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## MARILYN'S MESSAGE



A number of our committed supporters have asked me why Celiac Disease Foundation applauds the FDA's gluten-free labeling rule. As you well know, all FDA-regulated foods including dietary supplements bearing the claim "gluten-free" must contain less than 20 ppm [parts per million] of gluten. Health policy at Celiac Disease Foundation is directed by our Medical Advisory Board, comprised of globally respected experts in celiac disease and non-celiac gluten sensitivity. Our Medical Advisory Board members agree with the FDA scientific assessment that 20 ppm is the threshold level of gluten that is tolerated by those with celiac disease. The 20 ppm threshold is also consistent with gluten-free labeling standards in other countries.

I recognize that there are individuals who support a stricter standard. I believe, however, that this is a significant victory for our celiac and gluten-sensitive community as our medically required dietary needs have finally been validated by a federal government agency. We should be delighted the vast majority of consumers can finally be assured that food products labeled gluten-free are safe for consumption. And, as you read this, the FDA is reviewing the public comments it has received regarding options to limit gluten exposure from consumption of drug products. I encourage you to bookmark [www.celiac.org](http://www.celiac.org) to find the most current and concise information on FDA activities as the gluten-free labeling rule is implemented.

Despite this progress, 83% of the 3 million Americans with celiac disease remain undiagnosed. The fact is that the United States has one of the lowest celiac disease diagnosis rates in the developed world. This is a public health tragedy. Undiagnosed celiac disease is a life-threatening autoimmune disorder. For example, undiagnosed celiac disease is associated with a four-fold increased risk for lymphoma and other cancers.

We know there are significant challenges to improving this disgraceful diagnosis rate. But we at Celiac Disease Foundation are committed to moving the needle. We are rolling out a number of targeted programs designed to alert patients and doctors to consider celiac. I will be sharing more details with you in the days and weeks to come.

Finally, I want to thank you for your sustained support of Celiac Disease Foundation. Your gifts of money, time, and moral support are essential to our efforts to stop the needless suffering caused by celiac disease. Please continue to be generous,

To Your Health,

Marilyn G. Geller  
Chief Executive Officer

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## BOARD PRESIDENT & FOUNDER'S MESSAGE

As you read this, 83% of people with celiac disease are unaware that they have it. No one is more concerned about this lag in diagnosis than Celiac Disease Foundation (CDF). Daily we ask the question "Why are millions of children and adults allowed to suffer when a simple blood test exists to screen for celiac disease?" Through a generous gift from the Simon Family Foundation, CDF has been able to fund a study at Olive View-UCLA Medical Center to address this issue. The study seeks to determine if there is a benefit to screening symptomatic patients for celiac disease.

The study is under way and beginning to show results. The first patient diagnosed during this study met in early September with CDF Founder Elaine Monarch and Medical Advisory Board Member Kim Upton, RD. They discussed the seriousness of this disease and the importance of strictly adhering to the medically required gluten-free diet. Our goal is to raise awareness among those who are diagnosed with celiac disease so that they will make choices that will protect their health in the future and improve their quality of life. CDF is pleased to be able to partner with Olive View-UCLA Medical Center to assist with dietary education and support for study patients.

Not a day goes by that we don't hear about someone who no longer eats foods that contain gluten, or see a headline, blog or

tweet about gluten-free – "the fascinating new food phenomenon." Is this about gluten for health, weight loss or the myriad of other reasons why people are embracing the gluten-free diet? To us, it's deeper than that -- we have celiac disease. By strictly following the medically required gluten-free lifestyle, we have regained and continue to maintain our health.

For each of us who eat gluten-free, we applaud the current FDA ruling that will help make our gluten-free food choices easier in the future. There is an enormous need for educating the public about this disease, and Celiac Disease Foundation is at the forefront of this effort providing resources, dietary information and up-to-date research news. In order to fund our efforts to educate, raise awareness and drive diagnosis of celiac disease we need your support. Please consider making a donation today by returning the enclosed envelope or visiting [cdf.thankyou4caring.org](http://cdf.thankyou4caring.org).

