# **20 Years Strong**

**DRIVING PROGRESS FOR A CELIAC-FREE FUTURE** 



ANNUAL REPORT 2022

## 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.

# TABLE OF CONTENTS:

Letter from Alice Bast, CEO
and Alan Ehrlich, MD, Board Chair4
Advancing Research
Awareness, Community Support And Engagement 1
2022 Financials
Beyond Celiac Board & Advisors18
Reach Beyond Celiac Ambassadors and Staff

### Letter from Board Chair and CEO

# DEAR FRIENDS AND SUPPORTERS



Alan Ehrlich, MD



Alice Bast

We are thrilled to present our annual report for the year 2022, marking 20 years since the founding of Beyond Celiac. As we reflect on the last two decades, we are extremely proud of the progress we have made in raising awareness, driving diagnosis and supporting our community in countless ways. We are problem-solvers, and with your support and partnership, are leading the way in accelerating research for treatments and a cure, having put a stake in the ground for an effective therapy by 2030.

Our beginnings were humble. Our first office was a cramped spare bedroom! But we were bold and submitted a request to the National Institutes of Health, which against every prediction, was funded. From there, we've grown into a national organization with international reach that has significantly contributed to the community. Today we're the leading patient advocacy and research organization for celiac disease!

We launched the first-ever National Celiac Awareness Campaign in the early days with Heidi Collins of CNN as our spokeswoman. We also had partnerships with Quest Diagnostics and others, contributing to an increased rate of diagnosis from just 3% in 2003 to up to 50% today.

We have worked tirelessly to provide resources, support, and services to those in need, and we have seen the positive impact that our work has had on countless individuals and families. Then, with our pivot to accelerating research for treatments and a cure, we changed our name to Beyond Celiac and have gone all in for creating a future in which we can live our lives to the fullest.

Recently, a preeminent celiac disease researcher said, "Beyond Celiac is it," the organization with the best plan to reach this goal. He confirmed that our funding of the most promising research around the world, with support for early career and established career scientists, is crucial in a field with so little research support from major funders like the NIH and pharmaceutical companies. Researchers who want to devote their careers to the field find it difficult, if not impossible, due to the lack of available funding, but our grant program is making a difference in attracting and retaining talented clinician-scientists and funding their work.

Because we are taking a 360-degree approach to increasing clinical trial enrollment and overcoming hurdles in the drug approval process, in addition to funding research, we have the potential to take this research all the way to the finish line and bring a celiac therapy to market.

None of this would have been possible without the support of our dedicated staff, volunteers, and generous donors. Their commitment to our mission has been unwavering, and we are deeply grateful for their contributions over the years.

As we look to the future, we recognize that there is still much work to be done. Beyond Celiac remains committed to its mission to drive diagnosis, advance research and accelerate the discovery of new treatments and a cure. We will continue to work towards achieving our goals with the same passion and dedication that has driven us since our first day in 2003.

THANK YOU FOR YOUR CONTINUED SUPPORT OF BEYOND CELIAC. TOGETHER, WE CAN CREATE A WORLD IN WHICH PEOPLE WITH CELIAC DISEASE CAN LIVE HEALTHY LIVES AND EAT WITHOUT FEAR.

With Gratitude,

### ALICE BAST, CEO ALAN EHRLICH, MD, BOARD CHAIR

# **ADVANCING RESEARCH**

FUNDING THE MOST PROMISING RESEARCH FOR TREATMENTS AND A CURE

**Beyond Celiac is** committed to a competitive process to identify and fund the world's best and most promising science to accelerate research for treatments and a cure for celiac disease, and to help our celiac disease community members live longer, fuller lives. Over the last several years, we have committed more than \$3M to directly fund celiac disease research as part of our comprehensive Science Plan to have treatments toward a cure by 2030.



**\$1.6 MILLION IN GRANTS** – In March 2023, Beyond Celiac announced five multi-year grants totaling \$1.6M as part of a celiac disease research grant program. The grants fund research at prestigious institutions in five countries, making Beyond Celiac the premier nonprofit funder of celiac disease research worldwide. These grants will support research into non-invasive biomarkers, the microbiome, and restoring immune tolerance to gluten antigens.

