

**WE CAN. WE WILL. *TOGETHER.***



awareness • advocacy • action

**2017 ANNUAL REPORT**



#### ABOUT THE ARTWORK:

The artwork throughout this annual report illustrates the Beyond Celiac journey in driving research for better diagnosis, treatments and a cure for the estimated 3.2 million Americans living with celiac disease. Artist and graphic recorder Joe Azar captured the spirit and the commentary that underpinned our 2015 Research Summit and the 2017 Bold Beyond Research Symposium and Benefit as those events unfolded. These lively and memorable images serve to enhance the conversation about celiac disease research and our community's involvement to help researchers better diagnose, monitor, treat and ultimately cure celiac disease.



## Vision

A world in which people with celiac disease can live healthy lives free from fear of gluten exposure—a world Beyond Celiac.

## Mission

Beyond Celiac unites with patients and partners to drive diagnosis, advance research and accelerate the discovery of new treatments and a cure.



## 2018 IS OUR CRYSTAL ANNIVERSARY—OUR 15TH YEAR.



Alice Bast

Through the years, the goal for our work has become crystal clear: Cure celiac disease. When I launched this organization in 2003, then called the National Foundation for Celiac Awareness, I couldn't know exactly where we'd be right now, but I did know that we needed to forge pathways to a cure. My hope at the time? That the vast majority of people with undiagnosed celiac disease

who were suffering but didn't know why would get answers and a diagnosis. That they would ultimately get healthy by adopting the gluten-free diet, the only treatment we thought we'd need. That we could find gluten-free products where we live, work and play.

What I didn't know then was that the gluten-free diet – a lifesaver for me – is not a lifesaver for all of us. At least 30% of the celiac disease community on the gluten-free diet continue to have on-going damage to their small intestine. And, I'd hazard a guess that nearly 100% of us who are doing our best to stay strictly gluten-free find that it's impossible to do so 100% of the time. Our challenge is compounded by the worry we face with every morsel of food we eat, especially when we dine out, travel and socialize.

For decades the gluten-free diet was considered adequate, which is why our original mission was about

educating the general public and healthcare providers about celiac disease. Now that we know the diet is not enough, we need to demand more and better for our health and longevity. We need research that will get at the root cause of this serious genetic autoimmune disease. We need to accelerate research toward a cure. We simply cannot wait any longer.

When we changed our name to Beyond Celiac in 2015, we were announcing our intention to create a future where tomorrow's patients with celiac disease won't face the challenges of today's. Our work in unraveling the root of celiac disease may be the key to unlocking all of autoimmunity, benefiting the 50 million Americans living with other autoimmune diseases, such as lupus, multiple sclerosis, rheumatoid arthritis and more. We have made a complete pivot to research for treatment options.



In 2017, we launched *Go Beyond Celiac*, a platform in which those of us diagnosed with celiac disease and the parents of kids with celiac disease can tell our stories. Collected in one place, Beyond Celiac can convey the experiences of our community so that researchers pursue treatments in addition to the gluten-free diet that will address the real needs of real people.

This year we will continue to build our capacity to drive research. As you will read in this report, we have launched a fully-staffed Science Department, led by Beyond Celiac CSO Marie Robert, MD. And, we will add a comprehensive patient registry to *Go Beyond Celiac*. This will enable Beyond Celiac to connect patients with clinical trials and continue to accelerate research. In addition, we will launch a young investigator

awards program and provide funding for specific targeted research. We will not stop until we have a cure!

*To our community:* We are with you. Together, we can make a difference in creating a better future for ourselves and our loved ones. *To our donors and sponsors:* Thank you. We will continue to be excellent stewards of your gifts and trust.

Alice Bast, CEO

## GO BEYOND CELIAC? WE CAN. WE WILL. TOGETHER!

# BEYOND CELIAC LAUNCHES SCIENCE DEPARTMENT

After an extensive search, Beyond Celiac has hired Marie Robert, MD as Chief Scientific Officer. Dr. Robert is leading the development and implementation of a transformational patient-centered research agenda focused on accelerating solutions toward new pharmaceutical treatments and a cure for celiac disease. She will drive the Beyond Celiac research agenda that will impact clinical decision-making about diagnosis, disease management, treatment, and eventually a cure.



Marie Robert, MD

Gastrointestinal Pathology and Director of the Fellowship in Gastrointestinal Pathology at Yale University. She is an author of guidelines in the practice of gastrointestinal pathology diagnosis (American Gastroenterology Association, North American Society for the Study of Celiac Disease and Rodger Haggitt Gastrointestinal Pathology Society). She has served on numerous national boards and committees and is a

past president of the Rodger Haggitt Gastrointestinal Pathology Society.

Dr. Robert has studied celiac disease throughout her career. During residency at UCLA, she performed a study of the biopsy findings in refractory celiac patients. Her work on celiac disease also includes contributions on inflammatory conditions of the small intestine in the Odze, Goldblum and

Professor of Pathology and Medicine at Yale University School of Medicine, Dr. Robert is a nationally recognized gastrointestinal, liver, and pancreatic surgical pathologist with 25 years of experience in clinical diagnosis, teaching, and collaborative scientific endeavors across a wide spectrum of diseases. Specific areas of expertise include inflammatory and neoplastic conditions of the gastrointestinal tract. Dr. Robert has served as the Director of the Program in



Alan Ehrlich, MD

**“Investing in our scientific expertise will enhance the ability of Beyond Celiac to influence the direction and focus of celiac disease research, amplifying the patient’s voice as we look for much-needed answers for this burdensome disease.”** *Alan Ehrlich, MD, Board Chair, Beyond Celiac*

Crawford (eds) textbook “Surgical Pathology of the Gastrointestinal Tract, Liver, Biliary Tract and Pancreas,” considered the definitive text in gastrointestinal surgical pathology worldwide. She is the lead author of an upcoming best practices statement on the use of duodenal biopsy in the diagnosis of celiac disease, as well as a study on diagnostic approaches to refractory celiac disease. Dr. Robert is frequently invited to speak on celiac disease nationally and internationally. She is also continuing in her role at Yale.

