

# In it to \_\_\_\_\_\_





### 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:

#### Our community members are in it to win it!

Pictured on the cover are just a few of the many people who have shared their Voices of Celiac story and/or become Reach Beyond Celiac Ambassadors to help us accelerate research for treatments and a cure.

Left to right, top to bottom:

Jasmin Espinal
Jake Woods, Ambassador
Makamae from Illinois
Robert from Ohio
Hannah Riley, Ambassador
Annika Dhariwal, Ambassador
Aditi Dand
Natasha Prime, Ambassador
Frank from Nebraska
Valerie from Connecticut
Rochelle Siezega, Ambassador
Fatima Anjum, Ambassador

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### 3 CRITICAL WAYS BEYOND CELIAC IS PROPELLING US CLOSER TO A CURE



Alan Ehrlich, MD



Alice Bast

TODAY, WE WANT TO SHARE WITH YOU THREE OF OUR CURRENT AREAS OF FOCUS AND WHY WE HAVE, WITH YOUR SUPPORT, TAKEN ON EACH CHALLENGE.

We've invested \$1.6M in research. We have funded research to help identify celiac disease earlier in at-risk patients. We have also funded research that shows that celiac disease affects much more than the gut – in particular, examining neurocognitive effects, with the goal to propel the development of potential treatments for all symptoms, not just those GI-related, by understanding which cells to target.

Why it matters: Diagnosing earlier, understanding when and why celiac disease becomes active, developing a non-invasive diagnostic test, and understanding what the full impact of celiac disease is on various systems in the body will reveal significant clues to speed progress for treatments beyond the gluten-free diet. A better understanding of celiac disease may also enable us to prevent it from being triggered altogether. Investing in a variety of lines of inquiry gives us more "shots on goal"—approaching celiac disease from multiple directions will yield more chances to score and improve the lives of people in our community.

We've launched an ambitious initiative to identify and examine health disparities in the diagnosis and treatment of celiac disease in populations typically underrepresented in the celiac community. With our Health Disparities and Diversity Project and partnership with the National Minority Quality Forum, we are mapping the prevalence of celiac disease diagnosis, treatment and co-morbidities across the United States. Through this work, Beyond Celiac is uncovering possible missed diagnoses based on geography, race, ethnicity and economic status. Early indications suggest that celiac disease diagnoses are frequently missed in large parts of the country, and within key racial and economic groups.

Why it matters: Everyone living with celiac disease deserves a fast and accurate diagnosis. Furthermore, as noted by the FDA, "Ensuring people from diverse backgrounds join clinical trials is key to advancing health equity." The FDA is the regulatory body that determines if and how quickly potential treatments move along the process toward approval. It is important that we work to reduce and remove any obstacles, including lack of diversity in celiac disease clinical trials, from the regulatory process so that we can meet our goal of treatment options toward a cure by 2030.

Beyond Celiac is accelerating research by recruiting participants and reducing barriers for clinical trials. In the past several years, numerous companies and drug development efforts have begun targeting celiac disease. As the leading clinical trial recruitment partner for pharma companies, Beyond Celiac continues to serve as a leading catalyst engaging the entrepreneurs behind those efforts with other researchers, pharmaceutical companies, academics and regulators to accelerate the path from the lab to our community. Further, with our Go Beyond Celiac patient registry and database, and by working directly with clinical trial partners, Beyond Celiac has been able to connect hundreds of community members who are interested in and qualified for research projects to specific clinical trials.

Why it matters: Nearly a dozen different celiac disease treatments are in clinical trials—more than ever before. Without input from our community, studies may not take into account issues that would prevent people from signing up. Without people with celiac disease who meet the criteria to participate, research slows and can even be halted. Beyond Celiac informs and connects, thereby speeding the process for treatments toward a cure.

