

Introducing the Back-to-School and 504 Plan Guide

Celiac Disease Foundation creates Back-to-School and 504 Plan Guide to help parents and children manage celiac disease in school and college

Underscoring its role as a leader in the gluten-free community, Celiac Disease Foundation (CDF) has developed the Back-to-School and 504 Plan Guide to add to its online offering of tools and resources that also includes: the Symptoms Checklist, Healthcare Practitioner Directory, Gluten-Free Allergy-Free Marketplace, 7-Day Gluten-Free Meal Plan, and iCureCeliac® patient registry.

Parents of a child diagnosed with celiac disease or non-celiac wheat sensitivity understand that there are challenges at each age and in each environment. Required lifestyle changes can be especially difficult during the school-age and college years. CDF's Back-to-School and 504 Plan Guide provides instruction to help both parents and children better manage these transitions.

Celiac disease is considered a disability under the Americans with Disabilities Act. For children with celiac disease who attend

public school, a 504 Plan is the federally-recognized process of detailing any and all accommodations that need to be made by



the school to assure that the child receives a barrier-free, appropriate education. This requires parents to advocate on behalf of their children at the elementary, middle, and high school levels, and for young adults to advocate for themselves in college. CDF's Back-to-School and 504 Plan Guide outlines

the steps to take from preschool through college to keep students safe at school and to make sure they are receiving what they need for proper development and academic and social success.

"Celiac Disease Foundation is grateful for a generous gift from the Weitz family which has made this program possible," said Marilyn G. Geller, Chief Executive Officer of Celiac Disease Foundation. "As the parents of children with celiac disease, we understand first-hand how frustrating and intimidating the bureaucracy of public school administration can be, even when administrators are committed to doing the right thing. The CDF Back-to-School and 504 Plan Guide provides vital information for parents to help their children thrive and navigate this disease during their school-age and college years."

To review the full Guide, please visit celiac.org/back-to-school.



Back-to-School Recipes

Janelle Smith, CDF Registered Dietitian, provides simple and delicious recipes to get you into the Back-to-School spirit.

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Become an Advocate

Three new advocacy programs have been launched to help lift the burden for patients living with celiac disease and their caregivers.

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Partner Burden

A recent study at Columbia University shows that partner burden in celiac disease can strain long-term relationships.

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Marilyn's Message

Dear Friends,

We are pleased to feature the Back-to-School and 504 Plan Guide in this issue of INSIGHT. It is our goal to provide the tools to patients and caregivers that will help them advocate for themselves to improve the quality of their lives. We are grateful to the Weitz Family for their generous gift to fund the Back-to-School and 504 Plan Guide and the accompanying webinar. Through the philanthropy of our supporting families, we are able to develop our most successful programs.

With a gift from the Resnick Family, CDF partnered with Children's National Health System to create the Celiac Disease and Gluten-Related Conditions Psychological Health Training Program. This continuing education program provides a tool kit for medical and mental health practitioners to identify and treat patients living with celiac disease and non-celiac wheat sensitivity. Included in the program is an interactive manual with videos to increase practitioner awareness in pediatric populations. I encourage you to take advantage of this powerful resource by viewing it at celiac.org/psych-health.

Launched this summer, at the USC Keck School of Medicine, is a program to teach primary care physicians to correctly identify celiac disease symptoms and to order screening for the disease. This program, which will serve as a model curriculum for other medical schools, was made possible by a significant gift from the Simon Family Foundation. The Simon Family, long-time supporters of CDF, have also funded many other programs, including a low-income celiac disease screening program at Olive View-UCLA Medical Center, and the expansion of the Team Gluten-Free community fundraising program.

The CDF Board of Directors and staff are deeply appreciative of your continued support. It is with your contributions that we are able to provide programs for the millions of people with celiac disease and non-celiac wheat sensitivity, and their loved ones. If you are interested in sponsoring one of our initiatives, I would be delighted to speak with you. I can be reached at 818-716-1513, x102.

As always, I look forward to solving celiac disease together.

To Our Health,

Marilyn G. Geller

Chief Executive Officer

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CDF Appoints Two New Members to Board of Directors

Celiac Disease Foundation (CDF), the nation's leading voluntary health organization for celiac disease, announces the appointment of two new members to its Board of Directors for the 2016-2017 term.

