



celiac.org

ANNUAL REPORT 2017

OUR MISSION

CELIAC DISEASE FOUNDATION DRIVES DIAGNOSIS, TREATMENT, AND A CURE TO IMPROVE THE QUALITY OF LIFE FOR ALL PEOPLE AFFECTED BY CELIAC DISEASE AND NON-CELIAC GLUTEN/WHEAT SENSITIVITY.

For decades we have been told that investments into celiac disease research were not necessary because the treatment was simple: adherence to a strict gluten-free diet.

For decades we have been told that the damage from celiac disease is limited to the gastrointestinal tract only.

For decades we have been told that a gluten-free diet was enough to effectively manage the disease.

For decades we have been told that celiac disease is a rare and minor disease.

It turns out that what we were told about celiac disease was WRONG.



DIAGNOSIS. TREATMENT. CURE.

For almost 30 years, the Celiac Disease Foundation (CDF) has fought to improve the quality of life for those with celiac disease and non-celiac gluten/wheat sensitivity. Our work can be best distilled into three overarching agendas: research, education, and advocacy.

We know that there is nothing minor about an autoimmune disease...

- *whose patients have a mortality rate twice the rate of the general public.*
- *for which 40% of the population carries the genetic markers, from which 1% of the population suffers, and for which research indicates as many as 3% of all children have.*
- *that is correctly diagnosed in only a small fraction of those who suffer from it, and for which correct diagnosis, when made, comes 6-10 years, on average, after the patient first presents symptoms.*
- *that can present with hundreds of symptoms, and whose comorbidities include osteoporosis, cancer, infertility, depression, and other serious health complications.*
- *that appears to be doubling in the population approximately every 15 years.*
- *that requires the patient to adhere to a strict, gluten-free diet for life, even though for approximately 30% of the celiac disease population, that particular treatment may not mitigate the impact of the disease.*

Thanks to the tireless work of CDF and many others, including you, our partners, celiac disease is beginning to be taken seriously by the biomedical community. On the following pages, we will share with you some of our successes, as well as many of the significant challenges that remain. We will outline for you our plan to overcome many of these challenges, a plan anchored in supporting medical research through strategic investments, patient engagement, and advocacy. We want to end the needless suffering caused by celiac disease and non-celiac gluten/wheat sensitivity, and to improve the quality of life for all those affected. We want to do it soon. With your continued support, we believe we can.

Sincerely,

James J. Watson
Board Chair



Marilyn G. Geller
CEO





Increase diagnosis rate of celiac disease



Identify alternative treatments to gluten-free diet



Identify long-term implications of celiac disease



Find a cure

PATIENT-POWERED

iCureCeliac® is a patient-powered research network (patient registry) designed to help researchers better understand, treat, and ultimately cure, celiac disease. iCureCeliac® allows patients to contribute medical information and their experiences living with celiac disease and non-celiac gluten/wheat sensitivity to advance life-changing initiatives in research, education, and advocacy.

Your participation will help discover new ways to improve patient lives through better diagnostic tools, treatments for cross-contact and gluten consumption, governmental policy changes, and access to new and innovative clinical trials nationwide which may, one day, cure celiac disease.

ADD YOUR DATA TO FIND A CURE

Our best path toward a cure for celiac disease and non-celiac gluten/wheat sensitivity

"iCureCeliac® carries significant potential to facilitate patient-centered research. We need to better understand the patient experience, so as to focus on the issues that matter most to those living with celiac disease. There are so many unanswered questions and the job of researchers is to prioritize the questions. iCureCeliac® allows us to explore those aspects of living with celiac disease that have the greatest potential to affect the quality of life for our patients. It is a way for the patient community to collectively take action to improve the course of this condition."

Ben Lebwohl, MD, MS
Director of Clinical Research, Celiac Disease Center at Columbia University



THERE ARE NO APPROVED TREATMENTS FOR CELIAC DISEASE. THERE IS NO CURE. WHY? PRIMARILY ECONOMICS.