In addition to the hiring of Dr. Robert, Beyond Celiac has retained consultant Marla Gold, MD, FACP. With an extensive background in research strategy and public health, Dr. Gold will support research collaborations, corporate programs and the development of the *Go Beyond Celiac* patient registry. Dr. Gold is currently Dean Emerita and Professor of Health Management and Policy with the Dornsife School of Public Health at Drexel University. An infectious disease specialist, she has long served on the Beyond Celiac Scientific/Medical Advisory Council and has a personal interest in the organization’s mission because celiac disease affects her immediate family.

The Beyond Celiac science team also includes Kate Avery,

**“Beyond Celiac is uniquely positioned to engage patients and scientific partners in a synergistic effort to further clinical, basic and translational research on celiac disease. I am eager to work with this extraordinary organization to realize this vision.”** *Marie Robert, MD*

MPH, Director of Research and Patient Engagement. Kate earned her MPH in Health Behavior at University of North Carolina at Chapel Hill. Since March 2017, Kate has been leading the development, launch, enrollment and patient engagement for the Beyond Celiac interactive digital platform and patient registry, *Go Beyond Celiac*. She previously published on the topic of patient perspectives in disease management.

Also a member of the Beyond Celiac Science Department is Medical and Science News Analyst Amy Ratner. Through her reporting, Amy curates the latest in celiac disease research and shares it in patient—and

community—friendly language. Her work is the centerpiece of the popular Beyond Celiac Research News page.

Beyond Celiac has worked with experts in the field of celiac disease through its Scientific/Medical Advisory Council since its founding. Established in 2003, the Beyond Celiac Scientific/Medical Advisory Council has played an integral role in establishing and maintaining evidence-based standards for the organization and represents the very best in scientific and medical practice. Dr. Robert will work closely with the established Council and strengthen ties between staff and our external advisors.

**“As a non-profit advocacy organization, we are launching this patient-driven science model, proven in other areas such as cystic fibrosis, to further our mission of uniting patients and partners to drive diagnosis, advance research, and accelerate the discovery of new treatments and a cure for this serious, genetic autoimmune disease.”** *Robert J. Beall, PhD, Beyond Celiac Board Member*



## GO BEYOND CELIAC: Creating a complete picture of celiac disease to advance research.

Go Beyond Celiac is a place where people with celiac disease and their caregivers can share their stories before, during and after diagnosis. It is a unique online platform focused on the collection of information that can be used to help researchers better diagnose, monitor, treat and, ultimately, cure celiac disease. Participants can also see how their experiences compare with others, ask experts questions about celiac disease, get information about staying as healthy as possible, and get the latest research updates.

It was created through an in-depth 4-year process, which included participation by the research community, government, pharmaceutical companies, patients and their families in order to reduce barriers to developing treatments beyond the gluten-free diet.

## Sharing Stories:

### LIFE BEFORE DIAGNOSIS

- ✓ Medical History
- ✓ Celiac Disease Knowledge
- ✓ Emotional Impact

### AFTER DIAGNOSIS

- ✓ The Path to Getting Tested
- ✓ Experience Navigating the Healthcare System
- ✓ Financial Impact
- ✓ Emotional Impact

### THANK YOU, FROM THE COMMUNITY

Thank you for this informative video about what's happening in the gut and how future treatments might work. Great information...but even better, **it gives me hope that my son one day will either be free from this disease** or have treatment options that will make his life easier to navigate in the real world. What a gift that will be! *Lisa G.*

## Symptoms:

### LIFE BEFORE DIAGNOSIS

- ✓ Nutritional
- ✓ Gastrointestinal
- ✓ Neurological
- ✓ Psychological
- ✓ General Physical

### AFTER DIAGNOSIS—WHAT HAPPENS WHEN YOU GET GLUTENED?

- ✓ Nutritional and General Physical Impact
- ✓ Gastrointestinal
- ✓ Neurological
- ✓ Psychological

## Life after Diagnosis:



- ✓ Life on the Gluten-Free Diet
- ✓ Frequency of Gluten Exposure
- ✓ Impact on Lifestyle, Work/School and Education
- ✓ Related Conditions
- ✓ Family Health

## Looking Ahead:



- ✓ Future Treatments
- ✓ Participation in Research and Clinical Trials

“If those who have celiac disease don’t participate in research, we will go nowhere.” *Ciarán Kelly, MD director of the Celiac Center at Beth Israel Deaconess Medical Center and Beyond Celiac Board Member*



Anthony J. DiMarino, Jr., MD, Ciarán P. Kelly, MD, Alice Bast, Daniel A. Leffler, MD, MS, Ritu Verma, MD

**“I’d like to see people with celiac disease live a life as healthy and unburdened as someone who does not have it. It does not have to be fancy science to make that happen. It’s a goal we should share and feel is realistic.”**

**Dan Leffler, MD**

Patients who would like to see something more than the gluten-free diet to treat celiac disease have been looking to researchers for answers for years.