#### **RESEARCH ACCELERATOR GRANT AWARDS**

• Shed cell transcriptomics for the identification of celiac disease dynamics by Shalev Itzkovitz, PhD, at the Weizmann Institute of Science (Rehovot, Israel) in collaboration with the Schneider Children's Medical Center (Petah Tikva, Israel) • Novel Biomarkers of mucosal damage for non-invasive diagnosis and monitoring of celiac disease by Michael FitzPatrick, MRCP, DPhil, (previous Beyond Celiac awardee) at University of Oxford (Oxford, UK)



# **ADVANCING RESEARCH**

FUNDING THE MOST PROMISING RESEARCH FOR TREATMENTS AND A CURE

#### ESTABLISHED INVESTIGATOR AWARDS

• Identifying predictors for progressive phenotypes of celiac disease by Rok Seon Choung, MD, PhD, at Mayo Clinic (MN, USA) in collaboration with the Naval Medical Center (MD, USA) and Icahn School of Medicine at Mount Sinai (NY, USA)

• CeliAct(TIV) - Translocation, inflammation and virulence: dissecting mechanisms of glutenmicrobiota interactions in celiac disease by Sónia Gonçalves Pereira, PhD,

at the Instituto Politécnico de Leiria (Leiria, Portugal), in collaboration with the Celiac Disease Research Center at Tampere University (Tampere, Finland)

• Preclinical 2D celiac patient-based iPSCsmall intestinal epithelial in vitro model by Kati Juuti-Uusitalo, PhD, at Tampere University (Tampere, Finland)

#### EARLY INVESTIGATOR GRANT AWARD

#### Beyond Celiac-Society for the Study of Celiac Disease (SSCD) Early Investigator Grant

Award (Nov 2023) - The 2023 Beyond Celiac-SSCD Early Investigator Grant Award will be announced later this year and marks the third grant collaboration with SSCD. Including the 2023 award, Beyond Celiac has committed over half a million dollars in this partnership with SSCD toward supporting researchers early in their careers. We are privileged to have Dr. Ciarán Kelly, a former board member and the Medical Director of the Celiac Center at Beth Israel Deaconess Medical Center, leading the grant review committee. Our focus remains on translational research, and preliminary findings from the first grant have been presented at Digestive Disease Week. Further, we are actively working toward publishing the results in a peer-reviewed journal. We are proud of the progress we have made in supporting groundbreaking research, and we are dedicated to continuing our investment in advancing the understanding and treatment of celiac disease.

#### **COALITION LAUNCH**

The Beyond Celiac Coalition has brought together members of academia, key opinion leaders, government agencies, and pharmaceutical, biotech and diagnostic companies to identify and address significant roadblocks to the diagnosis and treatment of celiac disease. The Coalition currently has more than a dozen members that have worked together to identify a number of key goals and priorities for the coming year. Together, the Coalition will take on joint, precompetitive projects to help overcome barriers to treatments and a cure for celiac disease.

The Coalition's primary objectives have been outlined as the following:

• To focus on priority topics of drug development pathways for celiac disease, such as symptoms, histology, biomarkers, and endpoints.

• To highlight differences between approaches to celiac disease versus other chronic immunemediated GI disorders.

• To engage with the FDA & NIH throughout the process.

• To determine the best means of patient selection for clinical trials.

The Coalition plans to conduct a glutenexposure study using a *Go Beyond Celiac* Symptom Tracker. The tracker will collect real-world data on accidental gluten exposure and related celiac disease symptoms to gain a better and more accurate understanding of the patient experience. This project will be valuable in increasing knowledge and generating compelling evidence that the gluten-free diet is not a sufficient treatment for people with celiac disease. In addition, the data collected will help to inform the design of clinical trials.



