

CDF Launches iCureCeliac Patient-Powered Research Network

In keeping with our mission to advance research by leveraging technology, Celiac Disease Foundation (CDF) is pleased to announce the February launch of iCureCeliac, a patient-powered research network (PPRN). At iCureCeliac, people living with celiac disease and gluten sensitivity can help facilitate new treatments and a cure by safely and securely contributing their health information online. Patients will also be able to submit ideas for research on topics important to them. Data collected through iCureCeliac will be made available to the FDA and the research community.

By aggregating data from the profiles of thousands of people with celiac disease and other gluten-related disorders, iCureCeliac will provide much-needed insight into how celiac disease and gluten sensitivity impact those affected. Patient registries for other chronic diseases have been credited with improving treatment by as much as 50% through helping researchers and clinicians discover critical patterns in treatments and outcomes.

"CDF is a strong proponent of patient-centered research," says CDF CEO, Marilyn G. Geller. "Patients are the experts on their own disease. iCureCeliac allows them to share that expertise and shape research priorities

as a shared resource for the celiac disease community."

iCureCeliac is an initiative of the Community Engaged Network for All (CENA), a Patient Centered Outcomes Research Institute (PCORI)-funded project, led by the Genetic Alliance, of which CDF is a member. iCureCeliac was developed in collaboration with the University of California, San Francisco (UCSF), the University of California, Davis (UCD), the University of California, Los Angeles (UCLA), the CDF Medical Advisory Board and scientific and medical communities, Private Access, and ten disease advocacy organizations that were selected by Genetic Alliance from more than 100 applicants.

The power to shape new treatments and a cure comes from all of us sharing our experiences. The success of iCureCeliac relies on the contributions of our entire community.

For more information, visit celiac.org/icureceliac.



into diagnosis strategies, new treatments, and a cure. We can also effect change at the FDA regarding stronger gluten-free labeling rules for all products containing gluten. We are proud to launch this valuable tool



Patient Centered Outcomes Research

CDF receives \$250,000 PCORI award for patient participation in research. The training program will be offered at CDF's National Conference.

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CDF National Conference & Gluten-Free EXPO

Join us for Celiac Disease Foundation's National Conference & Gluten-Free EXPO on April 30-May 1, 2016 in Pasadena, California.

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CDF Expands Mental Health Training

Children's National Health System holds The Resnick Celiac Disease & Gluten-Related Conditions Psychological Health Training Program.

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Marilyn's Message

Dear Friends,

There is a television campaign running for a hospital chain in suburban Washington, D.C. that uses the tagline "Join the Future of Health." In the ads, they maintain that every patient receives cutting edge, personalized medical care. They may be a little ahead of themselves, but not by much. Personalized medicine is capable of answering many questions about celiac disease and, more importantly, yielding long-overdue treatments and a cure. A core mission of CDF is ensuring that the celiac disease and gluten sensitive community is positioned to benefit from advances and investments in personalized medicine.

One of our most important initiatives is the recently launched **iCureCeliac Patient-Powered Research Network (patient registry)**. As you may know, CDF has joined with more than a dozen disease advocacy organizations to build a massive database of patients and others that can be used by researchers to dive deep into the data patterns that reveal disease origins, pathways, relationships, anomalies, and, eventually, resulting in treatments and a cure. **iCureCeliac** is extraordinary because of the steps it takes to give enrolled patients complete control over what data researchers can see and use. With your help and the help of thousands like you, **iCureCeliac** promises to be the single most powerful tool created to find a cure for celiac disease. I encourage you to learn more at celiac.org/icureceliac.

Another initiative we are launching to take advantage of the future of personalized medicine is our new **Patient Engagement Celiac Disease Network (PECDN)**. We have received a PCORI (Patient Centered Outcomes Research Institute) grant to recruit and train dozens of celiac disease patients across the country who can give voice to the great variety of needs of the celiac disease community before state and federal regulators, academic researchers, and other key decision makers. Additionally, these advocates can also share information with the celiac disease community about what is happening with research and the pursuit of treatments and a cure. The first workshop will take place at the CDF National Conference on April 30, 2016. For more information and to download the application, visit celiac.org/workshop.