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# FAST FACTS ABOUT THE FDA GLUTEN-FREE FOOD LABELING RULE

## 1. What food products are covered by the FDA gluten-free labeling rule?

### Covered:

- All FDA-regulated foods
- Dietary Supplements (vitamins, minerals, herbs, amino acids)
- Imported food products that are subject to FDA regulations

### Not Covered:

- Meat, poultry and unshelled eggs (and any other products regulated by the USDA)
- Distilled spirits and wines that contain 7% or more alcohol by volume\*
- Malted beverages made with malted barley or hops\*
  - \* These alcoholic beverages are regulated by the Alcohol and Tobacco Tax and Trade Bureau (TTB). The FDA says it will work with the TTB to "harmonize" gluten-free labeling requirements between the two agencies.

## 2. After August 5, 2014, what food products may be labeled gluten-free?

A food product regulated by the FDA may be labeled gluten-free if:

- It does **NOT** contain wheat, rye, barley or their crossbred hybrids like triticale (a gluten-containing grain) OR
- It contains a gluten-containing grain or an ingredient derived from a gluten-containing grain that has been processed to less than 20 parts per million (ppm) of gluten.

## 3. What about products that are naturally gluten-free?

**Yes.** Food products that are naturally gluten-free, like bottled spring water or tomatoes, may be labeled "gluten-free."



## 4. Will there be a symbol to identify foods that meet the FDA definition of gluten-free?

**No.** The FDA has determined that consumers favor the label "gluten-free" to communicate that a food is free of gluten. Manufacturers are allowed to include a symbol as long as it is truthful and not misleading.

## 5. Are manufacturers required to test for gluten to label a product "gluten-free"?

**No.** Manufacturers are not required to test for the presence of gluten in ingredients or in the finished "gluten-free" labeled food product. However, they are responsible for ensuring that the food product meets all labeling requirements. Manufacturers will need to determine how they will ensure this.

## 6. How will the FDA enforce gluten-free labeling requirements after August 5, 2014?

The FDA may perform food label reviews, follow-up on consumer and industry complaints, and analyze food samples. Consumers and manufacturers may report a complaint to an FDA Consumer Complaint Coordinator in the state where the food was purchased.

## 7. Why did the FDA adopt < 20 ppm of gluten as the standard instead of zero ppm? Why does CDF support this?

The FDA adopted the standard based upon the recommendations of the scientific and medical communities, and because there are no analytical methods available that are scientifically validated to reliably detect gluten below 20 ppm. The CDF Medical Advisory Board supports the < 20 ppm of gluten standard for gluten-free labeling. According to Dr. Peter Green, director of the Celiac Disease Center at Columbia University, "The 20 ppm is a scientifically determined level of gluten that has been shown to be tolerated by those with celiac disease. It is in line with standards in other countries." Dr. Alessio Fasano, of the Center for Celiac Research states, "Twenty parts per million, or 20 parts of gluten per one million parts of food sample, is an accepted standard in many parts of the world for products that are labeled gluten-free. The evidence-based research published by our Center, which has been confirmed by studies from colleagues around the world, conclusively supports the 20 ppm level as a suitable safety threshold for gluten-free products." According to the Center's website, "research from the Center has shown that 10 milligrams per day of gluten consumption is a safe level for the vast majority of individuals with celiac disease." The Center's website goes on to state that 10 milligrams is roughly the equivalent of one-eighth of a teaspoon of flour, or 18 slices of bread with each slice containing 20 ppm of gluten.

## 8. What are the FDA and CDF doing about gluten-containing ingredients in medications?

The FDA's Center for Drug Research and Evaluation (CDER) is reviewing the public comments it has received regarding options to limit gluten exposure from consumption of drug products. CDF is asking the public to support the HR 2003: Gluten in Medicine Disclosure Act of 2013 sponsored by Representatives Tim Ryan (D-OH) and Nita Lowey (D-NY) which requires drug labels to contain a parenthetical statement identifying the source of any ingredient constituting or derived from a grain or starch.