### **Members:**

Robert P. Anderson, MD

American Gastroenterological Association

Anokion

Beyond Celiac

imaware

Edwin Liu, MD

Joseph A. Murray, MD

Provention Bio

Marie Robert, MD

Jocelyn Silvester, MD, PhD

Marisa Stahl, MD

Adam C. Stein, MD

Takeda Pharmaceuticals



Launched "Do I Have Celiac?" campaign with CNN anchor Heidi Collins Launched the Celiac Disease Symptoms Checklist, the first of its kind

Partnered with Quest Diagnostics to provide resources to healthcare providers

2006

Created resources to help the community voice their opinion on gluten-free food labeling

Launched a national effort to make affordable gluten-free products available Launched CeliacCentral.org

Joined Alliance for a Stronger FDA & the FDA Panel on Food Labeling

2007

Organized the nation's first Gluten-Free Cooking Spree expo

6 BEYOND CELIAC ANNUAL REPORT 2022

#### BEYOND CELIAC ORIGINAL RESEARCH

#### 2023 DIGESTIVE DISEASE WEEK (DDW) POSTER PRESENTATIONS

• Geographic distribution and potential disparities in celiac disease in the US: Evidence from medical claims data analysis

• *Frustration, fear, and luck* – Factors facilitating celiac disease diagnosis and support seeking behaviors: A *Go Beyond Celiac* analysis

• Correlations between relative prevalence of celiac disease and sociodemographic variables in the United States

#### 2022 INTERNATIONAL CELIAC DISEASE SYMPOSIUM (ICDS) POSTER PRESENTATIONS

• *Changing patient perceptions* of the gluten-free diet as sufficient treatment for celiac disease

• *Thinking outside the gut:* patientreported gluten exposure symptoms in celiac disease and gluten-related disorders







#### **ORIGINAL RESEARCH**

Over the past two years, Beyond Celiac has conducted innovative research projects utilizing patient surveys, our Celiac Index, and data from our *Go Beyond Celiac* patient registry. The insightful results of these analyses have been accepted and presented at prestigious events worldwide, including Digestive Disease Week (DDW) and the International Celiac Disease Symposium (ICDS). Through these efforts, we continue to make significant contributions to the field, solidifying our position as a leading authority in celiac disease research. Moving forward, we are dedicated to pursuing further impactful research, shaping the future of diagnosis, treatment, health equity, and overall wellbeing for individuals with celiac disease.

Beyond Celiac Chief Science and Strategy Officer Salvo Alesci, MD, PhD, and CEO Alice Bast at the 2022 ICDS conference in Sorrento, Italy presenting Beyond Celiac research posters.



Launched GREAT Healthcare, a program to increase education among healthcare professionals 2009 Initiated continuing

medical education

(CME) for primary

care providers

Launched continuing education programming for pharmacists

# **ADVANCING RESEARCH**

**4,693** completed research surveys in *Go Beyond Celiac* 

#### **GO BEYOND CELIAC**

In 2022, the Beyond Celiac patient registry, Go Beyond Celiac, reached a significant milestone with over 8,500 participants. We introduced a longitudinal survey, enabling us to gain deeper insights into the evolving experiences and perceptions of individuals living with celiac disease over time. This addition to our registry will enhance our understanding of the disease and pave the way for more targeted support and interventions. Furthermore, we have expanded the capabilities of Go Beyond Celiac by introducing a range of new features. Users can now benefit from in-app notifications and survey scheduling, keeping them informed about important updates and opportunities.

Additionally, the introduction of a symptom tracker capability will provide a valuable tool for individuals to monitor and manage their symptoms effectively. These enhancements to Go Beyond Celiac underscore our commitment to continually improving the patient experience and advancing our understanding of celiac disease. By leveraging the power of technology and the collective knowledge of our diverse participant base, we are driving forward our mission to transform the lives of those affected by celiac disease. Also for 2023, stay tuned for added features to accelerate research and maximize the potential of our Go Beyond Celiac patient registry.





