



A piece of cake
Gluten-free activists apply pressure for FDA standards



Safe travels
Gluten-free on-the-go

**MEDIA
PLANET**

December 2011

CELIAC AWARENESS

3
TIPS

SWEET SUCCESS

Actress Jennifer Esposito
dishes about how she has fully
embraced a gluten-free diet

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CHALLENGES

Mostly undiagnosed, **celiac disease**, affects more Americans than Type 1 diabetes, Crohn's disease and cystic fibrosis combined.



Going against the grain

When you think of the holidays, you often think of food. Not just any food, but the mouthwatering kind that is filled with gluten like turkey and cornbread stuffing, dinner rolls and delicious breads, pumpkin pie, chocolate cake and lemon tarts. Every family has their favorite "gluten-filled" holiday treat. In 2003, we opened a "Pandora's Box" of disorders related to gluten, a toxic protein found in wheat. That year the University of Maryland Center for Celiac Research released revolutionary research now known as the "prevalence study" showing that one in 133 Americans has celiac disease, a widely recognized autoimmune disorder that damages your intestine and can also wreak havoc on your metabolism, neurological, musculo-skeletal and even cardiovascular system.

A rising concern

Formerly thought of as a rare childhood illness, the rate of celiac disease is rising among all age groups,

particularly among the elderly. Causing damage to the small intestine that leads to nutritional deficiencies, this autoimmune disorder spares no age, race, or gender.

Now, close on the heels of the growing diagnosis and awareness of celiac disease comes another condition related to the consumption of wheat, barley and rye: gluten sensitivity. The numbers are tricky, but we estimate that approximately 15 million Americans suffer from some form of gluten sensitivity. Our recent research shows that although the condition mimics the clinical symptoms of celiac disease, it doesn't cause the same intestinal damage.

If you suspect that you are suffering from symptoms that might be related to gluten consumption, don't diagnose yourself. Visit your physician to rule out celiac disease before giving up gluten to see if your symptoms resolve.

Healthy holiday fare

If you have celiac disease or suffer from gluten sensitivity, don't despair as you think about those holiday goodies. Not only are there

"If you have celiac disease or suffer from gluten sensitivity, don't despair as you think about those holiday goodies."

Alessio Fasano, M.D.
Professor of Pediatrics, Medicine, and Physiology Director, Center for Celiac Research University of Maryland School of Medicine



many good gluten-free alternatives for dessert and breadstuffs, there are many "naturally" gluten-free foods to enjoy.

As for the Fasano family, we'll be dining on our favorite fish and seafood recipes, accompanied by fresh salads and lightly cooked vegetables—a tradition true to my southern Italian heritage. Happy gluten-free holiday eating!

Alessio Fasano, M.D., is director of the University of Maryland Center for Celiac Research and professor of pediatrics, medicine and physiology at the University of Maryland School of Medicine. Founded in 1995, the Center

for Celiac Research is an international leader in promoting the awareness of celiac disease to provide better care, improved quality of life, and more adequate support for the celiac disease community worldwide through excellence in research, clinical care and education. www.celiaccenter.org.

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WE RECOMMEND



A gluten-free lunch box
Tips for parents on keeping food fun and interesting

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and a Gluten Free New Year



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INSIGHT



BEST TIPS

Your gluten-free lunchbox

Packing a nutritious school lunch for children can be a challenge for any parent, but for those with children who are gluten-intolerant, it can be especially difficult to make sure they're getting the nutrients they need each and every day. Because children following gluten-free diets may not get enough fiber or critical nutrients like calcium and iron, parents should strive to choose foods that are good sources of these nutrients.

With a little research and support, parents can find the balance between a nutritious, gluten-free diet and ensure that their children will grow and thrive.

■ Include foods that are high in protein like eggs and nuts to pro-



Rallie McAllister, M.D., MPH
Family physician and coauthor of *The Mommy MD Guide to Your Baby's First Year*

vide energy throughout the day.

■ Dairy products, like milk and cheese, are good sources of calcium. Calcium-fortified orange juice and broccoli are additional sources of this important mineral.

■ While food is always the gold standard for providing complete, balanced nutrition, I recommend incorporating nutritional shakes to supplement a healthy diet, as long as they are gluten-free. These beverages are portable, nutritious, and easy for parents to pack in a lunchbox.