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## GLUTEN IN MEDICINE DISCLOSURE ACT OF 2013

The North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) reached out to Capitol Hill this past June to talk about the organization's legislative priorities, one of which is gluten labeling in medicine. As a result of the meetings, Senator Gillibrand (D-NY) has taken a strong interest in the issue. Sen. Gillibrand has drafted a bill that calls for a different approach to the gluten in medicine labeling issue by comparison to the proposed HR 2003: Gluten in Medication Act introduced by Representatives Tim Ryan and Nita Lowey.

Sen. Gillibrand's bill would direct the FDA to exercise its authority and issue a proposed rule that requires labeling within two years of the bill's enactment. The proposed rule would also require a statement to disclose the presence of gluten on the label of any drug intended for human use that has an inactive ingredient containing gluten. In order to provide an appropriate amount of public health protection and consumer health knowledge, the rule would define, based on scientific consensus, at what level gluten must be disclosed. A final rule from the Secretary of Health and Human Services would be required within four years following the enactment of the bill.

In addition to the proposed rule, the Comptroller General of the United States would be required to conduct a study in order to determine:

- To what extent the presence of allergens (other than gluten) in medication is a public health issue;
- To what extent it is practicable to eliminate the use of gluten in medications;
- What policy and regulatory issues the FDA should consider when evaluating whether to require labeling; and
- Any other pertinent public health, regulatory, and business considerations consistent with this section.

No later than one year after the date of enactment, the Comptroller General would publish a report describing the results of the study.

It is unclear at this point whether Sen. Gillibrand will get the opportunity to have the language used as an amendment to the drug compounding bill.

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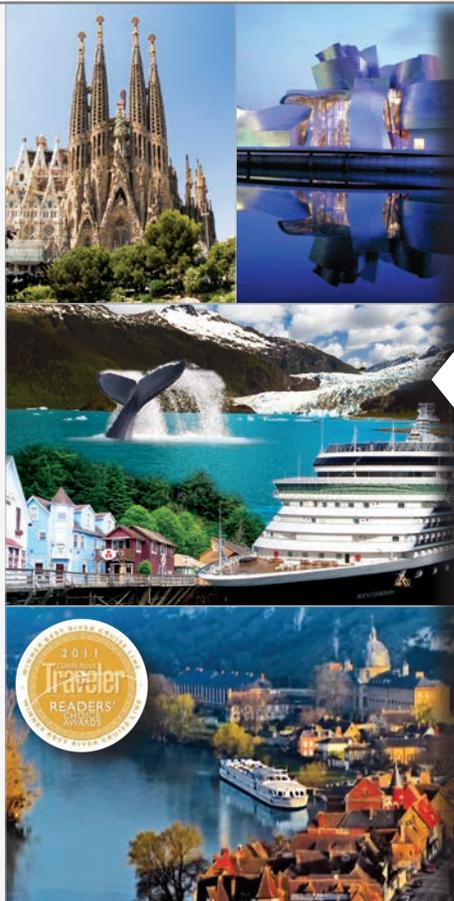
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## AMERICAN COLLEGE OF GASTROENTEROLOGY DEVELOPS NEW GUIDELINES FOR DIAGNOSIS AND MANAGEMENT OF CD

Celiac disease is estimated to affect roughly 1% of the American population. Yet, despite the large number of people living with the condition, it still remains grossly under diagnosed in the medical community. Practitioners are much more likely to consider celiac when treating a patient with gastrointestinal symptoms, but tend to miss more subtle presentations that could appear completely unrelated to the untrained eye.

In order to increase the diagnosis rate amongst patients with celiac disease, the American College of Gastroenterology (ACG), including Rubio-Tapia, Murray and colleagues around the country, have put together a set of evidence-based guidelines. These ACG guidelines are focused on increasing awareness of celiac disease as a potential diagnosis and highlight some important updates regarding how practitioners can come to the correct diagnosis through proper thinking and testing methods.

The typical diagnostic test has changed over the years in order to accommodate more accurate and up-to-date testing methods. The ACG guidelines state that the antigliadin antibody testing is no longer part of the screening process and should not be considered as part of the diagnostic test. Instead, practitioners are

now focusing on IgA TTG testing, which is more likely to detect whether or not a person has celiac disease.