"Our two new Directors bring talent, expert knowledge, and passion to the Board, and we are grateful to have their support of the Foundation," said Marc Riches, CDF Board Chair. "The full Board looks forward to working together to drive diagnosis, treatment, and a cure for this woefully underdiagnosed genetic autoimmune disease."

The newly elected Board Members are Adrienne Bender and Linda Solomon.

Adrienne Bender has been a volunteer for Celiac Disease Foundation since 2012 when her son, Alex, was diagnosed at age three. Alex was born premature at a little over four pounds, and spent his first three years on the lowest point of the growth curve. After one year with no weight gain, Alex's pediatrician recommended that he be tested for celiac disease. Alex's diagnosis

drove Adrienne to seek help and guidance and also inspired her to help others. Adrienne has primarily focused her efforts on fundraising for Celiac Disease Foundation by coordinating Team Gluten-Free events throughout the year. Since 2012, Adrienne has raised tens of thousands of dollars and was named CDF's 2016 Volunteer of the Year.

Professionally, Adrienne is a Vice President in the Alternatives Investment Solution division of State Street Corporation. She is a 2001 graduate of Franklin and Marshall College in Lancaster, Pennsylvania with a Bachelor of Arts degree in Accounting and Finance. Adrienne resides in Montgomery, New Jersey with her husband, Aaron, and two children, Alex and Ava.

Linda Solomon was diagnosed with celiac



Adrienne Bender



Linda Solomon

disease in 2015, after having no idea it was an autoimmune disorder. Shortly thereafter, two of her children were diagnosed. After attending the Celiac Disease Foundation National Conference, she knew that she had to be a part of this organization and its mission. Linda has joined the Board of Directors of Celiac Disease Foundation to help further research and development to support the community at large with celiac disease.

Linda is a Systems Engineer with a major Aerospace company in Southern California. Linda holds a Bachelor's of Science degree in Electrical Engineering from California State University, Northridge, as well as a Master's of Science Degree in

Electrical Engineering from the University of Southern California. Linda brings a nurturing mind and a passion for advocacy to the Board. Linda resides in Los Angeles with her husband and three children.

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GAS

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WEIGHT LOSS

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What is iCureCeliac?

iCureCeliac is a patient-powered research network dedicated to accelerating research efforts to better understand and ultimately cure celiac disease. iCureCeliac allows patients to contribute medical information and their experiences living with celiac disease and gluten sensitivity to help researchers improve treatments and find a cure.

Why is this so important?

Your medical data is incredibly valuable. By aggregating large amounts of data from thousands of patients living with celiac disease and gluten sensitivity, we are able to help answer questions most important to patients. Your data can shape the types of research studies to be conducted that are most beneficial to you – the patient.



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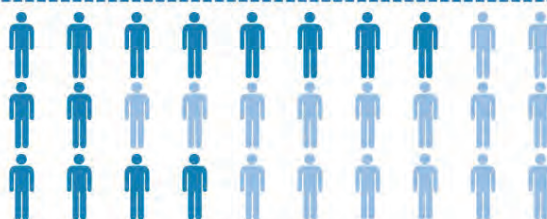
The First Four Months

What is iCureCeliac?

iCureCeliac is an online patient powered research network that allows patients and caregivers to enter health information and their experiences living with celiac disease and gluten sensitivity to help researchers improve treatments and find a cure.

Who Has Entered Data So Far?

1200
Users



Diagnosis

73% Celiac Disease
4% Gluten Sensitivity
23% Other

iCureCeliac Users Have Reported...

Length of Time to
Diagnosis

33%

Reported that diagnosis took longer than 5 years from the onset of their first symptoms

Infertility Prior to Diagnosis

12%

Infertility After Diagnosis

3%

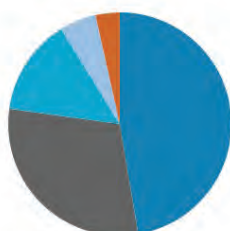
Miscarriage Prior to Diagnosis

19%

Miscarriage After Diagnosis

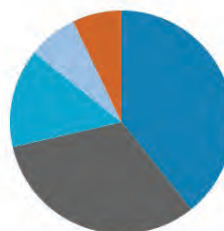
2%

Top Comorbid Diagnoses Prior to Celiac Disease Diagnosis



IBS 27%
Thyroid Disease 17%
Psoriasis 8%
Rheumatoid Arthritis 3%
Type 1 Diabetes 2%

