



ANNUAL REPORT

Accelerating Diagnosis, Treatments,
and a Cure for Celiac Disease

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LETTER FROM MARILYN

Dear Friends and Supporters,

As we reflect on a year of remarkable progress, I am filled with immense appreciation for all we have accomplished together at the Celiac Disease Foundation. Our steadfast commitment to advancing the diagnosis, treatment, and ultimately a cure for celiac disease shines through, and this annual report stands as a testament to the collective impact of our efforts.

In 2024, the Foundation achieved significant milestones that reinforce our mission and vision. We awarded over \$1.5 million in research grants and three prestigious global prizes, celebrating groundbreaking work and nurturing the next generation of researchers. Additionally, through our relentless and powerful patient advocacy efforts, we successfully secured the renewal of National Institutes of Health and Department of Defense federal funding for celiac disease research, solidifying critical support for advancing scientific discoveries.

One of our most significant accomplishments this year was the expansion of our clinical trial recruitment efforts. Through targeted campaigns and strategic international partnerships, we successfully engaged thousands of patients in applying for clinical trials, with a strong emphasis on promoting diversity to ensure better representation within the diagnosed population. This initiative is a crucial step toward accelerating the development of better treatments and a cure for celiac disease.

Our collaboration with leading academic centers and esteemed medical organizations has further strengthened our research landscape, driving innovative insights and solutions. Our efforts to elevate the international standing of celiac disease advocacy also led to my appointment to the US Codex Delegation for the Committee on Food Labelling, where, for the first time, celiac disease is positioned to be recognized globally in precautionary allergen labeling—a monumental step forward for our community.

Our educational initiatives and community engagement programs have vastly expanded our reach and impact, from the Culinary Medicine Program to our School Support Sessions and Celiac Teen Talks. These efforts have empowered thousands of patients and families, providing essential tools and support to navigate life with celiac disease. We have also educated hundreds of health providers through our continuing medical education programs.

We've listened closely to what patients and families need to hear most from us. Based on your feedback, we've transformed our communications and social media to focus on three key areas: education, engagement, and amplifying the patient voice. By providing accurate, accessible information, creating opportunities for meaningful interaction, and sharing real-life experiences, we're committed to supporting and empowering the celiac community in every way possible.

The dedication of our supporters and partners remains the cornerstone of our collective success. We are deeply grateful for your commitment and generosity.

Together we continue to push boundaries, advocate for change, and work towards a future where celiac disease no longer presents a barrier to a fulfilling life.



With heartfelt appreciation,

Marilyn D. Geller

Marilyn Geller
Chief Executive Officer
Celiac Disease Foundation



PUBLIC POLICY & GOVERNMENT AFFAIRS



As a celiac disease patient advocate, I hope to accomplish three things: government recognition of the condition, government regulation of the condition, as well as a cure.... Not just for me, but for the 3 million Americans that are dealing with the condition. Additionally, I strongly believe that by advocating for celiac disease and by finding a cure, it'll be a stepping stone to curing other autoimmune disorders such as diabetes which affect hundreds of millions of people worldwide.

— Sanjith Senthil, Teenage Celiac Advocate

PUBLIC POLICY & GOVERNMENT AFFAIRS

Pioneering Policy Change

Patient advocacy is the heart and soul of the Celiac Disease Foundation. Each day we strategically drive policy change that accelerates diagnosis, treatment, and a cure for celiac disease. In 2024 we partnered with our national network of advocates to secure increased federal research funding from both the National Institutes of Health (NIH) and the Department of Defense (DOD) -- an increase of more than \$7 million. We broadened our work with federal government agencies, partnering in critical efforts to raise awareness, including an NIH conference, and we significantly expanded our global presence, engaging international government regulatory institutions including Codex Alimentarius, the World Health Organization, the Food and Agriculture Organization of the United Nations, and partner coalition associations, facilitating alignment with U.S. policymakers.

Federal Funding

Secured critical funding for celiac disease research, with \$10 million allocated in both FY23 and FY24, an increase from \$9 million in FY22, through the NIH. Additionally, for the second consecutive year, celiac disease was included in the highly sought-after Peer Reviewed Medical Research Program (PRMRP) of the DOD, which awarded \$6.68 million to two celiac disease research projects.