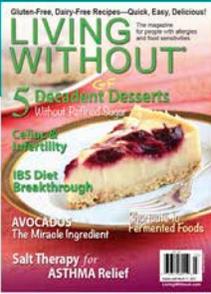
Genetic testing, on the other hand, is relevant to all patients and can be used to determine whether or not a patient has celiac disease. The test is based on the presence or absence of two genes, HLA-DQ2 and -DQ8. According to ACG guidelines, this testing method can be very helpful in specific cases such as refractory patients who appear to have celiac disease but are not responding to a gluten-free diet.

Following diagnostic testing, official diagnosis can be obtained by following the golden standard of intestinal biopsy. ACG guidelines specify exactly how many tissue samples should be taken during the biopsy and in which areas of the small intestine are most effective in order to increase the chance of patient diagnosis. Although multiple samples may seem excessive, it is important for practitioners to examine the entirety of the small intestine for the benefit of the patient.

Medscape members can read the full article at [Medscape.com](http://Medscape.com)

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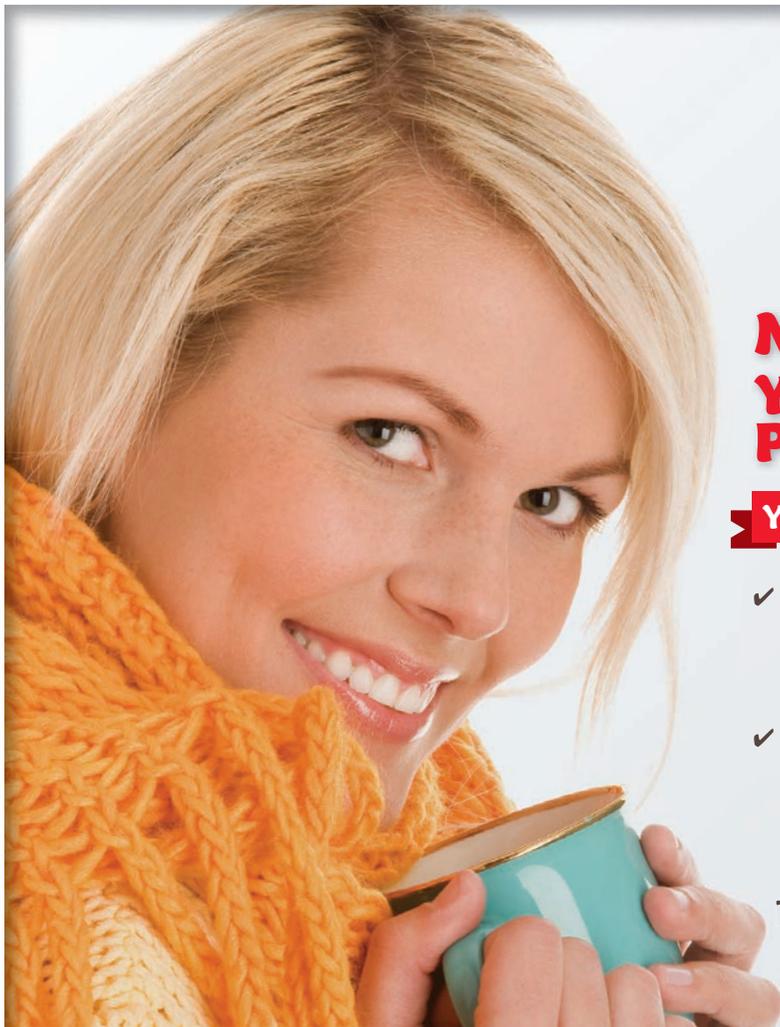
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## STUDY PROVIDES A STRATEGY TO IMPROVE DIAGNOSIS

**A study published in BMC Medicine provides a strategy to improve the diagnosis of celiac disease in the community by combining the benefits of antibody and genetic testing before proceeding to biopsy.**

<http://www.biomedcentral.com/bmcmed>

Dr. Bob Anderson, CSO ImmusanT and colleagues developed a new approach to detecting unrecognized cases of celiac disease in the community. The results reveal this immune disorder is far more common than previously recognized.

