



# CATALYST FOR A CURE



ANNUAL REPORT 2019

# 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.

ON THE COVER: Leadership for the New Decade. Beyond Celiac Science Team (left to right): Chief Scientific Investment Officer Ken Kilgore, PhD, MBA; Director of Research and Patient Engagement Kate Avery, MPH; CEO Alice Bast; Chief Scientist and Strategy Officer Salvatore Alesci, MD, PhD. Not pictured: Medical and Science News Analyst Amy Ratner.



Alan Ehrlich, MD



Alice Bast

## Letter from Board Chair and CEO: **ACCELERATING TREATMENTS AND A CURE**

When we first began work on our 2019 annual report, COVID-19 didn't yet exist. And while much of 2020 will have a coronavirus backdrop, we know that in the midst of it all, the celiac disease community still desperately needs solutions. We are so grateful for your support which have enabled our work thus far. We are proud of our accomplishments to date, and we are pleased to share with you how Beyond Celiac will improve the future for people with celiac disease and the 50 million people with other autoimmune diseases. Together with you, we still plan to cure this insidious disease in 10 years.

Because Beyond Celiac is a cure accelerator, we've expanded and amped up our science department. We are especially excited to introduce you to the newest members of our science team. Salvatore (Salvo) Alesci, MD, PhD, is our Chief Scientist and Strategy Officer (CSSO) and Ken Kilgore, PhD, MBA, is our Chief Scientific Investment Officer (CSIO). In addition to having exceptional scientific credentials, backgrounds, and experience, both have a family connection to celiac disease. Both care deeply about our cause and our community. Finding solutions to help patients and their families overcome the burden of this disease has become both a personal and professional goal for them.

In 2019 we launched our grant-making program, committing \$600,000 to fund exciting research projects in this country and in the U.K. We expanded our work and enhanced our community engagement through the scaled up Step Beyond Celiac 5K series, the Go Beyond Celiac patient database, our rich partnership with Beyond Celiac ambassador, opera star Arturo Chacon-Cruz, and our symposium and summit. We are in this together — and Beyond Celiac is the catalyst for a new era of transformational advances in celiac disease treatments. We are so happy to be on the journey with you as we envision a world in which our community can eat without fear and live life to the fullest.

With our deep thanks,  
Alan Ehrlich, MD, Board Chair  
Alice Bast, CEO



Salvatore Alesci,  
MD, PhD

## From the desk of the Chief Scientist and Strategy Officer, Salvatore Alesci, MD, PhD

In my new role as the Beyond Celiac Chief Scientist and Strategy Officer and Executive Chair of the Beyond Celiac Scientific Advisory Council, I am leading the organization's science team and overseeing the design and implementation of the scientific strategy and plan, with a particular focus on deepening partnerships with scientists, key opinion leaders, policy makers and influencers across pharmaceutical companies and academic and government institutions. We began this work at our 2019 Research Summit, and we will continue the momentum from there.

I am passionate about finding real treatment solutions and eventually a cure for celiac disease, and committed to working closely with pharmaceutical, biotech and startup partners to make sure they understand what people with celiac disease truly feel, need and want. For me, this is both personal as well as professional – my daughter was diagnosed with celiac disease 10 years ago. I look forward to helping make the world a better and safer place for her and for all of the celiac disease community through our transformational science plan.

Sincerely,

Salvatore Alesci, MD, PhD



Ken Kilgore,  
PhD, MBA

## From the Desk of Chief Scientific Investment Officer, Ken Kilgore, PhD

Adjusted for inflation, the NIH budget is almost 20% less than it was 18 years ago. Celiac disease is the least funded GI-related disease, despite the prevalence and mortality rate. The decline in federal funding for biomedical research has led to fewer grant applications being funded, and we are losing the opportunity to cultivate new researchers who may not see a career in biomedical research. We can't let the fate of celiac disease research lie in the hands of inconsistent and inadequate funding from public sources. If we want a cure, we need a transformational approach.

Traditional ways of investing in research have rarely included community-based nonprofits. Beyond Celiac is changing that model. We are creating an avenue by which donors can support research beyond the narrow confines of one specific research institution. As the Chief Scientific Investment Officer of Beyond Celiac, I will lead the work of assessing the opportunities and risks for philanthropists who want to accelerate research for celiac disease and will create an avenue by which they can put their resources to work on the most promising solutions. If this grabs your attention, we need to talk! We can work together for a cure.