Raising happy, gluten-free kids

Parents: Implementing a gluten-free diet is no walk in the park

A diagnosis of celiac disease or gluten sensitivity significantly impacts children and families, and there are challenges when raising a child with special dietary needs. With the right information, a few helpful hints and a good attitude, parents and kids can live, learn and thrive on a gluten-free diet.

■ **Early education and empowerment are essential.** Children

with celiac must learn how to advocate for their health. This means more than knowing the basics of a

gluten-free diet; they also need the social skills and confidence to stay safe wherever they go. Plan meals together and use role play to teach your child how to communicate his or her needs.

■ **Look at it as a bonding experience.** A gluten-free diet can be a major adjustment, but it also provides opportunities for families to bond through learning. Activities like reading labels, cooking, or ordering in a restaurant can be a chance to make lasting memories together.

■ **The art of substitution.** Staying focused on healthy gluten-free foods is important, but sometimes children with celiac just want to fit in with all the other kids. Feelings of deprivation and isolation can

impact gluten-free diet compliance and overall emotional health. With a little research, you can easily find kid-friendly gluten-free foods like pizza and cupcakes at grocery stores in your area.

■ **It's not always about the food.** The holiday season is a wonderful time to teach your child the value of volunteerism. NFCA's Awareness All-Stars Fundraiser is a wonderful way for kids across the country to unite and raise money for celiac disease! Whatever the project, encouraging your child to support a cause they feel passionate about can help them find happiness and build character.

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NEWS



A TOWER OF HOPE. A 12-foot gluten-free cake brings attention to the need for FDA standards.
PHOTO: CHARLES VOTAW

3 TIPS

'Tis the Season to be gluten-free

If you happen to be hosting a gluten-free guest, you can still prepare a flavorful feast that includes all of the trimmings without the gluten.

1) New traditions. Making minor adjustments to traditional family recipes is easy and you don't have to look beyond the aisles of your local grocery store to find celiac-friendly alternatives to gluten-laden ingredients. Use gluten-free bread to create a tasty stuffing or cornstarch to thicken gravy.

2) Clean cooking. Ensure all cooking surfaces and utensils are carefully cleaned to avoid cross-contamination.

3) Label literacy. Many prepared condiments and sauces contain hidden sources of gluten. If in doubt, leave it out! Remember, gluten-free doesn't mean it can't be gourmet. When the family gathers around the table, you can provide an array of food to please every palate while ensuring a healthy, happy holiday for all!

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The icing on the gluten-free cake

Grassroots movement spurs gluten-free labeling process

This May, when nearly 12 feet of gluten-free goodness towered above a crowd that included Food and Drug Administration Deputy Commissioner for Food, Michael Taylor, activists knew little of the progress that would be left in the cake's shadow. Gluten-free cooking expert and author **Jules Shepard**, and gluten-free activist and athlete **John**

Forberger began the experiment to bring attention to labeling needs of gluten-free products. With the help of many activists and Whole Food Market's baker Lee Tobin, that cake's soaring legacy now holds the promise of change.

"It's one thing to have a community back something at an event and then it falls off the radar and you didn't get a hold on people who actually make a change," Forberger said. "For them (FDA officials) to show up and not just listen to us on the social

stage, or newspapers or blogs, but actually spend their time to come over and listen to us ... I think it says a lot."

Gluten-free is currently the fastest growing grocery sector, and labeling regulations will bring consistency to the market. Taylor took ownership of the issue following the recent event, and the FDA reopened the issue at a pace that even shocked issue champions. A comment period recently closed and the agency expects final regulations during 2012.

"With this new regulation in place standardizing what gluten-free means, everyone has to play by the same rules as far as testing and set some sort of equilibrium," Shepard said. "When they go into effect, it will make label-reading easier for families and take a little of the stress out of shopping when you do have gluten restrictions."

These activists can now have their cake and eat it too!

WENDY TAYLOR

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INSPIRATION



DON'T MISS!

From care to cure

When the term “celiac disease” comes up, everyone’s first thought is “gluten-free diet.” This association is so common that the gluten-free diet is considered to be the cure; however, this is a major misconception. While the gluten-free diet is the only current treatment for celiac disease, it is not and never will be a cure.