Our bottom line is clear: we want to improve the quality of life for those living with celiac disease and other gluten-related disorders. We know that the push toward personalized medicine holds great promise to do just that. We must do everything we can to ensure that the celiac disease community is well-positioned to take full advantage. Please continue to support our efforts.

To Our Health,

Marilyn G. Geller
Chief Executive Officer

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CDF Receives \$250,000 PCORI Award for Patient Participation in Research

Training program for patients and caregivers will be offered at Celiac Disease Foundation's National Conference on April 30, 2016.

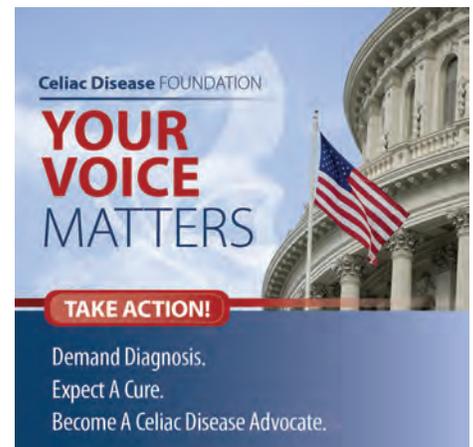
In 2016, Celiac Disease Foundation (CDF) continues to push researchers to investigate what is most important to patients when it comes to celiac disease potential treatments and cures. An award from the Patient Centered Outcomes Research Institute (PCORI) is helping this effort. The PCORI Eugene Washington Engagement Award allows CDF to train patients and caregivers to become more involved in research in ways that will impact the treatment of their disease, by creating a national network of advocates trained in patient-centered outcomes research (PCOR), known as the Patient Engagement Celiac Disease Network (PECDN).

While patients and caregivers are eager to participate in research, many feel unprepared when working with researchers. Researcher expectations and usage of medical lingo can be

intimidating. The goal of the PECDN is to break down those barriers by training patients and caregivers to feel confident, prepared, and ready to engage in PCOR. The intent of this training is to provide the knowledge and tools needed to be active partners in PCOR, not to merely fill a traditional, passive patient or study subject role.

The PECDN is part of a comprehensive effort by CDF to meet the public health challenge of increasing the diagnosis of and improving treatments for celiac disease and other gluten-related disorders, while working toward a cure. Immediate projects in which PECDN advocates may participate include serving on the steering committees for research projects at USC and UCLA Medical Centers, and the iCureCeliac Patient-Powered Research Network.

The PECDN will kick off with a pilot workshop at Celiac Disease Foundation's



National Conference on April 30, 2016 at the Pasadena Convention Center in California. PECDN participants will receive a stipend upon workshop completion. Participants will evaluate the training program and become the first cohort of PECDN advocates, so that lessons learned may inform the additional workshops planned throughout the country in 2016 and 2017.

For more information on how to apply to participate in PECDN, please visit celiac.org/workshop.