Sincerely,

Ken Kilgore, PhD



## 2019 BEYOND CELIAC RESEARCH SYMPOSIUM

Patients are used to hearing that the first drug to treat celiac disease is likely to be approved in about five years. But at the 3rd Annual Beyond Celiac Research Symposium on May 30, 2019, Beyond Celiac shared a behind-the-scenes look at what it is really going to take to get new treatments to the market. The Symposium was free and open to the public and live streamed around the world for those who couldn't make it in person.

Moderated by Marie Robert, MD, celiac disease and drug development experts on the symposium panel had a wide-ranging discussion before an international live and webcast audience detailing the many steps taken before, during and after a new treatment enters even the earliest phase of clinical trial. Emphasis was given to the importance of the patient voice throughout the drug development process.

Panelists Sonia Kupfer, MD, a gastroenterologist at the University of Chicago Celiac Disease Center, Joseph Murray, MD, a celiac disease expert and professor of medicine at the Mayo Clinic, and Linda Deal, MS, head of patient centered outcomes assessment at the pharmaceutical company Pfizer, also explored non-celiac gluten sensitivity and symptoms, the celiac disease diagnosis rate, the risks of minor gluten exposure and follow-up health care.



2019 Research Symposium reception



Sonia Kupfer, MD and Joe Murray, MD



Moderator Marie Robert, MD with panelists Sonia Kupfer, MD, Joe Murray, MD and Linda Deal, MS at the 2019 Beyond Celiac Research Symposium



Thousands of viewers worldwide watched the symposium webcast. A replay is available at [BeyondCeliac.org/symposium](http://BeyondCeliac.org/symposium)



Visit [BeyondCeliac.org/symposium](http://BeyondCeliac.org/symposium) to watch a replay of the full proceedings.

## 2019 BEYOND CELIAC RESEARCH SUMMIT

On November 15, the 2019 Beyond Celiac Research Summit brought together stakeholders crucial to accomplishing the goal of developing new celiac disease treatments.

Getting over the Peak: The Final Ascent to Realizing Therapies in Celiac Disease, brought together:

- Clinician scientists
- Patients
- Entrepreneurial drug developers
- Patient advocacy leaders
- Private and public health care insurance
- Food and Drug Administration representatives



2019 Research Summit patient panel – *Participating in a Clinical Trial: Experiences from the Trenches*. Left to right: Roz Schneider, MD, MSc, Moderator; Ellen McKinley; Ann Horsburgh; Jen Arters; Tina Ramos

Several panel discussions were webcast about the challenges that our community faces in managing celiac disease, experiences that community members have had in participating in clinical trials, and barriers to research.

The 2019 summit built on the results of our innovative 2015 summit, which was widely hailed as highly impactful and led to new scientific collaborations and honing the steps to advance patient-centered celiac disease research.

The 2019 summit took place against the backdrop of at least 12 clinical trials for celiac disease treatments. The aim of Beyond Celiac was to comprehensively address elements that must be in place to get a drug to market, including the remaining barriers in this decades-long journey to help patients with celiac disease. Visit [BeyondCeliac.org/ResearchSummit](http://BeyondCeliac.org/ResearchSummit) to watch a replay of the morning sessions.



Beyond Celiac Board member and former CEO of the Cystic Fibrosis Foundation Bob Beall, right, responds to questions from the audience at the keynote address of the 2019 Summit. Pictured: Ritu Verma, MD and Alice Bast.



2019 Beyond Celiac Research Summit attendees, including physicians, researchers and patients, and representatives from health insurance, government and regulatory agencies.



Melissa Secort, Executive Director of the Canadian Celiac Association and Amy Ratner, Beyond Celiac Medical and Science News Analyst discussed the Role of Patient Advocacy Groups in Getting Therapies to Patients.



Artist Joe Azar captured the proceedings of the 2019 Beyond Celiac Research Summit in a 4' X 10' graphic recording.

The outcome of the summit is a white paper that provides an overview of the summit discussions as well as a list of action items for all stakeholders involved. These action items will serve as a guide as we work together to bring a treatment to the celiac disease community.

## GO BEYOND CELIAC EXPANSION

In August 2019, Beyond Celiac launched a first-of-its-kind mobile app to complement its online research database, *Go Beyond Celiac*, providing more convenience and opportunity for patient engagement.