CDF, with our partners, has led the increasingly successful effort to educate the biomedical and research communities about the severity of celiac disease and the inadequacy of the gluten-free diet. That alone, however, is not enough to shift the economic realities of drug research.

We have seen in other disease markets, especially cancer, how robust patient registries can help researchers more efficiently test proposed treatment hypotheses for safety and efficacy, thus lowering the costs of research. In March 2016, with the support of the Genetic Alliance, CDF launched iCureCeliac®, the only public patient registry for celiac disease in the United States.

Even at this early stage, iCureCeliac® is a singular success. Already, the registry has been deployed in support of several clinical trials for celiac disease therapeutic development. And we had our first two studies accepted for presentation at the 2017 International Celiac Disease Symposium.

We must grow iCureCeliac® to 10,000 participants in order to yield the quantity of very specific data needed to support broader biomedical research. To this end, and with your support, CDF is investing heavily in marketing the patient registry to attract new patients.

“Clinical research in celiac disease is finally getting momentum with over a dozen programs in clinical trials. Understanding the patient populations and their needs is essential to match the right approach to the right subject. iCureCeliac® will be a key tool in the solution tool box.”

— Francisco Leon, CEO & Chief Medical Officer of Celimmune

THANK YOU MARC RICHES

Celiac Disease Foundation would like to extend our deepest thanks to Marc Riches for his 13 years of service on the Board of Directors. Marc became involved with CDF in 2003 after his child was diagnosed with celiac disease. He joined the Board and served as Chairman from 2010 to 2016. In 2011, he, too, was diagnosed with celiac disease. Under Marc’s leadership, the Foundation has grown from a grassroots patient support group network to the nation’s leading disease advocacy organization for celiac disease, providing services to millions worldwide. Thank you, Marc, for all that you have done, and continue to do, for CDF.





RESEARCH

DEPRESSION, SYMPTOMS, AND DIET ADHERENCE

CDF collaborated with researchers at Columbia University Celiac Disease Center on an iCureCeliac® study that seeks to understand how depression modifies the association between gluten-free diet adherence and symptoms in celiac disease patients.

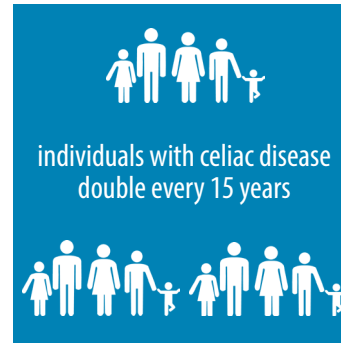
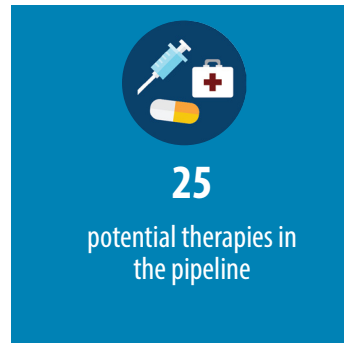
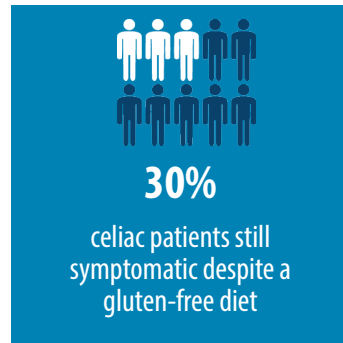
AUTOIMMUNE DISEASE CO-MORBIDITY

iCureCeliac® was used to determine that diagnosis of one or more autoimmune diseases in addition to celiac disease is common, particularly in women and older adults. These results have implications for primary care, gastroenterology, and rheumatology practice, and will allow healthcare providers to better predict and manage the additional autoimmune diseases that may develop in patients with celiac disease.

RETHINKING CELIAC DISEASE

Although there are still no FDA-approved therapies for celiac disease, there are more treatments in the pipeline today than ever before

CDF has developed a number of tools to support, wherever and whenever we can, biopharmaceutical companies seeking to advance therapies sought by the celiac disease patient community through the drug pipeline to market.



iCureCeliac®

iCureCeliac® is an online portal to help researchers better understand, and ultimately cure, celiac disease and non-celiac gluten/wheat sensitivity. iCureCeliac® allows patients to contribute medical information and their experiences living with celiac disease to advance life-changing initiatives in research, education, and advocacy.