Around the World

CEO Marilyn G. Geller was selected to serve with the U.S. Codex Office delegation to represent the needs of celiac disease patients at the 48th Session of the Codex Committee on Food Labeling in Quebec City and appointed to the International Society for the Study of Celiac Disease (ISSCD) Gluten Challenges, Safety, and Standards Committee (GSSC) as the patient advocate.

Federal Agencies

Engaged nine federal agencies within the U.S. government to raise awareness and advocate for policy changes in support of celiac disease. The Celiac Disease Foundation and Crohn's & Colitis Foundation partnered to co-chair a panel at the National Institutes of Health Conference, *Exploring the Impact of Dietary Exposures on the Development of Mucosal Immunity and Immune-Mediated Digestive Diseases.*

In Congress

Held 25 bipartisan meetings on Capitol Hill to advocate for increased research funding, modernization of food labeling, insurance coverage for dietitian visits, medical nutrition therapy, and food security initiatives. More than 3,000 advocacy actions were taken to support our legislative priorities. We also introduced the Policy Leadership Award, honoring Representative Betty McCollum for her distinguished leadership on behalf of patients everywhere.



SCIENTIFIC AFFAIRS



I have been an admirer of the tremendous progress at the Foundation over recent years, and especially of their initiatives to advance high quality research applicable to patients' needs now and in the future. I first spoke at a Foundation meeting 15 years ago and have seen the rapid growth in the organization. The Celiac Disease Foundation is a world leader in supporting research in celiac disease; I am excited to have the opportunity to join as Principal Science & Innovation Advisor.

— **Robert Anderson**, MB ChB PhD, Principal Science & Innovation Advisor, Celiac Disease Foundation

SCIENTIFIC AFFAIRS

Driving Research for Life-Changing Treatments and a Cure

In 2024, the Celiac Disease Foundation made significant strides in research to improve the lives of those affected by celiac disease. Our unwavering commitment to scientific discovery and innovation has achieved major milestones, solidifying our position as a global leader in celiac disease research and clinical trials.

Highlights

- ▶ 3 new global partnerships across 3 continents
- ▶ 8 biopharmaceutical companies leveraged iRecruitCeliac services
- ▶ 37,000+ patients screened for clinical trials and studies
- ▶ First-ever international iCureCeliac® Patient Registry launched in New Zealand
- ▶ 14 publications featuring data from the Foundation co-authored and presented at national and international conferences

Key Accomplishments

Accelerating Clinical Trials for a Cure: Through our iCureCeliac® registry and iQualifyCeliac platform, we screened over 37,000 patients worldwide for clinical trials. New iQualifyCeliac features also boosted diversity, promoting broader representation in clinical research.

Expanding Global Impact: We established key international partnerships with Celiac Canada, the Coeliac Society of Ireland, and Coeliac New Zealand, expanding trial participation across borders.

Leveraging Expert Leadership for Breakthroughs: Robert Anderson, MB ChB, PhD, President of ISSCD and recipient of the global Prize for Excellence in Celiac Disease Research, was appointed as our Principal Science & Innovation Advisor, bringing unparalleled expertise to guide our therapeutic development efforts.

Harnessing Patient Data to Advance Treatment: iCureCeliac® data was instrumental in the study *Celiac Disease Symptom Profiles and Their Relationship to Gluten-Free Diet Adherence, Mental Health, and Quality of Life*. We also played a key role in the *Virtual Celiac Symptoms Study* and the *Physician Management of Celiac Disease* study, both of which provided valuable insights into patient care and treatment strategies across multiple countries.

Presenting Breakthrough Research on a Global Stage: Fourteen studies were presented at prestigious conferences, including Digestive Disease Week, the International Celiac Disease Symposium (ICDS), United European Gastroenterology Week, the NASPGHAN Annual Meeting, and the AO ECS General Assembly. These presentations showcased our leadership in research. CEO Marilyn Geller co-chaired the 2024 ICDS

Panel on End Points in Clinical Trials, where she emphasized the vital role of patient advocacy in driving clinical breakthroughs. Additionally, our collaboration with UC Davis resulted in a groundbreaking study that took a major step toward developing celiac-safe wheat.

Join Us in the Fight for a Cure

These achievements demonstrate the Celiac Disease Foundation's leadership in advancing research, driving clinical trials, and improving patient care—bringing us closer to life-changing treatments and, ultimately, a cure. Your support is critical to continuing this momentum.

