

Beyond Celiac Amplifies the Patient Experience of Celiac Disease through Research Presented at International Conference

Celiac disease patients report they experience more than just GI symptoms and growing dissatisfaction with the gluten-free diet as a sufficient treatment

AMBLER, PENNSYLVANIA, UNITED STATES, October 21, 2022 /EINPresswire.com/ -- [Beyond Celiac](https://www.beyondceliac.org), the leading catalyst for a celiac disease cure, is taking the lead in presenting the patient perspective on celiac disease symptoms and the dissatisfaction with the gluten-free diet at an international meeting of celiac disease researchers and physicians in Sorrento, Italy.

Two posters based on data gathered by Beyond Celiac directly from those who have celiac disease are being presented by Alice Bast, chief executive officer, at the International Celiac Disease Symposium.

One poster shows that those with celiac disease report having more than just gastrointestinal symptoms when they are exposed to gluten and the other that there is growing dissatisfaction with the gluten-free diet as a sufficient treatment.

Additionally, scientists whose research is being funded by Beyond Celiac are also presenting at ICDS. Michael Fitzpatrick, MD, of the University of Oxford, is giving an oral presentation on the investigation into the pathogenic role of so-called killer T-cells in celiac disease, work funded



DISTRIBUTION OF SYMPTOMS IN THOSE SYMPTOMATIC AFTER GLUTEN EXPOSURE (N=2235)

GI SYMPTOMS			NON-GI SYMPTOMS		
	n	%		n	%
Abdominal pain or discomfort	1740	85.6	Fatigue	1695	83.4
Abdominal bloating	1667	82	Brain fog	1557	76.6
Gas	1506	74.1	Irritability or fussiness	1294	63.6
Diarrhea or loose stool	1495	73.5	Headache or migraine	1289	63.4
Stomach rumbling (intestinal noise)	1360	66.9	Anxiety	1213	59.7
Nausea	1138	56	Joint pain	1164	57.3
Constipation or hard, bulky stool	793	39	Sadness	947	46.6
Incomplete bowel movements	774	38.1	Lack of interest in eating or in food	900	44.3
Vomiting	651	32	Numbness or tingling	846	41.6
Pale, foul smelling stool	645	31.7	Itchy skin rash	789	38.8
Black tarry stool	317	15.6	Canker sores	551	27.1
Blood in stool	234	11.5	Problems with muscle coordination or ataxia	464	22.8
			Difficulty or pain when swallowing	336	16.5

Distribution of symptoms in patients with celiac disease after gluten exposure

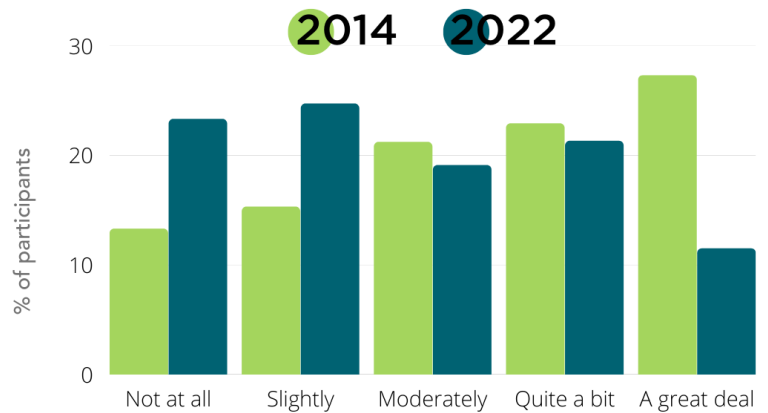
through the 2019 [Beyond Celiac Established Investigator Award](#).

Iain Croall, PhD, of Sheffield University, is presenting a poster on early findings from research into the neurological and neuropsychological manifestations of celiac disease and gluten-related disorders. This work was funded by the 2021 Beyond Celiac Established Investigator Award.

The Beyond Celiac symptoms poster is based on an online survey taken by more than 2,200 adult participants registered in the Go Beyond Celiac patient registry. About 98 percent of the 2,000 symptomatic participants reported having gastrointestinal symptoms and about 96 percent reported non-gastrointestinal symptoms, the poster shows.



