CELIAC DISEASE FOUNDATION®

ADVOCACY. BREAKTHROUGHS. CURE.

ANNUAL REPORT

Accelerating Diagnosis, Treatments, and a Cure for Celiac Disease

2026

celiac.org

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LETTER FROM MARILYN

To Our Global Celiac Disease Community,

2026 was the year the Celiac Disease Foundation fundamentally elevated what is possible for our community. For decades, the standard was defined by adapting, coping, and accepting a strict gluten-free diet as the sole solution. Today, we are setting a bold new course. As the leading organization fighting for the nearly 100 million people affected worldwide, we are driving aggressive innovation across science, healthcare, and public policy.

This year, we launched the Celiac Disease Foundation Impact Fund, a venture philanthropy initiative with a $15 million target designed to deploy disciplined capital directly into transformative diagnostics, treatments, and an eventual cure. Taking our mission to the floor of the New York Stock Exchange, we made it clear: traditional grantmaking alone is not enough. By reinvesting returns into high-potential ventures, we are building a compounding model that accelerates breakthroughs while ensuring long-term sustainability.

Across every front, our leadership produced tangible results:

- **Pioneering Research:** We allocated more than $1.1 million to forward-looking research, education, and symposiums, uncovering cellular mechanisms of autoimmune triggers, engineering less immunogenic wheat varieties at UC Davis, and piloting AI tools to train future clinicians. Through our formal integration with the Society for the Study of Celiac Disease (SSCD), we nearly doubled professional membership to advance unified diagnostic standards.

- **Relentless Advocacy:** We mobilized tens of thousands of advocates to introduce the federal Celiac Safety Act in Congress, protected dedicated NIH and Department of Defense research funding, and drove the multi-year effort that led the FAO/WHO Codex Alimentarius to update international precautionary allergen labeling for gluten cross-contact.

- **Securing Future Access:** In partnership with SSCD, our landmark policy symposium convened researchers, regulators, and insurers to build the reimbursement and diagnostic infrastructure needed so emerging therapeutics reach every patient without administrative barriers.

- **Deepening Community Impact:** We expanded our nutrition education programs, launched the *Inside Celiac* podcast with Katie Lowes, and nearly doubled our Celiac Disease Food Insecurity Resource Network (CD-FIRN) to 36 sites across 23 states and Washington, D.C.

Backed by our growing network of donors, fundraisers, and endurance athletes, our net assets grew to over $6.8 million, ensuring we have the financial strength to think big and act decisively. We are no longer waiting for progress – we are building it. Thank you for standing with us as we lead the fight for a cure.



With gratitude and determination,

Marilyn G. Geller, MSPH
Chief Executive Officer
Celiac Disease Foundation



POLICY SYMPOSIUM

By uniting every key stakeholder now, the Celiac Disease Foundation and SSCD are building a clear roadmap to ensure future celiac treatments reach the people who need them – without avoidable diagnostic, administrative, or coverage barriers.

– Dawn Adams, MD, MS, CNSC, SSCD Chair

POLICY SYMPOSIUM

Building the Path from Discovery to Delivery



Scientific breakthroughs mean nothing if patients cannot access them. In June 2026, the Celiac Disease Foundation and the Society for the Study of Celiac Disease (SSCD) convened an unprecedented summit uniting pioneers from research, clinical medicine, federal regulation, health economics, commercial insurance, and patient advocacy.

With promising treatments advancing through pipelines, our objective was urgent and clear: build the policy, reimbursement, and clinical infrastructure today so that tomorrow's therapeutics reach patients equitably, affordably, and without delay.

1. **Diagnosis**
   Validating inclusive clinical pathways and legacy records.
2. **HLA Testing & Trial Design**
   Harmonizing trial criteria with real-world practice.
3. **Treatment Eligibility**
   Defining medical need based on total patient burden.
4. **Payer Evidence**
   Demonstrating economic value and quality-of-life outcomes to insurers.
5. **Advocacy & Access Lessons**
   Centering patient needs in reimbursement policy.

What This Accomplishment Made Possible

- **A Unified Access Agenda:** Aligned drug developers, clinicians, and payers on the real-world evidence required alongside late-stage clinical trials.
- **Modernized Diagnostic Pathways:** Advanced a graded diagnostic model that recognizes legacy patient records, preventing past paperwork gaps from blocking future care.
- **Patient-Centered Eligibility:** Established that treatment eligibility must reflect holistic disease burden — symptoms, intestinal damage, gluten exposure, daily lifestyle limits, and patient goals — not single biomarkers alone.
- **Proactive Payer Engagement:** Defined the concrete outcomes that insurers require for coverage, including reduced healthcare utilization and measurable quality-of-life gains.
- **Guardrails Against Coverage Barriers:** Determined that rigid trial parameters, mandatory repeat biopsies, or genetic variations must not become arbitrary coverage denials.

THE CENTRAL TAKEAWAY

Regulatory approval alone will not guarantee access. By bringing the right voices together now, the Foundation and SSCD are helping ensure that future celiac treatments can reach the people who need them without avoidable diagnostic, administrative, or coverage barriers.

SSCD
SOCIETY FOR THE STUDY OF CELIAC DISEASE



PUBLIC POLICY & GOVERNMENT AFFAIRS

The Celiac Disease Foundation has been an invaluable partner in advancing the CAPE Act and SNACCK Act. Their leadership brings together scientific expertise and the voices of patients and families, helping us turn community needs into meaningful legislation. I'm proud to work alongside them to build a healthier, safer Massachusetts for people with celiac disease.

– Massachusetts State Representative Michelle Badger,
Recipient of the 2026 Policy Leadership Award

PUBLIC POLICY & GOVERNMENT AFFAIRS

Transforming Advocacy into Historic Policy Victories

Patient advocacy is the heartbeat of the Celiac Disease Foundation. In 2026, we translated grassroots passion into landmark systemic change, from introducing historic federal legislation on Capitol Hill to reshaping international food labeling standards on the world stage. By aligning thousands of dedicated patient advocates with clinical experts and global allies, we solidified our role as the preeminent authority in celiac health policy. From state capitols to international governing bodies, our targeted advocacy delivered measurable wins, dismantling barriers and securing vital resources that will protect and empower our community for generations.