RESEARCH AWARDS & PRIZES



On behalf of Anokion, we are excited to be able to continue our support of the Prize for Excellence in Celiac Disease. . . We really believe that supporting this foundational research will help all of us achieve the drug that we all desperately want for this population.

— Kristie Grebe, Chief Scientific Officer, Anokion

RESEARCH AWARDS & PRIZES

Research Grant Awards



In 2024, the Celiac Disease Foundation has awarded more than \$1.5 million in research grants, supporting scientific breakthroughs in celiac disease. Since 2022, the Foundation has presented three annual global prizes for outstanding contributions to the field. Over the past year, we funded research at 10 leading academic centers and, in collaboration with the International Society for the Study of Celiac Disease (ISSCD), the Society for the Study of Celiac Disease (SSCD), and the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) Foundation, announced 4 new research awards, reinforcing our commitment to advancing celiac disease understanding, diagnosis, and treatment.

New Research Grant Awards in 2024



Esen Sefik, PhD
Yale University

\$180,000



CELIAC DISEASE FOUNDATION-TAKEDA

EARLY CAREER

Research Award

Dr. Esen Sefik's research is focused on modeling celiac disease in a humanized mouse model—a mouse that has been re-engineered to have a human immune system. *This innovative mouse model holds tremendous potential to provide real-time understanding of celiac disease in humans and, ultimately, help pave the way for a cure.*



Fleur du Pré, PhD
Oslo University Hospital

\$300,000



INTERNATIONAL SOCIETY FOR THE STUDY OF CELIAC DISEASE

CELIAC DISEASE FOUNDATION

Research Fellowship Award

Dr. Fleur du Pré aims to uncover why people with celiac disease develop an autoimmune response against transglutaminase 2 when they eat gluten. Using an experimental mouse model, her research focuses on studying the interaction between B cells and T cells. *By unraveling the mechanisms behind this immune response, Dr. du Pré's research could provide crucial insights that lead to new treatment strategies for celiac disease.*



New Research Grant Awards in 2024



Nan Du, MD, MPH
Boston
Children's Hospital

\$150,000

★
CDF/NASPGHAN FOUNDATION
— CELIAC RESEARCH YOUNG INVESTIGATOR —
Development Award

In the Gluten-Free Nutrition Optimization through Ultra-Processed Food Reduction and Improved Strategies for Health (GF-NOURISH) study, Dr. Nan Du and her team will conduct a randomized controlled trial utilizing the recently validated Gluten-Free Food Guide (GFFG) in a new pediatric cohort in the United States. The hypothesis is that children educated with the GFFG will demonstrate improvements in diet quality, body composition, and reduced toenail arsenic levels.



Vahe Badalyan, MD
Children's
National Hospital

\$25,000

★
CDF/NASPGHAN FOUNDATION
— CELIAC DISEASE —
Pilot Grant

Dr. Vahe Badalyan and his team will explore systemic disparities in the screening, diagnosis, and referral processes for celiac disease. The aim of this pilot program is to build a robust data foundation to support a task force, composed of clinicians and affected families, to develop strategies for overcoming diagnostic barriers.

Continued Support for Research Grant Awards

Immune Responses to Gluten In Vivo and Ex Vivo

Boston Children's Hospital and Colorado Children's Hospital

Jocelyn Silvester, MD, PhD, and Marisa Stahl, MD

\$166,460

Dr. Jocelyn Silvester and Dr. Marisa Stahl are evaluating a potential new diagnostic test for celiac disease that could be an alternative to small intestinal biopsy. The test involves looking for changes in IL-2 in blood in a single-dose gluten challenge in children with celiac disease. They are also evaluating if blood may be exposed to gluten outside of the body, eliminating the need for patients to consume gluten to be diagnosed with celiac disease.

Development of Novel Dietary Treatment for Celiac Disease

Wenjun Zhang, PhD, and Maria Rottersman

\$360,000

Dr. Wenjun Zhang, Maria Rottersman, and Dr. Jorge Dubcovsky are continuing to develop a new type of wheat that removes harmful proteins (epitopes) responsible for triggering celiac disease, while maintaining wheat's bread-making quality. This breakthrough could lead to safer wheat products for people with celiac disease and reduce the number of those who develop the condition.