LEVEL OF AGREEMENT WITH SUFFICIENCY OF THE GLUTEN-FREE DIET



Patient surveys from 2014 and 2022 reveal a significant change in perception of the gluten-free diet as a treatment for celiac disease

The most common gastrointestinal symptoms were abdominal pain or discomfort, abdominal bloating, gas, and diarrhea. The most common non-gastrointestinal symptoms were brain fog, fatigue, irritability, and headaches. Most participants with symptoms reported a combination of gastrointestinal and other symptoms.

“

Beyond Celiac is playing a vital role in educating the community, physicians and researchers about challenges posed by gluten exposure, the burden of the disease, and the need for treatment options.”

Kate Avery, MPH, Beyond Celiac Director of Research and Patient Engagement

“Physicians should be aware of common non-GI symptoms when considering diagnostic screening or celiac disease management,” according to authors of the poster.

The second poster, based on two community surveys taken by Beyond Celiac eight years apart, shows that celiac disease patient attitudes about the gluten-free diet have shifted significantly in the last decade.

Survey participants who agreed “a great deal” that the gluten-free diet is an adequate treatment has decreased by more than half. In 2014, of the 1460 survey participants,

about 27 percent agreed compared to about 12 percent of the 1140 who answered the survey in 2022. Meanwhile, the proportion of participants who agreed “not at all” that the gluten-free diet

was a sufficient treatment increased from about 13 percent in 2014 to about 23 percent in 2022.

“Beyond Celiac is playing a vital role in educating the celiac disease community, physicians and researchers about challenges posed by inadvertent gluten exposure, the burden of the disease, and the need for treatments beyond the diet,” notes Beyond Celiac Director of Research and Patient Engagement Kate Avery, MPH, who is an author on both Beyond Celiac posters.

Meanwhile, the poster being presented by Croall is based on the survey response of 84 patients treated at Sheffield for neurological conditions who were asked to report symptoms associated with acute gluten exposures and/or symptoms they persistently experience. Overall, survey participants ranked the gluten-free diet as being moderately successful in controlling their symptoms.

Those surveyed had gluten ataxia/encephalopathy with and without a diagnosis of celiac disease. Survey participants also reported on quality of life and how well they followed the gluten-free diet, with both groups reporting high adherence.

Both groups also reported similar rates of neurological symptoms that occurred acutely and persistently. Balance problems were an exception, occurring in about 60 percent of those with celiac disease and about 80 percent of those who don't have celiac disease.

Overall, the perceived effectiveness of the gluten-free diet in controlling acute symptoms was about 55 percent compared to 50 percent for persistent symptoms. “Indications of depression and particularly anxiety are found at high rates, the poster concludes. “Experiencing persistent “movement problems” appears to be an important symptom in predicting depression and physical issues pertinent to the patient,” according to the poster authors.

The survey is part of the larger study developing a retrospective blood test sample and brain imaging database of almost 1,000 patients who have been seen at Sheffield over 20 years.

ICDS, which takes place every other year in a different country around the world, is forum where scientists, clinicians, health allied professionals, patients associations and industry meet to exchange knowledge and experience and to foster cooperation, according to ICDS organizers.



Beyond Celiac Chief Science and Strategy Officer Salvo Alesci, MD and Beyond Celiac CEO Alice Bast with research posters at the International Symposium for Celiac Disease 2022 in Sorrento, Italy

Celiac disease is a serious autoimmune condition. The disease causes damage to the small intestine, resulting in debilitating symptoms, and if left untreated can lead to a number of serious, long-term health problems including brain damage, infertility and some types of cancer. Celiac disease affects one in 133 Americans.

About Beyond Celiac

Founded in 2003, Beyond Celiac is the leading catalyst for a celiac disease cure in the United States, serving as a patient advocacy and research-driven organization working to drive diagnosis and accelerate the discovery of new treatments. By engaging with the top scientists in the field, making the right investments in research and supporting the broad community of those with celiac disease and gluten sensitivity, Beyond Celiac envisions a world in which people can live healthy lives and eat without fear – a world Beyond Celiac.

Claire Baker
Beyond Celiac
+1 267-968-5491
[email us here](#)

This press release can be viewed online at: <https://www.einpresswire.com/article/596991858>

EIN Presswire's priority is source transparency. We do not allow opaque clients, and our editors try to be careful about weeding out false and misleading content. As a user, if you see something we have missed, please do bring it to our attention. Your help is welcome. EIN Presswire, Everyone's Internet News Presswire™, tries to define some of the boundaries that are reasonable in today's world. Please see our Editorial Guidelines for more information.

© 1995-2022 Newsmatics Inc. All Right Reserved.