#### **BENCHMARK SURVEY**

To gain a better understanding of the knowledge and perceptions that Americans have about celiac disease, Beyond Celiac commissioned The Harris Poll to conduct a national benchmarking survey. The Harris Poll on behalf of Beyond Celiac was conducted online February 8-10, 2022 among 2,039 adults nationwide. It provided insight into how much Americans know about gluten sensitivity and celiac disease. This report revealed what the survey shows regarding how little Americans know about celiac disease, presented the facts about the disease, and outlined how Beyond Celiac is working to address the challenges. Picked up by the Associated Press, HealthDay, US News and World Report and nearly a thousand AP outlets, the story "Not just 'gluten-sensitive': What people with celiac disease want you to know" featured statistics gleaned from the report and included interviews with Beyond Celiac ambassador Hayden Bishop and Board Chair Alan Ehrlich, MD. A supplementary survey for 2023 will reveal additional insights.

2010 2011 Ranked Launched Produced first Gluten-Rated as one Launched Philadelphia FDA awarded Informed Petitioned Free Pavilion at of "10 Great the FDA for "#1 Website celiac disease research Award NFCA grant Congress about for Celiac women's health National Restaurant Websites on celiac recoanized to study the need for aluten-free gluten in food labeling initiative Association with Accurate disease and Alice Bast's aluten-free food Facts' (NRA) Show Information" fertility leadership medications labeling standards regulations

# Clinical Trial Recruitment



### We have made significant progress in our clinical trial recruitment efforts,

undertaking various projects with a focus on creative and unique awareness components. These initiatives signify our commitment to driving innovation in celiac disease research and fostering collaboration with esteemed partners.

We successfully completed the recruitment phase of the IMGX Solutions for Celiac Phase 2 trial, marking a significant milestone in our pursuit of groundbreaking treatments for celiac disease. In addition to our completed projects, Beyond Celiac is thrilled to kick off two promising clinical trial recruitment projects in collaboration with renowned pharmaceutical companies, Takeda and Chugai. These trials, named Illuminate and LILY, respectively, hold immense potential to advance our understanding of celiac disease and pave the way for novel treatment options. Looking ahead, Beyond Celiac is actively engaged in identifying and facilitating additional clinical trials that align with our mission. We recognize the urgent need for improved treatment options, and we are committed to advancing research that benefits individuals with celiac disease.



Pediatric Clinical Trials panel, with Hilary Jericho, MD, Alessio Fasano, MD, Aden Lipson, Jaime Lipson, and Shayna Coburn, PhD





Attendees from across the United States and Europe

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

#### **RESEARCH SUMMIT**

On April 6, 2022, Beyond Celiac hosted its third research summit: "The Evolving Landscape of Celiac Disease." This prestigious event served as a dynamic platform for the convergence of diverse expertise, uniting celiac disease clinician-scientists, neuroscientists, immunologists, patients, entrepreneurial drug developers, and leaders in health equity. The summit provided a unique opportunity to delve into cutting-edge advancements and discoveries in celiac research, fostering a rich exchange of ideas and insights. Esteemed professionals and individuals with lived experiences gathered to explore the latest breakthroughs and promising directions in the field. This collaborative gathering not only highlighted the importance of interdisciplinary collaboration but also emphasized the significance of involving patients in shaping the future of celiac disease research. The summit sparked meaningful discussions and forged connections that will undoubtedly contribute to the advancement of celiac research and ultimately improve the lives of those affected by the condition. With each iteration, this landmark event propels us closer to a future where individuals with celiac disease can benefit from improved diagnosis, treatment, and overall well-being.



### RESEARCH SYMPOSIUMS, SUMMITS AND MINI-CONFERENCES HOSTED

Surpassed 1 million website visitors Named exclusive celiac disease partner of *Allergic Living* magazine

2012 Introduced Family

Talk, a campaign to prompt testing of at-risk family members Alice Bast represented the patient's voice and facilitated a panel of physicians at the 14th International Coeliac Disease Symposium 2013

Championed the Gluten in Medicine Disclosure Act Endorsed the Gluten-Free Certification Program (GFCP)

# **ADVANCING RESEARCH**

In 2022, Beyond Celiac launched its first Diversity, Equity and Inclusion staff committee. The committee kicked off their work with an internal survey to better understand where the need was greatest. The committee then worked with the entire staff to create a Beyond Celiac **DEI** Mission and Vision statement, hosted a staff training session on intersectionality, and compiled research for a Health Equity web page, which launched in 2023.