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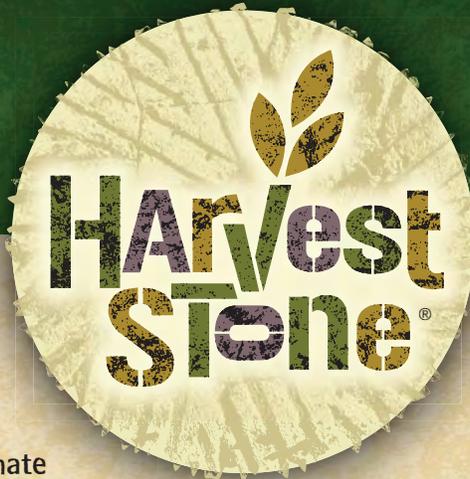
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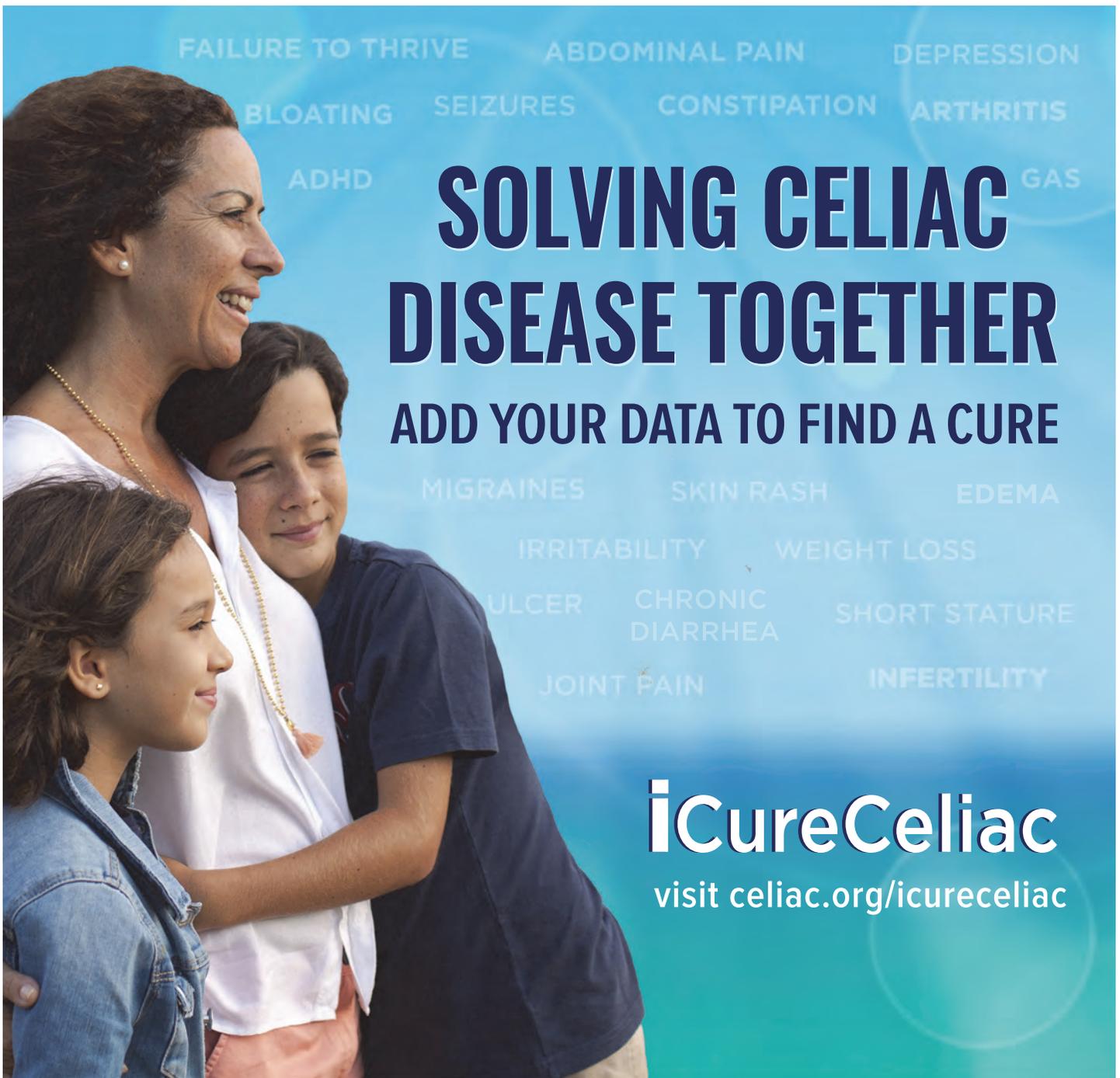


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What is iCureCeliac?

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

A PROGRAM OF



Children's National Health System Holds The Resnick Celiac Disease & Gluten-Related Conditions Psychological Health Training Program in Washington, D.C.

Living with a chronic illness that requires a lifelong commitment to a strict gluten-free diet can be difficult for anyone.

