

2022

**ANNUAL
REPORT**

celiac.org

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



EFFECTIVE ADVOCACY



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



363

2020 - 2022

**STATE
ADVOCACY
AMBASSADORS**
trained



16,026

2020 - 2022

**LETTERS/
EMAILS**
sent to
Congress



27

2022

**U.S. REPRESENTATIVES
IN THE CELIAC DISEASE
CONGRESSIONAL
CAUCUS**

Driving Policy Change – Today and Tomorrow

- ATTAINED** ▶ **Secured FY2022 federal budget report language** encouraging NIH to devote focused research to celiac disease and its cause and urging NIAID to support better coordination of existing research and a new focus on diagnosing and effectively treating celiac disease.
- ALIGNED** ▶ Partnered with the **Celiac Disease Congressional Caucus** to request the **U.S. Centers for Disease Control** include celiac disease in its CDC A-Z Index, a CDC.gov website navigation tool containing important public health information.
- ASSISTED** ▶ Advocated for the bipartisan **Medical Nutrition Therapy Act** which expands access through Medicare to patients with chronic diseases, including celiac disease.
- COLLABORATED** ▶ Partnered with the **Los Angeles County Food Equity Roundtable**, a multi-organization campaign focused on solving food insecurity in populations including those with dietary restrictions; this work was represented in September at the **White House Conference on Hunger, Nutrition, and Health**.
- DELIVERED** ▶ Submitted comments to inform the **U.S. Preventive Services Task Force** proposed framework seeking assurance that celiac disease is included in investigation of how food insecurity is assessed by healthcare providers, the impact of interventions on food security, and outcomes for patients.
- PARTNERED** ▶ Advocated for progress in celiac disease awareness, treatment, and cure through ongoing partnerships with **Autoimmune Association, Association of European Coeliac Societies, Crohn's and Colitis Foundation, Defense Health Research Consortium, Digestive Disease National Coalition, Food Allergy Research and Education, and the National Health Council**.

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.

Expanding Reach in 2022



5.8M

CELIAC.ORG
VISITORS



3.4M

SOCIAL MEDIA
REACH



3,500

COMMUNITY
FUNDRAISING
PARTICIPANTS

Educating Providers and the Public

Sponsored **Columbia University Celiac Disease Center International Symposium, University of Chicago** and **Boston Children's Hospital celiac disease seminars**, educating thousands of patients and providers worldwide on the latest in research, diagnosis, and treatment of celiac disease.

Hosted **Ask-the-FDA Educational Webinar** with representatives from the **U.S. Food and Drug Administration and Association of European Coeliac Societies (AOECS)** to educate patients, providers, and the public on gluten-free labeling rules.



37,752

2017 - 2022

PHYSICIANS
EDUCATED
(clinical.celiac.org)



28

2019 - 2022

MONTHS
DEVELOPING
CRITICAL DIETARY
GUIDELINE
UPDATES



2,700

2020-2022

PEOPLE TRAINED
THROUGH
CELIAC DISEASE
MANAGEMENT
FOR LEARNING
ENVIRONMENTS
Training Program
(school.celiac.org)

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.

Marilyn Geller, CEO, served as celiac disease patient advocate on Expert Panel Workgroup for the Academy of Nutrition and Dietetics,

shaping policy for first update in 10 years to guidelines for registered dietitians working with celiac disease patients and caregivers.

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 on what is medically and psychologically necessary for children with celiac disease to succeed at school.

ACCELERATING RESEARCH



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



17,000

2018 - 2022

TOTAL REGISTRANTS
in iQualifyCeliac



14

2022

TRIALS & STUDIES
supported



\$1,000,000

2019 - 2022

FUNDING OF RESEARCH & MEDICAL EDUCATION GRANTS

Driving Innovation and Advancing Treatment



Premiered Curing Celiac: A Short Story by filmmaker Hayley Repton as part of a nationwide initiative to encourage patients to join the iCureCeliac® patient registry, resulting in over **1,700 new registrants**, with **112,718 views**.

icure.celiac.org



iQualifyCeliac: Expanded patient recruitment services to include patient advisory board implementation to solicit valuable patient insights, study site identification to accelerate enrollment, and site coordinator contact center module for trial sponsors and site coordinators to seamlessly manage patient referrals.

iqualify.celiac.org



Continued to fund critical investigation at five of the world's leading academic research centers to advance understanding of celiac disease, its diagnosis, treatment, and a potential cure.

▶ Secured the first **National Institutes of Health Notice of Special Interest (NOSI) for Celiac Disease in November 2021** – a dedicated research grant targeting an area of interest identified by the NIH – resulting from focused, years-long efforts on behalf of the celiac disease patient community.

▶ Secured, for the first time, celiac disease as a listing in the **National Institutes of Health Research, Condition, and Disease Categorization** – a database that lists diseases and conditions receiving funding. NIH reports that **\$9 million** was spent on celiac disease research in FY2021.

▶ **Issued white paper advocating for \$12 million in medical research funding from the Department of Defense** featuring data on the effects of celiac disease on military readiness, retention, and families.