WE COULD NOT HAVE COME SO FAR SO FAST WITHOUT THE COMMITMENT FROM OUR COMMUNITY, AND FOR THAT WE THANK YOU. TOGETHER WE FACE THE CHALLENGES OF STAYING HEALTHY FROM DAY TO DAY WHILE ALSO MAKING THE INVESTMENTS THAT WILL KEEP US ALL HEALTHY LONG INTO THE FUTURE. WITH YOU, WE WILL CONTINUE TO LEAD THE CHARGE FOR TREATMENTS AND A CURE. BY SUPPORTING OUR WORK, YOU'RE LEAVING YOUR MARK ON A FUTURE BEYOND CELIAC.

WITH OUR DEEP THANKS,

ALICE BAST, CEO
ALAN EHRLICH, MD, BOARD CHAIR

### BEYOND CELIAC COALITION

# BEYOND CELIAC COALITION LAUNCHED

Beyond Celiac has launched a multi-stakeholder coalition to advance clinical research in celiac disease. Members include top representatives from pharmaceutical, biotech and diagnostic companies as well as leading researchers and clinicians in the field, including participants such as Takeda; Provention Bio; Anokion; imaware™ at-home health testing; Marisa Stahl, MD and Edwin Liu, MD of Children's Hospital Colorado; Adam C. Stein, MD of Northwestern University Feinberg School of Medicine, Joseph A. Murray, MD of the Mayo Clinic and more.

Beyond Celiac formed this precompetitive partnership with the overarching goal of addressing significant roadblocks on the path to a cure for celiac disease, with a particular emphasis on breaking down barriers to patient engagement in clinical trials. "Strategic partnerships are a key enabler of our science plan," said Salvo Alesci, Beyond Celiac Chief Scientific Strategy Officer. "Accelerating research into treatments for celiac disease will only happen through the concerted effort of many strong, committed partners."

The coalition is broadly inclusive, and more members are continuing to join this important work. Members of the coalition share expertise, resources, and funding, designing short- and longer-term projects to make advancements toward a cure in a collaborative setting. To start, the coalition is sponsoring two initiatives:

- A systematic analysis of perspectives of patients, sponsors, and clinical research sites regarding the barriers to and facilitators of clinical trial recruitment and retention.
- The development of best practices (i.e., guidance, toolkits, etc.) for adult and pediatric clinical trials to increase patient participation and satisfaction.

These and future projects will be informed by a continuous dialogue between representatives of the healthcare industry, researchers and the Beyond Celiac community of patients, caregivers and consumers.

### "STRATEGIC PARTNERSHIPS ARE A KEY ENABLER OF OUR SCIENCE PLAN."

SALVO ALESCI, BEYOND CELIAC CHIEF SCIENTIFIC STRATEGY OFFICER



### **ADVANCING RESEARCH**

#### **CELIAC DISEASE SCIENCE AND RESEARCH**

BEYOND CELIAC RESEARCH GRANTS,

2019-PRESENT



#### BEYOND CELIAC AND SSCD EARLY CAREER RESEARCH AWARD — ABNORMAL CELIAC DISEASE IMMUNE RESPONSE RESEARCH

\$180,000 two-year grant awarded to Arnold Han, MD, PhD, Columbia University, to help enable development of new therapeutic strategies.

### BEYOND CELIAC ESTABLISHED INVESTIGATOR AWARD — IMPACT ON THE BRAIN RESEARCH

\$209,000, 2.5 year grant awarded to Nigel Hoggard, MD, and Iain Croall, PhD, University of Sheffield, UK, to investigate the neurological and neuropsychological manifestations of celiac disease and gluten-related disorders.

#### **GUT MICROBIOME RESEARCH**

Through a commitment of up to \$1 million in funds and services, Beyond Celiac is focusing on risk detection, prevention, interception and finding a cure for celiac disease, with emphasis placed on gaining an increased understanding of areas such as the gut microbiome, induction of immune tolerance and biomarkers of risk and progression.

#### BEYOND CELIAC AND SSCD EARLY CAREER INVESTIGATOR AWARD — PEDIATRIC CELIAC DISEASE SCREENING STUDY

\$150,000 two-year grant to Marisa Grant Stahl, MD, Children's Hospital Colorado

#### BEYOND CELIAC PILOT AND FEASIBILITY AWARD — RNA SEQUENCING STUDY

\$120,000 two-year grant awarded to Jocelyn Silvester, MD, Boston Children's Hospital, for her research on RNA sequencing for improved assessments of celiac disease in biopsies.