For children and teens, the emotional and psychological impact associated with celiac disease can have particular and profound challenges. We know from emerging brain research, for example, that the teenage brain is especially sensitive to peer approval as they develop the ability to see themselves as others see them. No wonder, then, that celiac disease and the need for strict adherence to a gluten-free diet can cause severe stress on families and social relationships, and can contribute to a sense of social alienation, feelings of worthlessness, low self-esteem, and depression.

In the first national effort to systematically address the emotional and psychological issues of people with celiac disease and other gluten-related disorders, Celiac Disease Foundation (CDF) and Children's National Health System (Children's National) have launched a new partnership to expand mental health education around this specific issue and to empower healthcare providers and community-based peer support facilitators to provide counseling. CDF is grateful for this partnership, funded by a generous endowment from the Resnick Family, longtime supporters of the Foundation. Resnick family members, Rhonda and Alexis Resnick, and Celiac



Children's National™

Disease Foundation CEO, Marilyn Geller, and Communications Manager, Talia Hassid, were proud to represent the Foundation at The Resnick Celiac Disease & Gluten-Related Conditions Psychological Health Training Program on February 17th, 2016 in Washington, D.C.

The Training Program was a half-day multidisciplinary seminar providing education for healthcare providers about 1) the importance of proper diagnosis and management of gluten-related conditions, 2) the unique psychosocial challenges related to celiac disease and other gluten-related conditions, and 3) how to facilitate adaptive coping with chronic health conditions, such as celiac disease and other gluten-related conditions. The Training Program offered an overview of celiac disease, practical applications to addressing psychological

needs, how to help individuals and families advocate for themselves and connect with the larger celiac disease and gluten-related conditions community, and exposure to the most recent trends in gluten-free nutrition.

There is a critical need for healthcare providers to be more aware and knowledgeable about celiac disease, including accurate diagnosis and treatment, as well as recognizing and addressing the psychological factors related to living with a chronic illness. It is important to encourage collaboration across mental and medical health providers so patients can receive comprehensive care for optimum health and disease management.

The Training Program will be offered at the CDF National Conference on April 30, 2016 at the Pasadena Convention Center. Visit celiac.org/cdfconference to register.

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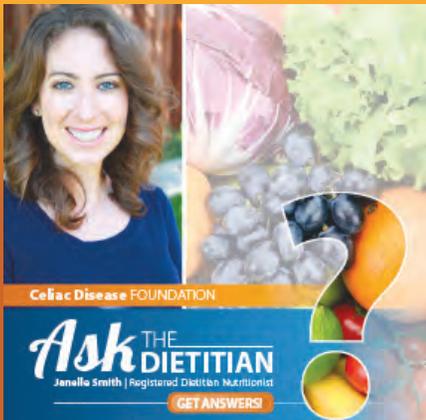
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Exploring the Low FODMAP Diet

Janelle Smith is a UCLA-educated Registered Dietitian Nutritionist. As CDF's resource to help our community live gluten-free, she is here to provide tips and tricks for simple and delicious eating throughout the year. To view Janelle's webinars online, please visit celiac.org/webinars.

Irritable Bowel Syndrome, Gluten-Related Disorders, and the Low FODMAP Diet

by Janelle Smith, RD

At least 20% of individuals with celiac disease continue to have symptoms on a gluten-free diet. Other estimates show that more than one third of celiac disease patients have altered gut motility or "IBS-like" symptoms (Sainsbury, Sanders, & Ford, 2013). Likewise, about 25% of those with non-celiac gluten sensitivity also continue to have symptoms on a gluten-free diet (Biesiekierski et al, 2014). While continued gluten ingestion is the most common cause of persistent symptoms in both populations, a dual diagnosis of irritable bowel syndrome (IBS) is also common (read more on poorly responsive celiac disease at celiac.org/poorlyresponsive).

IBS is a functional gastrointestinal disorder affecting the large intestine, where function of the large intestine is abnormal but no physical disease is present (i.e. no damage to tissue or abnormal anatomy). Approximately 10-20% of the population worldwide suffers from IBS, experiencing symptoms of constipation, diarrhea, gas, bloating, abdominal pain, fatigue, and mood alterations (IFFGD 2015).

