CELIAC DISEASE FOUNDATION

Strategic Plan
2023 - 2028
The Celiac Disease Foundation (CDF), established in 1990, is a leading global patient advocacy organization committed to accelerating diagnosis, treatments, and a cure for celiac disease. Our mission is to improve the health and well-being of the millions of individuals around the world affected by this genetic autoimmune disease through our strategic investments in research, advocacy, and education.

In 2022, the Board of Directors, working together with staff, launched a strategic visioning process to define the 30-year vision or “Big Goal” for CDF to anchor a refreshed set of five-year goals and objectives as part of its Strategic Plan. At the time of developing this plan, the organization was (and still is) experiencing significant growth in both its annual budget and staff size, making possible more expansive opportunities for impact. The refreshed vision for CDF – Create a world free of celiac disease – was developed through a series of survey and interview data collection efforts that generated the fodder for board and staff conversation. In a two-day retreat in the Summer of 2023, the new vision was unpacked and operationalized into the goals and objectives presented here.

Later in 2023, the CDF staff team defined the implementation plan for these strategic goals and objectives.
Goal 1: Significantly increase awareness and change the narrative around celiac disease among patients, providers, policymakers, and payers.

Goal 2: Improve the lives of people with celiac disease by advancing promising new approaches to manage, treat, and cure the disease through advocacy and research.

Goal 3: Expand CDF’s capacity and funding base to enhance and sustain the organization’s financial health to achieve the long-term vision.

Create a world free of celiac disease
GOAL 1: Significantly increase awareness and change the narrative around celiac disease among patients, providers, policymakers, and insurance payers.

While celiac disease is one of the world’s most prevalent genetic autoimmune diseases, affecting an estimated 1 in 100 people worldwide, the vast majority of people with the disease (70-80%) are undiagnosed. We believe that to achieve our vision of a world free of celiac disease, we must engage in a set of large-scale communications campaigns to increase awareness and change the narrative among patients, providers, policymakers, and payers. We will pursue this goal in two phases (each requiring around two years to achieve).

Phase 1 Objectives:
• Develop a communications strategy and plan outlining specific audiences with goals and objectives around message development and media for reaching each.
• Define the economic costs of celiac disease and develop the additional data needed to craft compelling messages needed for communications campaigns.
• Define and test the messages to convey around common symptoms, severity and consequences, triggers and health economics of celiac disease.

Phase 2 Objectives:
• Define the systems, channels, and outlets, as well as critical messengers for raising awareness of celiac disease. We anticipate these will include available and existing outlets as well as new ones that could be a natural fit for CDF.
• Develop and disseminate an array of media types to achieve audience education and narrative change goals and objectives.
GOAL 2:
Improve the lives of people with celiac disease by advancing promising new approaches to manage, treat, and cure the disease through advocacy and research.

Alongside our efforts to raise awareness of the prevalence and health consequences of celiac disease, we will continue to engage in advocacy efforts to create policies that increase the available funding available for the research needed to make diagnosis, management, treatment, and ultimately a cure for celiac disease possible. Our primary focus is on federal legislation; however, we will explore opportunities to pilot legislation at the state level where there are ripe opportunities to do so.

At the same time, we will continue to build the celiac disease-focused research community and support research efforts directly.

**Advocacy Objectives:**
- Continue to build and strengthen relationships with congressional representatives, including growing the membership of the Congressional Celiac Caucus.
- Engage the Congressional Celiac Caucus – as well as other relevant agencies and coalitions – to sponsor and approve legislation that improves the lives of people with celiac disease.
- Develop a proof of concept at the state level (e.g., in CA) around expanding “food is medicine” to include the celiac patient population.

**Research Objectives:**
- Continue to build the Key Opinion Leader (KOL) core.
- Continue to develop CDF’s clinical trials service line.
- Assess the need for a Scientific Advisory Board (SAB); explore relationships with celiac societies.
- Evaluate funding availability through Key Opinion Leaders (KOLs) to assess the value of universal testing for celiac disease among children.
- Continue to grow and build the research community including through support of grants and prizes via international extension and collaboration.
- Continue to increase and diversify the patient profile of iCureCeliac and iQualifyCeliac.
- Assess and pursue research and venture project opportunities that advance our goals and objectives towards the long-term vision on an ongoing basis.
GOAL 3:

Expand CDF’s capacity and funding base to enhance and sustain the organization’s financial health to achieve the long-term vision.