### BEYOND CELIAC ESTABLISHED INVESTIGATOR AWARD — GUT PHYSIOLOGY STUDY

\$300,000 three-year grant awarded to Paul Klenerman, PhD, University of Oxford, UK, in support of his study of the role of specific cells in the inner gut lining that may give clues to potential drug therapy targets.



### CLINICAL TRIAL RECRUITMENT

Beyond Celiac continued its successful endeavors to support clinical trial recruitment in 2021. Through our partnerships with 9 Meters, ProventionBio, ImmunogenX, Anokion, Takeda and Janssen, Beyond Celiac has been instrumental in recruiting qualified participants in Phase 1, Phase 2 and Phase 3 studies.

#### CELIAC DISEASE, HIDDEN IN PLAIN SIGHT: A BEYOND CELIAC MINI-CONFERENCE

The virtual mini-conference took place November 18, 2021, and brought together researchers, clinicians, doctors, and the general public for an afternoon of conversation on the past, present and future of celiac disease. The goal of the Celiac Disease, Hidden in Plain Sight: a Beyond Celiac Mini-Conference was to discuss those who have been "left behind" in the celiac disease world due to missed diagnosis or challenges to diagnosis. Discussions focused on the diagnosis of celiac disease in the following areas:

- Missed diagnosis due to neurological manifestations
- Missed diagnosis due to patient demographics
- The future of diagnosis methods

You can watch a recording of the event at www.beyondceliac.org/celiac-conference-2021

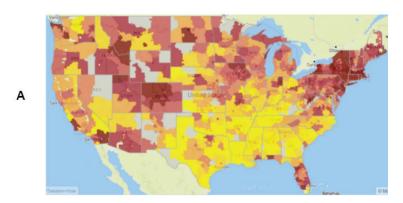
#### **BEYOND CELIAC ORIGINAL RESEARCH**

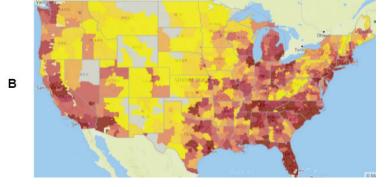
#### **UNCOVERING DISPARITY IN DIAGNOSIS:** ABSTRACT TO BE PRESENTED AT DIGESTIVE **DISEASE WEEK 2022**

Beyond Celiac and the National Minority Quality Forum, an organization which focuses on ensuring that high risk racial and ethnic communities receive optimal healthcare, presented a poster at Digestive Disease Week 2022, the largest GI-related conference in the United States. The joint project is examining health inequities in the diagnosis and treatment of celiac disease with the goal of finding solutions.

Beyond Celiac and NMQF are analyzing Medicare and Medicaid data to identify the incidence of potential missed diagnosis, which can be seen down to the zip code level through digital, color-coded maps, charts, graphs and tables. Early assessment reveals that there appear to be large sections of the country of under-diagnosis, particularly the South. Additional research will more fully illuminate racial disparities in celiac disease diagnosis.

Map A shows the number of celiac disease related Medicare claims in 2016. Map B are 2016 claims related to irritable bowel syndrome and anemia, which in combination may indicate undiagnosed celiac disease, in areas of the country that have very few celiac disease-related claims.







#### **BRAIN FOG STUDY PUBLISHED**

A survey conducted by Beyond Celiac asked 1,400 people with celiac disease and non-celiac gluten sensitivity (gluten sensitivity) about their experiences with brain fog, including what their brain fog was like, how guickly it starts, and how long it lasts. This research was done in collaboration with researchers from Northeastern University and Beth Israel Deaconess Medical Center and was published in 2021 in the Journal of Clinical Gastroenterology. 90 percent of survey participants (89% of celiac disease and 95% of gluten sensitivity) reported having brain fog, highlighting a key non-GI symptom that is often overlooked.