CLINICAL TRIAL FINDER

The CDF Clinical Trial Finder is designed to help people with celiac disease and non-celiac gluten/wheat sensitivity participate in medical research clinical trials. In addition to advancing the search for treatments and a cure, patients who choose to participate in clinical trials may experience symptom relief.

PATIENT ADVOCACY PROGRAM

The CDF Patient Advocacy Program teaches patients and their caregivers about the latest in celiac disease research, as well as clinical and scientific research processes. Participants learn how to ask their own research questions, and how to serve on research study committees. The Patient Advocacy Program gives patients a voice in the celiac disease research process.



Dr. Matthew Shale
Stanford University
Young Investigator Award Recipient

Due to the historical dearth of celiac disease research compared to other autoimmune diseases, most of the world's young researchers elected to go into better-funded disease fields. This shortage of young talent had to be addressed to continue the remarkable momentum being developed in celiac disease research. In collaboration with the North American Society for the Study of Celiac Disease (NASSCD), CDF committed \$150,000 to fund a three-year competitive research award, the Young Investigator Award.

The first award recipient, selected in February 2017, was Dr. Matthew Shale of Stanford University. Dr. Shale is interested in discovering the triggers for celiac disease – what causes the gene to turn on in some and not others. If he can identify the triggers for celiac disease, therapies may be developed to isolate them or cut them off, stopping the onset of the disease.



EDUCATION

More than 3,500 people – patients, family, caregivers, healthcare professionals, researchers, biopharmaceutical and diagnostic company representatives, and gluten-free foodies – attended **CDF's annual National Conference & Gluten-Free EXPO** on June 3-4, 2017 in Pasadena, CA. The Conference featured the Patients as Partners Research Symposium where attendees were trained to become Patient Advocates. A special thanks to sponsor ImmusanT, and to **Leslie Williams**, *Chief Executive Officer*, and **Dr. Robert Anderson**, *Chief Scientific Officer*, for their participation as panelists.

The EXPO celebrated food options now available for people with celiac disease, non-celiac gluten/wheat sensitivity, and others who seek benefits from the gluten-free diet. CDF thanks our exhibitors, expert speakers, volunteers, and especially the attendees for making this the biggest and best National Conference & Gluten-Free EXPO to date.

CONFERENCE & GLUTEN-FREE EXPO

We lead the way in educating patients, health professionals, and the food and restaurant industries about celiac disease and how to most effectively diagnose, treat, and manage it



1 in 100

worldwide have celiac disease
1 in 10 risk in families

24

MILLION

undiagnosed Americans at risk for long-term health complications



DAYS

average number of work/school days missed per iCureCeliac® patients

USC KECK SCHOOL OF MEDICINE RESIDENCY TRAINING PROGRAM

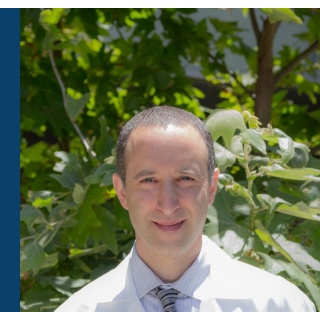
Supported by the Simon Family Foundation, this model program trains young physicians in the recognition, screening, and treatment of celiac disease.

NASPGHAN CLINICAL GUIDE FOR PEDIATRIC CELIAC DISEASE

Developed in partnership with the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition, this online diagnostic tool helps pediatricians diagnose celiac disease patients in their practices.

PSYCHOLOGICAL HEALTH TRAINING PROGRAM

This pioneering protocol, a collaboration with Children's National Health System and the Resnick Family Foundation, teaches mental health and primary care providers how to manage depression and anxiety in celiac disease.



