

Pre-Budget Submission  
July 2022

# COELIAC SOCIETY OF IRELAND



## Contents

At a Glance .....	3
The Ask .....	3
The Cost.....	3
The Benefit.....	3
Introduction.....	4
History .....	5
Proposed Financial Aid for non-PAYE Coeliacs in Ireland.....	6
Dietary Supplement in 2013.....	6
Safefood Report June 2022.....	6
Statistical Information on Social Welfare Services Annual Report 2020 .....	6
Proposal .....	7
Consequence of reintroduction of Dietary Supplement .....	7

*“ There is an evidence base from controlled trials and well-designed observational studies on the effectiveness of a wide range of health promotion and disease prevention interventions that address risk factors to health. Moreover, the cost effectiveness of a number of health promotion and disease prevention interventions has been shown in multiple studies. Some of these interventions will be cost saving, but most will generate additional health (and other) benefits for additional costs. “*

WHO Regional Office for Europe and European Observatory on Health System and Policies.

## At a Glance

### The Ask

Reinstate the Dietary Supplement abolished in 2014 to help with the cost of a gluten-free diet prescribed by a doctor or hospital consultant.

Budget a maximum of €7.85m per annum to cover a maximum of 14,664 estimated coeliacs currently in receipt of a form of social welfare payment.

A cross-departmental awareness campaign in collaboration with the Coeliac Society of Ireland to encourage awareness, diagnosis, and treatment.

### The Cost

€7.35m to fund the reinstated Dietary Supplement.

€500,000 to fund a cross-departmental awareness campaign to “Think, Test, Treat Coeliac Disease”, targeted at those of lower socioeconomic status where there are lower rates of health-seeking behaviour and access to healthcare.

**Total budget request = €7.85m**

### The Benefit – Cost Savings

**Reduces risk** of undiagnosed coeliac patients from developing one of the four major conditions associated with coeliac disease:

1. Intestinal Cancers
2. Type 1 diabetes
3. Infertility & Miscarriage
4. Osteoporosis

**Potential savings €234.4m per annum**

**Removes pressure** on already heavily burdened Irish healthcare system.

**Improves quality of life**, well-being, and overall health for a marginalised section of society.

## Introduction

Coeliac disease is estimated to affect up to 76,500<sup>1</sup> people in Ireland today. There is no cure for coeliac disease and no medication for the disease. The only treatment is a strict gluten free diet and therefore the only foods that coeliac people can and must consume are gluten-free products.

When we talk about specific gluten-free products, we refer to those that have been made specifically for people with coeliac disease (bread, pasta, sweets, flour, etc.) avoiding the use of gluten-containing flours and preventing cross-contamination in their production. Although the supply and availability of these foods has expanded considerably in the last decade, the price of these products is still too high.

A study<sup>2</sup> conducted by the Coeliac Society of Ireland in 2021 demonstrated that some GF foods cost up to 75% more than non-GF foods.

The recently published safefood report on “The Socio-Economic Cost of Food Hypersensitivity on the Island of Ireland” found the following in relation to the cost of gluten free food for citizens living with coeliac disease in Ireland.

- Direct costs of following a gluten free diet for coeliac disease are €444 (€501 with no tax-rebate) more expensive for adults and €903 for parents of children with coeliac disease.
- Costs of following a strict gluten free diet were higher than for food intolerances.
- Additional costs on healthcare for people with coeliac disease are €426 for adults and €679 for children.

Therefore, for families on low incomes treating coeliac disease through a strict gluten free diet is financially stressful and draining as well as increasing anxiety and affecting mental health.

The findings from a survey by the Federation of Coeliac Societies<sup>3</sup> in Spain (FACE) in March 2022 revealed that Ireland is an outlier amongst its EU Partners in providing support for

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<sup>1</sup> In Finland which has a similar population size and demographic to Ireland, they have a register of people diagnosed and living with coeliac disease. The Finnish register reveals that up to 2.5% of Finns are coeliacs. In Ireland it is therefore fair to estimate that with a similar population size and make up that the number of coeliacs in Ireland is also above the European average. In the Society we therefore estimate at a median figure of 1.5% of the Irish population have coeliac disease of which an estimated 17% (13,000) are diagnosed.

<sup>2</sup> Nutritional and Cost Comparison of Gluten Free and Gluten Containing Products on an Irish Market

<sup>3</sup> <https://celiacos.org/ayudas-alimentarias-y-economicas-en-la-union-europea/>

coeliac patients who fall outside the PAYE tax system in Ireland. This affects a substantial proportion of Irish people on lower incomes who primarily rely on the social welfare system.

## History

The decision to close the special Dietary Supplement scheme, which offered social welfare recipients who have coeliac disease a contribution towards the cost of medically necessary diets, was taken in 2014.

Then Minister for Social Protection, Joan Burton, referred to research commissioned by the Department Social Protection on the cost of specialised diets. Based on this research, the Minister decided to discontinue the scheme.

Prior to this decision (February 1<sup>st</sup>, 2014) a Dietary Supplement was available via the Department of Social Protection Supplementary Welfare Allowance (SWA) supplements, to help with the cost of a special diet prescribed by their doctor or hospital consultant.