*Go Beyond Celiac*, which has enrolled more than 5,800 participants since its launch in 2017, is an online database created by people with celiac disease, for people with celiac disease. Users can

participate in research by sharing their stories and experiences and learn how to become involved in celiac disease research studies.

The new app now makes *Go Beyond Celiac* more interactive and engaging, and the mobile convenience encourages more people to visit and share their experience of living with and managing celiac disease. This is done through surveys that can be filled out at users' convenience. The app also offers helpful insights about events, educational opportunities and more. *Go Beyond Celiac* members will be able to see how they compare to others as a more complete picture of celiac disease emerges from the data collected.



## BEYOND CELIAC ORIGINAL RESEARCH

Survey of Patient Receptivity to Participating in Research Accepted for presentation at national conference

People who have celiac disease are willing to participate in celiac disease research, but less so if a study involves eating gluten or getting a biopsy, a 2019 survey by Beyond Celiac has found.

The survey of about 4,500 adults with celiac disease was done in advance of the recent Beyond Celiac Research Summit and results were shared there. Nearly 500 parents of children with celiac disease also completed a separate survey.

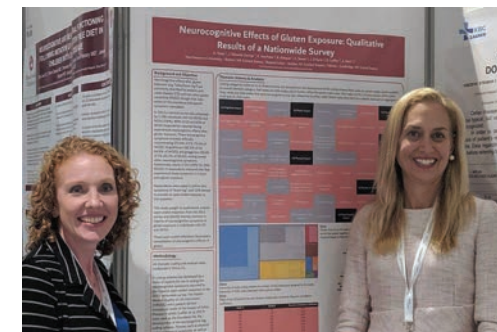


Only about 9 percent of both adults and parents said they would not participate or allow participation in any kind of celiac disease research.

This original Beyond Celiac research was accepted for presentation at Digestive Disease Week 2020 in San Diego.

## BEYOND CELIAC ORIGINAL RESEARCH

Brain Fog Study Presented at the International Celiac Disease Symposium



Brain Fog Research highlighted by Jessica Edwards George, PhD and Alice Bast at the 2019 International Celiac Disease Symposium in Paris

A step toward better understanding of brain fog and other neurocognitive symptoms in celiac disease and how they affect day-to-day life is described in research Beyond Celiac presented at the 2019 International Celiac Disease Symposium in Paris. The study details the analysis of nearly 500 open-ended survey responses in which those who have celiac disease and nonceliac gluten sensitivity (NCGS) described neurocognitive symptoms after gluten exposure.

The responses were part of a larger survey of nearly 1,400 patients who identified difficulty concentrating, forgetfulness and grogginess, often one to four hours after being exposed to gluten.

The portion of the survey in which patients described symptoms in their own way is the basis of the new analysis. Cognitive, psychological and quality of life symptoms were most commonly mentioned and emerged as themes.

## 2019 GO BEYOND CELIAC GALA AND CONCERT

Beyond Celiac held its signature benefit event on October 24, 2019 at The Kimmel Center for the Performing Arts.

Well-known Philadelphia philanthropist and activist Carole Haas Gravagno received the 2019 Samuel Gee Award in recognition of her commitment to our mission to forge pathways to a cure for celiac disease. The evening culminated with an unforgettable performance by Beyond Celiac ambassador and acclaimed opera tenor Arturo Chacón-Cruz in the Kimmel's Perelman Theater. The event raised over \$300,000 in funding for research to accelerate a cure for celiac disease.



Arturo Chacón-Cruz and Carole Haas Gravagno backstage



Richard Mandel, MD, Will Bast, Stan Richelson and Paula Mandel. Richard and Paula are co-chairs of our 2020 event, Together for a Cure: An Evening Beyond Celiac



Accompanist Roberto Berrocal and Arturo Chacón-Cruz

In October 2020, we will host our annual event in Philadelphia, convening Beyond Celiac supporters to celebrate our 2020 accomplishments and dedication towards a cure.

## STEP BEYOND CELIAC 5K

2019 was a wonderful year with three SBC5K events in Philadelphia, Kansas City, and Dallas.



