2023 ANNUAL REPORT
celiac.org

Accelerating Diagnosis, Treatments, and a Cure for Celiac Disease
Driving Innovation and Advancing Treatment

**iRecruitCeliac**

Launched 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

Strategic investments in cutting-edge biomedical research and patient engagement are driving advancement and progress toward treatments and a cure for celiac disease.
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, MMS 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**
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.
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.
## For the Year Ended 12.31.2022

### ASSETS

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### SUPPORT AND REVENUE

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