Qualification for this supplement was based on meeting the following conditions:

- Have a specified medical condition, i.e., a diagnosis of coeliac disease, dermatitis herpetiformis or medically diagnosed food gluten allergy
- Meet the conditions for Supplementary Welfare Allowance (SWA)
- Satisfy a means test

In addition to qualify for the Dietary Supplement a hospital consultant or hospital registrar had to certify:

- The individual or adult dependant or child dependant has been prescribed a diet for a specified medical condition
- The type of diet prescribed
- How long they will need the prescribed diet

A gluten-free diet for an adult or a child aged 18 to 22 could be prescribed by a family doctor (GP).

## Proposed Financial Aid for non-PAYE Coeliacs in Ireland

Currently there are an estimated 1.6million<sup>4</sup> in receipt of social welfare in Ireland. Taking the estimation that 1.5% of the Irish population is coeliac and applying that to the number in receipt of social welfare assistance it can be argued that an estimated 24,000 social welfare recipients are coeliac.

The FACE<sup>5</sup> study in March 2022 identified six EU countries where monthly financial aid is given to coeliacs in that country. Payments range from €105 per month in Norway to an estimated €20 per month in Turkey. Averaging the range of payments across these countries works out at about €67.66 per month in financial aid to coeliacs in these countries.

### Dietary Supplement in 2013

According to Dáil records, the Diet Supplement Scheme in 2013 cost €3.5m and served 5,900 people. Using the number on the Dáil record, the €3.5m would calculate as €593.22 per person per annum, €49.44 per person per month or €11.41 per person per week in additional food aid. It is not recorded on the Dáil record how many of this number are diagnosed coeliac.

### Safefood Report June 2022

Interestingly a Safefood report published week beginning 27<sup>th</sup> June 2022 titled, "*The socio-economic cost of food hypersensitivity on the island of Ireland*", has found that direct costs for adults with medically diagnosed coeliac disease (MDCD) were €501 per annum **before** a tax rebate for gluten-free food.

### Statistical Information on Social Welfare Services Annual Report 2020

According to the Department of Social Protection annual statistics report 2020, the Miscellaneous Services section of the DSP budget covers Food Aid as paid through the SWA. Food Aid payments account for 38.9% of the Miscellaneous Services costs. This can be interpreted that 38.9% of the estimated 24,000 coeliacs currently in receipt of a social welfare payment are also in receipt of SWA for Food Aid. This would indicate that there are an estimated 14,664 still not served by the SWA.

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<sup>4</sup> <https://assets.gov.ie/152643/d6371436-0518-471e-9674-a2b6a92739a2.pdf>

<sup>5</sup> <https://celiacos.org/ayudas-alimentarias-y-economicas-en-la-union-europea/>

## Proposal

It is proposed that in Budget 2023 that Ireland offer a monthly additional payment of €41.75 p.m. (€501/12mths) for coeliacs not covered by the PAYE system's Med1 reimbursement, which is the estimated 14,664 coeliacs in receipt of a payment from the Department of Social Protection but not already in receipt of SWA for Food Aid and not captured within the PAYE system.

Accordingly, should all estimated coeliacs currently in receipt of a social welfare payment the cost per annum is estimated to be:

$$14,664 \times €501 = €7.35\text{m per annum}$$

## Consequence of reintroduction of Dietary Supplement

### Potential savings €234.4m per annum

**Removes pressure** on already heavily burdened Irish healthcare system.

**Improves quality of life**, well-being, and overall health for a marginalised section of society.

Coeliac disease is estimated to affect up to 76,500 people in Ireland today. Of this number it is estimated that only 17% of this figure is diagnosed. That leaves 62,250 people living with undiagnosed coeliac disease in Ireland today. Undiagnosed coeliac disease has been proven to lead to the development of other serious illnesses and conditions, in particular intestinal cancers, type 1 diabetes, infertility and miscarriage and osteoporosis.

The Coeliac Society of Ireland is currently conducting research on the economic impact of undiagnosed coeliac disease to the Irish healthcare system and initial findings reveal that combined these four major illnesses in conjunction with undiagnosed coeliac disease cost the Irish healthcare system, at a conservative estimate, €234.4m per annum.

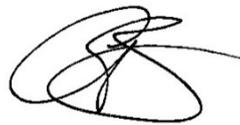
Patients with coeliac disease are less likely to be diagnosed if they are of lower socioeconomic status. Coeliac disease may be under-recognized in this population due to socioeconomic factors that possibly include lower rates of health-seeking behaviour

and access to healthcare<sup>6</sup>. An investment of €7.35m per annum to support the purchase of gluten-free foods, the only treatment for coeliac disease, in combination with a targeted awareness campaign in conjunction with the Irish Blood Transfusion Service and the Department of Health, has the potential to get a significant cohort of the Irish population started on a safe gluten-free journey and reduces the risk of their developing the related conditions listed above.

Signed



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Niall Kavanagh  
Chair of the Board



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Gill Brennan  
Chief Executive Officer

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<sup>6</sup> Roy A, Mehra S, Kelly CP, Tariq S, Pallav K, Dennis M, Peer A, Lebwohl B, Green PH, Leffler DA. The association between socioeconomic status and the symptoms at diagnosis of celiac disease: a retrospective cohort study. *Therap Adv Gastroenterol*. 2016 Jul;9(4):495-502. doi: 10.1177/1756283X16637532. Epub 2016 Mar 18. PMID: 27366218; PMCID: PMC4913330.