But at the November 9, 2017 Beyond Celiac Research Symposium, experts said patients themselves hold the key to developing a drug, vaccine or other option that can halt symptoms and intestinal damage suffered when those who have the disease consume gluten.

“If those who have celiac disease don’t participate in research, we will go nowhere. We can’t do research in celiac disease if we

**“Adhering to a gluten-free diet forever is really very difficult. Up to 50% or so [of people with celiac disease] can’t do it. And it looks like at least 30% of the people don’t get better.”**

**Anthony J. DiMarino, MD**

don’t have cooperation across the spectrum of individuals who have celiac disease,” Ciarán Kelly, MD, director of the Celiac Center at Beth Israel Deaconess Medical Center, told a symposium audience of 1,700. “It’s an absolute essential. Without it, we might as well go home.”

The symposium audience included those who attended the event at Drexel University in Philadelphia and those who tuned in from five continents via live webcast. Alice Bast, Beyond Celiac CEO, moderated. The Bold Beyond Research Symposium was the first presented by Beyond Celiac as part of its mission to advance research to find a treatment and, eventually, a cure for celiac disease. Lead Author sponsors for the symposium were: Alice and Will Bast; Goldman Sachs Gives, C. Kane Brennan; The

**“In pediatrics, constant long-term exposure to gluten is going to give long-term risks for certain conditions, and in the short-term, [it can impact a child’s] growth and [affect] malnutrition.”**

**Ritu Verma, MD**



Snider Foundation; and Takeda Pharmaceuticals U.S.A., Inc.

“You can have all the money in the world and the smartest people (working on celiac disease), but if people don’t show up you aren’t going to go anywhere,” agreed Daniel Leffler, M.D., medical director, clinical science, gastroenterology, Takeda Pharmaceuticals U.S.A., Inc.

Kelly, a member of the Beyond Celiac Board of Directors, and Leffler, a member of the organization’s Scientific/Medical Advisory Council, were participants in the symposium panel along with advisory council members Anthony J. DiMarino,

Jr., MD, chief, division of gastroenterology & hepatology, Thomas Jefferson University Hospital, and Ritu Verma, MD, section chief, gastroenterology, The Children’s Hospital of Philadelphia. They tackled issues in celiac disease treatment that ranged from misconceptions about how complete a treatment the gluten-free diet really is, to lack of funding for research, to the path research is taking to find treatment targets.



# BOLD BEYOND BENEFIT

Together, the Bold Beyond Research Symposium and Benefit raised over \$272,000 to support celiac disease research.

Following the symposium, we gathered together to celebrate past milestones and look ahead to a future beyond celiac at the Bold Beyond Benefit, held at The Study, University City. The reception offered an opportunity to honor the contributions of long-time friend and board member Dorothy Binswanger while enjoying delicious gluten-free

dishes. Featured chefs included Monica Glass, Executive Pastry Chef for Starr Catering; Timothy Spinner, Executive Chef/Co-Owner of the Feliz Family restaurants; Adam DeLosso, Garces Events' Director of Culinary; and Andrew Freese, Executive Chef, Not Your Average Joe's. It was an evening to remember!