20,000+
constituent emails

60+
congressional offices

30
state proclamations

FEDERAL LEGISLATIVE ACTION

THE CELIAC SAFETY ACT

Working with Representatives Emanuel Cleaver and Betty McCollum, we advanced legislation to classify gluten-containing grains as major allergens. Community advocacy – including Call Your Rep Day and more than 20,000 emails – helped secure **over 50 co-sponsors.**

INTERNATIONAL STANDARDS

A GLOBAL FOOD SAFETY MILESTONE

Under CEO Marilyn Geller's leadership, coordinated advocacy helped bring gluten into FAO/WHO Codex guidance. Together with the Global Celiac Advocacy Alliance, AOECS, and the ISSCD Gluten Safety Standards Committee, we helped advance **science-based standards** for "May Contain" statements.

2026 ADVOCACY SUMMIT

RESEARCH FUNDING PROTECTED

In March, **35 trained patient advocates** met with more than 60 congressional offices. Celiac disease retained dedicated NIH research allocations in FY26 and remained eligible for the Department of Defense's Peer-Reviewed Medical Research Program.

GRASSROOTS LEADERSHIP

PROGRESS IN MASSACHUSETTS

Advocates secured a record 30 state proclamations recognizing Celiac Disease Awareness Month. In Massachusetts, we helped introduce the **CAPE Act** for routine pediatric celiac screening and the **SNACCK Act** for safer gluten-free meals in schools.



Advocates at Hill Day 2026

Patient voices. Scientific leadership. Lasting change.



CLINICAL **OPERATIONS**

"I'm deeply grateful to the Celiac Disease Foundation for connecting me with this clinical trial and helping me turn my experience with celiac disease into a contribution to science. Their work creates opportunities for patients like me to be part of the search for better treatments. It means so much to have a role in building a better future for our community."

–Gabrielle Hemmond, Clinical Trial Participant

CLINICAL OPERATIONS

Accelerating Celiac Disease Research

In 2026, we turned momentum into meaningful progress for the celiac disease community. From expanding access to clinical research to generating original evidence and equipping the field with practical tools, our work is advancing celiac disease research and bringing better treatments within reach.

HIGHLIGHTS:

11
clinical trials and studies supported through iRecruitCeliac Services

1300+
patients contributed to lived experience research

37,500+
patients engaged in our iQualifyCeliac study screening platform, with 3 original research posters using iQualifyCeliac data presented at global conferences

Trial recruitment spanned **6** countries across **3** continents

Advancing the Evidence Base for Celiac Disease

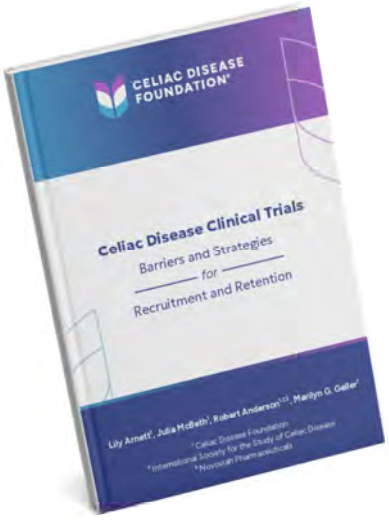
Celiac Disease Foundation research conducted with Chugai Pharmaceutical was presented at ISPOR 2026, the leading global conference for health economics and outcomes research. The study provides new evidence of the real-world burden of accidental gluten exposure, including lost productivity, financial strain, healthcare use, and restricted daily activities. ISPOR placed this evidence before the researchers, health economists, and industry leaders who shape decisions on treatment value and unmet need. The findings were also presented at Digestive Disease Week 2026, the AOECS Annual Conference, and the International Celiac Disease Symposium.

Our data also powered partner research presented at DDW 2026. Using iCureCeliac® registry data, Columbia University and Teva, led by Dr. Benjamin Lebwohl, found that a quarter of patients with excellent gluten-free diet adherence still carry a significant symptom burden. Takeda's Virtual Celiac Symptom Study, supported by the Foundation, showed that symptoms often persist even without known gluten exposure.

Improving Recruitment, Retention & Engagement in Clinical Trials

We released a new white paper and Best Practices Toolkit translating insights from clinical trial investigators and coordinators into practical strategies to improve recruitment, retention, and participant engagement in celiac disease research.

These findings were also presented at Digestive Disease Week and the International Celiac Disease Symposium, bringing this work to a broad audience of gastroenterology and clinical research professionals. Our toolkit provides actionable recommendations that research teams can apply to real-world clinical trials to strengthen trial participation and advance new treatments for celiac disease.





SCIENTIFIC AFFAIRS

Bringing the Celiac Disease Foundation and SSCD together has created new opportunities to connect the people advancing celiac disease research, clinical care, and education. From strengthening clinical standards to supporting emerging investigators, we are building a more connected professional community and creating greater opportunities for progress across the field.

– Maureen Leonard, MD, MMSc, SSCD Chair Elect

SCIENTIFIC AFFAIRS

Uniting Science, Medicine, and Clinical Excellence

As North America's professional medical society dedicated to celiac disease, the Society for the Study of Celiac Disease (SSCD) brings together clinicians, researchers, and other professionals advancing the field. Through its formal integration as the Celiac Disease Foundation's Scientific Advisory Committee, SSCD is strengthening connections across research, clinical care, education, and advocacy. This collaboration also supported significant growth in SSCD's professional membership, which doubled in 2026.

Doubled
professional membership in 2026

13
Celiac Recognized Units of Excellence at premier medical centers.

5
active volunteer committees

STRATEGIC LEADERSHIP

IMPROVING CLINICAL STANDARDS

Setting New Benchmarks of Care: Formulated the first-ever joint Society for the Study of Celiac Disease-American Gastroenterological Association (SSCD-AGA) clinical guideline on treating asymptomatic celiac disease.