Dr. Michael Karp

Division Chief, Keck School of Medicine

USC Keck School of Medicine Residency Training Program

The gluten-free diet fad has gripped America, leading to increased awareness of celiac disease. Yet, the diagnosis rate remains stubbornly low at roughly 20%. This means that most Americans with celiac disease are seeing physicians, with complaints about the more than 200+ known symptoms, and are not being diagnosed.

Enter CDF Board Member, Dr. Michael Karp, Chief of the Division of Geriatric, Hospital, Palliative and General Internal Medicine at the USC Keck School of Medicine. Dr. Karp, with a grant from the Simon Family Foundation, conceived and launched a groundbreaking celiac disease training program for Internal Medicine and subspecialty residents.

"The USC program is currently exploring a number of different models to improve screening and detection rates including large group didactics, small group workshops, electronic reminders, and novel strategies centered around social media."



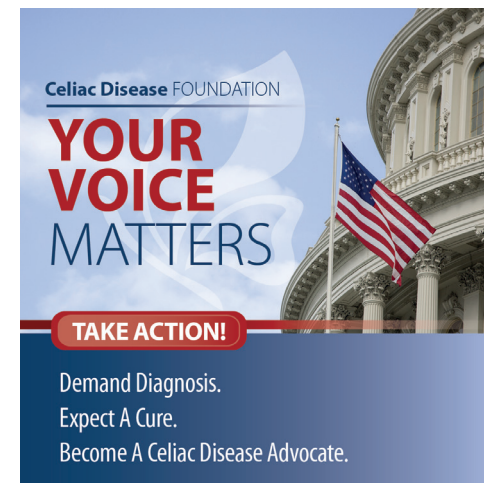
ADVOCACY

Some of the most important decisions about healthcare for celiac disease patients are not made in a doctor's office, but in conference rooms and offices scattered in and around Washington, D.C.

The array of healthcare issues that surface in the Washington, D.C. legislative and regulatory environment that impact the celiac disease community is staggering, from pre-existing conditions, to research funding at NIH, to shaping drug approval protocols at the FDA. CDF has established a respected presence in Washington, D.C. to give voice to the needs of the celiac disease community.

TOGETHER OUR VOICE MATTERS

We ensure that decisions made by healthcare policy leaders advance a future where celiac disease is readily diagnosed and effectively treated





10,000

letters and emails sent to Congress in 2017

GLUTEN-FREE

99.5%

FDA sampled gluten-free products in compliance



\$0

for celiac disease in the NIH line item budget

FOOD & DRUG ADMINISTRATION (FDA)

We work tirelessly with the FDA to help improve the quality of life of people living with celiac disease and non-celiac gluten/wheat sensitivity. As a founding member of the American Celiac Disease Alliance (ACDA), which achieved the 2014 FDA Gluten-Free Labeling Rule, we are pleased that the FDA has found extensive compliance with products labeled "gluten-free."

NATIONAL INSTITUTES OF HEALTH (NIH)

From serving on the landmark 2004 NIH Consensus Conference Planning Committee which resulted in celiac disease being recognized as a common autoimmune disorder instead of a rare pediatric disease, to today, we work to inform the NIH of the critical need for patient-centric research and increased funding for genetic diseases at the federal level.

PATIENT PROTECTIONS

We are a strong proponent of insurance coverage for pre-existing healthcare conditions. We continue to rally our community to urge their local congressional leaders to demand immediate action on both short-term and long-term solutions to America's healthcare crisis that protect the interests of the celiac disease community.



The Yarema Family

When our eldest daughter, Maeve, was two years old, she developed a poky little belly, which swelled so much it looked like she had swallowed a basketball. Then, she stopped growing. She seemed very ill, but her pediatrician could not find a problem. After a months-long journey, we learned Maeve was suffering from celiac disease. Later, we learned that celiac disease runs in my family. My mother experienced symptoms her whole life, but was only tested and diagnosed recently. Other family members are affected, too.

We are so grateful that the Celiac Disease Foundation is here to help give practical advice on how to live with and manage celiac disease. But even more than that, they are relentless in their efforts to support research that will help us understand celiac disease much better. Our family is proud to support CDF and we look forward to the day researchers will find treatments beyond a gluten-free diet, and a cure.

