treatment is a lifelong, strict gluten-free diet. Gluten is a protein found in wheat, barely and rye. Without a gluten-free diet, coeliac disease may lead to infertility, multiple miscarriage, osteoporosis, neurological deficits and small bowel cancer.

The research, commencing in early 2013, will be conducted at University of Nottingham and will use newly available linked data in anonymous electronic patient records to answer questions such as:

- Is diagnosis affected by where you live or how affluent you are?
- How likely are you to be misdiagnosed with other conditions such as irritable bowel symptoms?
- How likely are you to develop coeliac disease or DH if your mother is diagnosed with the condition?
- What is the risk of pneumococcal disease and how many patients are vaccinated against the disease?
- What do people with coeliac disease or DH die from and how does that compare with the general population?

Sarah Sleet, Chief Executive of Coeliac UK said: "We know coeliac disease is under diagnosed but we don't know exactly how big the gap is. With an average diagnosis period of 13 years, people are enduring many years of symptoms which will impact on NHS resources."

"To plan health services for the future it is crucial to understand the numbers of people affected by coeliac disease and the health consequences. The results from this study will help the NHS focus resources to improve diagnosis rates and help clinicians manage patients better to follow up preventable complications and reduce drain on the NHS," continued Ms Sleet.

The studies will be large with approximately 10,000 people with coeliac disease; 150,000 with irritable bowel and representative of the whole of the UK. The results obtained will contribute significantly to future diagnostic and management pathways for coeliac disease in the UK and worldwide.

Professor Roger Jones Chair of Core said: "This study is exciting because it will enable us to get a precise measure of the incidence of coeliac disease in the population, and also that of dermatitis herpetiformis, which is a chronic blistering skin condition closely linked to coeliac disease. The study will analyse the medical records of a large number of patients and, as well as giving us an up-to-date estimate of the extent of these conditions, it is likely to provide insights on how to improve their management. We know that the diagnosis of coeliac disease can be challenging and may be delayed for many months. We hope this research will have a real impact on improving services for patients."

The symptoms of coeliac disease range from being mild to severe and can vary between individuals. Symptoms include bloating, abdominal pain, nausea, constipation, diarrhoea, wind, tiredness, anaemia, headaches, mouth ulcers, weight loss – but not in all cases, skin problems, joint or bone pain as well as nerve problems (headaches, depression, loss of balance).

End

Notes to editors:

- Coeliac disease is a serious illness where the body's immune system reacts to gluten found in food, causing the body attack itself.
- 1 in 100 people in the UK have coeliac disease, however only 10-15% 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.
- Around 1200 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).