Nancy Ginter and Chef Monica Glass



Team Binswanger



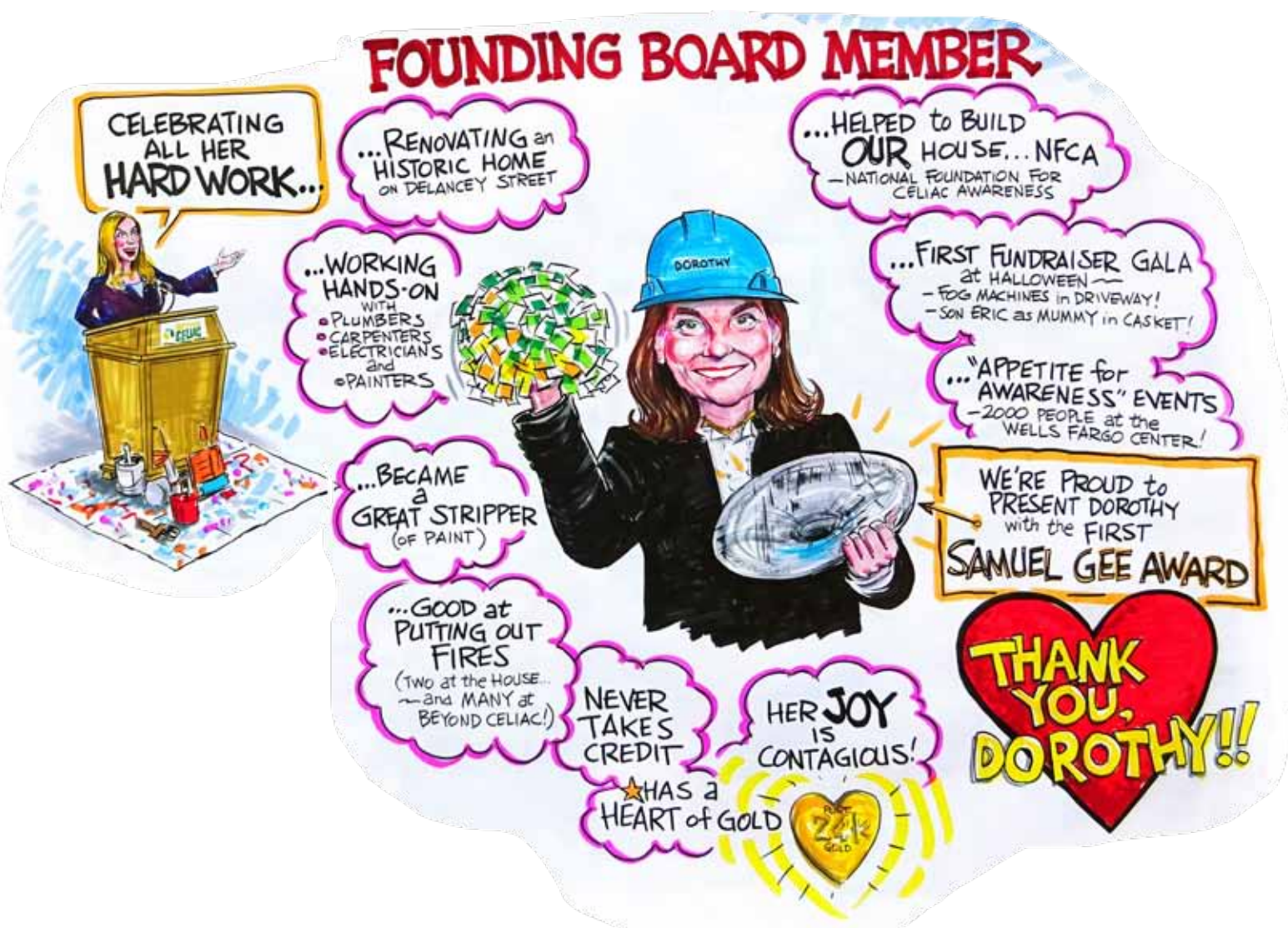
Dorothy Binswanger and Alice Bast



Kathleen and Richard Herwig



Margie Jackson and Lindsey Goebel





# STEP BEYOND CELIAC KANSAS CITY 5K

The inaugural 2017 *Step Beyond Celiac* Kansas City 5K and Car Show (KC5K) was a fun walk/run event held on October 14th. KC5K was the fulfillment of a dream by one of the event's organizers, Jilian Hunt, who was joined by a group of over 50 volunteers who made it happen.

**YOU MADE OUR DAY!** A heartfelt 'thank you' to all of the organizations that supported our inaugural Step Beyond Celiac KC5K with generous sponsorships, enticing gifts for the silent auction and overflowing goodie bags.

**The event was a remarkable success by all measures.**

- Over 600 "in person" participants, including runners and supporters from Arkansas, Oklahoma, Nebraska, Iowa and Arizona
- Online contributions from supporters in twenty four states
- \$60,000 raised for celiac disease research
- 3,000 pounds of food valued at \$4,000 collected for the local Food Equality Initiative
- Dozens of local restaurants and bakeries featured as exhibitors

**THANK YOU, FROM THE COMMUNITY**  
 "Thank you for all the information you share. I was diagnosed 17 years ago and thought I knew a lot. I've been on two clinical trials to help people, I am 69 now and nothing may be found in my lifetime but wanted to help."  
 Lori G.



Step Beyond Celiac KC5K participants



Jilian Hunt, Step Beyond Celiac KC5K organizer



Step Beyond Celiac KC5K participants



Step Beyond Celiac KC5K participants



Beyond Celiac Board Member and Step Beyond Celiac KC5K organizer Chad Shaffer, MD, FAFP



# GOING THE EXTRA MILE

Beyond Celiac is grateful to have the support of these creative supporters who dedicated themselves to raising funds for celiac disease research.

## **PARTY WITH A PURPOSE! —BACK TO THE 80S!**

Beyond Celiac donors Alison and Eric Seiferth hosted the party of the season at the Venetian Club in Philadelphia on November 17, raising a net total of \$15,000 for our research efforts. We are honored and touched by the Seiferths' dedication and commitment to Beyond Celiac as we unite with patients and partners to advance research and accelerate the discovery of new treatments and a cure.



## **THE MIKAYLA MAQUERADE BALL**

Long-time supporter Mikayla Morell hosted The Masquerade Ball at the University of the Arts, raising more than \$900 for Beyond Celiac at this gluten-free event. The school gladly donated the space for the fundraiser and many students and guests attended.



Mikayla Morell and friends at The Masquerade Ball

## **ART AUCTION FOR CELIAC AWARENESS, HOSTED BY ARTIST RON ABRAMS**

Ron Abrams lost his 29-year old daughter Carly on March 4, 2017 after a brief, but painful, struggle with liver and kidney failure complications, compounded by celiac disease. Ron, who has also been diagnosed with celiac disease, hosted an auction of his work on August 26, 2017 at Blue Skies Gallery in Hampton VA. Through the auction, Ron and the gallery raised more than \$1,500 for Beyond Celiac for our work to raise awareness. We were honored to have Ron as our guest at our Bold Beyond Benefit. We were very moved by his story and galvanized in our efforts not to lose another life to celiac disease.



Ron Abrams

## **HALLE GRAY—RUNNING FOR RESEARCH**

Baltimore native Halle Gray laced up her sneakers on October 21, 2017 and ran 13.1 miles in honor of her sister Kiley, who has celiac disease. And, not only did she run a half marathon, she used it as a vehicle to raise money to drive research for treatment options for her sister and for the estimated 3.2 million Americans who have celiac disease. Raising more than \$1,000 for Beyond Celiac, Halle is a part of the grassroots support that is propelling Beyond Celiac to cross the finish line—finding a cure altogether.



Halle & Kiley Gray



“INSERT YOUR STORY HERE...”

# 2017 FINANCIALS



Our story for 2018 is being written right now.  
How can you help?

THE OPTIONS ARE LIMITED ONLY BY YOUR IMAGINATION...  
ORGANIZE A STEP BEYOND CELIAC EVENT IN YOUR TOWN.