### Diversity, Equity and Inclusion (DEI) Vision

Beyond Celiac believes in a world where we all can live healthy lives free from bias and barriers. Across our work, we must engage diverse perspectives and promote equity in our community to realize our vision of a world beyond celiac.

### Diversity, Equity and Inclusion (DEI) Mission

Beyond Celiac fosters a sense of belonging by elevating underrepresented voices as we work together for a cure. We seek to be a community that welcomes diverse perspectives and provides meaningful opportunities to empower marginalized populations.

### Data to Understand Diversity in Celiac Disease

Further, Beyond Celiac launched IMPACT CD, a project sponsored by Takeda Pharmaceuticals focused on identifying and reducing disparities in celiac disease diagnosis and management and helping minority patients participate in clinical trials. Beyond Celiac also continued our work with the National Minority Quality Forum, mapping Medicare and Medicaid celiac disease claims focused on uncovering and better understanding potential disparities in celiac disease diagnosis. In addition, in 2023, Beyond Celiac is working with Takeda on an initiative to do private payer data analysis, which will provide a more complete picture of celiac disease diagnosis and care across the US, including in diverse racial and ethnic populations by complementing the Medicare and Medicaid data being collected and analyzed. The Takeda data analysis will be incorporated into a broader investigation of published studies related to diversity in celiac disease diagnoses, resulting in a comprehensive report on the state of celiac disease diagnosis and management in underserved populations.



# AWARENESS, COMMUNITY SUPPORT AND ENGAGEMENT

### Ambassador Program Expansion



# In preparation for the year ahead, our team of volunteer

ambassadors engaged in productive one-on-one meetings with Director of Community Engagement Valerie Kraft for each member to outline their individual project plans for 2023 and discuss personal fundraising goals. Instead of imposing a universal fundraising target on all ambassadors, we recognized the importance of tailoring goals to each individual's network, potential, and personal circumstances. Our aim was to create an empowering and attainable fundraising experience for our team, ensuring that it felt like a meaningful endeavor rather than an overwhelming obligation. We are thrilled to share that our current ambassador team has expanded to include 40 dedicated members, with additional expansion throughout 2023. The Ambassador program was featured at the annual fundraiser Evening Beyond Celiac which proved to be a significant highlight, generating heightened attention and attracting both long-standing supporters and new enthusiasts eager to learn more and actively participate in our program. This increased interest and engagement from a diverse range of supporters signifies the growing impact of our ambassador program and reinforces our commitment to fostering greater awareness and community involvement in our mission.

#### SUMMER INTERN PROGRAM

The Beyond Celiac Summit intern program remains a vibrant and dynamic platform, attracting exceptional students from various esteemed institutions across the United States. In the summer of 2022, we welcomed a talented cohort specializing in communications, podcasting, data analysis, fundraising, and diversity, equity, and inclusion (DEI). Their contributions propelled our organization's success in numerous areas such as elevating our podcast, which garnered an impressive milestone of over 100,000 downloads. Their dedication and expertise also led to the creation of abstracts that were accepted at prestigious events such as Digestive Disease Week (DDW), further solidifying our presence in the scientific community. These remarkable accomplishments exemplify the interns' exceptional abilities and commitment to excellence. For 2023, a new cohort of talented individuals are contributing with equal productivity and passion. Building on the successes of 2022, their energy, fresh perspectives, and diverse skill sets are instrumental in driving further growth and impact across our organization.

Celiac Straight Talk podcast downloads in 2022, **83,000** total since 2017



#### **COMMUNITY SUMMIT**

As a part of commitment to our community members and with the generous support of Mary Bianco and the Moca Foundation, Beyond Celiac is hosting our first Community Summit on September 30, 2023 in Old Greenwich, CT. The Summit will feature a full day of fun and information, with a game show theme. We have clinician experts, patient advocates, and social media influencers with millions of followers speaking, along with sponsor booths, games, and fun for the whole family. We conduct a Research Summit every two years, but the introduction of a Community Summit recognizes our commitment to connect and meet the needs of the celiac disease community, even as we pursue our mission of new treatments and a

treatments and a cure. We are excited to share that TV personality Jenna Wolfe will kick off the summit, with an additional special celebrity guest soon to be announced.





