



ANNUAL REPORT

2021

Accelerating
Diagnosis,
Treatments,
and a **Cure** for
Celiac Disease

celiac.org



ACCELERATING RESEARCH

Strategic investments in cutting-edge biomedical research and patient engagement to advance the pursuit of treatments and a cure for celiac disease.

PROMOTING EDUCATION

Outreach to patients and healthcare providers has improved the diagnostic rate of celiac disease. Focused investments continue to close the gap and end the needless suffering of millions.

EFFECTIVE ADVOCACY

Committed to being the worldwide voice of the celiac community before key policy makers in Congress and federal research and regulatory agencies.

Driving Innovation

Presentation by CEO Marilyn Geller on patient unmet needs at **NIAID Accelerating Progress in Celiac Disease Workshop** to secure NIH funding for celiac disease research.

Trained Patient Advocates to present at the FDA's **Gastroenterology Regulatory Endpoints and the Advancement of Therapeutics VI (GREAT VI) Workshop on Celiac Disease** to inform clinical trial endpoints for celiac disease drug development.

Recruited for **Boston Children's Hospital's** study evaluating access to gluten-free food to inform federal policy changes for low-income food assistance.

Impacting Patients



6.5M VISITORS TO **CELIAC.ORG** annually

Providing Support to the **CELIAC DISEASE COMMUNITY** Through **SOCIAL MEDIA OUTREACH**

3.3M REACHED in 2021



3,000 COMMUNITY FUNDRAISING PARTICIPANTS in 2021

Expanding Reach in 2021

Convened the **2021 Patient Education & Advocacy Summit**, supported by a **PCORI Engagement Award**, resulting in more than 420 advocates trained to effectively advocate to their Members of Congress, in addition to more than 120 advocates trained through **iadvocate.celiac.org**.

Partnered with Congresswoman McCollum to introduce the **first ever Congressional Celiac Disease Caucus** to support innovative celiac disease research and advance legislation to ease the suffering of celiac disease patients.

Secured FY2021 federal budget report language directing NIH to study celiac disease for the second consecutive year.

Advancing Therapeutic Treatment Development

iCureCeliac Patient Registry
icure.celiac.org

Probiotic Use in Celiac Disease: Results from a National Survey published August 2021 in the Journal of Gastrointestinal and Liver Diseases using data from iCureCeliac®.

15,000 TOTAL REGISTRANTS in iQualifyCeliac

iQualifyCeliac Trial Screening Tool
iqualify.celiac.org

First time simultaneously recruiting for clinical trials in three different phases: the ACeD Study (phase 1), PROACTIVE Celiac Study (phase 2b), and CeDLara Study (phase 3).

22 TRIALS & STUDIES supported

Young Investigator Research Grant Award

Funded four Research Grant Awards in developing less allergenic wheat, determining whether blocking B cells can reduce intestinal damage, mortality rates for celiac disease patients and risk of psychiatric disorders, and evaluation of a diagnostic test that requires only a single dose of gluten.

\$1,300,000 2018-2021 FUNDING OF RESEARCH & MEDICAL EDUCATION

Educating Providers and the Public

NASPGHAN Clinical Guide for Pediatric Celiac Disease web-based tool to assist healthcare professionals in the diagnosis and management of celiac disease patients, improving the quality and effectiveness of care provided.
clinical.celiac.org

25,000 PHYSICIANS EDUCATED since 2017

Certificate of Training in Treating Gluten-Related Disorders developed by the Academy of Nutrition and Dietetics with the support of the Celiac Disease Foundation and reimbursement grants offered to increase the pool of registered dietitians skilled in celiac disease nutritional therapy.

62 REIMBURSEMENT GRANTS since October 2020

Celiac Disease Management for Learning Environments Training Program web-based instruction for schools, parents, and caregivers on implementation of standardized accommodations required by the Americans with Disabilities Act, based upon what is medically and psychologically necessary for children with celiac disease to succeed at school.
school.celiac.org

2,100 TRAINED since 2020

Driving Policy Change

Launched a campaign to support the reintroduction of the **Medical Nutrition Therapy Act of 2021**, bipartisan legislation to provide coverage of nutrition therapy to Medicare beneficiaries.

540 STATE ADVOCACY AMBASSADORS trained

Partnered in a multi-organization campaign in support of the **Food Labeling Modernization Act of 2021** to update front-of-package food labeling requirements to make it easier and safer for individuals with celiac disease to purchase food items by disclosing when foods contain gluten.

9,785 EMAILS SENT TO CONGRESS since November 2020

Coordinated with Congressman Ryan's office to launch a campaign supporting the reintroduction of the **Gluten in Medicine Disclosure Act of 2021** to make it easier for consumers to identify gluten in prescription drugs.

1,700 PATIENT EDUCATION & ADVOCACY SUMMIT attendees

▶ **ASSETS**

Cash and Cash Equivalents	\$ 2,378,171
Contributions Receivable	\$ 177,043
Accounts Receivable	\$ 160,500
Investment in Partnership	\$ 89,268
Deposits	\$ 3,250
Property and Equipment	\$ 128,301

Total Assets	\$ 2,936,533
---------------------	---------------------

▶ **LIABILITIES**

Accounts Payable	\$ 32,942
Accrued Salaries	\$ 52,814
Unearned Revenue	\$ 179,084
Loan Payable - Payroll Protection Program	\$ 130,800
Grants Payable	\$ 361,650

Total Liabilities	\$ 757,290
--------------------------	-------------------

▶ **NET ASSETS**

Unrestricted	\$ 2,179,243
--------------	--------------

Total Liabilities and Net Assets	\$ 2,936,533
---	---------------------

▶ **SUPPORT AND REVENUE**

Contributions and Grants	\$ 1,093,597
Annual Meeting	\$ 9,173
Gifts in Kind	\$ 354,373
Sponsorships, Program Income, and Special Events	\$ 778,175

Total Revenue	\$ 2,235,318
----------------------	---------------------

▶ **EXPENSES**

Program Expenses	\$ 1,569,409
Management and General	\$ 73,021
Fundraising	\$ 100,679

Total Expenses	\$ 1,743,109
-----------------------	---------------------

Change in Net Assets	\$ 492,209
-----------------------------	-------------------