Walk, run, bike, or swim! Get moving at your local 5K, biathlon or cycling event and invite your friends and family to sponsor you. We make it easy!

**GET CREATIVE! THROW A PARTY!**

Set up an individual giving page! Direct birthday, wedding, corporate or holiday gifts!

And we're here to help you get started. Call Bob Gray, Beyond Celiac Executive Director of Development, 267-419-2110 and start writing your own story.



In 2017, Beyond Celiac realized revenue of \$2,183,872 and incurred expenses of \$1,584,111. We thank our generous donors and sponsors for supporting our aggressive research agenda geared to accelerate the discovery of new treatments and a cure.

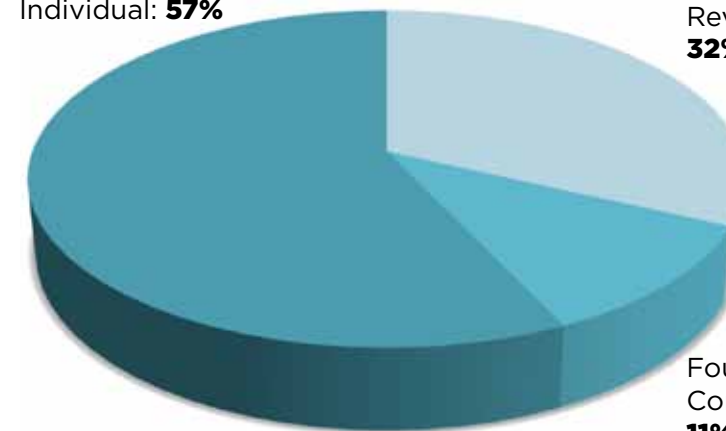
Beyond Celiac earned the top level platinum status on GuideStar and 4-Star rating on Charity Navigator. Both organizations are major information sources about non-profits used by donors and potential donors to review the financial health of organizations.



## REVENUE

Individual: **57%**

Earned Revenue: **32%**



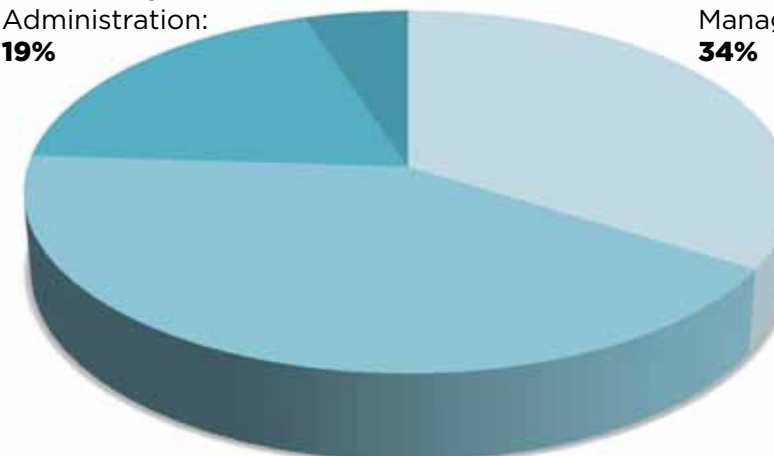
Foundation & Corporation: **11%**

## EXPENSES

Fundraising & Administration: **19%**

Driving Diagnosis: **5%**

Disease Management: **34%**



Research Initiatives: **42%**

## LOOKING AHEAD

**OCTOBER 6**  
2ND ANNUAL STEP BEYOND CELIAC - KC5K FUNDRAISER  
Kansas City, KS  
[www.StepBeyondCeliac.org](http://www.StepBeyondCeliac.org)

**OCTOBER 10**  
2ND ANNUAL BEYOND CELIAC RESEARCH SYMPOSIUM  
Philadelphia, PA

**OCTOBER 11**  
CELEBRATING 15 YEARS OF ACHIEVEMENT  
*Gala and presentation of Samuel Gee Award to Joseph H. Jacovini, Esq, Dilworth Paxson LLP*  
Co-Chairs:  
Daniel J. Hilferty, President & CEO, Independence Blue Cross  
Ajay Raju, Chairman & CEO, Dilworth Paxson LLP  
Jennifer Snyder, Dilworth Paxson LLP  
Philadelphia, PA

Contact Bob Gray, Executive Director of Development for more information: 267-419-2110



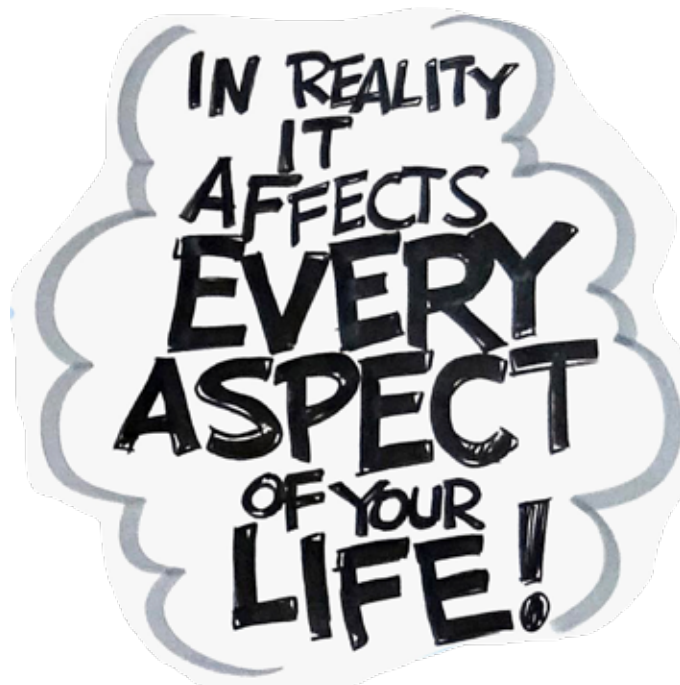
## SERIOUSNESS OF THE DISEASE

**"I was undiagnosed/misdiagnosed for the better part of 10 years. I was told I was "stressed" and that's why I felt the way I did... even after my [antinuclear antibody test] came back positive for an autoimmune disorder. It wasn't until my digestive system went into a full attack and finding an amazing GI doctor [that diagnosed me] that I've finally felt relief!"**