Joined National Health Council representing celiac disease

Joined the US Agency for Healthcare Research and Ouality

Rebranded as Beyond Celiac and relaunched website as BeyondCeliac.org 2015 Launched "Seriously Celiac Disease: Talk. Tell. Test." – a nationwide family

testing PSA campaign

Cited as the most effective non-TV recruitment partner for phase IIb clinical trial Envisioned, created and hosted Research Summit to drive innovation and collaboration among researchers, supporting access to effective treatment options Represented the patient experience at the FDA's landmark GREAT3 Workshop.

# AWARENESS, COMMUNITY SUPPORT AND ENGAGEMENT





The 2023 Evening Beyond Celiac

#### **EVENING BEYOND CELIAC**

Following the success of last year's Evening Beyond Celiac, we aimed to raise \$225,000 at this year's event on May 17th. The night featured gluten-free culinary delights from Chef George Kralle as we honored Kane Brenan with the 2023 Samuel Gee Award and recognized Schär and Dr. Francisco Leon for their exceptional commitment to the celiac disease community! Having raised approximately \$240,000, we shot far past our fundraising goal. In addition to continuing on with the live auction and special appeal components from the successful 2022 Evening Beyond Celiac, we added a silent auction and a wine pull as additional revenue enhancers. This tremendous success is thanks to our exceptional committee and our honorees and their incredible efforts to help raise critical funds for Beyond Celiac programs.

Celiac Disease



clinical trials

Richard & Paula Mandel





disease patients

advancements in the field

Conditions blog



Georgine Trumpbour, Beyond Celiac Board Member Carole Haas Gravagno, Michelle Kelly



Evening Beyond Celiac Event Co-Chairs Bethann Kagan and Sophia Kagan with Alice Bast



Creative for a Cure Silent Auction



Francisco Leon, MD, PhD, 2023 IMPACT Honoree

CAN EVENING BEYOND CELIAC Celebrating Years of Service



Meghan Donnelly, MS, RDN, CDN, accepts the 2023 Corporate Champion Award on behalf of Schär, with Alice Bast.



Pninah and Elle Miller





# AWARENESS, COMMUNITY SUPPORT AND ENGAGEMENT

### **AMBASSADOR HIGHLIGHTS**



"Through this experience, I've come to believe that the communities Beyond Celiac fosters play a crucial role in supporting those with celiac disease facing similar roadblocks. I also believe the work of Beyond Celiac will have a smoother path forward for those who have yet to be diagnosed."

**AMBASSADOR TORI MAYERNICK** 

"Becoming a Beyond Celiac ambassador gives me the opportunity to be part of a support system for those who are recently diagnosed–something I didn't have when I was diagnosed all those years ago."

#### **AMBASSADOR ALYSSA MEGEE**





"As a Beyond Celiac Ambassador, I am excited to help others adjust to the lifestyle and help them gain confidence in educating and advocating for themselves. I want to help others learn how to deal with tricky situations like shopping for groceries and going out to eat with friends."

#### AMBASSADOR ASHA MAISURIA





Beyond Celiac partners with National Minority Quality Forum to target inequalities in celiac disease diagnosis and treatment

#### 2020

Beyond Celiac chosen as the exclusive patient organization to recruit for the first-ever phase 3 clinical trial for celiac disease Summer Intern Council launches to engage college students in the mission to cure celiac disease



"I have felt really empowered, and I would like to be able to share that with other people and help other people feel this same way and take action to move our cause forward. I think it's a great cause and I'm really excited for all of the positive change that we can make."

#### AMBASSADOR BILL MOGAVERO



"As an ambassador for Beyond Celiac, I am excited to help get rid of the stigma people have about gluten-free food. I'm so excited to be a part of this amazing group of ambassadors and help others navigate through celiac disease."

#### AMBASSADOR BROOKE GOLDBERG



"Throughout the years, I have learned so much (many things the hard way), and I hope as a Reach Beyond Celiac Ambassador, I can do my part in easing others through the transition to a gluten-free life. Together, we can overcome the barriers to healthier and happier lives."