Strengthening Global Collaboration at ICDS: SSCD Executive Council members Marisa Stahl, Marie Robert, Ritu Verma, Maureen Leonard, Stephanie Moleski, Nan Du, and Christopher Cao contributed to scientific, clinical, and educational programming at ICDS. Sessions addressed disease triggers, histology, clinical and dietitian education, lessons from recent therapeutic trials, and international perspectives.

TRANSFORMING

PEDIATRIC GUIDELINES

Elevating the Patient Voice in Medical Protocols: In partnership with NASPGHAN, secured approval to author updated pediatric diagnostic guidelines. Chief Programs Officer Vanessa Weisbrod was appointed as patient representative, collaborating alongside SSCD Executive Council leaders Drs. Maureen Leonard and Ritu Verma to directly shape future standards of pediatric care.

Establishing Standards for Pediatric Clinical Trials: SSCD leadership and CEO Marilyn Geller co-authored an ESPGHAN/NASPGHAN position paper providing consensus recommendations for the design of clinical trials for novel, nondietary therapies for pediatric celiac disease, accepted for publication in the Journal of Pediatric Gastroenterology & Nutrition.



Left to right: Dr. Stephanie Moleski, Dr. Dawn Adams, Dr. Marisa Stahl, Dr. Maureen Leonard, Dr. Ritu Verma, and Dr. Hilary Jericho.

SSCD
SOCIETY FOR THE STUDY OF CELIAC DISEASE

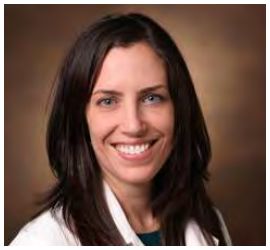
SCIENTIFIC AFFAIRS

Investing in the Next Generation of Research Leaders

- **Funding High-Impact Research:** Launched dietitian-specific and early-career research grants and awarded two fellowships advancing research into early screening pathways and microbiome mechanisms.
- **Expanding Professional Opportunities:** Established a visiting fellowship and awarded it to an investigator from the University of Nebraska Medical Center, who will complete the fellowship at Vanderbilt University Medical Center, alongside eight competitive travel grants enabling rising investigators to present their research at DDW, ICDS, and NASPGHAN.

Professional Education & Higher-Education Policy

- **Standardizing Higher Education Accommodations:** Convened more than 150 collegiate administrators, clinicians, and student advocates at the annual SSCD College Summit to establish actionable, national best practices for supporting celiac students in higher education.
- **Translating Science into Practice:** Produced an intensive, seven-part professional webinar series dedicated to optimizing clinical trial performance and equipping emerging investigators with clinical research tools.
- **Digital Reach for Clinicians:** Launched the dedicated professional platform on Instagram (@sscdceliac), delivering SSCD updates, research updates, clinical pearls, and critical celiac disease news directly to healthcare practitioners.



Dawn Adams, MD, MS, CNSC
Chair



Maureen Leonard, MD, MMSc
Chair Elect



Ritu Verma, MD
Past Chair



Stephanie Moleski, MD
Secretary



Marisa Stahl, MD, MSCS
Treasurer



Christopher Cao, MD
Councilor-At-Large



Nan Du, MD, MPH
Councilor-At-Large



Andrew Ford, MD
Councilor-At-Large



Marie Robert, MD
Councilor-At-Large



Janelle Smith, MS, RDN, CSDH, CEDS
Councilor-At-Large

Our Research, Shared with the World

POSTERS AND PRESENTATIONS

Posters presented at Digestive Disease Week (DDW), ISPOR, AOECS, National Health Council Summit, and ICDS 2026

- High Frequency, Prolonged Duration and Substantial Functional Impact of Acute Gluten Exposure in Adults with Celiac Disease: A Large National Study of Real-World Burden
- Symptom Severity and Inadvertent Gluten Exposure Among Patients with Celiac Disease
- Barriers and Strategies for Recruitment and Retention in Celiac Disease Clinical Trials: Insights from a Mixed-Methods Analysis of U.S. Research Sites
- Gluten-Free Diet Adherence, Symptom Burden, and Productivity Loss in Patients with Celiac Disease
- Real-World Functional, Economic, and Behavioral Burden of Acute Gluten Exposure in U.S. Adults with Celiac Disease: Insights from a Large National Cohort
- Implementation of the Celiac Disease Food Insecurity Resource Network (CD-FIRN): A Multi-Center Program Integrating Food Insecurity Screening with Gluten-Free Food Assistance
- Improving Knowledge and Confidence in Individuals Managing Celiac Disease Through a Dietitian-Led Virtual Education Program
- Virtual Culinary Medicine Programming Is an Effective Educational Tool for Individuals with Celiac Disease
- The Road to Insurance Coverage for Celiac Disease Therapeutics: Identifying Critical Gaps Before Market Approval
- Quantifying Dietary Gluten Exposure From Shared Fryers: Implications for Nutritional Management & Health Outcomes in Celiac Disease
- Evaluation of ANB033, an Investigational CD122 Antagonist Monoclonal Antibody, for the Treatment of Celiac Disease: A Novel Phase 1 Clinical Study Design

PEER-REVIEWED PUBLICATIONS AND ACCEPTED MANUSCRIPTS

- Weisbrod VM, McKeon MD, Stahl MG, Germone M, Nagle S, Jossen J, Lebovits J, Leonard MM, Perl J, Geller MG, et al. Shared Fryers May Not Always Be as Risky for Gluten Cross-Contact in Celiac Disease as Dietary Guidance Suggests. *Nutrients*. 2026; 18(20):3433. https://doi.org/10.3390/nu18203433
- Weisbrod V, Donnelly McKeon M, Kowzun E, et al. Accommodating Celiac Disease in Higher Education: Evidence-Informed National Recommendations. *Nutrients*. 2026;18(2):294. DOI: 10.3390/nu18020294
- Ghura S, Adams DW, Geller MG, et al. Psychometric Evaluation of the Celiac Disease Symptom Diary 2.1© Using Data from the Virtual Celiac Symptoms Study. *Patient Related Outcome Measures*. 2026;16:271-284. DOI: 10.2147/PROM.S553006
- Popp A, Leonard MM, Koletzko S, Geller MG, et al. Designing clinical trials for novel therapies for pediatric celiac disease: An ESPGHAN/NASPGHAN position paper. *Journal of Pediatric Gastroenterology & Nutrition*. Accepted for publication.