A new dietary treatment, the low FODMAP (Fermentable Oligo-Di-Monosaccharides and Polyols) diet, has been research- and clinically-proven to reduce all of these symptoms in 75%

of those with IBS. A recent study from Monash University also found that 100% of participants with both gluten sensitivity and IBS found better symptom relief on a low FODMAP diet than on a gluten-free diet, and only 8% of participants had symptoms when gluten was added back into the diet (Biesiekierski et al, 2013). This has led many clinicians and researchers to think that a gluten-free diet may help to alleviate symptoms in those with IBS because of the reduction of carbohydrates in wheat grains that are fermented by gut bacteria (i.e. FODMAPs).

"FODMAP" is an acronym for many different short-chain carbohydrates that are poorly digested and absorbed in the small intestine, even in healthy individuals without IBS. Because FODMAPs are poorly absorbed, they make their way down to the large intestine where gut bacteria digest them for their own food. When these bacteria feast via fermentation, they release gas as a normal byproduct, which causes distention of the intestines and abdomen. The large particles of undigested food also cause the colon to draw water inside in an effort to move things along. Together, this gas and water can cause intolerable pain and bloating in those with irritable bowel syndrome, while healthy individuals may not be distressed by this normal process. Those with IBS can also

experience constipation, diarrhea, foggy-brain, fatigue, and cramping from eating high amounts of FODMAPs.

One solution that researchers have discovered is to minimize the amount of FODMAPs in the diet. FODMAPs are found in many fruits, vegetables, and grains; some examples include: honey, garlic, watermelon, cow's milk, wheat, onions, and legumes. A low FODMAP diet involves temporarily eliminating these trigger foods for a period of weeks, and then reintroducing them slowly to determine individual causes of symptoms. The low FODMAP diet should be initiated only with a specialized dietitian so that the least-restrictive diet can be found for long-term symptom relief and nutritional variety.

Non-celiac gluten sensitivity, celiac disease, and irritable bowel syndrome are all separate disorders with very similar symptoms, often requiring specialists to determine proper diagnosis and treatments. A significant portion of each of these populations will respond well to a low FODMAP diet, minimizing many symptoms that are debilitating and significantly impair quality of life. Read more on page 13 for easy low FODMAP and gluten-free recipes for those with both IBS and a gluten-related disorder.

To read more on the low FODMAP diet, visit celiac.org/poorlyresponsive.

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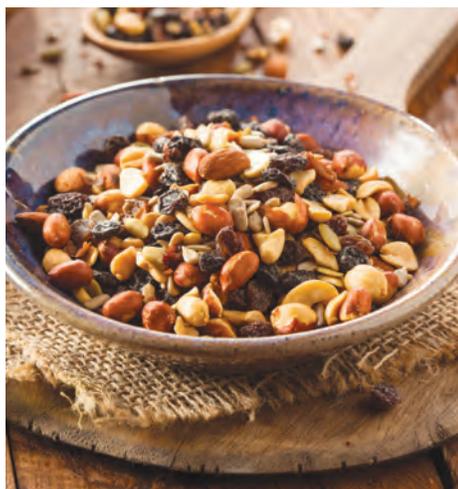
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Low FODMAP Recipes

Low FODMAP Recipes for Those with Both IBS and Gluten-Related Disorders

*Note: any precautions given are for following a low FODMAP diet, which may be helpful for those with IBS but is not necessary for those with only celiac disease or gluten sensitivity. See article on page 11 for more information.

Power Trail Mix



Ingredients

- 2 cups General Mills **Gluten-Free Corn or Rice Chex** cereal (unflavored)
- 2 cups **Gluten-Free Cheerios** (unflavored)
- 1 cup roasted almonds
- 1 cup roasted peanuts
- 1 cup toasted pumpkin seeds
- ½ cup dried cranberries (may have real sugar added; no honey, agave, or artificial sweeteners)
- ½ cup banana chips (may have real sugar added; no honey, agave, or artificial sweeteners)
- ½ cup semisweet or bittersweet chocolate chips

Directions

Mix and enjoy!

