

2023

ANNUAL
REPORT

celiac.org

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





Strategic investments in cutting-edge biomedical research and patient engagement are driving advancement and progress toward treatments and a cure for celiac disease.

Driving Innovation and Advancing Treatment



iRecruitCeliac

Patient Recruitment. Solved.

Leading website that brings together solutions to optimize and accelerate enrollment into clinical studies for celiac disease and comorbid conditions.

Formalizing the global recruitment process to speed patients into clinical trials to rapidly accelerate treatments and a cure.



**Research
Grant Awards**

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

PRESENTING POSTERS AND ABSTRACTS

- ▶ Co-authored and presented six abstracts at industry gatherings, including **Digestive Disease Week**, the world's largest gathering of gastrointestinal researchers; the **North American Society for Pediatric Gastroenterology, Hepatology & Nutrition (NASPGHAN) Annual Meeting**; **United European Gastroenterology Week**; and the **Association of European Coeliac Societies (AOECS) General Assembly**:
 - ▶ ***The Virtual Celiac Symptoms Study: Symptom and Gluten-Free Diet Perceptions at Baseline*** – co-authored by Marilyn G. Geller in partnership with Takeda
 - ▶ ***Diagnosing Celiac Disease in the United States of America, Germany, Italy and Spain: Findings from a Real-World Survey*** – co-authored by Marilyn G. Geller in partnership with Adelphi Real World
 - ▶ ***Physician Management of Celiac Disease: A Comparison of Disease Knowledge, Diagnosis, and Patient Management Between Gastroenterologists and Primary Care Physicians in Germany, Italy, Spain, and the United States – Findings from a Real-World Survey*** – co-authored by Marilyn G. Geller and Julia McBeth in partnership with Adelphi Real World
 - ▶ ***The Virtual Celiac Symptoms Study: Reported Symptoms Over 12 Weeks in Adults*** – co-authored by Marilyn G. Geller in partnership with Takeda
 - ▶ ***The Virtual Celiac Symptoms Study: Reported Symptoms Over 12 Weeks in Adolescents*** – co-authored by Marilyn G. Geller in partnership with Takeda
 - ▶ ***The Virtual Celiac Symptoms Study: Symptom and Gluten-Free Diet Perceptions of Adolescents at Baseline*** – co-authored by Marilyn G. Geller in partnership with Takeda

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 \$1M**, fund critical investigations to advance this mission. Beginning in 2022, the Foundation created and now awards three annual global prizes to recognize exceptional investigators in the field of celiac disease.

GRANT AWARD RECIPIENTS



BENJAMIN LEBWOHL, MD, MS • *Columbia University*

AWARD: \$145,650

Dr. Lebwohl has published four articles with his findings that people with celiac disease have a slightly increased risk of mortality, psychiatric and skin disorders, and that differences in the gut microbiome do not account for the diverse symptoms people with celiac disease experience.

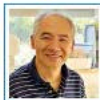


JOCELYN SILVESTER, MD, PHD • *Boston Children's Hospital*

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

AWARD: \$118,460

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 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.

PRIZE FOR *Excellence* IN CELIAC DISEASE RESEARCH



\$25,000 ★

SIGNIFICANT IMPACT
ON CELIAC DISEASE RESEARCH

Robert (Bob) Anderson, MB ChB PhD is in clinical practice at Mackay Base Hospital, is co-founder and director of Novoviah Pharmaceuticals in Queensland, Australia, and is current President of the International Society for the Study of Celiac Disease. His work was first to show that T cells specific for gluten circulate in celiac disease patients' blood, confirming celiac disease is a systemic disease.

YOUNG *Investigator* PRIZE IN BASIC SCIENCE



\$10,000 ★

EARLY CAREER ACHIEVEMENTS
IN CELIAC DISEASE RESEARCH

Valerie Abadie, PhD is a Research Associate Professor at the University of Chicago, Department of Medicine, section of Gastroenterology. Her groundbreaking work includes the identification of the immune mechanisms leading to the loss of oral tolerance to gluten, and the development of the first pathophysiological mouse model of celiac disease.