▶ Supported researchers presenting data on celiac disease, and the results from two Foundation-supported clinical trials at **Digestive Disease Week**, the world's largest gathering of gastrointestinal researchers.

Celiac Disease Foundation Research Grant Awards & Prizes

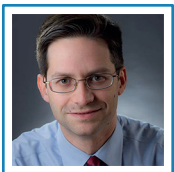
The Celiac Disease Foundation is committed to driving diagnosis, treatments, and a cure for celiac disease. Our Research Grant Awards, **totaling more than \$850,000**, fund critical investigations to advance this mission. The Foundation this year created and awarded two annual prizes: The Prize for Excellence in Celiac Disease Research and The Young Investigator Prize. These Awards and Prizes promote breakthrough research so we can, one day, live in a world free of celiac disease.

Grant Award Recipients



VALÉRIE ABADIE, PHD • *The University of Chicago* • **Award: \$180,000**

Dr. Abadie is employing specially developed mice models that mimic celiac disease to learn if blocking B-cells can mitigate or prevent damage to the intestinal villi when someone with celiac disease ingests gluten to determine if B-cell targeted treatments for celiac disease should be developed.



BENJAMIN LEBWOHL, MD, MS • *Columbia University* • **Award: \$145,650**

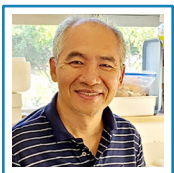
Dr. Lebwohl and team are researching the microbiome in celiac patients exposed to gluten and if it relates to the variance in symptom severity in these patients; and, whether the relative mortality rate of patients has changed over time given higher diagnostic rates, improved access to gluten-free foods, and better patient awareness.



MARISA STAHL, MD • *Colorado Children's Hospital AND*

JOCELYN SILVESTER, MD, PHD • *Boston Children's Hospital* (*pictured below) • **Award: \$166,460**

Dr. Silvester and Dr. Stahl are collaborating to evaluate a potential new diagnostic test for celiac disease that could be an alternative to small intestinal biopsy by looking for changes in IL-2 in blood in a single-dose gluten challenge in children with celiac disease, and evaluating if blood may be exposed to gluten outside the body, so patients do not need to consume gluten for a diagnosis.



WENJUN ZHANG, PHD • *University of California, Davis* • **Award: \$360,000**

Dr. Wenjun Zhang and Dr. Jorge Dubcovsky aim to reduce wheat allergenicity by eliminating the wheat proteins that carry celiac epitopes with a long-term goal of developing bread and pasta wheat varieties that are safe for people with celiac disease.

2022 Prize for Excellence in Celiac Disease Research

(\$25,000, recognizes investigators making significant impact on celiac disease research)



JOSEPH MURRAY, MD - Dr. Joseph Murray, an internationally recognized expert in celiac disease, is a Professor of Medicine, Mayo Clinic College of Medicine, and a clinician investigator and consultant in the Division of Gastroenterology and Hepatology and Department of Immunology. Dr. Murray donated his full prize award to the AOECs Emergency Crisis Fund to support the celiac disease community.

2022 Young Investigator Prize

(\$10,000, recognizes investigators making significant early career achievements in celiac disease research)



JOCELYN SILVESTER, MD, PHD - Dr. Jocelyn Silvester is an attending physician at Boston Children's Hospital, an instructor of pediatrics at Harvard Medical School, and chairs the NASPGHAN Celiac Special Interest Group. Dr. Silvester donated her full prize to establish the Jocelyn A. Silvester Student and Resident Celiac Disease Research Award for promising medical and graduate students and residents.

2021 FINANCIALS



For the Year Ended 12.31.2021

ASSETS

| | |
|---------------------------|--------------|
| Cash and Cash Equivalents | \$ 2,028,969 |
| Contributions Receivable | \$ 247,068 |
| Investments | \$ 1,717,228 |
| Other Assets | \$ 104,890 |

| | |
|---------------------|---------------------|
| Total Assets | \$ 4,098,155 |
|---------------------|---------------------|

LIABILITIES

| | |
|---------------------|------------|
| Accrued Liabilities | \$ 632,321 |
| Deferred Revenue | \$ 283,459 |

| | |
|--------------------------|------------------|
| Total Liabilities | \$915,780 |
|--------------------------|------------------|

NET ASSETS

| | |
|-------------------------|--------------------|
| Total Net Assets | \$3,182,375 |
|-------------------------|--------------------|

SUPPORT AND REVENUE

| | |
|---------------|--------------|
| Contributions | \$ 1,936,456 |
| Other Income | \$ 1,374,627 |

| | |
|----------------------|--------------------|
| Total Revenue | \$3,311,083 |
|----------------------|--------------------|

EXPENSES

| | |
|------------------------|--------------|
| Program | \$ 2,105,164 |
| Management and General | \$ 87,596 |
| Development | \$ 115,191 |

| | |
|-----------------------|--------------------|
| Total Expenses | \$2,307,951 |
|-----------------------|--------------------|

| | |
|-----------------------------|---------------------|
| Change in Net Assets | \$ 1,003,132 |
|-----------------------------|---------------------|