#### AMBASSADOR ISABELLA CARDONA

"I was faced with the hard reality of how difficult the gluten-free diet can really be to follow and how challenging it is to get others to understand what it is, as well as how it works. I now hope to help others and share my story."

#### AMBASSADOR JACK GOLDBERG





"I was shocked when my doctor told me I had celiac disease. I mourned the loss of my previous foodie lifestyle and then decided to turn it all around and educate myself. Going forward, I want to help everyone with celiac disease live a supported, healthy, gluten-free life!"

#### AMBASSADOR NATASHA PRIME







Beyond Celiac hosts a miniconference to discuss those "left behind" in the world of celiac disease diagnosis Beyond Celiac announces an early-career grant in partnership with SSCD to attract researchers to the field of celiac disease Beyond Celiac partners with the University of Sheffield to research neuropathology of celiac disease

2021

First Virtual Town Hall launched to connect the community with celiac disease experts Beyond Celiac partners with Janssen (Johnson & Johnson) to commit up to \$1 million to accelerate celiac disease research

# AWARENESS, COMMUNITY SUPPORT AND ENGAGEMENT

#### **STEP BEYOND CELIAC**

Our 2023 Virtual Step Beyond Celiac spanned through Celiac Awareness Month and saw tremendous engagement. With nearly 800 participants, our community has raised over \$68,000 through grassroots fundraising thus far, combined with \$40,000 from our corporate partners! We had participants register from as far as Canada, Switzerland, Australia, Portugal, Czech Republic, and the UAE, demonstrating our increasing international presence. We look forward to the fall, when we will have our in-person Philadelphia race on September 9th and our in-person Boston race on October 14th.









37 likes thebradt WE DID IT! \$1,200 raised for Celiac research. 100k ran/biked in May. THANK YOU!! View 1 comment 4 days ago











Beyond Celiac launches a precompetitive coalition to accelerate clinical research Beyond Celiac Research Summit brings together scientists, clinicians, pharma, and patients to discuss the latest in celiac science

2022

Beyond Celiac and SSCD award \$180,000 to Arnold Han, MD, PhD, to investigate CD8 T-cells 2023 Beyond Celiac celebrates 20 years of service to the community



@beyondceliac





In Fiscal Year 2022 Beyond Celiac combined \$3,302,445 in new operational revenue and \$3,399 in cash prior year surplus to cover expenses of \$3,305,844. 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**



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#### Ritu Verma, MD

Professor of Pediatrics Chief, Section of Pediatric Gastroenterology, Hepatology, and Nutrition Medical Director, Celiac Disease Center The University of Chicago Medicine

#### **BEYOND CELIAC COALITION**

Accelerating Clinical Trials in Celiac Disease by Addressing Major Patient Barriers

#### Robert P. Anderson, MD Anokion

Anokion Beyond Celiac imaware Edwin Liu, MD Joseph A. Murray, MD Provention Bio Jocelyn Silvester, MD, PhD Marisa Stahl, MD Adam C. Stein, MD Takeda Pharmaceuticals

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Mary Tackett, MLIS

Senior Director of Grants and Donor Relations

### **BEYOND CELIAC 2023 RESEARCH GRANTS**



#### **MINI-GUTS IN THE LAB: UNLEASHING THE POWER OF CELIAC DISEASE MODELS**

Restoring tolerance to gluten



**KATI JUUTI-UUSITALO, PHD** at Tampere University (Tampere, Finland)

#### **GRANT TYPE** Established Investigator Award **GRANT AMOUNT** \$100,000 for each of three years WHY IT MATTERS

This project aims to create a special model that mimics the intestines of people with celiac disease. Just as an airplane simulator allows pilots to learn more quickly, this new research model will hopefully enable scientists to unlock important information about celiac disease more quickly and advance our understanding of how the disease works, paving the way for new therapeutic approaches. This two-dimensional model of celiac disease grown in a petri dish in the research lab will help scientists uncover the secrets of celiac disease and potentially develop new treatments.