Top Comorbid Diagnoses After Celiac Disease Diagnosis



IBS 11%
Thyroid Disease 9%
Psoriasis 4%
Rheumatoid Arthritis 2%
Ulcerative Colitis 2%

53%

Feel that the gluten-free diet is not sufficient

43%

Feel that they cannot live a normal life due to their gluten-related disorder

20

Average number of work/school days missed annually due to gluten exposure

23

Average number of work/school days missed annually due to gluten-related disorder



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Back-to-School Recipes

Blue Diamond Lunchables



Recreate this classic lunch so your child can feel part of the crowd. Purchase containers with multiple partitions to mimic the Lunchables look, and keep crackers and cookies from getting soggy. There are unlimited variations of this simple idea based on what your child enjoys.

Ingredients:

- 2 oz sliced cheddar cheese or dairy-free substitute
- 12 **Blue Diamond** Nut Thins in favorite flavor
- 3 oz ¼-inch thick cut gluten-free deli turkey, cut with small circular cookie cutter
- 10 baby carrots
- 2 tbsp gluten-free dressing for dipping
- 1 gluten-free cookie

Approximate nutrition information per serving:

Serves 1; 600 calories; 44 g carbohydrate; 27 g fat; 40 g protein; 15 g sugar

Hodgson Mill Apple Pancakes



Start your child's day off right with these pancakes by sneaking in a dose of fiber and omega-3 fatty acids. Make all of the batter on Sunday night, and keep cooked pancakes in the fridge in an airtight container for up to four days. For quick prep on those hurried school-day mornings, heat individual pancakes in the microwave for 10-20 seconds or on a dry pan over low heat on the stove. Top with apple butter, almond butter for protein, vanilla yogurt, slivered nuts, and/or syrup as desired.

Ingredients:

- 1 cup **Hodgson Mill** Gluten-Free Pancake and Waffle Mix
- 1/2 tsp cinnamon, optional
- 1/2 cup milk, divided (or 1/4 cup yogurt plus 3 tbsp milk), or dairy-free substitute
- 1 egg
- 1/2 tsp vanilla
- 1/2 cup apple butter
- 1 tbsp ground flaxseed

Directions:

Measure dry ingredients into a medium sized bowl. Add apple butter, ¼ cup of the milk, egg, and vanilla, and mix well with whisk or fork until no dry bits remain. Add 2-4 tbsp more milk, one tbsp at a time, and mix until you have a thin batter for scooping or pouring.

Spoon or pour batter onto greased pan or griddle over medium heat. Wait for bubbles to form near edges before flipping; check underneath for golden color to make sure it doesn't burn. Do not press down with your spatula, as this will ruin the fluffy consistency.

Approximate nutrition information per serving:

Serves 2; 370 calories; 70 g carbohydrate; 8 g fat; 12 g protein; 9 g sugar

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Back-to-School Recipes, continued

Crunchmaster Avocado Tuna Salad



This tuna salad is packed full of healthy fats to support your child's developing brain. Pairing with crackers in a separate container means no soggy sandwich!

Ingredients:

2 (5-6oz) cans solid white albacore tuna in water, drained	1/3 cup fresh chopped cilantro, packed (optional for kids)
1 1/2 avocados	1 stalk celery, chopped
1/2 cup diced cucumber	1/2 tsp garlic salt
2 tbsp finely chopped red onion (optional for kids)	1/2 lime, juiced (or more if desired)
1 green onion, sliced (optional for kids)	Salt and fresh ground black pepper
	Crunchmaster Multi-Seed Crackers

Directions:

Flake the drained tuna with a fork in a medium bowl. Add avocado to the tuna and mash with a fork, breaking up any large chunks. Add cucumber, celery, red onion, cilantro, green onion, and garlic salt. Stir together and add lime juice, mixing to combine. Season with salt and fresh black pepper to taste. Keep in the fridge up to three days. Serve chilled with an ice pack in your child's lunch box with one cup of Crunchmaster crackers for dipping.

Approximate nutrition information per serving:

Serves 2; 525 calories; 34 g carbohydrate; 24 g fat; 47 g protein; 0 g sugar

Enjoy Life Margherita Pizza Meatballs



These meatballs are simple and delicious when served cold in a lunchbox packed with an ice pack. Serve with a side of marinara sauce for dipping, or mix over zucchini noodles with sauce.