ADDITIONAL RESEARCH OUTPUTS

- Rottersman MG, Zhang W, Zhang J, et al. Deletion of wheat alpha-gliadins from chromosome 6D improves gluten strength and reduces immunodominant celiac disease epitopes. Theoretical and Applied Genetics. 2025;138:94. DOI: 10.1007/s00122-025-04882-3
- Rottersman MG, Laudencia-Chingcuanco D, Zhang W, et al. A genetic toolkit to reduce wheat immunogenicity and incidence of celiac disease. bioRxiv. Posted June 25, 2026. Preprint, not peer-reviewed. DOI: 10.64898/2026.06.23.734071



FUNDED PROJECT UPDATES

Support from the Celiac Disease Foundation has been instrumental in helping us advance our research from an idea into meaningful work that can ultimately benefit people living with celiac disease. I'm grateful for the Foundation's commitment to supporting researchers and helping move promising ideas forward.

– Nan Du, MD, MPH Boston Children's Hospital

FUNDED PROJECT UPDATES

Accelerating Discovery, Empowering Clinicians, and Driving Global Innovation

At the Celiac Disease Foundation, we invest in bold ideas and innovative programs that accelerate research, strengthen clinical care, and improve the lives of people with celiac disease. From funding studies and global symposia to supporting training programs that prepare the next generation of providers, our commitment ensures that science advances faster, patients are diagnosed sooner, and every family has access to the care and resources they deserve.

Research Projects

Celiac Disease Foundation Research Grant

Maureen Leonard, MD, MMSc
Massachusetts General Hospital

Defining Early Biological Signals in Celiac Disease

This research aims to identify the earliest biological signals that precede celiac disease. By analyzing blood samples collected over time from children at genetic risk, the study will identify protein signatures associated with progression to celiac disease and integrate these findings with changes in immune cells and gene expression. The work could reveal new biomarkers, laying the groundwork for earlier prediction and intervention.

Celiac Disease Foundation-SSCD Outreach Program Award

Amelia Therrien, MD, MS
Beth Israel Deaconess Medical Center

Outreach Program to Improve Detection of Celiac Disease

Expanded screening access in Greater Boston's Latino community with 208+ Spanish-speaking patients enrolled, identified primary-care gaps, and piloted an EHR home-screening approach reaching 11,000+ patients.

Celiac Disease Foundation – NASPGHAN Foundation Celiac Disease Pilot Grant

Monique Germone, PhD
Children's Hospital Colorado

Caregivers to Uncover Barriers and Facilitators to Diagnostic Confirmation

Investigated family perspectives following positive pediatric screens, identifying critical barriers (insurance referrals, costs) and motivators to build family-centered pathways from screening to confirmed care.

Celiac Disease Foundation – NASPGHAN Foundation Young Investigator Development Award

Nan Du, MD, MPH
Boston Children's Hospital

GF-NOURISH: Gluten-Free Nutrition Optimization

Enrolled 91 participants to evaluate whole-food dietary patterns as an alternative to ultra-processed foods; 70% increased fruit intake without added gluten risk, and 82% rated the guidance very helpful. Findings to be presented at NASPGHAN and ICDS 2026.

UC Davis Wheat Grant

Maria Rottersman & Research Team

UC Davis & USDA-ARS

Engineering Less Immunogenic Wheat Varieties

Successfully eliminated celiac-triggering proteins in experimental wheat lines while maintaining gluten dough strength and grain yield, advancing California as a leader in less immunogenic wheat varieties.

Research Projects

ISSCD – Celiac Disease Foundation Research Fellowship Award

Fleur du Pré, PhD
Oslo University Hospital

B-Cell T-Cell Cross Talk in Celiac Disease

Developed a novel mouse model demonstrating how intestinal transglutaminase 2 (TG2) interacts with gluten to spark the autoimmune antibody cascade, revealing key targets to block disease development at its source (submitted for publication).

Celiac Disease Foundation / NASPGHAN Foundation Pilot Grant

Stephanie Camhi, MD, MPH
Massachusetts General Hospital

Interrogation of a novel *Bifidobacterial* strain to protect against gliadin-induced enteropathy in a model of pre-celiac disease

The goal of this work is to understand if a specific probiotic can protect against inflammation and increased intestinal permeability, thereby preventing the onset of celiac disease.

Celiac Disease Foundation Research Grant

Ritu Verma, MD
University of Chicago Celiac Disease Center

Celiac Disease Siblings Study

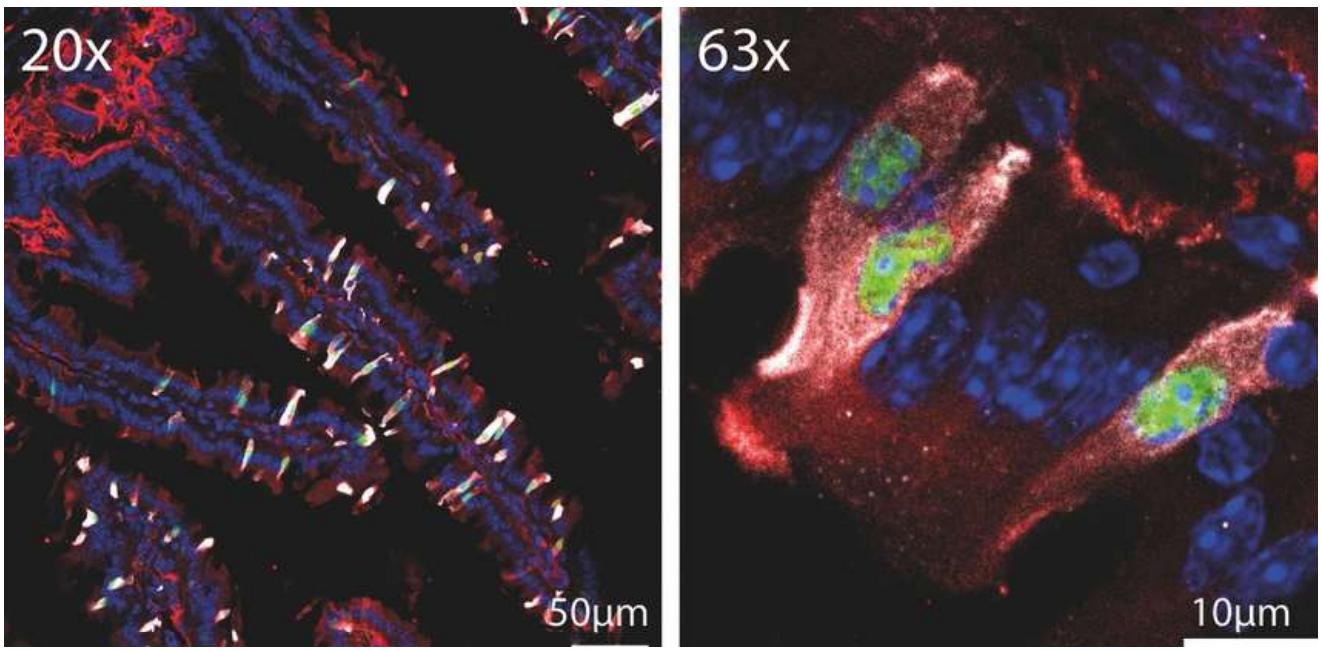
Developed the framework for a family-centered educational booklet addressing the experiences and needs of siblings of children with celiac disease, with a sibling focus group planned to inform the final resource.