Together we:

- Hosted over 2000 SBC5K participants in 3 cities
- Raised over \$80,000 for celiac disease research
- Welcomed 200+ volunteers who came together to support our community and each other
- Brought together dozens of local restaurants and bakeries as vendors at our events, all safely gluten-free
- Filled goodie bags for every participant with over 20 gluten-free treats and coupons to help keep them safe beyond race day



BEYOND CELIAC RESEARCH GRANTS 2019 AWARDEES



**Marisa Gallant Stahl, MD**, Children’s Hospital Colorado

**RESEARCHER** .....  
**NAME OF GRANT** ..... *Society for the Study of Celiac Disease/Beyond Celiac Early Career Investigator grant*

**DESCRIPTION OF WORK** ..... The study addresses the dilemma of weighing the potential health problems related to undiagnosed celiac disease in asymptomatic children with the potential burden of the gluten-free diet, which can be socially limiting and lead to problems with anxiety, depression and a general reduction in quality of life, plus some nutritional concerns.

**PRIMARY STUDY FOCUS** ..... *Psychosocial Impact of Celiac Disease*



**Paul Klenerman, PhD**, University of Oxford, Oxford, England

**RESEARCHER** .....  
**NAME OF GRANT** ..... *Established Career Award grant*

**DESCRIPTION OF WORK** ..... Research focuses on T-cells in the inner gut lining – killer CD8 T-cells. The role of another type of T-cell, the CD4 T-cell, has been more thoroughly studied and scientists know it responds to gluten and plays a key role in celiac disease. Less is known about CD8 T-cells though they lead to the myriad of consequences of celiac disease.

**PRIMARY STUDY FOCUS** ..... *Development of future treatment options*

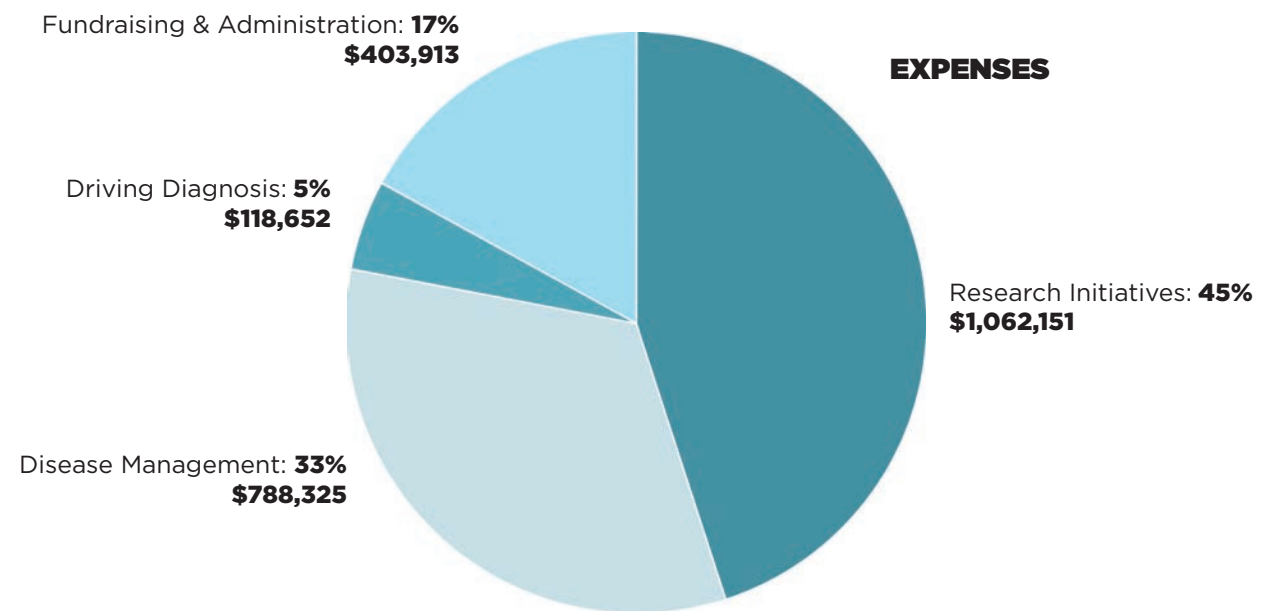
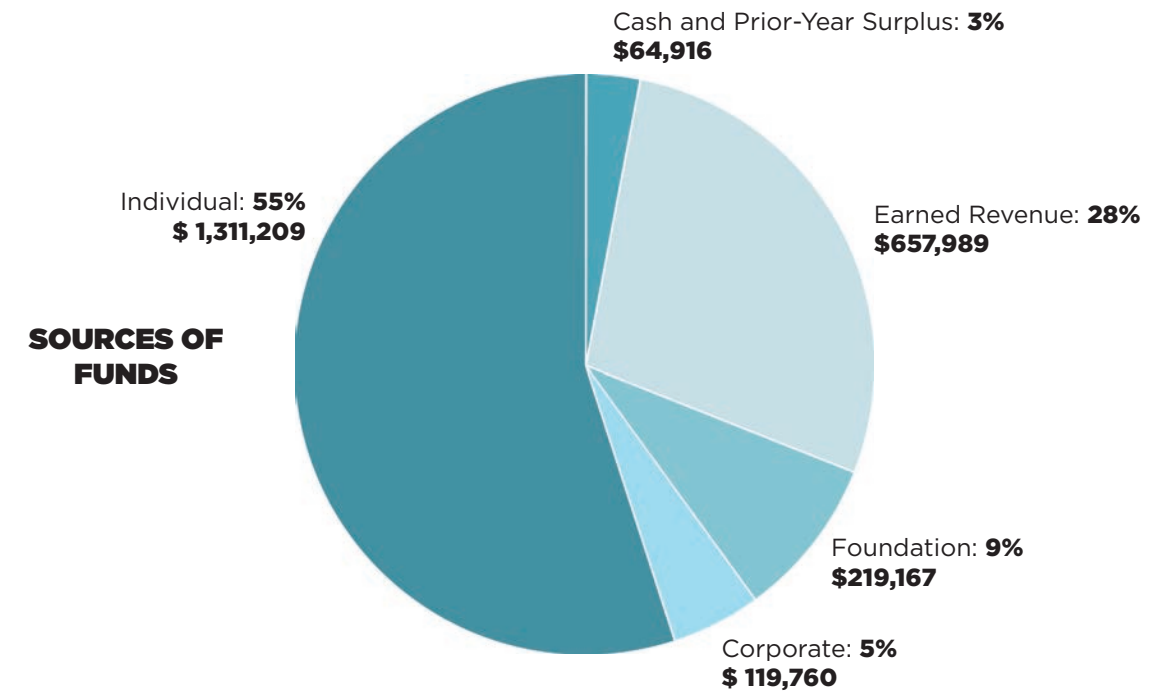