Kristin Yarema and Mike Nohaile

CELIAC.ORG

We are the leading information

INTERACTIVE TOOLS



SYMPTOMS & CONDITIONS CHECKLIST

Our Checklist has been viewed by more than 2.4 million people since its launch in 2014. This Checklist helps patients document for their physician if they have any of the common symptoms or conditions of celiac disease.



HEALTHCARE PRACTITIONER DIRECTORY

The CDF Healthcare Practitioner Directory is a free listing of physicians, dietitians, mental health professionals, and allied health providers in all 50 states, who treat patients with celiac disease and other gluten-related disorders. More than half a million people have used this valuable tool.



ADULT & PEDIATRIC FOLLOW-UP CHECKLISTS

If you or your child has been diagnosed with celiac disease you are encouraged to complete and print the Adult or Pediatric Follow-Up Checklists and use them with your physician and your dietitian to ensure proper post-diagnosis treatment.



WHAT YOU NEED TO KNOW VIDEO SERIES:

Whether you are newly diagnosed, or want the most up-to-date information on celiac disease and non-celiac gluten/wheat sensitivity, this video series hosted by national experts is what you need to watch.

resource for celiac disease



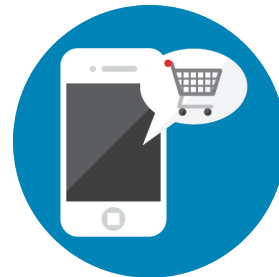
7-DAY GLUTEN FREE MEAL PLANS

We offer 7-Day Gluten-Free Meal Plans for adults, children, and seniors to help the newly diagnosed and those struggling with a strict, gluten-free diet. Used by more than 1.5 million people, the customizable plans provide clear and concise menus of meals and snacks, with easy-to-make recipes.



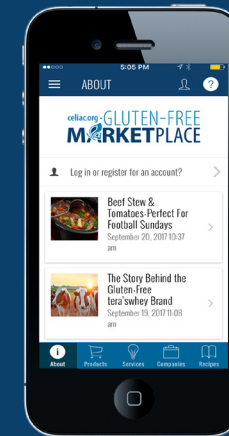
GLUTEN-FREE RECIPES:

Our innovative recipe tool lets you explore hundreds of gluten-free recipes from bountiful breakfasts to delicious dinners, and everything in between. Search by course, type of cuisine, ingredients, and even your favorite gluten-free companies to find the perfect recipes with nutrition facts and simple instructions.



GLUTEN-FREE MARKETPLACE

The Gluten-Free Marketplace is a one-stop destination to search for gluten-free products, services, companies, and recipes. These are products and services from companies that care about the gluten-free community, and have made a deep commitment to supporting CDF's mission.



Gluten-Free Marketplace App

Anyone who must adhere to a strict gluten-free diet, or who is a caregiver of someone who does, can tell you the many challenges they face daily. CDF's Gluten-Free Marketplace app, available for iOS and Android, is a creative, all-inclusive tool to help manage these challenges. In one place, app users can access:

- **Products and services from companies that care about the gluten-free community**
- **Gluten-free recipes that they can filter and "favorite"**
- **Nutrition and ingredient information on the best gluten-free products, with the option to order the products directly from Amazon**
- **CDF's dietitian-developed gluten-free meal plans for adults, children, and seniors to help plan weekly meals**
- **The latest in gluten-free lifestyle news**



Celiac Disease FOUNDATION®
STUDENT AMBASSADOR PROGRAM

GET INVOLVED!

KNOWLEDGE IS POWER

Raise Awareness of Celiac Disease in Our Communities.

COMMUNITY

STUDENT AMBASSADOR PROGRAM

The CDF Student Ambassador Program is geared toward students in elementary, middle, high school, or college who want to raise awareness of celiac disease at their school and in their local community. The Student Ambassador Program helps children, teens, and young adults become role models for others with celiac disease while raising awareness in the community and educating their peers.