### **2021 HAPPENINGS**

#### AWARENESS, COMMUNITY SUPPORT AND ENGAGEMENT



#### **EVENING BEYOND CELIAC**

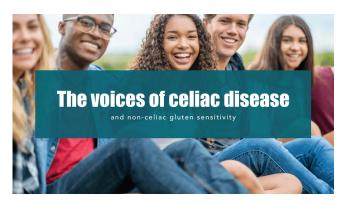
On October 28, 2021, we hosted a virtual event called "An Evening Beyond Celiac – At Home" to honor the Ravitz Family Foundation with the 2021 Samuel Gee Award.

We chose to honor the Ravitz Family Foundation for their longstanding commitment to Beyond Celiac – dating back to 2005 – and their service to the region's celiac disease and gluten-sensitive communities through their five-store chain of ShopRite supermarkets in southern New Jersey.

The Ravitz Family Foundation is a non-profit, 501c3, private foundation. Grants are issued by the foundation to organizations and causes whose requests for financial support best meet the "mission" Doris and Stanley Ravitz created in 1996 – to aid children and families in need.

Brett Ravitz, the current chairman of the Ravitz Family Foundation, is proud that the foundation continues to "touch the lives" of more people in the South Jersey area than ever before. With his family's dedication to the community in mind, Brett communicates the foundation's mission and activities to the company's business partners. Having two daughters with celiac disease has led to his strong commitment to working with Beyond Celiac and the celiac disease community.

The event was a major success, raising more than \$200,000 to support Beyond Celiac programs and research initiatives.



#### LAUNCH OF VOICES OF CELIAC CAMPAIGN

Beyond Celiac is spreading awareness and understanding by highlighting diverse stories of people with celiac disease and non-celiac gluten sensitivity. These stories illustrate the breadth of our journeys to diagnosis and help Beyond Celiac raise awareness, improve diagnosis rates and support those living with gluten-related disorders.

We created a form to make it easier for our community to share their experiences and have received over 130 submissions so far. We share one story on our social media handles each week, and the posts consistently receive positive engagement.



#### EXPANSION OF AMBASSADOR PROGRAM

Our Reach Beyond Celiac Ambassador

program expanded to 28 Ambassadors for the 2022 fiscal year. Ambassadors are located throughout the country and focus on inclusion, establishing personal connections and building supportive networks for those with celiac disease and gluten sensitivity at every stage of life. Ambassadors work both independently and collaboratively on initiatives designed to increase awareness, support Beyond Celiac initiatives and raise money.

Read more: www.beyondceliac.org/ambassador/

#### **AWARENESS, COMMUNITY SUPPORT AND ENGAGEMENT**



#### AWARD-WINNING PSA

The Beyond Celiac awareness video/public service announcement ran on Comcast and Channels and Hulu for the second straight year. In 2021, it was shown more than 1.5 million times. The PSA, which features people who actually have celiac disease, won the 2021 National Health Information Award Silver prize for a Health Promotion/

#### FOOD LABELING MODERNIZATION ACT (FLMA) SUPPORT

On August 4, 2021, Representatives Frank Pallone, Jr. (D-NJ) and Rosa DeLauro (D-CT), along with Senators Richard Blumenthal (D-CT), Sheldon Whitehouse (D-RI) and Ed Markey (D-MA) reintroduced the Food Labeling Modernization Act of 2021 (FLMA) to the House and the Senate. This bill is extremely significant for those living with celiac disease and non-celiac gluten sensitivity as it requires all manufacturers to disclose any glutencontaining grains on their labels.

Currently, wheat is the only gluten-containing grain that is required to be disclosed on food and beverage labels. If the legislation passes, barley and rye ingredients would also need to be listed. People with celiac disease and other gluten-related disorders may be at a loss to know if they can safely consume a particular item, since barley and rye may be included in ingredients such as malt, yeast, and flavorings, but not always. This bill would amend the FALPCA (Food Allergen Labeling and Consumer Protection Act) requiring that all gluten-containing grains (including barley and rye) be disclosed on

food product packaging. This would greatly reduce the guesswork currently required for people to safely eat gluten-free.