**Jocelyn Silvester, MD**, Boston Children’s Hospital

**RESEARCHER** .....  
**NAME OF GRANT** ..... *Innovative Research grant*

**DESCRIPTION OF WORK** ..... This study focuses on RNA sequencing for diagnosis and follow-up, and the comparison of biopsies taken when gluten was in the diet and after a gluten-free diet was being followed.

**PRIMARY STUDY FOCUS** ..... *Increasing the rate of diagnosis and managing the gluten-free diet*



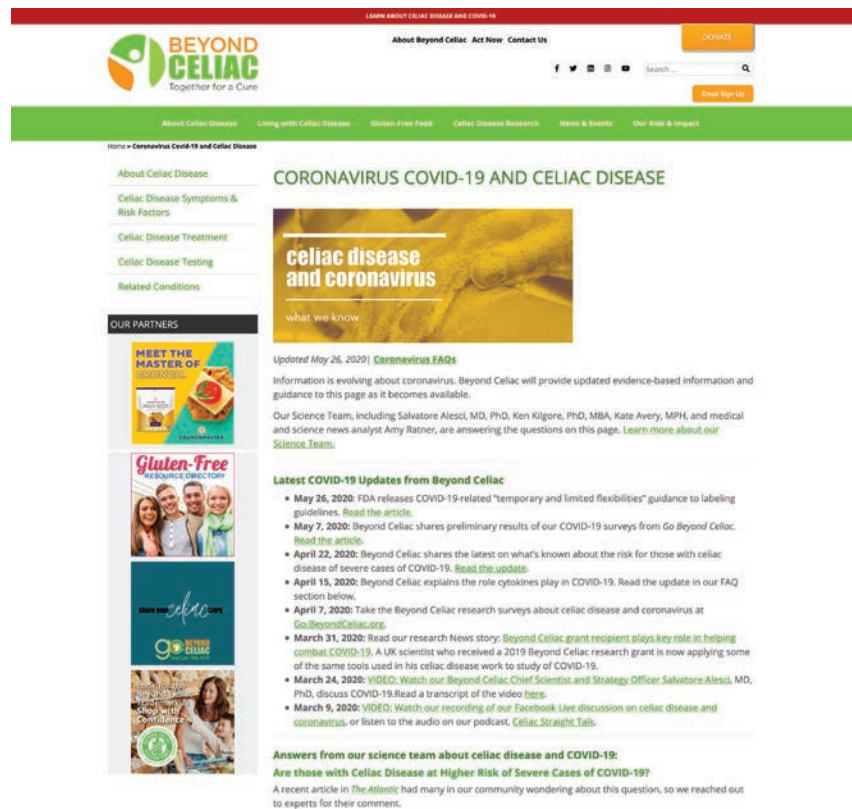
In 2019 Beyond Celiac combined \$2,308,125 in new operational revenue and funds raised with \$64,916 of funding from investments, cash and prior-year surplus to cover expenses of \$2,373,041. We thank our generous donors and sponsors for supporting our aggressive research agenda geared to accelerate the discovery of new treatment and a cure.