*Kaitlin K.*

**"I was sick off and on most of my life. Doctors could not figure out what was wrong. By late 1991, I was suffering constant diarrhea, overall weakness, severe leg cramps and extreme weight loss. I went from about 125 lbs down to 98 lbs in a few weeks and still losing. Right after New Years 1992, I collapsed at work and was taken to the ER. They did an endoscopy and I finally got a diagnosis of Celiac Sprue—what it was called back then. **I could have died.** I was a few months shy of 42 with three teenaged children. But I didn't die and it's been a journey that has certainly gotten easier since 1992."**

*Janice M.*



**I'm a shadow of my former adventuresome self.** I was a serious foodie who would always try the newest stuff at the oddest restaurants. Now, it's both a crap shoot and a research project to find a place that won't poison me, and will offer anything creative. I'm TIRED. I'm sick of cooking at home...it never was my thing. Celiac disease is a disability. It forces me to pretend to be something I'm not – a cautious nitpicker, and the one person that a group always has to work around when dining out.

*Bonnie E.*

I expect to be disappointed. Disappointed any time my family or friends get together and have food because most, if not all of it has gluten. Hesitant to buy anything new that's gluten-free because it's just not as good as the real stuff. I feel like I'm a princess when I go out to eat with my family because they can't just go anywhere they want. They have to limit their choices to where there is something gluten-free for me. **I would just love to be normal again.**

*Jane C.*

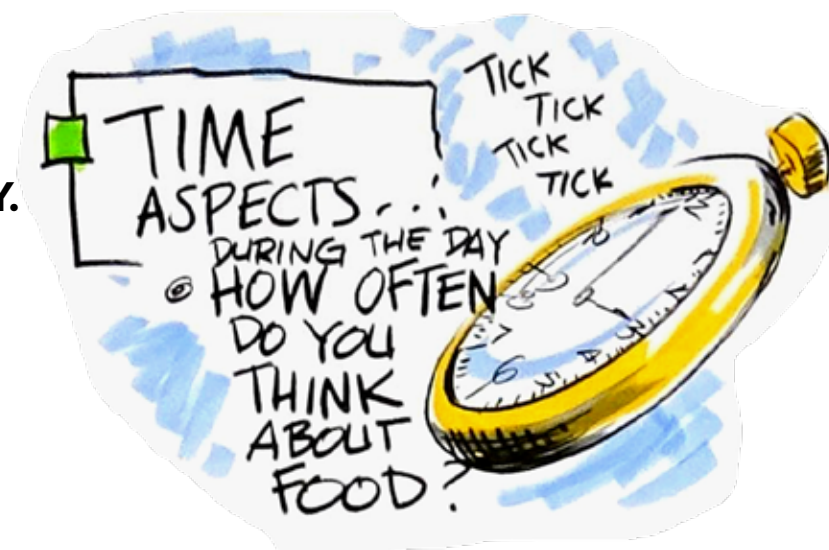
## THE FUTURE

IT WOULD BE NICE TO NOT SUFFER SYMPTOMS. **GLUTEN-FREE DIET AND I STILL SUFFER ALMOST DAILY.**

*Elizabeth P.*

Oh boy, oh boy... what are the odds I'll be enjoying some pizza in the next two years?!

*Marguerite B.*



**IT HAS TO BE A CURE OR NOTHING.** *Coleen S.*



IT WOULD BE REALLY NICE TO BE ABLE TO **GO OUT TO EAT AND NOT WORRY** ABOUT CROSS CONTAMINATION.

*Sara C.*



# CORPORATE AND FOUNDATION SUPPORTERS



Georgine Trumpbour, Ed Trumpbour, Laura Coogan, Jay Coogan, Janine Brenan, C. Kane Brenan, Kristin Sims, Peter Sims

## CORPORATE AND FOUNDATION SUPPORTERS

BB&T  
 Bell & Evans  
 Beneficial Bank  
 Binswanger Management Company  
 BNY Mellon Wealth Management  
 Boar's Head  
 Conservest Capital, Inc.  
 Cour Pharmaceuticals Development Co., Inc.  
 Crunchmaster  
 The Davis/Dauray Family Fund  
 Dilworth Paxson, LLP  
 Dr. Schar USA  
 The Education Projects Foundation  
 Focus on Health  
 Glutenostics  
 Goldman Sachs Gives  
 Green Family Charitable Foundation  
 GSK  
 Hewlett Packard Enterprise  
 ImmusanT  
 Independence Blue Cross  
 Innovate Biopharmaceuticals, Inc.  
 KAP Foundation  
 The Jane & Leonard Korman Family Foundation  
 Liberty Mutual  
 Lockheed Martin Employees Charity  
 The Lubert Family Foundation  
 Merck Partnership for Giving  
 The Alan & Jill Miller Foundation  
 O'Connell & Company  
 The Pfizer Foundation  
 The Philadelphia Eagles  
 Premier Healthcare Solutions, Inc.  
 The Ravitz Family Foundation