### The study had several important messages:

- Essentially 100% of patients proven to have celiac disease based on intestinal biopsy changes were positive in the gene test which is simple and only requires a blood sample or a cheek swab.
- The gene test can be used to rule out and or reverse the diagnosis of celiac disease in gluten-free patients.
- The genes that place people at risk of celiac disease are common. Over 50% of the Australian population (similar to figures in the US and Europe) possess HLA-DQ2.5, HLA-DQ8 or HLA-DQ2.2, but “only” one in 60 women and one in

80 men in the community are predicted to have celiac disease compared to previously estimates of 1:100.

- Genetic testing along with TG2 in addition to other confirmatory antibody tests (DGP) could substantially improve diagnosis and reduce the overall costs of testing. The number of endoscopies requested as a follow up to abnormal TG2 alone could be cut by over 70%.
- Some people with celiac disease are not detected by the “standard” screening blood test for TG2. The optimal antibody blood screen included testing for antibodies to both TG2 and DGP.
- Diagnosis of celiac disease based on improvement of symptoms when on a GFD is not sufficient, but finding an abnormal TG2 antibody test by itself was also likely to be misleading (false positive) in 80% of the cases.
- The study strongly supported the importance of combining antibody and gene tests with intestinal biopsy in the diagnosis of celiac disease and not basing diagnosis on current blood tests alone.

**Conclusion:** Initial screening for celiac disease with a blood test for TG2/DGP followed by genetic testing and additional serology prior to confirmatory biopsy could improve the accuracy and reduce the cost of diagnosing celiac disease.

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## CDF'S 2ND ANNUAL CAMP GLUTEN-FREE™

### 2013 marked another year of success for CDF Camp Gluten-Free™!

Sixty-seven campers made their way up to the San Bernardino Mountains for a week full of gluten-free food and outdoor activities! They started the night with spaghetti and garlic bread, every kid's favorite. The week continued with archery, Frisbee, arts and crafts, song competition, S'mores and a dance night. Camp wouldn't be complete without a hike to the lake. The mile-long hike took the campers down to beautiful Lake Nawakwa, where they went canoeing and fishing. After enjoying a delicious picnic buffet, it was back to the cabins for a well needed siesta. Red Brick Pizza returned this year to throw another Pizza Party. Each camper lined up to design his or her own pizza, topped anyway they liked. They finished the night with Red Brick's homemade gelato and outdoor games.

Because of your support these children got to spend their summer being a kid, without worry of being sick or constantly asking "is that gluten-free?" It was just like any other camp, filled with new friends and memories.

Thank you for all your donations and CDF Team Gluten-Free™ fundraising over this past year to make this all possible.

#### Special thanks to those who supplied all the gluten-free products for camp meals and snacks:

Deanna's Gluten-Free Bakery, Red Brick Pizza, French Meadow, Pamela's Products, Udi's Gluten Free, Glutino, Crunchmaster, Hodgson Mill, Hidden Valley Ranch, Breads From Anna, Jovial Foods, Arctic Zero, Canyon Bake House, Surf Sweets, Go Picnic and Goldbaum's.

#### Special thanks to the donors and supporters who provided scholarship funds:

Isabelle Persh, Elliott Taft, Julie Bradley, Jennifer Becker, Benjamin Field, Valerie Pastor, Judith Lawson, Gluten-Free Saver LLC, Sun Pacific Insurance Brokers Inc, Deborah Magee, Michelle Gasaway, Alan Parnes, Warren Dycus, Linda Kotzin, Susan Wolfe, Mavorene Gugino, Heather Gearheart, RedBrick Worldwide Inc, Lori Jones, Libby Pevsnek, Elaine Monarch, Caren Gerszberg, Diana Ajuria, Rosti Tuscan Kitchen, Rudi's Gluten Free Bakery, Alan Gilbert, CSA San Diego, CDF Greater Phoenix Chapter.





