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## Introduction

Celiac disease (CeD) is associated with other autoimmune diseases (AID) and conditions, but the prevalence and related predictive factors for these comorbidities of CeD have not been fully explored. Additionally, little is known about the disease etiology, long-term outcomes, and patient attitudes regarding non-dietary treatments.

To address these needs, the Celiac Disease Foundation launched the first patient-powered research network (self-reported patient registry) for CeD in March 2016, known as iCureCeliac<sup>®</sup>, designed to help researchers better understand, and ultimately cure, CeD.

## Objective

In this study, we summarize self-reported patient data pertaining to disease onset, comorbid autoimmune diseases, and other associated conditions. We compare our results with previously documented associations in order to validate the use of this patient-powered research network as a source of medical research.

Studies show that patients with CeD are at an increased risk for developing other autoimmune diseases and associated conditions. This study focuses on the correlation of self-reported patient data between CeD and irritable bowel syndrome (IBS), thyroid disease, psoriasis, ulcerative colitis, rheumatoid arthritis, and type 1 diabetes.

Table 1. Number of iCureCeliac<sup>®</sup> Participants with Additional AID/Associated Conditions

Number of Additional AID/AC	Entire Sample (n=1090)	Males (n=189)	Females (n=901)
0	686 (62.9%)	141 (74.6%)	545 (60.5%)
1	250 (22.9%)	30 (15.9%)	220 (24.4%)
2	111 (10.2%)	13 (6.9%)	98 (10.9%)
3 or more	43 (3.9%)	5 (2.6%)	38 (4.2%)

## Methods

Under informed consent, participants voluntarily entered their information pertaining to medical history and experiences living with CeD into iCureCeliac<sup>®</sup>. Participants had control over who viewed their information and what information they shared. Participants were recruited to iCureCeliac<sup>®</sup> through email, website, social media marketing, and printed communications. Participants must be 18 years or older; caregivers are permitted to complete the questionnaire on behalf of minors. The questionnaire requires approximately 45 minutes to complete.

Data obtained from 1,090 participants with biopsy-reported CeD enrolled in iCureCeliac<sup>®</sup> were used to describe the frequency of previously associated AID and conditions, as well as their relationship to gender, age, and race/ethnicity.

The Institutional Review Board of the Genetic Alliance approved the use of this research network (IRB approval number NCDN-002).

## Results

Among the 1,090 biopsy-reported iCureCeliac<sup>®</sup> participants, 91.3% were Caucasian and 82.7% were female, and the majority (44%) of patients were between the ages of 26 and <50 years old. The mean diagnosis age was 34.3 ± 15.2 years, the mean duration of CeD was 4.5 ± 6.4 years, and the mean number of years to a CeD diagnosis was 7.6 ± 12.2 years.

37% were diagnosed with at least one additional AID and/or associated condition. The most common AID/associated conditions were irritable bowel syndrome (19.5%), thyroid disease (15.5%), psoriasis (5.3%), ulcerative colitis (3.1%), rheumatoid arthritis (2.5%), and type 1 diabetes (2.1%). The prevalence of one or more AID/associated conditions was increased in females and as age increased, with more than 50% of participants aged 50 and above reporting an additional AID.

Chart 1. Percentages of Most Common AID/Associated Conditions in iCureCeliac<sup>®</sup>