Approximate nutrition facts: Serves 10; 360 calories; 31g carbohydrate; 23g fat; 11g protein; 145g sodium; 9g sugar

Recipe courtesy of **General Mills**.

It can be challenging to navigate snacks on-the-go when following both a gluten-free and low FODMAP diet. Whip up a batch of this trail mix and portion it into individual-size bags to enjoy in between meals!

Decadent Chocolate Chip Pretzel Bars



Ingredients

- 2 cups all-purpose gluten-free baking mix (avoid any containing bean, soy, or legume flours)
- 1 tsp baking soda
- ½ tsp salt
- 1 ½ sticks unsalted butter (or non-dairy alternative), at room temperature
- 1 cup light brown sugar
- ½ cup granulated sugar
- 2 large eggs
- 2 tsp vanilla extract
- 12 oz bittersweet or semisweet chocolate chips
- 1 ½ cups **Snyder's of Hanover** Gluten-Free Pretzels coarsely chopped (may use food processor, blender, or crush in a sealed plastic bag)

Directions

Whisk together flour, baking soda, and salt. In a separate bowl, beat butter and both sugars at medium speed with a mixer until light and fluffy, about one minute. Beat in eggs and vanilla extract. On low speed, beat in dry ingredients just until incorporated. Stir in chocolate chips and pretzel pieces. Spread batter evenly in 9x13" greased pan and press down evenly with a spatula. Bake for 30 minutes at 350° F, until golden brown. Cool completely before cutting and serving.

Approximate nutrition facts: Serves 16; 320 calories; 44g carbohydrate; 15g fat; 2g protein; 150g sodium; 24g sugar

Recipe courtesy of **Snyder's of Hanover**.

Low FODMAP Recipes, continued

Low FODMAP Mix-and-Match Stir-fry



Choose two servings from each category to combine low FODMAP veggies, grains, protein, and flavor for a perfectly balanced meal that won't cause unnecessary gas or bloating. Sauté in oil of your choice (all are low FODMAP), and add the low FODMAP stir-fry sauce to taste (recipe below):

Choose Protein:

Tempeh, unflavored
Firm tofu, unflavored
Chicken breast
Beef sirloin
Pork tenderloin

Choose Veggies:

Bamboo shoots
Bok choy
Bean sprouts
Bell peppers
Carrots
Corn
Kale
Swiss chard
Water chestnuts
Zucchini

Choose Grain:

Quinoa
Brown rice
White rice
Millet

Add Flavor:

Green scallions
Fennel
Chives
Garlic-infused oil
Ginger

Low-FODMAP Stir-fry Sauce Ingredients:

| | |
|--|----------------------|
| ½ cup San-J Gluten-Free Tamari | 1 tsp sesame oil |
| ½ cup gluten-free chicken or vegetable broth | 1 tbsp sugar |
| 1 tbsp corn starch | 1 tsp rice vinegar |
| 1 tsp garlic-infused oil | 1 tbsp ground ginger |

Directions

Whisk all ingredients together. Cook for three minutes after adding to stir-fry to allow sauce to thicken.

Nutrition facts vary between ingredient choices.

Recipe courtesy of **San-J**.

Limoncello Martini



Ingredients

3 oz **Pangea** 49th Parallel Vodka
1 oz **Pangea** Dolce Cilento Limoncello Liqueur
1 tbsp fresh lemon juice
White sugar and lemon wheel for garnish

Vodka, gin, wine, and gluten-free beer are mostly all low FODMAP, but we recommend limiting to one serving of alcohol in a sitting to avoid GI upset for those with sensitive stomachs.

Directions

Combine vodka, limoncello, and lemon juice in a cocktail shaker with ice, and briskly shake to chill. Strain into glass prepared with sugar rim and lemon wheel (slide the lemon along half of the glass then dip into sugar for it to stick).