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The money raised by CDF Team Gluten-Free™ participants goes directly towards summer camp scholarships for children on the gluten-free diet as well as celiac disease and non-celiac gluten sensitivity research, support and awareness programs.

Celiac Disease Foundation is proud to announce that we have five (5) runners in this year's ING NYC Marathon on November 3rd.

**Meet our runners:**



Todd's son Madden was diagnosed earlier this year. Running a marathon was already on his bucket list, so once he found out about the opportunity to run for CDF Team Gluten-Free™, he couldn't say no. "Madden has been lucky and is now thriving, but other kids still need help and support in leading healthy, productive lives," says Todd. "Your donation will go towards research and medical research as well as support and resources for kids living with celiac disease."

Kris is a true athlete. She is an Ironman veteran and living and thriving athletically. After being diagnosed, she had her daughters tested, and sure enough one has celiac disease and one has non-celiac gluten-sensitivity. Being active and healthy is important to Kris and her family.

The money she will be raising goes directly towards summer camp scholarships for children on the gluten-free diet. It will also go toward raising awareness of celiac disease and non-celiac gluten sensitivity among the medical community.



This will be Lee's 3rd marathon. "I'm adding meaning to my miles," says Lee. She'll be running with a special young friend in mind, Quinn Delorme. Quinn has celiac disease and faces many medical, dietary and emotional challenges - always with a super-positive attitude. Quinn's inspirational story has Lee ready to run and inspire more people.

Jeff's son Riley was diagnosed with celiac disease before he was two. A few years later, his wife Jill was diagnosed. "Their positive spirit when tackling a disease that most people don't understand inspires me." This has inspired Jeff to run for CDF Team Gluten Free™. "It's an honor."



Dave's daughter was diagnosed with celiac disease last summer. Her gluten-free diet has helped with healing and she is on the road to recovery! "I am so proud of her fight for wellness! As a husband, father, and physician, I thank you for your donation and support."

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## BACK TO SCHOOL RECIPES FROM CDF PROUD SPONSORS



### Bob's Red Mill Pumpkin Chocolate Chip Muffins

- 3 cups **Bob's Red Mill** Brown Rice Flour
- 1 cup **Bob's Red Mill** Hazelnut Flour/Meal
- 1 Tbsp + 1 tsp Baking Powder
- 2 tsp Pumpkin Spice
- 1/2 tsp Sea Salt
- 2 Eggs
- 1/2 cup Oil
- 1 Tbsp Vanilla
- 1-1/2 cups Pumpkin Puree
- 1 cup Evaporated Cane Sugar
- 1-1/3 cups Whole Milk
- 1 cup Chocolate Chips

#### Directions

1. Mix dry ingredients in a medium bowl and set aside. Combine egg, oil, vanilla, pumpkin and evaporated cane sugar with a whisk.
2. Mix dry ingredients into wet with a spatula, alternately with the milk. Fold in chocolate chips.
3. Using a flat muffin scoop, portion out into 12 lined and greased muffin cups. These portions will be heaping, so divide accordingly.
4. Bake double panned with a sheet pan underneath at 375°F for 25 minutes. Muffins will brown, but will stay soft when done.

### Gorton's Seafood Easy Fish Tacos with Rudi's Gluten-Free Tortillas

- One package **Gorton's Seafood** Gluten-Free Grilled Pollock, Tilapia or Salmon
- 4 **Rudi's** gluten-free Tortillas
- Taco fixings of choice: cheese or cheese alternative, lettuce, tomato, avocado, salsa, sour cream

#### Directions

1. Prepare grilled fillets according to package directions. Cool slightly. Cut each fillet lengthwise into 5 strips.
2. Fill tortillas with lettuce, tomatoes, and any desired toppings. Place 2 fillet strips in each taco. Top with shredded cheese

### Hodgson Mill Chicken Caesar Pasta Salad

- 3 cups chicken, roasted and shredded
- 3 cups **Hodgson Mill** gluten-free Brown Rice Penne
- 2 cups Romaine lettuce, thinly sliced
- 2 cups tomato, grape tomatoes, halved
- 1/3 cup Caesar dressing (gluten-free, of course)
- 1/4 cup parsley, fresh, chopped
- 1 cup parmesan cheese

#### Directions

1. Prepare pasta according to package directions, strain and cool
2. Put all ingredients in a large bowl and toss well to combine.
3. Serve room temperature or chilled.

