Celiac Canada's Submission to the Senate Committee on Social Affairs, Science and Technology on Bill S-243

Celiac Canada supports Bill S-243, An Act to establish a national framework for women's health and appreciates the opportunity to provide comments on this important legislation.

In 2024, Celiac Canada conducted our ***State of Celiac Disease in Canada*** health survey, collecting responses from about 7,500 Canadians living with celiac disease. The findings of the survey highlight the differences in diagnostic pathways and records for women and men living with celiac disease. Women were more likely to report:

- Longer symptom duration before diagnosis
- Lower quality of life prior to diagnosis
- A greater number of symptoms overall

These differences underscore the importance of a national framework to support improved health outcomes and health access for women. Key elements of the approach proposed in Bill S-243 would help reduce the time to diagnosis, mitigate long-term health risks, and improve quality of life including:

- Enhancing training and education for Canadian health care professionals across all disciplines to improve knowledge and skills in women's health;
- Strengthening primary health care services for women and prioritizing preventative health measures for women through all age and life stages;
- Deploying targeted solutions to improve access to health care for women.

What is Celiac Disease?

Celiac disease is a serious autoimmune disorder affecting approximately 1 in 100 Canadians. When someone with celiac disease consumes gluten (a protein in wheat, barley, rye, and related grains) it triggers an immune response that damages the small intestine, impairing absorption – especially iron, vitamin D, calcium, folate, and B vitamins. This can lead to a wide range of complications including:

- Gastrointestinal: diarrhea, bloating, constipation, pain
- Systemic: anemia, fatigue, bone/joint pain, osteoporosis
- Neurological: migraines, seizures, neuropathy, ataxia
- Dermatological: dermatitis herpetiformis
- Reproductive: infertility, delayed puberty, pregnancy difficulties
- Mental health: depression, anxiety
- Oral health: dental enamel defects, canker sores
- Pediatric: failure to thrive, delayed puberty, behavioural issues

Currently the only treatment is a Medical Nutrition Therapy consisting of strict gluten-free diet for life – a diet that is medically necessary and difficult to maintain. Even inherently gluten-free foods may be contaminated through harvest, storage, or preparation.

A Path to Diagnosis

The survey results showed that the path to receiving a diagnosis is rarely straightforward. Symptoms can vary greatly, change over time, and sometimes be dismissed as something entirely different or all in their head. Many patients with celiac disease spend months or even years trying to understand why they feel unwell before finally receiving answers

One of the clearest patterns in the data was how long people reported experiencing symptoms before receiving a diagnosis. Women were more likely than men to report longer periods of symptoms prior to diagnosis with nearly 57% of women reporting having symptoms for five years or longer before receiving their diagnosis.

At the same time, once patients entered the diagnostic process, men and women receive similar types of testing. For two-thirds of patients this means diagnosis through intestinal biopsy with the remaining patients being diagnosed through serology alone (19%) or based only on symptoms (13%).

Quality of Life

With longer timelines to diagnosis, women are at an increased risk of health outcomes that negatively impact health. Living with untreated celiac disease can have significant long-term health consequences, including nutritional deficiencies, osteoporosis and bone fractures, infertility and adverse pregnancy outcomes, increased risk of infections, and, rarely, an increased risk of gastrointestinal cancers like lymphoma.

Beyond its health consequences, living with symptoms can also impact one's quality of life. Responses from the State of Celiac Disease show that women were more likely to report poor quality of life before diagnosis with two-thirds rating their quality of life as either "poor" or "fair". Statistically women had 43% lower odds of reporting higher quality of life levels than men.

Consistent with these findings, women were more likely to report greater number of celiac-related symptoms, including digestive symptoms like bloating and abdominal pain as well as symptoms like fatigue and iron deficiency. Patients receiving a diagnosis and beginning a gluten-free diet report a significant difference in how they feel day to day. Across the survey, participants were more than five times as likely to report a higher quality of life after diagnosis compared to before. However, women were less likely to report recovery from symptoms like bloating, abdominal pain, weakness or tiredness, and iron deficiency which means there is still more work to be done in understanding how celiac disease affects women over the long-term.

Impacts of the Proposed Legislation on Women with Celiac

Our *State of Celiac Disease in Canada* report demonstrates that diagnosis is associated with substantial improvements in quality of life. Simply put, timely recognition and management of the condition is the most important step in managing symptoms and long-term health complications. The national framework for women's health proposed by Bill S-243 would help doctors better recognize the symptoms of celiac disease and how they present for women. This is likely to result in shorter timelines for women with celiac disease to be referred for testing and ultimately be diagnosed.

For these reasons, Celiac Canada supports Bill S-243 and the proposed national framework for women's health. We look forward to this legislation moving forward and delivering better health outcomes for Canadians.

About Celiac Canada

For over 50 years, Celiac Canada has been the only national charity proudly working to find, treat and cure celiac disease in Canada. Rooted in science, we provide education, support services, programs and promote awareness of the disease to improve diagnosis rates and long-term health outcomes. We are the largest single non-governmental funder of celiac research in Canada.

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