Approximate nutrition facts: 120 calories; 0g carbohydrate; 0g fat; 0g protein; 0g sodium; 12g sugar

Recipe courtesy of **Pangea**.

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

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Thank You for Making a Difference

by Marc Riches, Board Chair

Dear Friends,

One of the best parts of my job as the Celiac Disease Foundation Board Chair is calling and writing donors to thank them for their generous contributions to support CDF's work. Over the last several weeks, we have received an incredible response to our year-end Gift of Hope Challenge, and I have had the opportunity to reach out to dozens of good people. Among the many things that amaze me about these calls is the variety of reasons folks like you give to CDF. Some, like me, have the disease, went years without a diagnosis, and give because they appreciate CDF's tireless efforts to educate both the public and healthcare community about the disease, and to urge testing for celiac disease. Others give because they support CDF's mission to spur research for treatments and a cure. I am heartened because our donors are committed to doing what they can to improve the lives of those living with celiac disease and other gluten-related disorders. They understand that the work that we do at CDF is only possible because of their generosity. That is the real power of giving – making a positive difference through philanthropy. I thank each and every one of you.



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- No Lactose
- No Sugars
- No Trans Fats

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Gluten-Free snack bars
in 6 flavors. Learn more at
PamelasProducts.com





Team Gluten-Free Goes Off-Road at Renegade XTERRA Events as the Official Charity Partner!

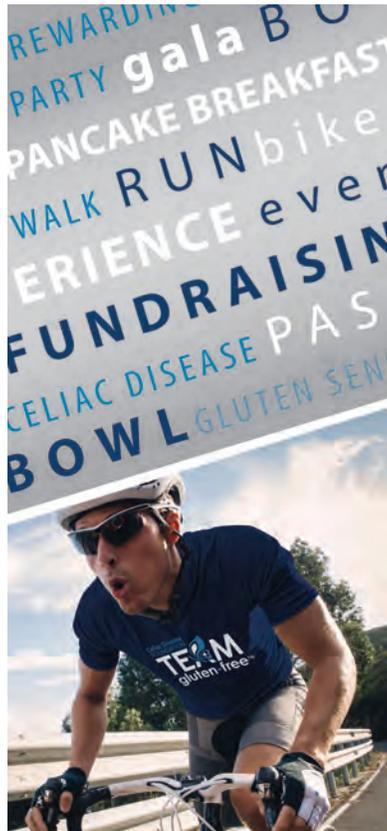
Celiac Disease Foundation Team Gluten-Free is excited to partner with Renegade Racing, a premier running, triathlon & adventure sports production company as the Official Charity Partner of the Off-Road Renegade XTERRA Events for the second year in a row.

A calm lake and abundant trails make Bonelli Park the perfect setting for the XTERRA Renegade Off Road events. There is a recreational triathlon as well as a duathlon, which travels on the same course and is a 3.0 mile run, 15.0 mile (2-loop) bike, and finishes with another 3.0 mile run. Trail runners love the 3-Mile Trail Run Challenge along the scenic lake with beautiful forest views.

Want a chance to run with the CDF National Office Staff while fundraising for Team Gluten-Free? Join our Team! When you register, you may join Team Gluten-Free, or you can create your own team. If you create your own team, please remember to select that your team will be fundraising for "Celiac Disease Foundation." **Use code TEAMCDF for 10% off your race registration.**

For more information or to register, visit celiac.org/tgf/event/renegade, or email gillian.entin@celiac.org

Don't forget to stop by the TGF booth at the CDF National Conference & Gluten-Free EXPO on April 30-May 1, 2016 to meet other Team Gluten-Free members, learn about other upcoming events, and pick up some TGF swag!



Ready To Do Something Extraordinary?

JOIN THE TEAM

Celiac.org/TGF

GETT'N DIRTY
MAY 14, 2016
 BONELLI PARK | SAN DIMAS

XTERRA
RENEGADE

OFF ROAD TRIATHLON
 1/2 MILE SWIM | 15 MILE BIKE | 3 MILE RUN

RENEGADE 3 MI TRAIL RUN CHALLENGE
3 mile trail run

OFF ROAD DUATHLON
3 MI RUN | 15 MI BIKE | 3 MI RUN

JOIN "TEAM GLUTEN-FREE" ON THE REGISTRATION PAGE TO RUN WITH THE CDF NATIONAL OFFICE STAFF AND FUNDRAISE FOR TGF!