We expressed our support for the Food Labeling Modernization Act (H.R 4917/S. 2594) and encouraged everyone in our community to contact their representatives and senators to urge them to support it. We drafted a sample letter for community members to use as well.

#### Read more:

#### www.beyondceliac.org/celiac-news/flma-2021/

We also had the opportunity to speak with members of Congress about this issue. Bailey Arman, Beyond Celiac Digital Media Manager, celiac disease patient and resident of MN, met with a staff member from Senator Amy Klobuchar's office (D-MN) and Claire Baker, Beyond Celiac Sr. Communications Director, celiac disease patient and PA resident, met with staff from Senator Bob Casey's office (D-PA) to talk about the need for accurate labeling for the celiac disease community.

### 2021 HAPPENINGS

#### **AWARENESS, COMMUNITY SUPPORT AND ENGAGEMENT**









#### STEP BEYOND CELIAC VIRTUAL 5K

Undeterred by the pandemic, Beyond Celiac held two Step Beyond Celiac events virtually in 2021, our main 5k in May for Celiac Awareness month, and a smaller event in September.

Our May event highlighted our newly-introduced Ambassador program. We joined together with the celiac disease community to amplify, empower and engage positive voices around the country to celebrate Celiac Awareness Month. The program and virtual 5K worked together to expand local reach across the nation, encouraging those with celiac disease to share their experiences and create grassroots change in their communities.

Our September event focused on the gut-brain connection. This is an understudied area in celiac disease research, and we at Beyond Celiac believe that it is imperative to understand just how deeply and widely celiac disease affects the body. Until we have a treatment or a cure that better allows us to live healthy lives across all aspects of life—body, mind and soul—we must use any tools at our disposal, such as exercise and community, to ensure we are caring for every part of ourselves, not just the gut.

We also held a virtual Step Beyond Celiac 5K in May of 2022, which set new fundraising records for the virtual 5Ks.







Beyond Celiac-funded Researcher Panel at the 2022 Beyond Celiac Research Summit: Jocelyn Silvester, MD, PhD; Marisa Stahl, MD; Iain Croall PhD; Michael Fitzpatrick, MA, MBBS, DHMSA, MRCP, DPHIL; Paul Klenerman, MRCP, DPHIL

### 2022 BEYOND CELIAC RESEARCH SUMMIT: THE EVOLVING LANDSCAPE OF CELIAC DISEASE

In April 2022, Beyond Celiac hosted its third research summit, with the goals of hearing the latest in research from Beyond Celiac-funded grantees and bringing together key stakeholders to discuss pediatric clinical trials and expanding diversity in celiac disease. Convened at the summit were

- Clinician scientists
- Patients
- Entrepreneurial drug developers
- Media representatives
- Food and Drug Administration representatives

The event was video recorded to ease access for public review. The 2022 summit built on the results of our 2015 and 2019 summits, which were widely hailed as highly impactful and as precursors to new scientific collaborations and sharpening the focus of celiac disease physician scientists.

The 2022 summit took place against the backdrop of at least 12 clinical trials for celiac disease treatments. Our aim 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.



#### 2022 BENCHMARK CELIAC DISEASE LANDSCAPE SURVEY

In March, Beyond Celiac partnered with The Harris Poll to survey more than 2,000 Americans about their understanding of celiac disease as a serious autoimmune disease and their familiarity with the glutenfree diet as the only available treatment. Results were shared in an information campaign in May and will be available on the Beyond Celiac website:

#### www.beyondceliac.org/celiac-disease/2022celiacreport

At the same time, Beyond Celiac surveyed our own community about their experiences. We will be able to compare answers from our community to that of the general public, and we will be able to note over time how much more receptive the community is to considering a pharmaceutical treatment than they were even 5 years ago.

#### **SAVE THE DATE!**

Beyond Celiac will be hosting an in-person family fun Step Beyond Celiac on October 1, 2022 on the campus of Montgomery County Community College. Lace up your sneakers, bring the kids, and enjoy camaraderie of spending time with others in the region who have or support someone with celiac disease.