STUDENT AMBASSADOR SPOTLIGHT: Jillian Estell

Jillian is a young actress who was featured in the movie *Black or White* and the TV show *The Night Shift*. She was diagnosed with celiac disease as a baby, but struggled over the last year, feeling very sick and losing all of her hair. She is excited to partner with CDF to educate others about celiac disease.

TEAM GLUTEN-FREE IN ACTION

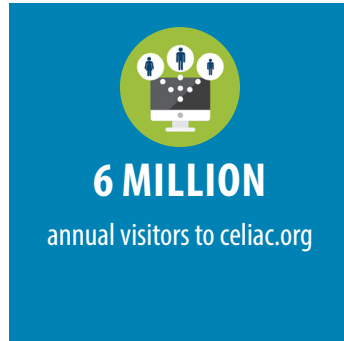
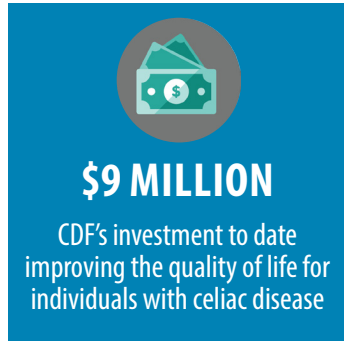
We create a welcoming and supportive environment for the celiac disease community

MAKING A DIFFERENCE

Top Twenty Team Gluten-Free and Student Ambassador Fundraisers:

Warren Saft	Skylar Weitz	Avery Bloomberg
Adrienne Bender	Shira Ravera	Kennedy Hatfield
Maizy Boosin	Deidre Lind	Reese Burke
Ariel Spiegelman	Rinata Zhivov	Jennifer Quinn
Zoey Kornblau	Jacob Castleman	Tracy Fischetti
Jackson Resin	Iliana Mouhlas	Melissa Sternsheim
Jonny Grossman	Jeremy Bedwell-Coll	The Morris Family





TEAM GLUTEN-FREE

CDF Team Gluten-Free is our community fundraising program that provides a simple way for athletes and non-athletes alike to raise awareness and funds for CDF's programs for research, education, and advocacy. Team Gluten-Free continues our annual Charity Partnership with the TCS New York City Marathon and the Sketchers Performance Los Angeles Marathon.

WARREN SAFT, TGF MEMBER AND VOLUNTEER OF THE YEAR

When Gabbi Saft was diagnosed with celiac disease, her parents, Warren and Amber, turned to the Celiac Disease Foundation (CDF) to begin researching the challenges that she would face.

In an effort to support Gabbi, and all those who are living with celiac disease, Warren joined Team Gluten-Free and rode his bike 150 miles from New York City to Montauk, raising \$25,000 to support CDF's Young Investigator Award. CDF is proud to honor Warren as our Volunteer of the Year.



Student Ambassadors



Jonny Grossman and Skylar Weitz

Jonny held a raffle at the New York Club Soccer League Cup Finals and Skylar created The Skylar Project, making and selling beautiful bracelets, to help raise awareness and funds for a cure. Having met through the CDF Student Ambassador Program, they joined forces at the Special Needs EXPO, educating attendees about celiac disease and the Celiac Disease Foundation.



Maizy Boosin

At 12 years old, Maizy competed on *Chopped Junior*, but Maizy had a unique challenge because of her celiac disease – she chose to cook everything exclusively gluten-free while given the same basket of ingredients as her competitors. Maizy donated a portion of her winnings to CDF, generously matched by her family.