RENEGADE RACE SERIES FOR REGISTRATION AND MORE INFO GO TO: WWW.RENEGADERACESERIES.COM

Agency for Healthcare Research and Quality (AHRQ) Releases Final Evidence Review on Diagnosis of Celiac Disease

On February 1, 2016, the Effective Health Care (EHC) Program at the Agency for Healthcare Research and Quality (AHRQ) released its first-ever evidence review on *Diagnosis of Celiac Disease*. AHRQ is a government agency tasked with producing evidence to improve the quality of healthcare while working with partners to ensure that the evidence is understood and used. Celiac Disease Foundation is proud to have provided input for this much-needed and critical study.

There are many reasons why the release of this long-awaited review is important. The diagnosis rate for celiac disease is estimated to be as low as one in six. This is an ongoing tragedy. Now, for the first time, the U.S. government has decided that celiac disease is worthy of a comprehensive evidence review. We can only conclude that they are beginning to take celiac disease more seriously. Second, the evidence report represents recognition by the Federal Government that the abysmal diagnosis rate for celiac disease is adversely impacting public health, and that they should be doing something, however incremental, to address the problem. Third, when the *Clinician Summary* of the report is released by AHRQ this spring, doctors will have a federally sanctioned working document that explains celiac disease, presenting symptoms, and suggested tests to confirm the presence of the disease. We will be doing everything we can to make sure that the document



“Now, for the first time, the U.S. government has decided that celiac disease is worthy of a comprehensive evidence review.”

is distributed and employed by clinicians. Below is an excerpt from the document. You can view the full report at celiac.org/AHRQ.

“New evidence on accuracy of tests used to diagnose CD supports the excellent sensitivity of IgA tTG tests and excellent specificity of both IgA tTG and IgA EmA tests reported in prior SRs. High strength of evidence of accuracy, particularly in children, was found for DGP tests in recent SRs. Regarding comparative accuracy, IgA EmA tests have lower sensitivity but similar specificity to IgA tTG tests. IgA DGP and IgG DGP tests are not as sensitive as IgA tTG tests in non-IgA-deficient adults. These conclusions are based primarily on indirect evidence—i.e., pooled results on accuracy of individual tests rather than head-to-head studies comparing accuracy of different tests in the same samples. However, strength of evidence is high given the large numbers of studies, the consistency of results, and the precision of the confidence intervals.

Notably, current ESPGHAN guidelines state that a patient with a tTG result greater than 10 times the normal limit should

undergo an EmA test and HLA typing. If the patient tests positive and then responds to a gluten-exclusion diet, a diagnosis of CD can be made without use of biopsy. These guidelines have not been adopted by societies in the United States. Evidence seems to support the accuracy of a multiple-testing strategy without biopsy; however, additional studies are needed to confirm the threshold levels that provide the highest accuracy and population differences, if any.

VCE is a safe and fairly accurate means of diagnosing CD in adults who wish to avoid biopsy; risk of retaining the capsule is approximately 4.6 percent. However, our pooled results reveal that some serological tests have higher sensitivity and specificity. No data are available on how VCE accuracy varies by population characteristics or setting. Endoscopy with biopsy has a very low risk of adverse events; accuracy appears to be greater in academic than community settings.

Importantly, few applicable studies on the sequelae of false positive or false negative diagnoses were identified. Long-term followup of patients, regardless of diagnosis results, should be encouraged.”





ALEX C. SAYS,

“awesome”



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#foodallergies

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gluten, wheat, dairy, peanuts, tree nuts, egg, soy, fish & shellfish



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enjoylifefoods.com #eatfreely



Frozen to Fabulous...

Sweet!



*Recipe-ready goodness right from the freezer!
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