#### GO BEYOND CELIAC EXPANSION

The Beyond Celiac patient database and registry *Go Beyond Celiac* is expanding its reach and the number of surveys included to gather even more quantitative and qualitative information about the celiac disease journey before, during and after diagnosis. You can sign up today and add share your celiac disease experiences.

www.go.beyondceliac.org

#### 2022 SPRING EVENING BEYOND CELIAC

On June 16, 2022, we celebrated at The Kimmel Center 2nd Floor Balcony in Center City Philadelphia and enjoyed cocktails and all gluten-free hors d'oeuvres as we launched our Summer Beyond Celiac activities. We celebrated our Samuel Gee Award 2020 honoree Barb Powers and 2021 honoree The Ravitz Family Foundation in person.



The Kimmel Center balcony offered outdoor enjoyment



Evening Beyond Celiac auctioneer Joshua Katz helped raise thousands of dollars for research and programs



Barb Powers receiving the 2020 Samuel Gee Award



Brett Ravitz, President of the Ravitz Family Foundation



## together for a cure BEYOND CELIAC



2021 and 2022 Evening Beyond Celiac Co-Chairs Amy and Bill Green



Beyond Celiac Board Chair Alan Ehrlich, MD



Doug Petillo, Myke Rogers, Carole Haas Gravagno



Carolyn Powers, Kate Powers, Stephani & Andrew Whittaker, Todd & Christina Lukens



100% gluten-free cocktail reception by Garces Events



Bidding on auction items, David Yadgaroff with Jamie Yagaroff



Reach Beyond Celiac Ambassador Asha Maisuria and her mother, Jessica Maisuria



Beyond Celiac Intern Dana Schwarz and Reach Beyond Celiac ambassador Jack Goldberg



Marcus Muli & Aaron Patterson of Wilmington Trust



Eddie Bruce Band Combo



2020 Evening Beyond Celiac Co-Chairs Paula & Richard Mandel, MD



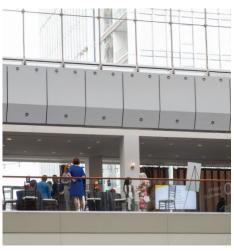
Ira Brownstein & Beyond Celiac Board Member Jenny Brownstein



Barb and Bruce Powers and family, with Barb's parents, Ken and Carol Weir



Eric and Alison Seiferth



Open air indoor/outdoor celebration at Philadelphia's Kimmel Center



Alice Bast, Beyond Celiac CEO and Linnea Bast

#### **BEYOND CELIAC RESEARCH SUMMIT**



Pediatric Clinical Trails panel, with Hilary Jerico, MD, Alessio Fasano, MD, Aden Lipsen, Jaime Lipson, and Shayna Coburn, PhD



Attendees from across the united States and Europe



Alice Bast, Beyond Celiac CEO



Expanding Diversity in Celiac Disease with Kate Avery, MPH, Dennis Spencer, MD, PhD, Martin Mendoza, PhD, Gary Puckrein, PhD, and Nieshia Williams, PhD



Beyond Celiac Board Member Bob Beall, PhD and Beyond Celiac Scientific Advisory Board Member Stephen Miller, PhD