Celiac disease is an autoimmune disorder. Since its triggering agent (gluten) is known and the targeted tissue is accessible, researchers have an opportunity to uncover disease mechanisms and establish new avenues for prevention and treatment.

The University of Chicago Celiac Disease Center has identified several goals in its research: developing a cure, preventing devel-

opment in high-risk children, identifying better treatments and identifying diagnostic markers and treatments for gluten sensitivity.

First, a mouse model with celiac disease was developed to help demonstrate that upregulation of the inflammatory factor IL-15 (found in active celiac patients) induces loss of oral tolerance to gluten and reproduces the early stages of celiac disease.

The next generation model will likely allow researchers to test treatments to cure active celiac, and to understand the link between celiac disease and autoimmunity.

Stefano Guandalini, MD, Founder and Medical Director and Bana Jabri, MD, PhD, Director of Research at The University of Chicago Celiac Disease Center.

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TIP

3

GET CREATIVE
IN THE KITCHEN

DELECTABLE DELIGHTS.
Jennifer Esposito makes
gluten-free baked goods.
PHOTO: JENNIFER ESPOSITO

Jennifer Esposito finds a new life overcoming celiac disease.

Cooking to cope

Everyone’s heard the clichéd demanding actress stories. When award-winning actress **Jennifer Esposito** arrives on set, it’s usually others making demands—for her homemade baked goods.

Diagnosed with celiac disease in 2009, Esposito learned the art of gluten-free baking through necessity and began bringing her own cooking to cope with her illness. Now, with her own website and in the process of opening a gluten-free bakery, she’s constantly hassled by the cast and crew of her TV series *Blue Bloods*.

“These are guys who are used to having coffee and cigarettes for breakfast,” Esposito laughs. “They ask me once a week if I don’t bring something in, ‘Jennifer, where’s your stuff? Bring in the cookies!’

No, bring in the bagels!’ It’s insane. These are guys who could care less—gluten-free, not gluten-free.”

Taking it to the kitchen

Esposito happily shares the flavors and health benefits of her gluten-free food. After years of misdiagnosis, painful symptoms, fatigue and hair loss so extreme it forced her to wear a wig when filming the series *Samantha Who?*, she was thrilled food choices could return her health.

Following months of online searches and physical gluten-withdrawals, she experimented and recreated her aunt’s carrot cake during a strong craving. She not only came out with a great cake, but a passion for recreating food—something she now does for others on her website jennifersway.org. Readers leave a wish list of missed foods, and Esposito takes to her kitchen, creat-

ing gluten-free alternatives.

“I realized so much of my life has been wonderful memories of food,” she said. “What Do You Miss is something I feel like I have to do for people. I understand watching someone eat your favorite food, and you can’t have it.”

She wants the website and bakery to give back a bit of hope to those who find themselves learning to live without gluten.

“Life is not over, it is changing,” Esposito offered. “Your self that you knew is not that way anymore. You were probably not well and doing a lot of adjusting to figure out how to live that way. Well, let that go, because now it’s a completely new journey.”

And, it’s a journey Esposito is determined to make satisfying.

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Gluten-free itinerary

While holiday travel doesn't rank high on any wish list, traveling with gluten-intolerance increases stress at every unknown rest stop and food court.

"I used to pride myself on not carrying any snacks," said **Cynthia Kupper, RD, CD**, the executive director of the Gluten Intolerance Group. "More and more, I've started carrying granola or trail mix. I think it's important to be prepared."

While those emergency supplies are key, experts also agree knowing the right questions to ask is crucial. **Kim Koeller**, president of GlutenFree Passport, notes that wait staff can answer questions about ingredients or dedicated fryers easier than determining if an item is gluten-free.

High-tech help

Kupper points to the number of standardized preparation practices among chain restaurants as security for those weighing options. Those who are gluten intolerant also benefit from websites, including Koeller's Gluten-Free Passport, that offer mobile apps identifying safe dining options. These lists keep options handy when on the road.

Tis' the season

Special conditions arise during the holidays with hotel buffets and fixed menus. In order to avoid sickness following that Christmas brunch or New Year's Eve dinner, experts recommend calling ahead to see if an off-menu meal can be arranged.

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