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## **STUDIES SHOW NUMBER OF PEOPLE SUFFERING FROM COELIAC DISEASE IN IRELAND COULD BE 50% HIGHER THAN ESTIMATED**

- **International research highlights urgent need for testing in Ireland**
- **Coeliac Society calls on Government to create central register for disease**

The Coeliac Society of Ireland has called on the Government to set up a central register for people with coeliac disease after it emerged that the number of people suffering from the condition could be 50% higher than previously thought.

New international research suggests the number of people suffering from coeliac disease in Ireland is likely to be 75,000, rather than 50,000. That figure is based on recent studies carried out in Finland and Norway, which found that the previously accepted incidence rate for coeliac disease had been vastly underestimated.

An estimated 13,000 people in Ireland are diagnosed coeliac – although there is no central register and therefore no way to be certain. Those who are undiagnosed are at risk of long-term damage to their health.

Sarah Keogh, Coeliac Society consultant dietitian, said: “For decades, doctors thought that coeliac disease was found in one in every 100 people. However, new scientific research suggests the incidence rate is much higher than this. A new study from Norway<sup>1</sup> tested more than 12,000 people in the general population to see how many had coeliac disease. They found the incidence rate was close to 1.5 per 100 – a 50% increase. This study backs up research from Finland,<sup>2</sup> where they found that more than two in every 100 people have coeliac disease.

“We know that up to 75% of people with coeliac disease are undiagnosed worldwide. The Norwegian study found that rates of diagnosed coeliac disease in that country were only 0.4 people per 100 people. But when they checked the general population, they found that 1.5 people in every 100 had the disease.

“These studies suggest that even more people in Ireland than previously suspected have coeliac disease and are continuing to suffer with symptoms including abdominal pain, bloating, malnutrition, and diarrhoea. They also risk increased likelihood of long-term damage caused by untreated coeliac disease, including infertility, poor growth in children, osteoporosis, nerve damage, and bowel cancer.”

The Coeliac Society said it is now a matter of urgency that the Government and HSE implement an awareness campaign and introduce a central register to record the prevalence of the disease in Ireland. A central register would inform medical practitioners who is at greatest risk because there is a one in 10 chance of having the disease if a family member also has it.

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<sup>1</sup> <https://www.nature.com/articles/s41598-022-16705-2>

<sup>2</sup> Finland, which has a similar population size and demographic to Ireland, has a register of people diagnosed and living with coeliac disease. It shows that up to 2.5% of Finns are coeliac. In Ireland, it is therefore reasonable to estimate, with a similar population size and make up, and knowing that the number of coeliacs in Ireland is also above the European average. The Coeliac Society of Ireland estimates a median figure of 1.5% of the Irish population have coeliac disease of which an estimated 17% (13,000) are diagnosed.

In its pre-budget submission, the Society estimated that there could be savings of close to of €243m<sup>3</sup> per year in healthcare costs if more people with the condition were diagnosed.

Ms Keogh added: “In the Norwegian study, the people found to have coeliac disease reported significant improvements after starting a strict gluten free diet – with 76% reporting reduced abdominal discomfort and almost 60% reporting improved energy levels. A large majority of these people had not previously been diagnosed with coeliac disease and had a poorer quality of life affecting their daily activities. Most people had not mentioned gut problems to their GP as they thought bloating, occasional diarrhoea and abdominal pain were ‘normal’.

“We are highlighting the need for doctors and healthcare professionals to think about coeliac disease in patients more often, even in patients who do not complain about gut problems. Healthcare professionals also need to think about coeliac disease in patients who do have gut problems, or who have ongoing fatigue, nutrient deficiencies like B12 or iron, as well as poor growth, migraine, and infertility.”

The Coeliac Society’s inaugural Gluten Free Roadshow – which takes place on October 8 in Tullamore, Co Offaly – will provide information and advice on diagnosis and living gluten free for people who are, or suspect they are, coeliac or gluten intolerant. The show runs from 11am to 4.30pm at the Tullamore Hotel and will have a limited attendance.

For more information on the event and the Coeliac Society of Ireland, please visit [www.coeliac.ie](http://www.coeliac.ie) or follow them on Twitter, Instagram, and Facebook.

**For further information, high resolution images please contact: Richard Burke at 4TC (01 531 3532 or 086 8167822) [richard@4tc.ie](mailto:richard@4tc.ie), or Craig McKechnie [craig@4tc.ie](mailto:craig@4tc.ie) 087 621 8839**

#### Notes for the editor

##### Available for interview

- Gill Brennan, chief executive of the Coeliac Society of Ireland
- Sarah Keogh, nutritionist, and dietitian (MSc. BSc. Dip. MINDI)

##### Notes for Editor

- Coeliac disease is an auto-immune disease where the affected individual reacts abnormally when gluten is ingested. The intestine becomes inflamed and damaged resulting in poor absorption of essential nutrients. Gluten is a protein found in many foods including bread, pasta, gravy, soy sauce and beer.
- There is no cure for coeliac disease and the only treatment is a gluten-free diet. Annual medical check-ups are also advised.
- Based on European averages and recent studies in Finland and Norway, there are estimated to be around 76,500 people in Ireland with coeliac disease. However, anecdotal evidence suggests that this may be higher in Ireland. There are also thought to be 500,000 people in Ireland who have some form of gluten intolerance.
- It is estimated that there are 63,500 children and adults who are undiagnosed coeliacs

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<sup>3</sup> Figure is based on analysis of the percentage of untreated Coeliacs who will develop Cancer, Type 1 Diabetes, Osteoporosis and Infertility, and the mean medical costs associated with treating these diseases. Detailed analysis available on request

- Symptoms include abdominal pain, recurring mouth-ulcers, weight-loss, vomiting and diarrhoea. If untreated, coeliac disease can affect fertility and lead to other health conditions such as osteoporosis.
- The first step to receiving a diagnosis is to visit your GP for a simple blood test. It is important to be on a gluten containing diet before testing. Eliminating gluten before testing could lead to a false negative test result. If the test is positive, you will be referred to a gastroenterologist for an endoscopy. Once diagnosed, it is advised you visit a dietician to ensure optimum nutrition.