Raynier Institute & Foundation  
 Takeda Pharmaceuticals, USA, Inc.  
 The Aileen K. & Brian L. Roberts Foundation  
 The Ivan Seidenberg Foundation  
 Thermo Fisher Scientific  
 The Snider Foundation  
 Sorghum Checkoff Program  
 Springbank Foundation  
 Thomas Jefferson University & Jefferson Health  
 The William T. Vogt & Lorine E. Vogt Charitable Foundation  
 Three Bakers  
 Venice Baking Company  
 Wakefern Food Corporation  
 Wells Fargo Community Support Campaign  
 Wegmans  
 Wilmington Trust

## GIFTS IN KIND SUPPORTERS

Allergic Living  
 Amy's Kitchen, Inc.  
 By The Way Bakery  
 Canyon Bakehouse  
 Crosby Marketing Communications  
 Crunchmaster  
 Dilworth Paxson, LLP  
 DLA Piper, LLP  
 Dr. Schar USA  
 Duane Morris, LLP  
 Entercom/KYW NewsRadio, Philadelphia  
 Feliz Restaurants  
 Froose Brands, LLC  
 Garces Events  
 Roger Glass  
 The Happy Mixer  
 Kathleen Helwig  
 High Point Philly  
 Inspire Human Resources  
 KIND  
 Lily's Sweets  
 NetReach  
 Not Your Average Joe's  
 Pamela's Products, Inc.  
 Barbara Weir Powers  
 Rich Products Corporation  
 Alison Clabaugh Seiferth  
 Starr Catering Group  
 Sweet Freedom Bakery

# BEYOND CELIAC BOARD OF DIRECTORS AND BEYOND CELIAC ADVISORY COUNCILS

## BEYOND CELIAC BOARD OF DIRECTORS

### Alice Bast

CEO  
 Beyond Celiac

### Robert J. Beall, PhD

Executive Advisor  
 Cystic Fibrosis Foundation

### Gerald Bertiger, MD

Hillmont GI, PC

### C. Kane Brenan

Managing Director,  
 Global Portfolio Solutions  
 Goldman Sachs

### Linnie Cook

Chief Advocacy Officer  
 The Cook Organization

### Aimee Corso

Healthcare Marketing Lead, Amazon Business  
 Amazon

### Linda S. Deal, MS

Head of Patient-Centered Outcomes Assessment  
 Pfizer

### Treasurer

#### Denise L. Devine

CEO & President  
 Froose Brands, LLC

### Chair

#### Alan M. Ehrlich, MD

Executive Editor  
 DynaMed  
 Associate Professor of Family Medicine  
 University of Massachusetts Medical School

### Ciarán P. Kelly, MD

Director, Celiac Center  
 Director, Gastroenterology Fellowship Training  
 Beth Israel Deaconess Medical Center  
 Professor of Medicine  
 Harvard Medical School

### Vice Chair

#### Gregg Melinson

Senior Vice President, Corporate Affairs  
 Hewlett Packard Enterprise

### R. Bennett Muskin

Managing Director  
 Sagebrook Partners, LLC

### Secretary

#### Barbara Weir Powers

Marketing Manager  
 Powers Equipment Company

### Chad P. Shaffer, MD, FAAFP

Assistant Professor of Medicine, Retired  
 University of Missouri-Kansas City School of Medicine

### Jennifer P. Snyder

Partner  
 Dilworth Paxson, LLP

## BOARD OF DIRECTORS—EMERITUS

### Joseph F. Coradino

CEO  
 PREIT Services, LLC

### Bill Green

Managing Partner  
 WSG Partners, LLC

## SCIENTIFIC/MEDICAL ADVISORY COMMITTEE

### Rita Balice-Gordon, PhD

Global Head, Neuroscience Research Therapeutic Area  
 Sanofi, Inc  
 Adjunct Professor of Neuroscience  
 Perelman School of Medicine at the University of Pennsylvania

### Rachel Begun, MS, RDN, CDN

Principal  
 Rachel Begun Food and Nutrition Solutions

### Keith Berkowitz, MD

Founder and Medical Director  
 Center for Balanced Health



# BEYOND CELIAC ADVISORY COUNCILS



Beyond Celiac Board of Directors at work.

## **Craig J. Brown, MD, FACS**

Optometrist, Founding Partner  
The Eye Center

## **Sheila E. Crowe, MD, FRCPC, FACP, FACG, AGAF**

President  
American Gastroenterological Association (AGA)  
Professor of Medicine and Director of Research  
Division of Gastroenterology  
UC San Diego, School of Medicine

## **Anthony J. DiMarino, Jr., MD**

Chief, Division of Gastroenterology & Hepatology  
Thomas Jefferson University Hospital

## **Nancy Patin Falini, MA, RD, LDN**

Registered Dietitian, Private Practice (Celiac)  
Consultant/Author/Lecturer

## **Alessio Fasano, MD**

Chief, Division of Pediatric Gastroenterology  
and Nutrition  
Director, Center for Celiac Research  
Director, Mucosal Immunology and Biology  
Research Center  
Massachusetts General Hospital

## **Paolo Fortina, MD, PhD**

Professor, Department of Cancer Biology and  
Medical Oncology  
Director, Cancer Genomics Laboratory  
Thomas Jefferson University

## **Marla J. Gold, MD**

Professor, Health Management and Policy  
Drexel University School of Public Health

