



ANNUAL REPORT

2019

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

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



iCureCeliac® is the USA's largest public patient registry for celiac disease.



iQualifyCeliac is the only patient-driven celiac disease clinical trial and study recruitment screening tool.



Encouraging the brightest minds in research to focus on finding treatments and a cure for celiac disease.

Impacting Patients



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



2,000 COMMUNITY FUNDRAISING PARTICIPANTS 2018-2019



3,000 ATTENDEES **GLUTEN-FREE EXPO** annually

Expanding Reach in 2019

House Appropriations Subcommittee testimony by CEO Marilyn G. Geller for dedicated **National Institutes of Health (NIH) funding for celiac disease research.**

Patient-Centered Outcomes Research Institute (PCORI) National Patient Engagement Advisory Panel appointment of Marilyn G. Geller, CEO.

NASPGHAN and Children's National partnership to create the **Celiac Disease Management Plan** to standardize federally-sanctioned accommodations in US schools.

Advancing Therapeutic Treatment Development

iCureCeliac® empowers patients to share their medical information and experiences to shape the future of celiac disease research.

iQualifyCeliac screening tool speeds participation in clinical trials and studies to advance the development of better treatments and a cure for celiac disease.

Funding the **Young Investigator Research Grant Award**, medical education conferences at leading institutions, research studies, and technology innovation including the MedAboutData Hackathon for early diagnosis of celiac disease.

Educating Providers to Improve Care

NASPGHAN Clinical Guide for Pediatric Celiac Disease assists physicians in the diagnosis and management of celiac disease.

Celiac Disease and Psychological Health Program partnership with Children's National educates medical and mental health providers on diagnosing celiac disease and its psychological impact.

Celiac Disease Residency Training Program at the Keck School of Medicine of USC trains new physicians in the recognition and treatment of celiac disease.

Giving Voice to the Celiac Community

The **Patient Advocate Program** prepares participants to engage in celiac disease research and public advocacy.

Collaboration with advocacy coalition partners on **federal initiatives to support patient protections** for autoimmune disease.

Partnered with Congressmen Tim Ryan and Tom Cole to introduce the **Gluten in Medicine Disclosure Act** for easier identification of gluten in prescription drugs.

7,000 TOTAL REGISTRANTS in iCureCeliac®

11 NUMBER OF CLINICAL TRIALS recruited for in 2018-2019

\$850,000 2018-2019 FUNDING OF RESEARCH AND CONFERENCES

15,000 PHYSICIANS EDUCATED since 2017

300 PROVIDERS EDUCATED since 2016

600 RESIDENTS EDUCATED since 2017

1,300 TRAINED PARTICIPANTS since 2016

12 2018-2019 EXECUTED initiatives

22,000 STAKEHOLDER EMAILS SENT TO CONGRESS 42 CONGRESSIONAL COSPONSORS to date

▶ ASSETS

Cash and Cash Equivalents	\$ 1,672,924
Contributions Receivable	\$ 92,104
Accounts Receivable	\$ 145,950
Prepaid Expenses	\$ 4,430
Investment in Partnership	\$ 37,450
Deposits	\$ 8,425
Property and Equipment	\$ 119,761

Total Assets **\$ 2,081,044**

▶ LIABILITIES

Accounts Payable	\$ 16,843
Accrued Vacation	\$ 44,234
Unearned Revenue	\$ 157,793

Total Liabilities **\$ 218,870**

▶ NET ASSETS

Unrestricted	\$ 1,862,174
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Total Liabilities and Net Assets **\$ 2,081,044**

▶ OPERATING SUPPORT

Contributions and Grants	\$ 1,030,976
Annual Meeting	\$ 69,306
Gifts in Kind	\$ 372,736
Sponsorships, Program Income and Special Events	\$ 662,289

Total Revenue **\$ 2,135,307**

▶ OPERATING EXPENSES

Program Expenses	\$ 1,318,016
Management and General	\$ 66,430
Fundraising	\$ 50,334

Total Expenses **\$ 1,434,780**

Change in Net Assets **\$ 700,527**