Aden Lipsen and Jaime Lipsen



Nieshia Williams, PhD

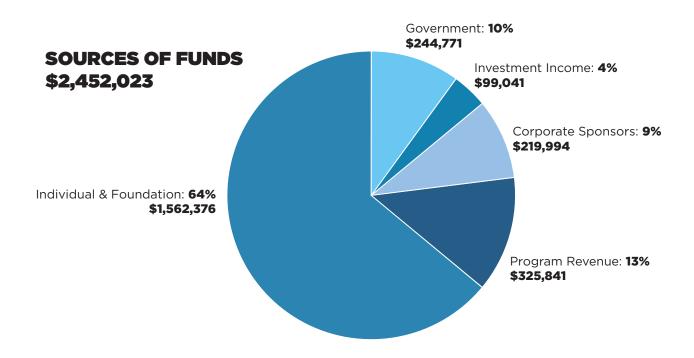


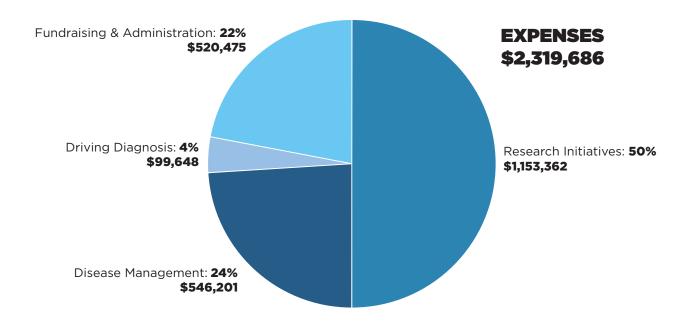
Alessio Fasano, MD



Beyond Celiac-funded researcher Iain Croall, PhD and Beyond Celiac Business Advisory Councill Member Rich Mandel, MD

### 2021 FINANCIALS







In Fiscal Year 2021 Beyond Celiac combined \$2,452,023 in new operational revenue and funds raised from investments and cash to cover expenses of \$2,319,686. 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 BOARD & ADVISORS**



Sam Goldberg, Beyond Celiac CEO Alice Bast and Rich Mandel, MD at the 2022 Research Summit

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#### Warren Strober, MD

Section Chief. The Mucosal Immunity Section National Institutes of Health

#### Ritu Verma, MD

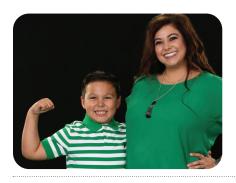
Chief of the Division of Gastroenterology University of Chicago Comer Children's Hospital Vice Chair, Pediatric Business Development Medical Director University of Chicago Celiac Center

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#### AMBASSADOR AND INTERN HIGHLIGHTS



#### **LUCÍA JAYDE AND JAYDEN**

"It is not always an easy journey. There are still hard days. Listening to his prayer for a cure still makes me cry many nights, but I have to stand firm so he learns to do the same. I have realized that if I do not raise my voice, if I am not willing to fight for us, then who?"

#### **BAILEE WILSON**

My time as a Qualitative Research Intern with Beyond Celiac has been exceptionally rewarding! I've developed real-world skills, received attentive mentorship, and uncovered new passions. I will forever cherish the opportunity I've had to make visible, valuable contributions to celiac disease research under the guidance of such a dedicated, inspiring team!





#### **HAYDEN**

"Let's face it, with the world we live in, you can't always eat the food you make. Sometimes you have to travel. Sometimes you have to do something, and you have to eat something someone else makes, and the stress and worry around that is just unfathomable. There's just nothing that compares to it, and there's nothing that can relieve that, except for a cure."



#### **ELYSE**

"She [Elyse] went out to the community with me and wrote her letter and story and got around local businesses and companies. The kids put their feet to the floor and sold raffle tickets, and we did an event with her school... None of our team members actually raised money on their own, it was really raised by Elyse by going out and getting donations."



#### **ANNIKA**

"In 2018, I started Gluten Free Jio, a social project that aims to increase awareness and access to information on celiac disease and glutenfree diets in India. Motivated to change

not just myself but also my broader community, I started conversations with various local leaders, government schools and community organizations. I began conducting interactive, educational sessions in government schools in Chandigarh and Punjab."



#### ELIANO

"Eli felt left out and struggled with not being able to eat the same things as his friends. This was very heartbreaking

for a 6-year-old. He had a love of YouTube and always wanted to be a YouTuber. We created Fun with Eden and Eli, a YouTube channel for him to cook gluten-free foods and made it exciting to eat gluten-free. It worked!



#### **LEAH POPVICH**

Being an intern at Beyond Celiac has been rewarding not only for my professional development, but also for the abundance of information I've learned about this serious autoimmune disease. Now as a part-time employee and

student, I credit so much of my growth to the Beyond Celiac team, whose guidance has been critical to paving the way towards my future career." After the close of the 2022 Summer Internship Program, Leah continues to work with Beyond Celiac as the Podcast Coordinator.