SSCD Dietitian Award

Alyssa Ramuscak, RD, MHSc, MSc
University of Guelph

Co-Designing a Digital Health Application to Support Gluten-Free Diet Adherence Among Adolescents with Celiac Disease

This project will co-design and usability-test a youth-centered digital health app to help adolescents with celiac disease manage a gluten-free diet. By partnering with adolescents throughout development, the project aims to provide accessible, evidence-based nutrition education and ongoing support that addresses both dietary and psychosocial challenges.



Images submitted by Fleur du Pré exploring how the interaction between gluten and tissue TG2 may contribute to the development of celiac disease in a mouse model.

FUNDED PROJECT UPDATES

Education Initiatives:

MedTutor AI

Nan Du, MD, MPH
Boston Children's Hospital

Harvard Macy Institute Program for Educators in Health Professionals

Created an interactive AI clinical simulation platform targeting fellow knowledge gaps in IgA deficiency and gluten-free management. Successfully piloted with 13 pediatric GI fellows with plans to expand deployment across multiple centers.

Celiac Smarts: From Hypervigilance to Harmony

Boston Children's Hospital Celiac Disease Program

Educational Program Grant

Boston Children's Hospital's Celiac Smarts program brought together 110 clinicians for a four-session, multidisciplinary course designed to sharpen the diagnosis and management of celiac disease in everyday practice. Proud to sponsor the program, the Celiac Disease Foundation supported a curriculum that awarded 44 continuing education credits and left a lasting impression: every single attendee reported satisfaction with the course, and 75% of participating providers said they now plan to change how they practice. It's a clear signal that investing in clinician education translates directly into better, faster care for patients with celiac disease.

10th Annual John D. Snyder Memorial Grand Rounds

Children's National Medical Center

Educational Grand Rounds Grant

This special Grand Rounds session on June 10, 2026, brought together Dr. Ritu Verma and Vanessa Weisbrod for a landmark conversation honoring Dr. John Snyder's memory and celebrating ten remarkable years of progress in the fight against celiac disease. Together, they traced a decade of transformation: breakthroughs that have reshaped pediatric research, advances that have redefined clinical care, and hard-won victories that have strengthened advocacy for patients and families everywhere. In the spirit of Dr. Snyder's legacy, the session offered both a heartfelt retrospective and a clear-eyed look at the work still ahead.



The staff of the Celiac Disease Program at Children's National Hospital in Washington, D.C.

International Symposiums

Celiac Disease Across the Lifespan CME Program

University of Chicago Celiac Disease Center

Clinical Education & Best Practices

The 2026 CME program brought together more than 100 healthcare professionals alongside international faculty for an in-depth look at celiac disease — from accurate diagnosis to management across every stage of life, through the emerging therapies now shaping the future of care.

Digestive Disease Week (DDW) 2026

Chicago, IL

Global Clinical & Research Congress

The Foundation brought its mission to Digestive Disease Week, the country's leading multidisciplinary gastroenterology meeting, supporting education and professional engagement among the field's top clinicians and researchers. While there, the Foundation hosted the Society for the Study of Celiac Disease Annual Meeting and brought celiac disease awareness beyond the conference halls with a dedicated Chicago Cubs game, where Dr. Ritu Verma threw out the ceremonial first pitch.

AOECS Annual Conference

Association of Coeliac Societies (AOECS)

Global Patient Advocacy Meeting

The Foundation partnered with AOECS to advance global collaboration on celiac disease — from clinical trials and research funding to the food labeling standards that help patients eat safely wherever they live.



CEO Marilyn Geller leading a patient advocacy workshop at 2026 AOECS Conference.

FUNDED PROJECT UPDATES

International Symposiums

NASPGHAN Annual Meeting

San Diego, CA

Funding Pediatric Discovery, Translating Evidence to Care

At this year's NASPGHAN Annual Meeting, the Foundation awarded its annual Pilot Grant, supporting the next wave of investigators. Vanessa Weisbrod also took the stage at the Council for Pediatric Nutrition Professionals (CPNP) Forum, presenting new evidence on gluten cross-contact — including findings from a first-of-its-kind shared-fryer study — and outlining how clinicians can begin preparing today for the therapies, and the coverage questions, on the horizon.

Colorado Celiac Disease Screening Symposium

Aurora, CO & Melbourne, Australia

Population Screening & Early Detection

Held alongside the International Celiac Disease Symposium (ICDS) this November in Colorado, this symposium brought together international stakeholders to share pilot data and build global consensus around routine, population-based celiac disease screening. Leaders from across the field compared early results and discussed the practical steps needed to move screening from isolated pilots to standard practice. Vanessa Weisbrod spoke on the Foundation's state-based efforts to advance screening in Massachusetts, offering a real-world model for how screening policy can move from pilot to practice — and a blueprint other states can follow.