Ingredients:

2 cups **Enjoy Life** Margherita Pizza Plentils
1 lb ground beef, turkey, or chicken
2 tbsp milk or dairy-free substitute

Directions:

Preheat oven to 325° F and coat mini-muffin tin with cooking spray. In food processor or blender, pulse Margherita Pizza Plentils until crumb consistency. In large mixing bowl, use your hands to mix ground beef, Plentils, and milk until well combined. Roll 1-inch meatballs and place individually into muffin tins. Bake for 7-8 minutes, turn meatballs, and bake for 7-8 more minutes on other side. Cool on paper towel-lined plate to absorb grease. Store in airtight container in fridge for 3-4 days, or freeze individually on tray for two hours and keep in freezer-lock bag for 3-4 months.

Approximate nutrition information per serving:

Serves 6; 290 calories; 9 g carbohydrate; 15 g fat; 31 g protein; 0 g sugar

For more recipes, please visit celiac.org and choose 'Gluten-Free Recipes' under the 'Live Gluten-Free' tab.

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Celiac Disease in Children

Edward Joel Hoffenberg, MD, Celiac Disease Foundation Medical Advisory Board Member and Medical Director of the Program for Pediatric Inflammatory Bowel Diseases at Children's Hospital Colorado, discusses celiac disease in children and adolescents

Celiac disease may develop any time after wheat or other gluten-containing foods are introduced into the diet, typically after 6-9 months of age. It is unknown why some children become ill early in life and others fall ill only after years of exposure. There is wide variation in the severity of symptoms – many children will experience symptoms within minutes to hours after consuming gluten, which may only last a few hours. In others, symptoms may last several days, or up to two weeks. Many children have mild symptoms that are easy to miss, such as having excessive gas, abdominal pain, or constipation. Other children have more severe symptoms that can result in an earlier diagnosis, including failure to thrive, weight loss, and vomiting. Fortunately, children and adolescents typically respond well to treatment with the gluten-free diet. Most children feel significantly better after two weeks on the diet and attain normal height, weight, and bone health.

Celiac disease affects children in different ways, depending on their age:

Infants and Toddlers

Infants and toddlers tend to have more obvious symptoms which usually manifest in the gastrointestinal tract. Symptoms include, but are not limited to:

- Vomiting
- Bloating
- Irritability
- Poor growth
- Abdominal distention
- Diarrhea with very foul stools

Infants and toddlers can suffer from malnutrition, leading to poor growth in weight and/or height.

School-Age Children

Vomiting is less common in school-age children than in infants and toddlers. Symptoms include, but are not limited to:

- Stomach aches or abdominal pain
- Abdominal distention



- Diarrhea
- Constipation
- Trouble gaining weight or weight loss

Older Children and Teens

Older children and teenagers may have symptoms or concerning signs that are not obviously related to the intestinal tract, which are called “extra intestinal” or “atypical” symptoms. These symptoms are what may convince a physician to test for celiac disease. Some of these manifestations include:

- Stunted growth
- Weight loss
- Delayed puberty
- Achy pain in the bones or joints
- Chronic fatigue
- Recurrent headaches or migraines
- Itchy skin rash (dermatitis herpetiformis)
- Recurring mouth sores, called aphthous ulcers, which look like canker sores

Adolescents with celiac disease may also have mood disorders, including anxiety and depression, as well as panic attacks.

Celiac Disease in Children with No or Mild Symptoms

There are two primary ways that celiac disease can be found in children without symptoms of concern. The first is to have an associated condition in which testing for celiac disease is recommended:

- Family member with celiac disease

- Type 1 diabetes
- Thyroid disease
- IgA deficiency
- Juvenile Chronic Arthritis
- Down syndrome (Trisomy 21)
- Williams syndrome
- Turner syndrome

The second is to have other signs of celiac disease that do not cause typical symptoms:

- Iron deficiency anemia
- High levels of liver enzymes, AST and ALT
- Osteopenia (thin bones)
- Dental enamel defects

Severe Celiac Disease in Children

Severe cases of celiac disease in childhood are now very rare. Symptoms of severe cases include:

- Chronic fatigue
- Very low blood pressure
- Excessive water loss in stool, leading to “electrolyte disturbance”
- Abdominal obstruction called “intussusception”

It is very important to test your child for celiac disease at the very first signs, or if celiac disease runs in your family. **First-degree relatives of someone with celiac disease have a 1 in 10 chance of developing celiac disease themselves.**

To learn more about screening and diagnosis, please visit celiac.org/diagnosing-celiac-disease.