#### **MORGAN**

"From classroom projects to parties, everything has to be safe for me. If I have gluten I get really sick (usually for days) and it's really hard on a secondary school student...This is a disease I will have forever—it never goes away! I have to watch everything I eat and how it is even made and where. There are many factors I have to consider in my day to day life. It is a constant reminder of just how serious being gluten-free is and having celiac disease is nothing to mess with."

#### **CARA**

"It's hard to be gluten-free because I don't know when I'm going to come in contact with gluten....It's really hard to be gluten-free and still feel safe...At family gatherings, there's so much gluten around you, you don't even notice. But for me, it sounds like a death trap."





#### **ROCHELLE**

"Our gluten-free journey began two years ago when our son was diagnosed with celiac disease. Since then, I have developed a new appreciation and understanding of the severity of this disease. I have realized the difficulties that patients with celiac disease face on a daily basis. I have also recognized the lack of knowledge society and medical professionals have regarding this disease. After my personal experiences, I acquired a passion to make a difference for my son and other celiac disease patients

#### **BEYOND CELIAC ADVISORS AND STAFF**

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#### REACH BEYOND CELIAC AMBASSADORS

Alexandra De Ghenghi in Fort Worth, TX Alyssa Megee in Lehigh Valley, PA Amy Venettucci in Chicago, IL Annika Dhariwal in Chandigarh, India & Cheltenham, UK

Asha Maisuria in Cherry Hill, NJ Ashleigh Kostesich in Westfield, NJ Bill Mogavero in New York City, NY Brooke Goldberg in Rockville, MD Christina Heiser in New York City, NY Clayton Steward in Leavenworth, KS Erin Ford in Casper, WY

Hannah Riley in Charlotte, NC Hayden Bishop in Los Angeles, CA Jack Goldberg in Cherry Hill, NJ Jaime Lipson in Philadelphia, PA

Jake Woods in Austin, TX

Julia Auerbach in Chicago, IL Justin Sundstrom in Wenatchee, WA Kelly Meehan in Scottsdale, AZ

Kenzie Goldsteen in Bethesda, MD Laura Mason in Clarksville, MD

Lauren Mengah in San Francisco, CA

Linda Schoepf in Atlanta, GA

Lucia Jayde Ochoa in Texarkana, TX

Merve Diler in Chicago, IL
Morgan Shondelmyer in Greensburg, PA
Natasha Prime in Mount Laurel, NJ
Noah Fond in San Mateo, CA
Noah Lustbader in Nashville, TN
Olivia Quinby in Dubuque, IA
Rachel Rutstein in Potomac, MD
Rochelle Siezega in Buffalo, NY
Tjuanika Griffin in Charlotte, NC
Tori Mayernick in Philadelphia, PA
Valerie Anderson in St. Louis, MO

#### **BEYOND CELIAC TEAM**

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#### Maria Luci

Director of Research Engagement

#### Erin Miller, MPH

Associate Science Project Manager

#### **Amy Ratner**

Director of Scientific Affairs

#### **Mary Tackett**

Senior Director of Philanthropy

# IN CLOSING



I've lived with celiac disease and have headed this organization for almost two decades, and as hard as we've all worked over the years, I've never in all that time seen what I see now on the horizon.

#### I SEE HOPE.

I see change coming for everyone who has lived with celiac disease and gluten sensitivity for so very long. I see a world where kids don't choose the colleges they attend based on their food choices. I see nobody else suffering from depression and anxiety caused by this disease, or dying from complications of not being properly diagnosed. I see an end to the constant struggle to manage celiac symptoms and a gluten-free diet.

It's within sight. There is a cure coming, and our community will see it happen. With the generosity of you, our supporters, we have uncovered the true connections between the gut and the brain. You're helping us address health disparities in access to diagnosis and care. You're helping push the science forward that will allow millions of Americans to eat without fear.

You showed up. You continue to show up for Beyond Celiac, and for every one of those children and families who depend on us to fund the research we're funding and get us to treatments and a cure.

Thank you from the bottom of my heart — I am so grateful for each and every one of you.

Alice Bast CEO, Beyond Celiac



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