International Celiac Disease Symposium (ICDS 2026)

Melbourne, Australia

Premier International Scientific Meeting on Celiac Disease

This meeting anchored the Foundation's presence at the world's leading scientific gathering for celiac disease, with a full slate of original research presentations and sessions spanning both the science and the patient experience. The Foundation also convened global patient organizations and the Global Celiac Advocacy Alliance (GCAA), and presented the ISSCD-SSCD Excellence and Young Investigator Prizes, honoring the researchers advancing the field's next breakthroughs.



Panelists at the Colorado Celiac Disease Screening Symposium



EDUCATION

I was diagnosed 6 months ago. I've attended all of the sessions and I am so thankful for the program. I really learned a lot and have more confidence in living with celiac. I have already had to deal with travel and work meetings and the program has really given me confidence to speak up and advocate for myself. Thank you so much!!

– Sarah H., *Foundations of Celiac Disease* participant

Closing Gaps in Celiac Disease Education

In 2026, the Celiac Disease Foundation broke down barriers to critical healthcare guidance, delivering trusted, evidence-based education directly to patients, families, clinicians, and educators. Recognizing that access to expert nutrition care is often out of reach, we introduced bold new initiatives to close systemic gaps while expanding cornerstone programs that empower our community. Together, these efforts reached thousands worldwide, equipping individuals with the knowledge, clinical insight, and confidence needed to navigate celiac disease with authority.

Milestones



Foundations of Celiac Disease breaks new ground:

Led by Senior Director of Education & Communications Meghan McKeon, MS, RDN, and developed alongside our Dietitian Advisory Council (CDF-DAC), this flagship initiative launched to provide vital dietitian-led education to underserved patients. The program engaged over **2,500 participants** in its debut year. Fueling this vital mission, the Foundation secured a **landmark $225,000 philanthropic gift** to build and launch a fully adapted Spanish-language version in 2027, substantially broadening health equity for Spanish-speaking communities.

Culinary Medicine:

More than **1,000 patients and healthcare professionals** participated in *Innovations in Culinary Medicine*, exploring how food and nutrition can be applied to celiac disease and co-occurring conditions. The virtual program brings patients and providers together to learn from experts and translate medical concepts into practical strategies.

Living with Celiac:

Connected hundreds of newly diagnosed patients and families directly to celiac disease experts through monthly interactive Q&As. Participants received real-time, actionable guidance on dietary management, emotional wellbeing, cross-contact prevention, and everyday lifestyle challenges.

School Support Sessions:

Continued our partnership with Boston Children's Hospital through monthly School Support Sessions, giving hundreds of families practical guidance on 504 Plans, gluten-free meals, cross-contact, communication with schools, and creating inclusive environments for students with celiac disease.

Celiac Disease Food Insecurity Resource Network

Sites enrolled in the program

The CD-FIRN program nearly doubled its reach in 2026, scaling to 36 hospital centers across 23 states and Washington, D.C. By collaborating directly with healthcare providers, CD-FIRN screened vulnerable patients and delivered monthly boxes of medically necessary gluten-free staples.





COMMUNITY ENGAGEMENT

Living with celiac disease affects so much more than what is on your plate. It shapes how you travel, celebrate, work, parent, and move through the world. I am thrilled to host Inside Celiac and create a space where people can hear honest stories, learn from trusted experts, and feel less alone. This series is about giving our community a stronger voice while helping the broader public understand the very real impact of this disease.

– Katie Lowes, actress and *Inside Celiac* podcast host

Stronger together. Breaking barriers everywhere.

In 2026, we brought celiac disease outreach to classrooms, ballparks, clinics, and digital platforms worldwide. Grassroots action and high-impact partnerships expanded our reach, challenged barriers to care, and advanced early diagnosis so no family stands alone.

A NEW VOICE FOR OUR COMMUNITY

Inside Celiac with Katie Lowes

Actress and advocate Katie Lowes hosts our new flagship podcast, bringing patient experience and medical science into the same conversation. Clinicians, researchers, and community voices explore diagnosis, gluten-free living, emotional health, and cutting-edge therapeutics.



Actress Katie Lowes





Foundation staff on Celiac Cruise

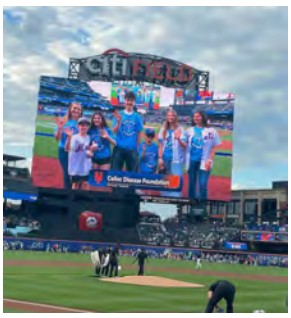
Education that travels further

2,000+ CREW MEMBERS TRAINED

Our Celiac Cruise partnership trained more than 2,000 crew members, brought educational programs and community events to guests, and raised funds that directly supported CD-FIRN.

Big-league visibility. Real community.

Celiac Disease Awareness Baseball Games reached tens of thousands of fans in Chicago, New York, Boston, Arizona, and Tampa Bay. Community events, in-stadium messages, and local engagement brought celiac disease into the spotlight.