Global Research Prizes Awarded in 2024



Riccardo Troncone, MD
Sponsored by Anokion

\$25,000

Dr. Riccardo Troncone, a renowned leader in pediatric gastroenterology and Full Professor at the University Federico II in Naples, has significantly advanced the understanding of celiac disease. His pioneering research has helped define potential celiac disease, explore the induction of oral gluten tolerance in groundbreaking animal models, and lead the PreventCD Project, a landmark study aimed at preventing celiac disease in at-risk infants. Dr. Troncone's influential contributions have shaped the future of celiac research, establishing him as a deserving recipient of the Global Prize for Excellence in Celiac Disease Research.

★
PRIZE FOR *Excellence*
IN CELIAC DISEASE RESEARCH

“ I'm deeply honored to receive the Prize for Excellence in Celiac Disease Research. I'm grateful to the Celiac Disease Foundation and the selection committee for recognizing my lifelong work dedicated to celiac patient care and research.

— Riccardo Troncone, MD

★
YOUNG *Investigator* PRIZE
IN BASIC SCIENCE



Iris H. Jonkers, PhD
Sponsored by Pfizer

\$10,000

Dr. Iris Jonkers, an Associate Professor at the University Medical Center Groningen, was recognized for her innovative research on the genetic and environmental triggers of celiac disease. While leading the University's Immunogenetics group, Dr. Jonkers' groundbreaking work has paved new pathways for understanding and treating celiac disease.

★
YOUNG *Investigator* PRIZE
IN CLINICAL SCIENCE



Marisa Stahl, MD, MSCS
Sponsored by Immundiagnostik

\$10,000

Dr. Marisa Stahl, Assistant Professor at the University of Colorado School of Medicine and Director of Research at the Colorado Center for Celiac Disease, was recognized for her contributions to pediatric celiac disease research, including advancing early detection and personalized screening strategies. She used her prize funds to support the university's first annual Celiac Disease Screening Symposium in November 2024.



Thank You to Our 2024 Research Grant Award and Prize Sponsors





EDUCATION



I had an amazing time on the Celiac Cruise and am grateful to the Celiac Disease Foundation for organizing the amazing educational and support events onboard the ship. I loved going off on my own with new friends who understand my challenges, and for the first time, I didn't worry about food. This experience has helped me better understand and accept my celiac disease.

— **Lucas Kumin** on Celiac Cruise

EDUCATION

Empowering Minds, Transforming Lives

We are deeply committed to educating and empowering the celiac disease community. Through dynamic initiatives like our *Culinary Medicine Program*, *School Support Sessions*, and *Living with Celiac Disease* for newly diagnosed patients, we provide essential tools and guidance for individuals of all ages. Programs like *Celiac Teen Talk* and *Celiac Strong Day* create powerful connections and inspire confidence in those living with celiac disease. We're also driving change on a global level by offering Continuing Medical Education (CME/CEU) for healthcare providers and sponsoring groundbreaking medical conferences and symposiums, advancing research and care for celiac disease worldwide.

Essential Milestones

Culinary Medicine Program ▶

Successfully provided practical medical, nutrition, and culinary guidance to over 5,000 patients and families, enhancing their quality of life. More than 600 physicians and dietitians claimed CME/CEU credits for attending the sessions.

Invited as presenters at the International Celiac Disease Symposium in Sheffield, UK to educate global celiac disease medical professionals on integrating culinary medicine into their clinical practices.

Celiac Strong Day ▶

United thousands of students in grades K-12 in raising awareness at their schools, building a resilient community dedicated to supporting those affected by celiac disease.

Global Investments in Education ▶

Major sponsor of international conferences including the International Celiac Disease Symposium, the Pan-Asian Celiac Disease Symposium, and the Latin American Celiac Disease Symposium.

School Support Sessions ▶

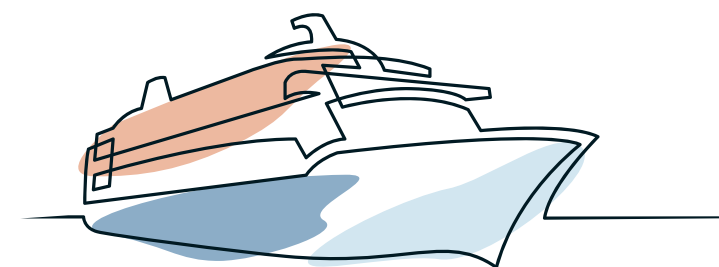
Empowered more than 1,000 families with the tools and knowledge needed to advocate for safe, gluten-free environments in schools.