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CDF Launches New Community Education and Research Programs

Celiac Disease Foundation (CDF) is continually introducing new programs that focus on community education and involvement with the goals of raising awareness and increasing the body of research that will lead to new treatments and a cure. We are proud to announce the establishment of three new programs this year.

Back-to-School and 504 Plan Program

Through a generous gift from the Weitz Family, CDF is able to offer a Back-to-School Program geared toward educating the parents of children, teens, and college students with celiac disease on how to advocate for the resources and accommodations necessary for their child to thrive. The Back-to-School Program launched in August with a webinar, hosted by American Celiac Disease Alliance former Executive



presentation, resources, and Team Gluten-Free swag to get them started. To find out more about the Student Ambassador program, please visit celiac.org/studentambassadors.

Patient Advocacy Program

Launched at the 2016 National Conference through a Patient Centered Outcomes Research Institute (PCORI) grant, we are proud to have established the CDF Patient Advocacy Program. Participants in this program gain medical, scientific, and advocacy skills so they can assist in the design, implementation, and dissemination of celiac disease research. Through a series of online videos and webinars, participants develop a working knowledge of current practices in the screening and diagnosing of celiac disease, its underlying genetics and mechanisms, the pathway to drug development, gluten-free nutrition, and more. To become a CDF Patient Advocate, please visit celiac.org/become-patient-advocate.



Director and 504 Plan expert, Andrea Levorio. Andrea joined CDF's Registered Dietitian, Janelle Smith, and Communications Manager, Talia Hassid, in presenting how to create and implement a successful 504 Plan to keep children safe at school. Find a recording of the webinar and the downloadable Back-to-School and 504 Plan Guide at celiac.org/back-to-school.

Student Ambassador Program

The CDF Student Ambassador Program helps children and teens become role models for others with celiac disease while raising awareness in their community and educating their peers. A program of Team Gluten-Free, Student Ambassadors work with their local elementary, middle, and high schools to teach the importance of celiac disease awareness and tolerance in schools. An outstanding community service project, Student Ambassadors receive a



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Study Shows That Partner Burden in Celiac Disease Can Strain Long-Term Relationships

Partners and loved ones can find it very challenging to be responsible for the care of someone with a chronic disease. A recent study at Columbia University looked at just how stressful caregiving for a celiac disease patient can be.

Specifically, the study found that the more severe a patient's symptoms, the more burden felt by the caregiver. Stress was also found to be higher when the caregiver was already dissatisfied in the relationship. Interestingly, the study found that longer relationships (greater than 10 years) usually revealed a higher stress or burden level. This may be because immediate issues (starting a gluten-free diet, managing symptoms) are of greater concern in shorter relationships, while longer-term

partners begin to look at further ranging issues, such as quality of life and longevity. It is critical that healthcare providers involve caregiving partners in treatment and management planning decisions.

"Our findings illustrate that the diagnosis of celiac disease has ripple effects beyond

the patient, and that the symptoms of celiac disease and the burden of treatment with the gluten-free diet can affect the patient's closest relationship," states Dr. Benjamin Lebwohl, CDF Research Committee member and one of the study's authors. "This should be acknowledged by providers so as to bring

this issue out in the open and make patients and their loved ones feel comfortable discussing the impact of celiac disease on all parties." To learn more, visit celiac.org/researchnews.

Would you like to help shape research on celiac disease? Share your caregiver experience and insight by registering with iCureCeliac® at celiac.org/icureceliac, and add your voice to the discussion.



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Your Gluten-Free Allergy-Free “Go-To” Source

The CDF Gluten-Free Allergy-Free Marketplace connects you to products and services from companies that care about the gluten-free and allergy-free community

-  **Browse products** by **allergens** and **dietary preferences**
-  **View** product pictures, **ingredients** and **nutrition facts**
-  **Connect** with **companies** for **coupons, discounts, recipes** and more
-  **Create a shopping list** that you can **print or email** to a friend
-  **Tap on home** for **recipes, diagnosis** and **treatment tools**, and the latest **research**
-  **Support CDF** by purchasing products directly from Amazon with a single click

 Shop today at celiac.org/marketplace



Dear Friends,

When I started Celiac Disease Foundation (CDF) in 1990, there was very little information available on celiac disease. How it affected both children and adults, the impact it had on our body and mind, and how it affected our families, were all uncertain. The few individuals with celiac disease I had met were trying to get information on their own. My goal was for CDF to be the number one resource for all reliable information – to generate a greater awareness, both in the medical community to increase the diagnosis rate, and in the celiac disease community to help people understand how to improve their quality of life. I am in awe of what we have accomplished.