While it's important to appreciate our accomplishments of 2019, Beyond Celiac is, as always, looking to the future.

**RESPONSE TO COVID-19**

When the novel coronavirus came to the United States, we received countless inquiries about how COVID-19 might impact people with celiac disease. The science and communications teams quickly built out an extensive page filled with resources to answer the most common questions and provide additional support to our community. Throughout the crisis we shared videos of our science team leaders answering questions about celiac disease and coronavirus. This page proved to be immensely popular and useful to our community and was cited on other websites, such as the National Health Council, as a source for reputable information.



In addition, to keep the spirits of our community up during periods of isolation, we started the virtual Beyond Celiac Book Club that highlighted relevant books and allowed for intriguing conversation and engagement over social media. We also created new recipes and recipe videos, including making your own gluten-free sourdough starter and baked goods—a popular project during quarantine. Our virtual running/walking club also gained steam during this period.

**ORIGINAL BEYOND CELIAC RESEARCH**

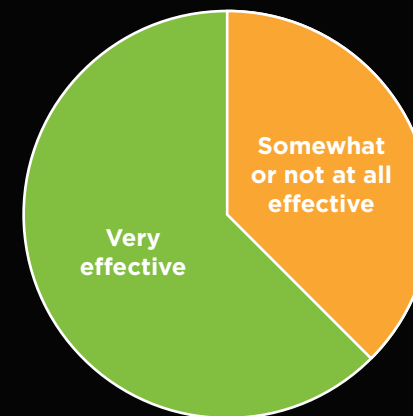
Beyond Celiac is sharing research insights learned from *Go Beyond Celiac*. This monthly update engages participants in the database and the wider research and patient communities in better understanding the journey and challenges before, during and after diagnosis.

Additionally, the Beyond Celiac science team swiftly created a COVID-19 and Celiac Disease survey as part of the *Go Beyond Celiac* database. More than 300 community members recorded both the physical and psychological impact of the global coronavirus pandemic on the celiac disease community.



Insight of the Month:  
Effectiveness of the gluten-free diet

**HOW EFFECTIVE IS THE GLUTEN-FREE DIET FOR YOU?**



**VIRTUAL STEP BEYOND CELIAC 5K**

At the start of 2020, Beyond Celiac announced the expansion of our Step Beyond Celiac 5K events to five cities across the United States. With the uncertainty of the COVID-19 crisis, we have built and expanded a companion Virtual Step Beyond Celiac 5K five-city tour. Additionally, we focused on using Step Beyond Celiac social pages to engage with our community and keep them informed with the latest on our races, promoting our Strava Run Club, and ways to stay healthy and active during quarantine.

**SUMMER INTERN COUNCIL**

Newly created starting this summer, Beyond Celiac has launched its Summer Intern Council. College student interns will work both independently and collaboratively on projects designed to drive the organization forward. Funded through the generosity of celiac disease community member Mary Bianco, the Summer Intern Council will support efforts to raise awareness, drive diagnosis and support research for treatments and a cure, and also provide the Beyond Celiac staff with a fresh perspective on the organization's programs and services.

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2019 Research Summit patient panel – *The Burden of Disease: Life with Celiac Disease on a Gluten-free Diet*. Left to right: Anne Lee, EdD, RDN, LD Moderator; Katie Kenyon; Prinyanka Chugh, MD, MS; Julie Kennedy, MPH, MEd, RDN, LDN; Natalie Dabrowski

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