CME/CEU Programs and Medical Conferences ▶

Educated healthcare providers worldwide, improving diagnosis and treatment of celiac disease through sponsored conferences and education courses at Boston Children's Hospital, the Harvard Macy Institute, the University of Chicago Celiac Disease Center, and Children's Hospital Colorado.

Living with Celiac Disease Program ▶

Offered critical support to over 1,000 newly diagnosed patients, helping them navigate their diagnosis and manage their health effectively.



Celiac Cruise ▶

In 2024, we partnered with Celiac Cruise to train over **7,000 crew** members across six sailings on **Royal Caribbean** and **AMA Waterways**, providing educational programs for over **2,000 guests**. This collaboration not only created a safe and inclusive environment for travelers with celiac disease but also raised significant funds to support our mission, while offering community-building and support programs for guests of all ages.



HEALTH EQUITY



The SSCD-CDF Health Equity Grant Award provides critical funding for researchers to study and address the disparities in celiac disease research and clinical care. By supporting innovative projects focused on improving access to diagnosis, treatment, and management in underrepresented communities, this grant empowers researchers to drive meaningful change and improve outcomes for all patients affected by this autoimmune disease.

— **Dr. Ritu Verma**, Pediatric Gastroenterologist and President of the Society for the Study of Celiac Disease

HEALTH EQUITY

Championing Fair Access to Celiac Disease Care

We are deeply committed to promoting health equity through our Celiac Disease Food Insecurity Resource Network (CD-FIRN) and research grants that address disparities in celiac disease diagnosis and management. With the support of our generous donors and partners, we strive to ensure that every individual living with celiac disease has access to the resources and support they need. Together, we are making a profound difference in the lives of those who need it most, building a future where no one is left behind.

Pivotal Successes



Safe food delivered directly to families

CD-FIRN provides gluten-free food to up to 150 families annually through the Food Equality Initiative.



Healthcare provider training

We offer training to hospital centers on screening for food insecurity using the Hunger Vital Sign and integrating these screenings into EHR systems.



Monthly cooking and nutrition programs

Enrolled families benefit from monthly sessions on gluten-free cooking, meal planning, and nutrition, along with guidance on accessing state and federal aid programs.



Surveys and research

Participants in CD-FIRN complete monthly surveys to contribute to research on the impact of food insecurity on the celiac community.



Advancing Equity: Broadening Clinical Trial Diversity

We drive health equity by expanding clinical trial diversity through targeted outreach to underrepresented communities. By addressing cultural and geographic barriers, we ensure broader participation, leading to more inclusive and effective treatments for celiac disease.



HEALTH EQUITY

Research Award

In partnership with the Society for the Study of Celiac Disease (SSCD), we support research on disparities in celiac disease diagnosis, management, and access to care, focusing on underrepresented populations.

The first grant awarded to:



Amelie Therrien, MD
Beth Israel Deaconess Medical Center

\$100,000

Dr. Amelie Therrien's project, *Detecting Celiac Disease Among the Hispanic/Latino Community*, aims to raise awareness of celiac disease within this population and promote greater diversity in patient representation. By implementing targeted interventions for primary care providers (PCPs), the project seeks to improve celiac disease detection rates and shorten diagnostic delays. Nationally, this outreach initiative has the potential to significantly boost detection in underserved areas, enhancing access to specialized clinical care and patient support.



COMMUNICATIONS



As a healthcare provider, I've seen firsthand how the Celiac Disease Foundation's social media content has become an invaluable resource. Its relatable, educational, and reliable information empowers both patients and healthcare professionals, making crucial resources more accessible than ever.

— **Dr. Jackie Jossen**, Celiac Disease Center at Columbia University

COMMUNICATIONS

Amplifying Awareness Through Engaging Storytelling

We've listened closely to what patients and families need most. Based on your feedback, we've transformed our communications and social media to focus on three key areas: **education, engagement,** and **amplifying the patient voice.** By providing accurate, accessible information, creating opportunities for meaningful interaction, and sharing real-life experiences, we're committed to supporting and empowering the celiac community in every way possible.

Defining Victories

Improved Social Media Metrics and Engagement

through new multimedia tactics, including increased video content, engaging carousels, and community content on hot topics in celiac disease.



5.5 Million Video Views

across all social media channels.



343% Increase

in Instagram impressions.



Delivered Over 200 Email Blasts

to nearly 85,000 subscribers with an average open rate of 41.1%, well above nonprofit industry average.



33% Growth

in Instagram followers.