FINANCIALS

FOR THE YEAR ENDED DECEMBER 31, 2016

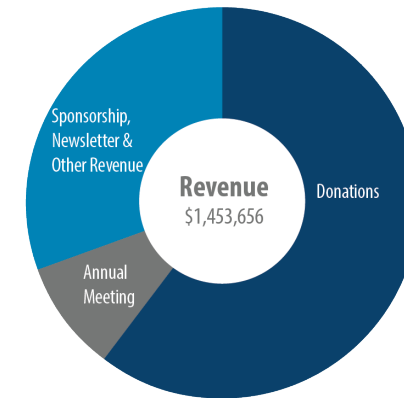
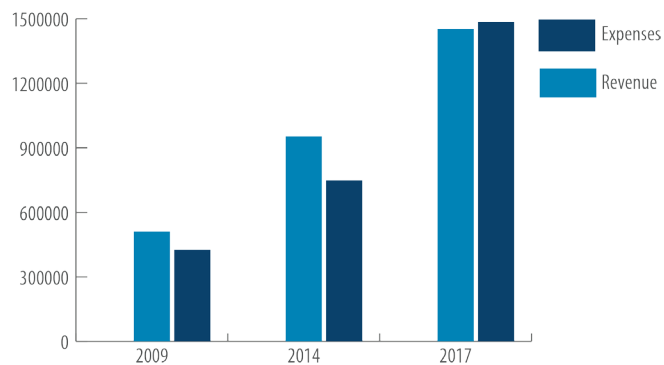
OPERATING SUPPORT

Donations	\$ 17,217
In Kind Goods and Services	\$ 266,015
Annual Meeting	\$ 109,432
Sponsorship, Newsletter & Other Revenue	\$ 360,992
Total Revenue	\$ 1,453,656

OPERATING EXPENSES

Program Activities	\$ 1,228,693
Administrative	\$ 140,338
Development	\$ 116,673
Total Operating Expenses	\$ 1,485,704
Excess Expenses Over Revenue	\$ 32,048

Revenue and Expense Trend



ASSETS

Cash and Cash Equivalents	\$ 942,065
Accounts Receivable	\$ 69,100
Prepaid Expenses	\$ 4,834
Property and Equipment, At Cost, Less Accumulated Depreciation	\$ 18,436
Website, Net of Amortization	\$ 45,495
Trademark, Net of Amortization	\$ 19,950
Deposits	\$ 6,133
Total Assets	\$ 1,106,113

LIABILITIES AND NET ASSETS

Accounts Payable	\$ 15,537
Accrued Expenses	\$ 39,402
Unearned Revenue	\$ 159,870
Total Liabilities	\$ 214,809
Net Assets, Unrestricted	\$ 846,962
Net Assets, Temporarily Restricted	\$ 44,342
Total Net Assets	\$ 891,304
Total Liabilities and Net Assets	\$ 1,106,113

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Thank you to our national sponsors for joining with us in our mission to improve the quality of life for all those with celiac disease and non-celiac gluten/wheat sensitivity.

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OUR DONORS

\$50,000 AND MORE

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OVER \$10,000

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Auri and Shari Weitz
Dr. Mike Nohaile and Dr. Kristin Yarema
Bruce Youngman

OVER \$5,000

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Christopher Scott
John Strek
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Deerfield Park District
The Kwit Family

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Maizy Boosin
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Erik and Edith Cornelissen
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Andrew Rebholz
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Lester and Maxine Saft
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Marianne Sekander
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The Dartmouth Company
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Timmins Cott Family Fund

OVER \$1,000

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Vijay Arora
Jerry Asmussen
A. Philip Auerbach
Eric Banks
Elizabeth Bawden
Helen Bernstein
Tina Bingham
Ruth C. Black
Ted Bloomberg
Rudolph Borneo
Jonathon Cookler
Hannah Cutmore-Scott
Matthew Cwiernia
Cindy Del Priore
Christopher DeWitt
Deb DuChateau

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Adam Handwerker
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Harold Katz
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Joel and Holly Kurtzberg
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Daniel Shapiro
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Walter Staudenmaier
Ellen Eugene Switkes
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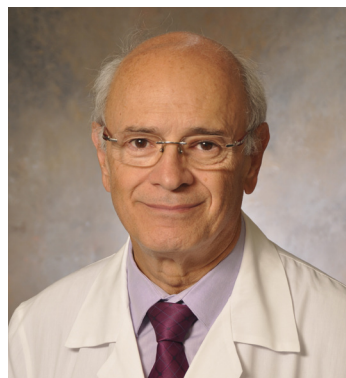


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