Today, CDF reaches more than seven million people annually worldwide. We pursue an aggressive public education, research, and advocacy agenda and, together with our Medical Advisory Board, we are improving the quality of life for patients with celiac disease and non-celiac wheat sensitivity, as well as leading the search for treatments and a cure.

I am now retired, and when you reach retirement age, it is only prudent to make plans for the rest of your life and beyond. If you are like me, you want to provide for your loved ones in your planning, but you also want to give careful consideration to your favorite charities. I have included CDF in my estate planning, and I encourage you to consider doing the same.



Power of Giving-Estate Planning

Including CDF in your estate planning is relatively simple. The first step is to clearly understand your options, including gifts of cash, stock, insurance, or other assets in your Will, charitable gift annuities, charitable remainder trusts, and more. Each has consequences for your estate. To learn more about how to include charitable giving in your estate planning, I suggest you consult your estate advisor, financial planner, or tax attorney, or go online to celiac.org/planned-giving.

Your gift of including CDF in your estate planning will provide far reaching, long lasting benefits to the celiac disease community. The work I started more than 25 years ago still has a long way to go. There are millions of undiagnosed celiac disease patients suffering here in the U.S., and millions more suffering with non-celiac wheat sensitivity. We must continue to support and fund research for more rapid diagnosis, treatments, and a cure. That is why I urge you to consider my request.

Very truly yours,

Elaine Monarch

Founder, Celiac Disease Foundation



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Ready To Do
Something
Extraordinary?

JOIN THE TEAM

Celiac Disease
FOUNDATION



Celiac.org/TGF

Team Gluten-Free is Proud to Be an Official Charity Partner of the 2017 Skechers Performance Los Angeles Marathon

On March 19, 2017, participants will run from “the Stadium to the Sea”! With one of the most exciting courses, runners of the 26.2 mile Marathon Course start at Dodger Stadium and pass by renowned iconic Los Angeles landmarks, including the Disney Hall and Music Center, Rodeo Drive, Chinatown, and more, before finishing on Ocean Avenue alongside the Pacific Ocean. This is truly a life-changing race.

Why join Team Gluten-Free? All runners receive:

- Training and fundraising tips
- Official Team Gluten-Free race shirt
- Personal online fundraising page
- Fundraising incentives and prizes
- Gluten-free swag bag
- And more!

Get Started!

With a lowered fundraising minimum, it has never been easier to run the LA Marathon for Team Gluten-Free!

1. Commit to raise a minimum of \$650 for Team Gluten-Free.
2. Claim your bib and register for the Los Angeles Marathon as an invited member of Celiac Disease Foundation Team Gluten-Free.
3. START FUNDRAISING – we help you set up your own fundraising page!

To claim your bib, email gillian.entin@celiac.org.



The monies raised by Team Gluten-Free participants fund Celiac Disease Foundation’s education, advocacy, and research programs. To learn more about how you can help in the fight against celiac disease, visit celiac.org/tgf.





PROUD SPONSOR OF
Celiac Disease
FOUNDATION
celiac.org



GLUTEN-FREE LIVING

Cutting out gluten from your diet may seem like a difficult and limiting task. Fortunately, there are many healthy and delicious foods that are naturally gluten-free! In fact, the most cost-effective and healthy way to follow the gluten-free diet is to seek out naturally gluten-free food groups like fruits and vegetables! (see celiac.org)

Dole markets many naturally gluten-free products, including No Sugar Added Diced Peaches Fruit Bowls®, Fruitocracy™ flavors, Frozen Fruit, Dark Chocolate Covered Banana Dippers, 100% Pineapple Juice and much more. Visit www.dolesunshine.com for more information on our gluten-free products.



DOLE'S COMMITMENT

At Dole we have long been committed to bringing the best products possible to your shelves. We continually strive to improve each aspect of our products from the individual ingredients to the outer packaging.

That's why we can say that all our packaging in NA is BPA-Free, none of our products contain High Fructose Corn Syrup and we strive to source NON-GMO* ingredients. Reference our packaging for these benefits.

Look for the label! →



*no genetically modified (or engineered) ingredients

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