Featured New Data and Leading Researchers

in easy-to-understand posts that highlighted key takeaways and implications for the community.



212,000 Total Followers

across all social media channels.



Established

the Ask-the-Dietitian and Ask-the-Chef weekly Instagram posts.



Through our Newly Established Research Communications Vertical,

we successfully secured the acceptance of over 20 abstracts highlighting cutting-edge original research from the Celiac Disease Foundation's team, alongside global Foundation-funded projects, for presentation at leading scientific conferences.



Launched Glutle

a new word game modeled after the popular Wordle game to provide a weekly educational lesson in a fun and engaging way.





DEVELOPMENT



As a junior at the U.S. Air Force Academy, I began experiencing stress fractures, fatigue, abdominal pain, and unusual neurological symptoms. Seven months later, I was diagnosed with celiac disease, which set me on a months-long journey to prove I could still commission as an officer. Two weeks before graduation, I was granted a waiver. Since then, educating fellow service members about celiac has been my mission, especially in an environment where autoimmune diseases are rare. This has fueled my drive to support celiac research, and I'm honored to be part of the 2024 New York City Marathon Team Gluten-Free.

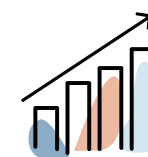
— Catherine Bakken, Team Gluten-Free

DEVELOPMENT

Bridging Today's Support with Tomorrow's Cures

Our mission is fueled by the generosity of individuals, corporations, and foundations who offer both philanthropic support and active involvement in our initiatives. From the annual Turkey Trot and May Celiac Disease Awareness Month to our Team Gluten-Free fundraisers and special campaigns, our donors show an ongoing commitment to improving the lives of those with celiac disease. We are deeply honored and grateful for their dedication, which plays a vital role in advancing our vision of a world free from celiac disease.

Major Achievements



Support Soars for Annual Turkey Trot

Supporters from 38 states and beyond rallied for the annual Turkey Trot, powering critical financial support to accelerate treatments and a cure for celiac disease. What began as a regional event in New York has flourished into a beloved national movement, with participants across the country coming together to advance life-changing research and make an even greater impact.



Raise it. Give it. Get it! Shines During Awareness Month

May Celiac Disease Awareness Month remains a vital platform to celebrate our community's passion for education, advocacy, and research acceleration. This year, the Raise it. Give it. Get it! Campaign, supported by Proud Sponsor King Arthur Baking Company, reached new heights with record-breaking donations. As a token of gratitude, participants received gluten-free goodie bags, reinforcing their critical role in driving progress and expanding our impact.



Team Gluten-Free Races to Cure Celiac Disease

The Celiac Disease Foundation proudly recognizes Team Gluten-Free for their extraordinary dedication. This year, participants in the Los Angeles and TCS New York City Marathons covered 366.8 miles, driving critical awareness and support for advancing treatments and finding a cure for celiac disease.



Foster Family Foundation Fuels Mission Forward with \$200,000 Gift

The Foundation is proud to announce a grant from the Foster Family Foundation to advance our mission of accelerating diagnosis, treatments, and a cure for celiac disease. Established in 1998 in Southern California, the Foster Family Foundation continues to support our efforts in research, advocacy, and education.

FINANCIALS



At the Celiac Disease Foundation, we are deeply committed to ensuring that every dollar entrusted to us makes a meaningful impact in the lives of those with celiac disease. Our financial stewardship allows us to continue advancing research, providing critical resources, and advocating for policies that protect our community. Together with our generous supporters, we are building a future where all people with celiac disease can thrive.

— Marilyn Geller, MSPH, CEO Celiac Disease Foundation

FINANCIALS

For the Year Ending 12.31.23

ASSETS

Cash and Cash Equivalents	\$1,615,687
Contributions Receivable	\$678,538
Investments	\$3,431,090
Other Assets	\$234,539
Total Assets	\$5,959,854

LIABILITIES

Accrued Liabilities	\$298,182
Deferred Revenue	\$335,608
Total Liabilities	\$633,790

NET ASSETS

Total Net Assets	\$5,326,064
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SUPPORT AND REVENUE

Contributions	\$2,275,544
Other Income	\$2,484,257
Total Revenue	\$4,759,801

EXPENSES

Program	\$2,777,308
Management and General	\$180,775
Development	\$348,409
Total Expenses	\$3,306,492
Change in Net Assets	\$1,453,309