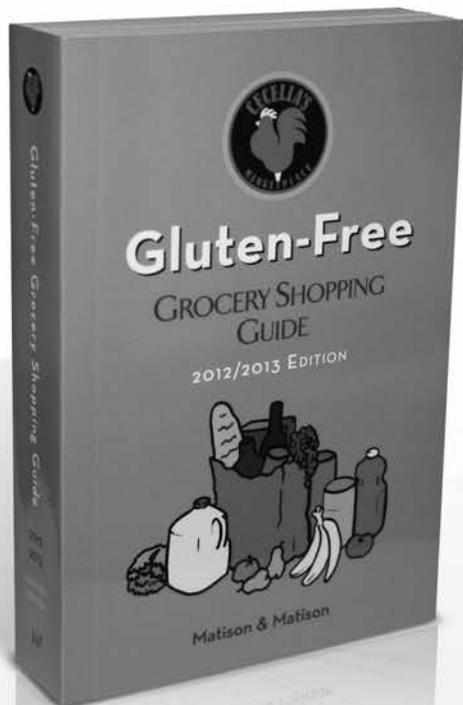


### Udi's Gluten-Free Apple & Peanut Butter Sandwich Stacks

- 1-2 of your favorite apples
- ½ cup Peanut Butter, Almond Butter or Sun Butter
- ½ **Udi's** gluten-free Granola in Vanilla, Original, Cranberry or Au Natural
- ½ Raisins, Dried Cranberries, Chocolate Chips or other toppings of your choice

#### Directions

1. Slice apples ¼ to ½ inch thick. A little lemon juice might keep them from browning.
2. Spread with butter of your choice, and top with granola.
3. Top with another apple slice.



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# Cecelia's Marketplace

MAKING GLUTEN-FREE LIVING EASY!

# YOUNG & GLUTEN FREE

Henry Grunzweig

Anna Rhoads (Intern), Carly Jackson (Intern), Cecilia Bonaduce (Intern), Hallie Himmelreich (Intern), Marilyn Cheng (Intern), JD Severino (Intern), Henry Grunzweig(Intern)

Working for Celiac Disease Foundation (CDF) this summer was a blast. Over the course of just a few weeks, our little group of interns, spread out across the country during the school year, became a tight-knit gluten-free family.

In addition to the design and editing of the new [celiac.org](http://celiac.org) website that will launch in October, we took on the project of making a gluten-free lunch for the office each day. Minus the lack of oven and stove, it seemed like an easy enough task. We certainly ended up consuming plenty of tasty dishes, and we all (myself in particular) learned a lot about self-sustainability.

However, there was one small catch to our assignment: we had to make each dish on a tight budget to prove that people can eat gluten-free food that is not only delicious, but also inexpensive. If you are a veteran Celiac reading this, or maybe just a mom adjusting to buying her child all new lunch foods, you realize that such a task can be a pretty tall order. So what did we learn?

The following is a quick summary:

1. Buy fresh produce from the local market. Fruits and veggies

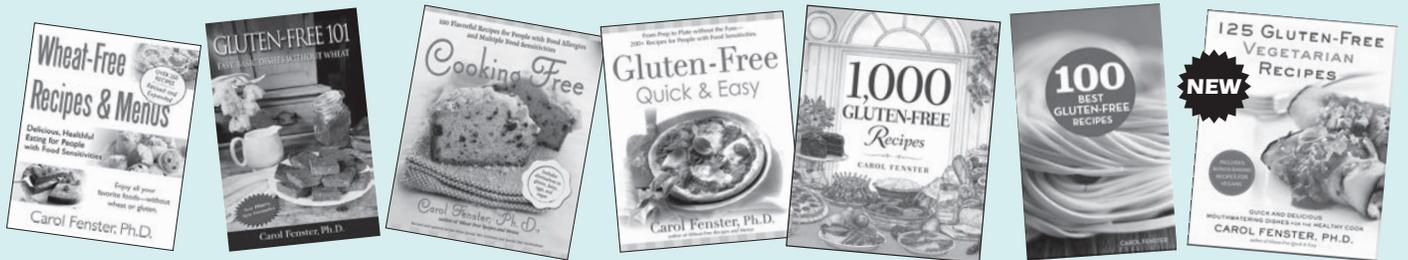
are always gluten-free, tasty, and inexpensive (at the right stores and when in season.)

2. Cook in big quantities, or even try to cook for the rest of the week.
3. Cook basic and from scratch. Buy simple ingredients and build your way up. Being affordable and easy, can also be very tasty!
4. Try to limit purchasing gluten-free substitutes. Instead of gluten-free cookies and breads, stick with naturally gluten-free grains and products to get the most value out of your food.

In the end, we came to the simple conclusion that cooking gluten-free can be both affordable and delicious, though gluten-free substitutes (such as pasta) often don't hold up as well as their 'regular' counterparts as leftovers. We kept plenty of meals under \$2 per person, including grilled tofu and veggies, quesadillas, and pasta salad. The least expensive meal we made was a delicious cabbage salad with a hummus/cucumber appetizer at \$1.26 per person.

This was a wonderful experiment and we hope that you find cooking as fun and easy as we did! View our recipes and cost-cutting tips at [youngandglutenfree.com](http://youngandglutenfree.com), the CDF Intern Tumblr.

## Books for Food Allergies, Celiac Disease, and Gluten Sensitivity



**Wheat-Free Recipes & Menus**  
By Carol Fenster, PhD

**Gluten-Free 101**  
By Carol Fenster, PhD

**Cooking Free**  
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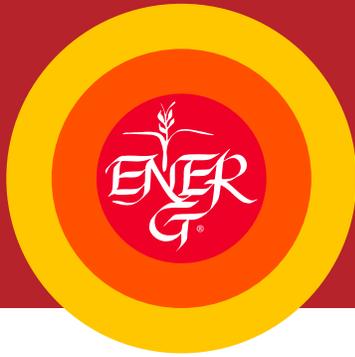
**100 Best Gluten-Free Recipes**  
By Carol Fenster, Ph.D.

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from Carol Fenster, Ph.D. at Savory Palate, Inc.  
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## The CDF First Annual Golf Outing held on August 12, 2013 at New York Country Club was a great success!

Hosted by CDF Board Treasurer Chris Holland, the day started with a beautiful continental breakfast donated by True Foods of Nyack, New York. Our golfers hit the links for the Scramble format at 9am. Byron Hunt of the 1986 New York Giants Super Bowl Champs offered great entertainment both on and off the course. He was a great auctioneer as well as good sport on the "Beat the pro" par 3 hole.

The gluten-free beers from New Planet and Bard's were a big hit... thanks also to Samuel Adams for their generous donation. Lunch sponsors Udi's and Kinnikinnick provided delicious gluten-free breads and rolls. All in high demand - the bidding got intense for the silent auction, raffle and live auction items.

We'd like to thank New York Country Club, all the sponsors, donors and golf participants for their amazing support and look forward to everyone's participation again next year.

## SAVE THE DATE



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The registration deadline for participants is October 18, 2013. Each runner must commit to raising a minimum of \$250.00 for CDF Team Gluten-Free™ which includes all race fees and a CDF Team Gluten-Free™ t-shirt – we make it fun, easy and provide lots of fundraising tips and tools.

Also needed are five (5) event weekend volunteers to help with various team activities. Individuals interested in becoming a volunteer have the opportunity to participate in up to five event weekend volunteer shifts, with each shift resulting in \$10 benefitting CDF.

For more information and to confirm your spot, please send an email to [sean.rubin@celiac.org](mailto:sean.rubin@celiac.org) or call 818-716-1513 x106.



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