Achieving the first two goals will require significant investment in CDF as an organization, continuing to build out staff capacity and to engage topnotch partners to implement the parts of the Strategic Plan that are outside of CDF’s wheelhouse.

**Fundraising Objectives:**
- Engage the Congressional Celiac Caucus and other congressional representatives to significantly increase federal funding.
- Significantly increase the amount of private funding for CDF (on the order of $15M+ in five years).
- Diversify CDF’s funding base in other ways, as possible.

**Board Development Objectives:**
- Increase the size of the board to 15-16 members, and in so doing also increase its diversity, focusing recruitment on representatives of the medical, finance, public relations, and other areas of expertise needed to succeed in accomplishing the Strategic Plan.
- Explore and consider establishing a Fundraising Council of high-net worth individuals who wish to be a part of generating the resources needed to achieve the long-term vision.

**Organizational Capacity Objectives:**
- Review progress on Strategic Plan objectives on an annual basis and assess the need for additional staffing, consulting support, and other capacity-building efforts / investments; refresh the Strategic Plan as needed (e.g., annually or biennially).
- Ensure the organization is resourced with the appropriate level of staffing, consulting support and expertise, and other capacities as needed to succeed in accomplishing the Strategic Plan.
OPPORTUNITY for IMPACT among PEOPLE WITH CELIAC DISEASE and the POLICIES THAT AFFECT THEM

- Celiac disease is one of the world's most prevalent genetic autoimmune diseases, affecting an estimated 1 in 100 worldwide, 70-80% of whom are undiagnosed.
- Causing the body to attack its own small intestine, it can lead to many other devastating health conditions, including cancer.
- Unfortunately for the millions who suffer, until recently celiac disease had largely been ignored by our federal government which provided little to no funding for research nor for public awareness of its serious consequences.
- CDF has achieved important federal changes in recent years. For example, we successfully lobbied for NIH and DOD research funding and helped to establish the House Celiac Disease Caucus. We are a partner with FDA for gluten-free food labeling and developing guidance for celiac disease drug development. We are advocating for coverage for dietitian services for people with celiac disease through CMS, to assure food subsidy programs include gluten-free foods and for inclusion of celiac disease in the CDC A-Z list, among other initiatives. CDF will continue to inform and shape policy at the national and local levels both strategically and as opportunities arise.

OUR MISSION
To improve the health and well-being of the millions of individuals around the world affected by this genetic autoimmune disease through strategic investments in research, advocacy, and education.

OUR VISION
Create a world free of celiac disease.
We are pursuing a cure for celiac disease while also working to free people with celiac of the symptoms, restrictions, and health risks associated with the disease.

Goal: To improve the health and well-being of the millions of individuals around the world affected by celiac disease through strategic investments in research, advocacy, and education.

Theory of Change

Through strategic investments in research, education, and advocacy, the Celiac Disease Foundation seeks to accelerate treatments and a cure.

Purpose and Partners

Research. On behalf of patients, CDF collaborates with physicians, dietitians, mental health professionals, researchers, and industry, as well as retail manufacturers, medical societies, associations, and academic research centers to advance research to help cure celiac disease.

Advocacy. CDF elevates the celiac patient voice, partnering with the Congressional Celiac Disease Caucus and our advocacy counsel at Baker Donelson, so that celiac disease receives the attention from the federal government that it has long deserved.

Education. CDF invests in programs developed by leading academic research centers in celiac disease to educate healthcare professionals, researchers, and the patient community.

Outcomes

• Expanded research output around, leading to increased understanding of, the causes, progression, and consequences of, as well as pathways, therapies, medications, and, ultimately a cure for, celiac disease.

• Federal policy accelerates research for treatments and a cure, as well as to advance other priorities to improve the quality of life for all those affected by celiac disease.

• Increase awareness of the prevalence and consequence of celiac disease to expand resources for the critical research needed to advance treatments and a cure.