## **Gary M. Gray, M.D.**

Professor of Medicine, Emeritus  
Director, Celiac Management Clinic  
Stanford University Medical Center

## **Edward J. Hoffenberg, MD**

Professor of Pediatrics  
Director, Center for Pediatric Inflammatory Bowel  
Diseases  
Children's Hospital Colorado  
University of Colorado Denver School of Medicine

## **Donald D. Kasarda, PhD**

Collaborator, Agricultural Research Service  
U.S. Department of Agriculture

## **Ciarán P. Kelly, MD**

Professor of Medicine  
Harvard Medical School  
Director, Celiac Center & Director Gastroenterology  
Fellowship Training  
Beth Israel Deaconess Medical Center

## **Daniel A. Leffler, MD, MS**

Medical Director, Clinical Science  
Gastroenterology TAU  
Takeda Pharmaceuticals U.S.A., Inc.  
Director of Research  
The Celiac Center at BIDMC  
Beth Israel Deaconess Medical Center  
Associate Professor  
Harvard Medical School

## **Robert H. Lerman, MD, PhD**

Functional Medicine Research Center  
MetaProteomics, Inc.

## **Ted Malahias, DDS**

Dental Consultant  
Celiac Disease Center at Columbia University



## **Robert A. Mangione, EdD, RPh**

Dean and Professor  
College of Pharmacy and Allied Health Professions  
Provost  
St. John's University

## **Stanton B. Miller, MD, MPH**

Assistant Professor  
Jefferson School of Population Health  
Assistant Professor  
Director, LIMR Center for Public Health Research  
Lankenau Institute of Medical Research

## **Stephen D. Miller, PhD**

Professor of Microbiology-Immunology and  
Dermatology  
Director, Interdepartmental Immunobiology Center  
Feinberg School of Medicine  
Northwestern University

## **Gerard E. Mullin, MD**

Associate Professor of Medicine  
The Johns Hopkins University School of Medicine  
The Johns Hopkins Hospital

## **Joseph A. Murray, MD**

Consultant, Division of Gastroenterology &  
Hepatology  
Professor of Medicine  
Mayo Clinic College of Medicine

## **Michelle Pietzak, MD**

Assistant Professor of Clinical Pediatrics  
USC Keck School of Medicine  
Division of Gastroenterology and Nutrition  
Children's Hospital Los Angeles

## **Ludvig M. Sollid, MD**

Professor of Medicine  
Rikshospitalet University Hospital

## **Warren Strober, MD**

Section Chief, The Mucosal Immunity Section  
National Institutes of Health

## **Ritu Verma, MD**

Section Chief, Gastroenterology  
The Children's Hospital of Philadelphia  
Professor of Clinical Pediatrics  
Perelman School of Medicine at the University of  
Pennsylvania

## **BUSINESS ADVISORY COUNCIL**

### **Richard Binswanger**

Non-profit Leader  
ITData, Inc.

### **Veenita B. Bleznak, Esq.**

COO  
IAmElemental

### **Stephen Bouikidis**

Chief Digital Strategist  
Magma Digital

### **Laura Carlsmith**

Licensing, Audience Development Director, retired  
The EatingWell Media Group

### **John M. Coogan, Jr.**

Partner  
DLA Piper LLC



# BEYOND CELIAC ADVISORS AND STAFF

## **Harry L. Cook**

President & Managing Partner  
Leadership Essentials, LLC

## **Michael Danke**

Manager-Pricing Systems  
Academy Sports + Outdoors

## **Lindsey Goebel**

Director, Social Media & Content Marketing  
Crosby Marketing

## **J.C. Henry III**

President & CEO  
EP Henry Corporation

## **Linda Holliday**

Founder & CEO  
Citia

## **Jaime C. Klein**

Founder and President  
Inspire Human Resources

## **Richard J. Mandel**

President  
Richard J. Mandel, MD, PC

## **Chris Mycek**

Chief Customer Officer  
Cadient Group

## **Michael S. Savett, Esq.**

Counsel  
Hill Wallack LLP

## **Jordana Schneider**

## **Roberta Snow**

Professor of Management, retired  
West Chester University

## **Margaret Fearey Walsh**

President  
Changing-Places, Inc.

## **Martin I. Weis, Esq.**

Partner  
Dilworth Paxon, LLP

## **David S. Yadgaroff**

Senior Vice President/Market Manager  
Entercom | Philadelphia

## **PATIENT AND FAMILY ADVISORY COUNCIL**

**Marge Benham-Hutchins, PhD, RN**—Texas

**Julie Kennedy**—North Carolina

**Shannon S. Myers MSN, FNP-C**—Arizona

**Michael Paroda**—Ohio

## **STAFF**

### **KATE AVERY, MPH**

Director of Research and Patient Engagement

### **CLAIRE BAKER**

Director of Communications and New Media

### **ALICE BAST**

CEO

### **NANCY GINTER**

Director of Administration

### **BOB GRAY**

Executive Director of Development

### **JILIAN HUNT**

Field Manager, Fundraising

### **MARIA LUCI**

Communications Coordinator

### **BECKEE MORELAND**

GREAT Kitchens Consultant

### **KIM PACINI**

Assistant Director of Digital Media

### **AMY RATNER**

Medical and Science News Analyst

### **MARIE ROBERT, MD**

Chief Scientific Officer

### **MARY TACKETT, MLS**

Director of Donor Relations





P.O. Box 544  
Ambler, PA 19002-0544  
215-325-1306  
Toll Free 844-856-6692  
info@BeyondCeliac.org

[www.BeyondCeliac.org](http://www.BeyondCeliac.org)