Advocates accepting the Amazin' Award at Citi Field

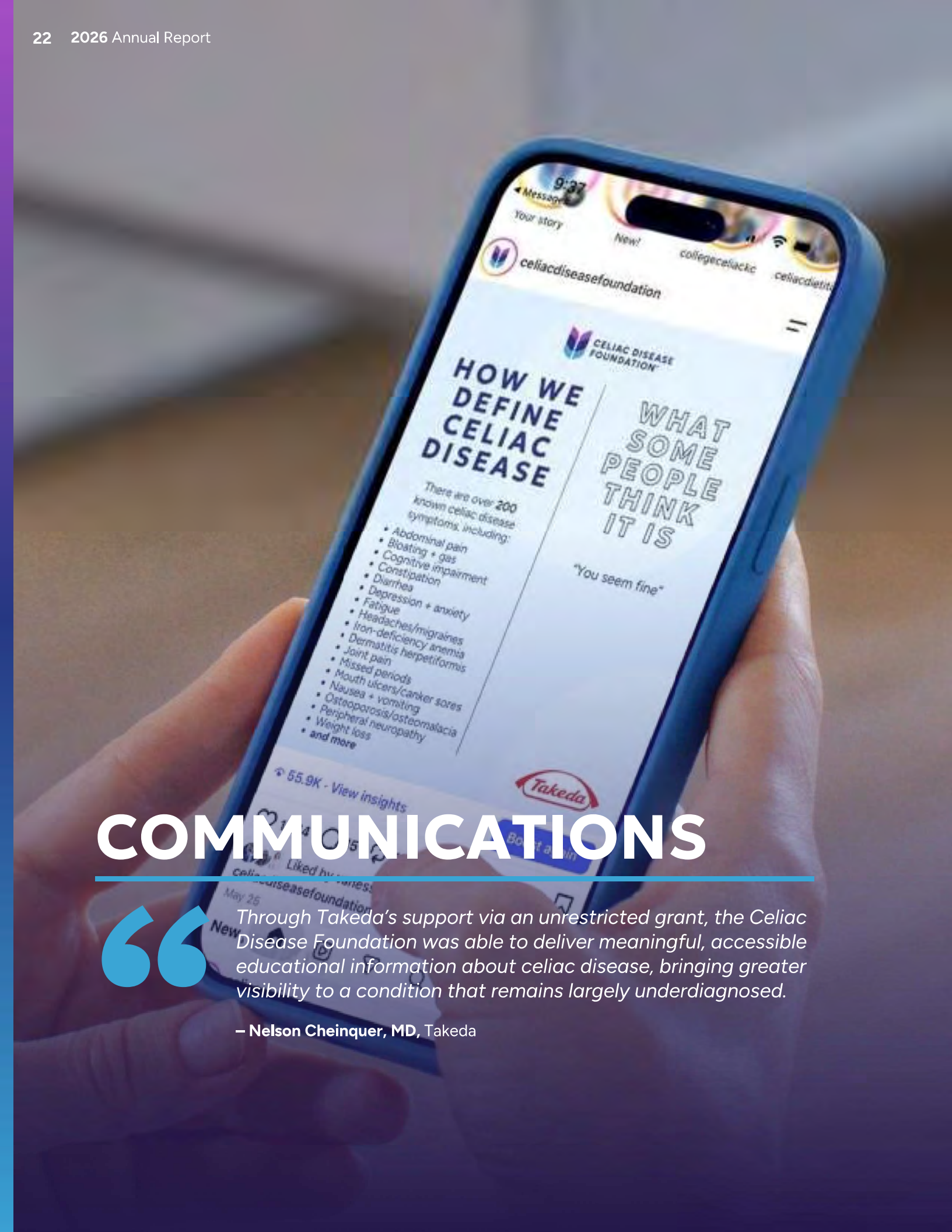


Celiac awareness at the Red Sox game

80+

Celiac Strong Day

More than 80 classrooms gained resources to help students and educators build understanding, inclusion, and support for students with celiac disease.



COMMUNICATIONS

Through Takeda's support via an unrestricted grant, the Celiac Disease Foundation was able to deliver meaningful, accessible educational information about celiac disease, bringing greater visibility to a condition that remains largely underdiagnosed.

– Nelson Cheinquer, MD, Takeda

COMMUNICATIONS

Amplifying the Message, Mobilizing Millions

In 2026, the Celiac Disease Foundation expanded its digital footprint to transform how patients, clinicians, and families access life-changing information. By pairing rigorous science with compelling, patient-first storytelling, our platforms became the definitive digital destination for the global celiac community. Through record-setting social engagement, high-impact influencer partnerships, and essential weekly reporting, we didn't just broadcast updates – we listened, engaged, and activated our community.

2026 Defining Communications Victories

RAPIDLY SCALED EMAIL SUBSCRIBER BASE:

Grew our direct email subscriber base by 25% to nearly 112,000 active subscribers between December 2025 and August 2026. Through our signature weekly Celiac Digest, we delivered clinical breakthroughs, advocacy alerts, community spotlights, and nutrition content directly to inboxes worldwide.

HIGH-PERFORMING EDUCATION AWARENESS CAMPAIGNS:

Surpassed all performance metrics on our digital education campaign with Takeda, amassing nearly **3 million total views** and tripling reach to bring attention to celiac disease science and symptom recognition.

DRIVING FEDERAL POLICY VIA INFLUENCER MOBILIZATION:

Activated key digital creators and community influencers to amplify national participation during Call Your Rep Day, driving grassroots support and widespread visibility for the Celiac Safety Act. Contributed to a **200% increase in co-sponsorship for the bill.**

COMMUNITY CONNECTION THROUGH INTERACTIVE PLAY:

Engaged thousands through Glutle, our custom celiac-themed word puzzle, **logging nearly 14,000 game plays** while incorporating celiac disease-related terms and educational content into clues, answers, and tips.

EXPANSIVE DIGITAL ENGAGEMENT & REACH

GENERATED 43.6 MILLION
views across Facebook and Instagram

STAGGERING 74% INCREASE
over 2025

REACHING 6.2 MILLION
unique individuals and expanding our global community to 277,944 followers across Facebook, Instagram, TikTok, YouTube, Threads, and LinkedIn.



Celiac Disease Foundation staff and hospital partners at an educational event in Massachusetts



DEVELOPMENT

When my daughter Kendall was diagnosed with celiac disease at 12 years old, our family quickly learned how important awareness, support, and community are for families impacted by this disease. Our Turkey Trot was an opportunity to bring people together, build that community, raise awareness, and support the Celiac Disease Foundation and the incredible work they do. Seeing everyone come together for such a great cause made the day incredibly special. This was our first Turkey Trot, but it certainly won't be our last – a new tradition was born, and we're excited to see it grow for years to come.

– Chad Graham, Celiac Disease Foundation Development Committee Member

Powering Progress Through Philanthropy

Our mission advances because of an extraordinary community that refuses to accept the status quo. From grassroots runners and family fundraisers to visionary foundations and corporate partners, our supporters invest in what is possible. In 2026, their dedication fueled bold programmatic growth, expanded our geographic footprint, and accelerated vital breakthroughs for the millions of people affected by celiac disease.