#### **CELIACT(TIV): UNRAVELING** THE BATTLE BETWEEN **MICROBES AND CELIAC DISEASE**

Helping the immune system to not react to gluten



#### SÓNIA GONÇALVES PEREIRA, PHD

at Instituto Politécnico de Leiria (Leiria, Portugal), in collaboration with the Celiac Disease Research Center at Tampere University (Tampere, Finland)

#### **GRANT TYPE** Established Investigator Award **GRANT AMOUNT** \$100,000 for each of three years WHY IT MATTERS



Imagine a lively party with harmonious guests, representing the delicate balance of our gut microbiome. In most people, gut bacteria coexist harmoniously with gluten, blending in without causing trouble. However, for those with celiac disease, gluten crashes the party and starts a brawl. Researchers aim to understand how gluten interacts with gut bacteria, contributing to celiac disease development. They seek to understand why only a small percentage of people with celiacrelated genetic markers develop the condition, and why some with high celiac-related antibodies remain symptom-free while others experience symptoms despite a gluten-free diet. This project aims to illuminate the intricate interactions between bacteria, gluten, and the immune system in celiac disease.





ARNOLD HAN, MD, PHD at Columbia University

#### **GRANT TYPE** Eary Career Grant Award GRANT AMOUNT \$90,000 for each of two years WHY IT MATTERS



#### UNVEILING THE SECRETS **OF CELIAC DISEASE: DISCOVERING HIDDEN CLUES IN SHEDDING CELLS**

New and non-invasive indicators of disease

#### SHALEV ITZKOVITZ, PHD

at Weizmann Institute of Science (Rehovot, Israel) in collaboration with the Schneider Children's Medical Center (Petah Tikva, Israel)

#### **GRANT TYPE** Research Accelerator **GRANT AMOUNT**

\$175,000 for each of two years WHY IT MATTERS



The goal of this study is to develop powerful new indicators, called biomarkers, that could make it possible to diagnose celiac disease without the need for an invasive biopsy and to better manage the disease after diagnosis. Just as a gardener can gather important insights about the soil and overall garden health without resorting to constant digging, these new indicators would enable researchers to "see" celiac disease before diagnosis, after diagnosis and after the start of a gluten-free diet by looking at cells shed from the intestine in stool. Having access to these biomarkers would be a powerful tool that can significantly improve medical diagnosis, speed up clinical trials, distinguish celiac disease from non-celiac gluten sensitivity, and monitor how well someone is sticking to a gluten-free diet.



#### **CRACKING THE CELIAC CODE:** PREDICTING CELIAC BEFORE **IT STARTS**

Risk, susceptibility, and preventing celiac

#### **ROK SEON CHOUNG, MD, PHD** at Mayo Clinic (MN, USA) in collaboration with the Naval Medical Center (MD, USA) and Icahn School of Medicine at Mount Sinai (NY. USA)

**GRANT TYPE** Established Investigator Award **GRANT AMOUNT** \$100,000 for each of three years WHY IT MATTERS



The study will focus on immune system reactions that come before symptoms of celiac disease develop. Like looking at radar on a weather map to predict a coming storm and potential damage, researchers are investigating the progression of celiac disease and the consequences of waiting until celiac disease symptoms occur before a diagnosis can be made, as well as who is at most risk for developing celiac disease. In addition, understanding early progression could lead to ways to prevent celiac disease.



#### **GUT DETECTIVES: FINDING CLUES FOR CELIAC DISEASE** WITHOUT INVASIVE PROCEDURES

New and non-invasive indicators of disease



#### MICHAEL FITZPATRICK. **MRCP, DPHIL**

(previous Beyond Celiac awardee) at University of Oxford (Oxford, UK)

#### **GRANT TYPE** Research Accelerator GRANT AMOUNT \$175,000 for each of two years

WHY IT MATTERS



This project also aims to address a significant unmet need for a non-invasive indicators that can accurately assess the how badly the small intestine is damaged in a person with celiac disease. This study is also like a gardener looking for clues in a soil samples. Indicators identified in the study could be used to monitor disease activity and as way to objectively measure the effectiveness of drugs being tested in clinical trials to treat celiac disease.





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