YOUNG *Investigator* PRIZE IN CLINICAL SCIENCE



\$10,000 ★

EARLY CAREER ACHIEVEMENTS
IN CELIAC DISEASE RESEARCH

Maureen Leonard, MD, MMSc is Assistant Professor of Pediatrics at Harvard Medical School, Clinical Director of the Center for Celiac Research and Treatment at Mass General Hospital for Children, and co-investigator of the Celiac Disease Genomic Environmental, Microbiome and Metabolomic Study, CDGEMM aims to identify biomarkers that may predict the onset of autoimmune disease.

TO BE AWARDED IN 2024

CELIAC DISEASE FOUNDATION-TAKEDA
EARLY CAREER

Research Award

AWARD: \$180,000

PROMOTING EDUCATION



Robust 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.

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, with **CEO Marilyn G. Geller providing updates on current developments in research and advocacy to these global audiences.**

TOOLS AND PROGRAMS

- ▶ **Celiac.org**, the world's most trafficked website for celiac disease information and support.
- ▶ **Online Symptoms Assessment Tool** web-based tool used by millions to determine if they have an increased risk for celiac disease based on questions about unexplained symptoms or a family member with celiac disease.
- ▶ **Healthcare Practitioner Directory**, a free listing of credentialed physicians, dietitians, mental health professionals, and allied health providers in all 50 states who treat patients with celiac disease. This directory connects with the Symptoms Assessment Tool to provide guidance for patients.
- ▶ **Eat! Gluten-Free website and app** with dietitian-created meal plans and recipes, plus product listings to help visitors discover what's new locally and globally on the gluten-free market.
- ▶ **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.
- ▶ **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.
- ▶ **Celiac Strong Day** supports schools nationwide to raise awareness of celiac disease among the next generation in their learning environments – providing students, teachers, parents, and faculty with materials to educate classrooms and communities.
- ▶ **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.

EFFECTIVE ADVOCACY



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

Driving Policy Change – Today and Tomorrow

DELIVERED ▶ Championed the advocacy effort in Congress to successfully secure first-ever **2023 U.S. Department of Defense** funding for celiac disease research.

LED ▶ Led expert 21-partner coalition recommendations to the **U.S. Department of Agriculture** to address food equity and insecurity, advocating changes to the **WIC Food Package Proposed Rule** to meet the needs of celiac disease patients.

CHAMPIONED ▶ Provided recommendations to the **U.S. Food and Drug Administration** advocating policy updates to standardize labeling for online grocery shopping so patients can shop with confidence.

LAUNCHED ▶ Established the **Celiac Disease Foundation Research Working Group**, bringing together researchers, experts from academia, and other stakeholders to inform advocacy efforts on current policy topics vital to patient health and well-being.

ATTAINED ▶ Joined Representative Betty McCollum (D-MN) to establish the **U.S. Congressional Celiac Disease Caucus** to support federal funding for celiac disease research and advance policies to ease the suffering of celiac disease patients.

PROMOTED ▶ Partnered with **U.S. Department of Defense** to drive global engagement in first-time research funding opportunities for celiac disease researchers and promote patient involvement to support ongoing government funding for treatments and a cure.

SUPPORTED ▶ Championed successful creation of the **National Institutes of Health Office of Autoimmune Disease Research** and serving as a coalition member to assist with office establishment.

DEBUTED ▶ Introduced **Policy Advocate training program**, educating celiac disease advocates on policy priorities, launched monthly **Advocacy Update** featuring current celiac disease news, and introduced **Patient Profile Series** highlighting stories from our community.

2022

FINANCIALS

\$

For the Year Ended 12.31.2022

ASSETS

Cash and Cash Equivalents	\$2,249,225
Contributions Receivable	\$487,294
Investments	\$1,523,002
Other Assets	\$208,882

Total Assets	\$4,468,403
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LIABILITIES

Accrued Liabilities	\$427,067
Deferred Revenue	\$168,582

Total Liabilities	\$595,649
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NET ASSETS

Total Net Assets	\$3,872,754
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SUPPORT AND REVENUE

Contributions	\$1,837,809
Other Income	\$1,386,624

Total Revenue	\$3,224,433
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EXPENSES

Program	\$2,010,112
Management and General	\$176,176
Development	\$347,765

Total Expenses	\$2,534,053
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Change in Net Assets	\$690,380
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