



ANNUAL REPORT

2020

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 for 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

Convened groundbreaking **Consensus Workshop on Research Opportunities in Celiac Disease** to inform NIH Research Priorities for 2021 and beyond.

Presentation by CEO Marilyn Geller to **NIH Autoimmune Diseases Coordinating Committee (ADCC)** of findings from Consensus Workshop on Research Opportunities in Celiac Disease.

Sponsored the Celiac Disease Center at Columbia University Biennial Symposium, University of Chicago Celiac Research Symposium, and Harvard Celiac Research Program.

Impacting Patients

 **celiac.org**

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

COVID-19 & CELIAC DISEASE RESOURCE CENTER

 **170,000**
VISITORS TO
COVID-19 RESOURCE CENTER
in 2020

 **TEAM**
gluten-free™

 **2020 VIRTUAL TURKEYTROT**

 **3,000**
COMMUNITY
FUNDRAISING PARTICIPANTS
in 2020

Expanding Reach in 2020

iAdvocate.celiac.org State Advocacy Ambassador training program and website launched to drive policy change to improve the health of those living with celiac disease.

Secured FY2020 federal budget report language **directing NIH to study celiac disease.**

Recipient of the PCORI Engagement Award to support the community convening of patient advocates and researchers to promote the patient voice in celiac disease advocacy and research.

Advancing Therapeutic Treatment Development

 **iCureCeliac**
Patient Registry

Disease Burden and Quality of Life Impacts in Patients With Celiac Disease on a Gluten-Free Diet: An Analysis of the

iCureCeliac Registry® presented at ACG 2020 (American College of Gastroenterology) and 2020 UEG Week (United European Gastroenterology Week).

 **8,000**
TOTAL
REGISTRANTS
in iCureCeliac®

 **iQualifyCeliac**
Trial Screening Tool

Recruited for the world's largest celiac disease study At Home to develop new

diagnostics and for the PROACTIVE Celiac Study, the first multi-country phase 2 trial for an accidental gluten exposure therapeutic.

 **18**
NUMBER OF
TRIALS & STUDIES
supported

 **Young Investigator**
Research Grant Award

Funded three Young Investigator Research Grant Awards in determining if blocking B cells can reduce intestinal damage, mortality rates for

celiac patients and risk of psychiatric disorders, and evaluation of a diagnostic test that does not require a gluten challenge or endoscopy.

 **\$1,000,000**
2018 -2020
FUNDING OF RESEARCH AND 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.

 **19,000**
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.

 **12**
REIMBURSEMENT GRANTS
since October 2020

Celiac Disease School Action Guidelines for Education Program web-based training for schools, parents, and caregivers on standardized federal 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.

 **50**
NATIONAL
STAKEHOLDERS
engaged

Driving Policy Change

Convened the inaugural **Patient Advocacy Summit in Washington, DC**, with 70 advocates representing 18 states, and through **iAdvocate.celiac.org** an additional 143 advocates representing 22 states, trained to effectively advocate to their Members of Congress on behalf of the celiac disease community.

 **213**
STATE ADVOCACY
AMBASSADORS
Trained

Launched campaign to support the **Medical Nutrition Therapy Act of 2020**, bipartisan legislation to provide coverage of nutrition therapy to Medicare beneficiaries.

 **2,200**
EMAILS
SENT TO CONGRESS
since September 2020

Partnered with Senator Blumenthal to introduce and secure cosponsors for S.3021, the **Gluten in Medicine Disclosure Act**, and continued to partner with Representatives Ryan and Cole for H.R. 2074.

 **26,000**
EMAILS
SENT TO CONGRESS
since April 2019

▶ **ASSETS**

Cash and Cash Equivalents	\$ 1,916,300
Contributions Receivable	\$ 62,779
Accounts Receivable	\$ 146,750
Prepaid Expenses	\$ 9,354
Investment in Partnership	\$ 72,961
Deposits	\$ 3,250
Property and Equipment	\$ 114,953

Total Assets	\$ 2,326,347
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▶ **LIABILITIES**

Accounts Payable	\$ 42,219
Accrued Salaries	\$ 64,761
Unearned Revenue	\$ 170,683

Total Liabilities	\$ 277,663
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▶ **NET ASSETS**

Unrestricted	\$ 2,048,684
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Total Liabilities and Net Assets	\$ 2,326,347
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▶ **SUPPORT AND REVENUE**

Contributions and Grants	\$ 951,680
Annual Meeting	\$ 63,146
Gifts in Kind	\$ 349,743
Sponsorships, Program Income, and Special Events	\$ 624,457

Total Revenue	\$ 1,989,026
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▶ **EXPENSES**

Program Expenses	\$ 1,647,070
Management and General	\$ 76,504
Fundraising	\$ 78,942

Total Expenses	\$ 1,802,516
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Change in Net Assets	\$ 186,510
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