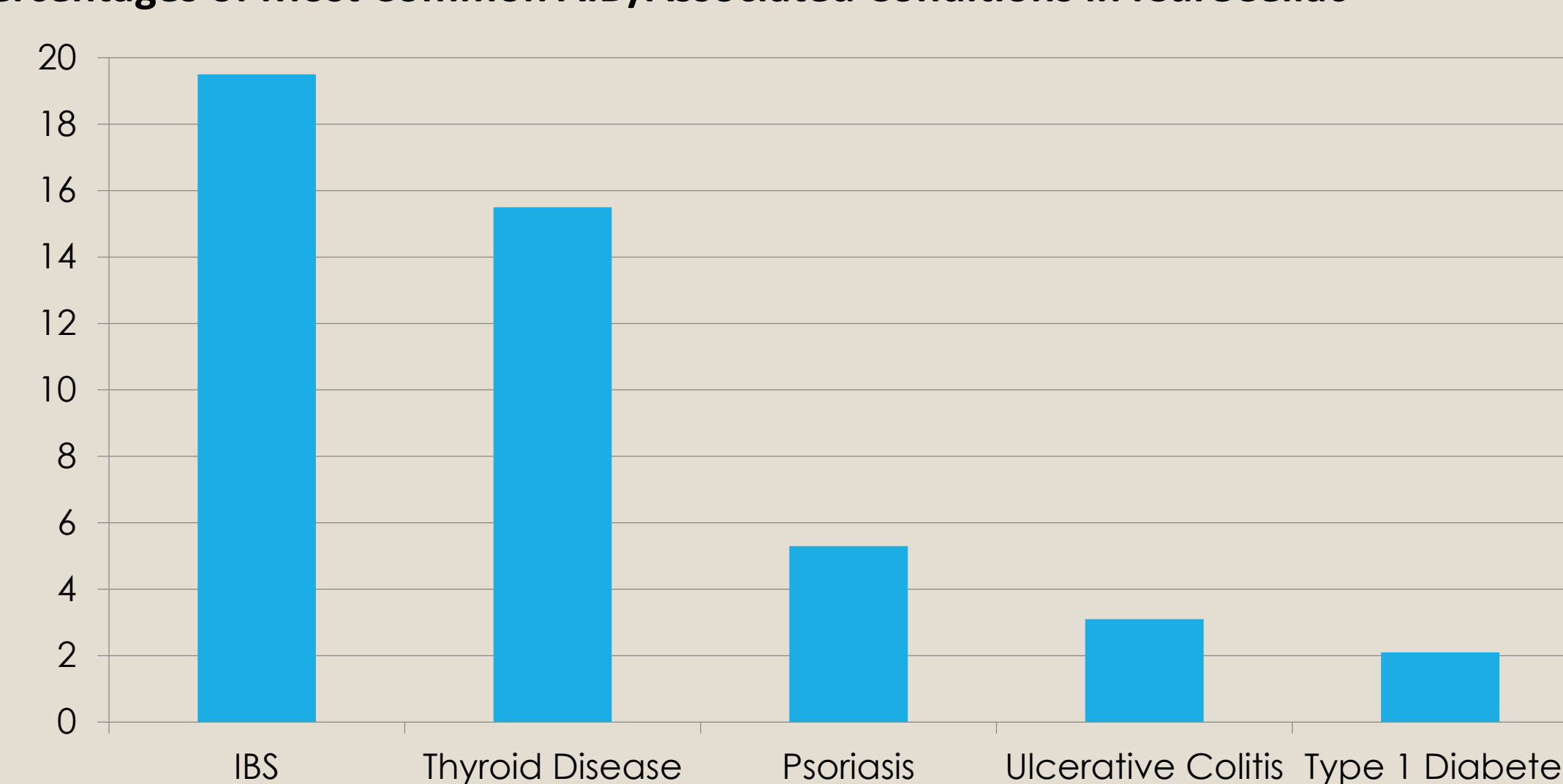


Table 2. Prevalence of AID/Associated Conditions in General U.S. Population vs iCureCeliac<sup>®</sup> Population

Condition	U.S. Prevalence	Source for U.S. Prevalence	iCureCeliac <sup>®</sup> Patient Reports
Irritable Bowel Syndrome	11%	Canavan, West, Card, 2014	19.5% (213)
Thyroid Disease	12%	American Thyroid Association	15.5% (169)
Psoriasis	2%	Langley, Krueger, Griffiths, 2005	5.3% (58)
Ulcerative Colitis	0.04-0.25%	Centers for Disease Control and Prevention	3.1% (34)
Rheumatoid Arthritis	0.46%	Arthritis Foundation	2.5% (27)
Type 1 Diabetes	0.40%	Juvenile Diabetes Research Foundation	2.1% (23)

## Conclusion

In iCureCeliac<sup>®</sup>, diagnosis of one or more AID/associated conditions in addition to CeD is common, particularly in women and older adults. The high prevalence of additional AID/associated conditions (37%) in our study supports the need to identify comorbidities during the follow-up of CeD patients. The most common AID/associated conditions were irritable bowel syndrome (19.5%), thyroid disease (15.5%), psoriasis (5.3%), ulcerative colitis (3.1%), rheumatoid arthritis (2.5%), and type 1 diabetes (2.1%). These findings are consistent with prior studies showing that the prevalence of these conditions is increased in the celiac disease population.

Results of this study have implications for primary care, gastroenterology, and rheumatology practice, and will ultimately allow healthcare providers to better predict and manage the additional AID/associated conditions that may develop in patients with CeD. Our results demonstrate that iCureCeliac<sup>®</sup> can serve as an important source of information for both research and patient care, and can ultimately yield a better understanding of CeD, leading to an improved quality of life.

## Contact

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