Major Philanthropic Achievements

26%

Turkey Trot goes the extra mile:

Our signature November tradition mobilized communities nationwide, driving a 26% year-over-year increase in fundraising. Across the country, families walked, ran, and rallied to turn holiday gratitude into critical research funding and public awareness.

46 ENDURANCE RUNNERS

Team Gluten-Free hits its stride:

46 endurance runners completed more than 1,000 miles across five premier races, expanding to the Marine Corps and Philadelphia Marathons, with Chicago slated for 2027. Meanwhile, grassroots passion surged as community-led fundraising more than doubled year over year.

24%

Donors deepen their commitment:

Through our Donor Circle and direct engagement with scientific leadership, supporters saw the measurable impact of their generosity firsthand. Returning donors deepened their investment, with over one-third increasing their giving and average gift sizes climbing by nearly 24%.

Raise It. Give It. Get It Raises $50,000+

Turning awareness into action:

During Celiac Disease Awareness Month, the Raise It. Give It. Get It! campaign rallied supporters nationwide to share their stories and raise critical funds. Backed by Proud Sponsor King Arthur Baking Company, hundreds of participants joined the fun, turning awareness into meaningful support for the celiac disease community.

103%

YEAR-OVER-YEAR GROWTH

Institutional leadership powers strategic growth:

Support from private foundations grew 103% year over year, demonstrating increased philanthropic investment in the Foundation's mission and providing critical resources to expand programs, advance strategic priorities, and deepen our impact across the celiac disease community.



Board member Blakely Braniff and Chief Advancement Officer Brett Spitale at a fundraising event in Houston, TX



IMPACT FUND

Disciplined capital allocation and strategic visibility are working hand in hand. We are not just funding hope—we are actively building the financial engine that will cure celiac disease.

- Brett Spitale, Chief Advancement Officer

IMPACT FUND

Investing in Cures. Compounding Our Impact.

Thanks to the extraordinary generosity of our donors, our research grantmaking has propelled the field forward—but closing the gap for the millions living with celiac disease worldwide demands bold, disruptive action. In March 2026, we launched the Celiac Disease Foundation Impact Fund, a venture philanthropy initiative with a Phase One goal of raising $15 million to deploy disciplined, mission-aligned capital directly into high-potential diagnostics, therapeutics, and enabling technologies.

By investing like a venture firm and thinking like a patient advocate, the Impact Fund redefines how progress is funded. Financial returns generated from these investments are recycled back into the Fund, creating an evergreen, compounding cycle of philanthropic capital that drives measurable health outcomes while ensuring long-term sustainability.
Four Pillars Driving Accelerated Innovation

- **Early Detection:** Financing next-generation screening tools to catch celiac disease before systemic damage occurs.
- **Prevention:** Investing in breakthroughs that identify genetic risks and stop the autoimmune cascade before it starts.
- **Education & Awareness:** Equipping clinicians and the global public with cutting-edge tools to accelerate accurate diagnosis.
- **Cures & Therapeutics:** Fast-tracking treatments that go beyond a restrictive gluten-free diet to restore health and achieve an eventual cure.

2026 KEY MILESTONES

› **A Historic Launch:** Formally debuted the Impact Fund to institutional investors, venture partners, and the celiac community in March 2026, marking a strategic evolution from traditional charity to high-impact capital deployment.

› **Taking Celiac Disease to Wall Street:** In May, Chief Advancement Officer Brett Spitale took the Impact Fund to the floor of the New York Stock Exchange for a nationally broadcast segment, bringing unprecedented visibility to celiac innovation and the untapped investment opportunities in digestive disease therapeutics.

› **Building an Evergreen Pipeline:** Established the strategic infrastructure to rigorously evaluate high-growth biotech ventures, ensuring donor dollars generate self-reinforcing financial returns alongside transformative patient solutions.



Celiac Disease Foundation handouts



FINANCIALS

Our fiscal year 2025 audited results reflect the Celiac Disease Foundation's continued commitment to disciplined, transparent financial stewardship. As we launched our Impact Fund and expanded investment in research and advocacy, we remained grounded in rigorous oversight and accountability to every donor. These results show an organization built to grow responsibly, strengthening our financial foundation today while ensuring resources remain available to advance our mission for the celiac disease community tomorrow.

- Lisa Shaevitz, MBA, Chief Financial Officer

Every Dollar. Greater Impact.

Your gift goes where it matters most: into innovative research, global education, federal advocacy, and life-changing support for people with celiac disease and their families. This uncompromising commitment to accountability and transparency has earned the Celiac Disease Foundation top-tier ratings and seals from Charity Navigator and GuideStar/Candid, alongside proud membership in the National Health Council, Independent Charities of America (ICA), and Health & Medical Research Charities of America (HMR).

Putting generosity to work

$1.27

MILLION

Growth in net assets



Your donation isn't just a gift – it's a sound investment in creating a future without celiac disease.

Assets

Cash and Cash Equivalents	$1,783,188
Contributions Receivable	$374,095
Investments	$4,886,731
Other Assets	$1,253,224
Total Assets:	**$8,297,238**

Liabilities

Accrued Liabilities	$1,111,526
Deferred Revenue	$356,416
Total Liabilities:	**$1,467,942**

Support and Revenue

Contributions	$2,777,201
Program Services	$2,012,580
Other Income	$1,558,604
Total Revenue:	**$6,348,385**

Expenses

Program	$3,666,738
Management and General	$774,148
Development	$637,222
Total Expenses:	**$5,078,108**

TOTAL NET ASSETS

$6,829,296

CHANGE IN NET ASSETS

$1,270,277

Source: 2025 audited financial statements (Hensiek & Caron). Available at celiac.org.

LEADERSHIP

LEADERSHIP

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- **M. Ines Pinto-Sanchez, MD, MSc, CNSC,** Research Committee Co-Chair, McMaster University, Ontario, Canada

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- **Michael Schumann, MD,** Charité University Hospital, Berlin, Germany
- **Marisa Stahl, MD, MS,** Colorado Children's Hospital, Aurora, CO
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Impact Fund

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