## No.2/May 2010 <br> MEANA

## CELAC DISEASE



Home Cooking Stocking up the gluten-free kitchen


Carefree Kids Healthy eating and a safer playtime


Summer Plans Gluten-free hot spots and getaways


> If asked, few could name the number one genetic condition in the United States. Most are surprised to learn this distinction. More unexpected is the fact that this disease affects one percent of the world's population, making it the most common genetic disorder of humankind.
What is celiac disease?

In the United States, one in 133 or roughly three milIion Americans are believed to have the disease. Of this number, a startling 95 percent have yet to be diagnosed. Although celiac disease is not well known, conditions associated with it are very familiar. Individuals with type 1 diabetes, Down syndrome, Fibromyalgia, Sjogren's syndrome, and rheumatoid arthritis have a higher risk of developing celiac disease.

## Common Misconceptions

1Many health professionals think of celiac disease as a pediatric condition yet it can present at any time after gluten is introduced into the diet. Patients have been diagnosed as young as 15 months up to 92 years of age. Gastrointestinal symptoms such
as stomach pain, bloating, diarrhea, and constipation, are thought to be most common. However, it is just as likely that an individual will have non-intestinal symptoms such as: anemia, migraines, short stature, joint pain,seizures, and muscle cramps.

## The Challenges

Following a strict glutenfree diet, a celiac patient's symptoms will subside and damage to the small intestine will be reversed. Learning the diet can be difficult. Engaging the services of a registered dietitian helps ease the transition to the gluten-free lifestyle. A particular challenge and point of frustration for celiac patients is the lack of labeling for gluten-free foods.
Students with celiac disease experience another challenge. Schools are required to accommodate medically prescribed diets


Andrea Levario American Celiac Disease Alliance American Celiac Disea
Photo: Robert Serveri
in order to make it easier for celiac students to have meals with their classmates. Unfortunately, schools don't receive funding for gluten-free or other medical diets. The additional cost, and lack of trained dietitians to assist in modifying meals, deters schools across the country from meeting the needs of their celiac students.

## Embrace The Lifestyle

Attitude is everything, particularly with celiac disease Those who embrace the glutenfree lifestyle will find endless opportunities to try new restaurants, attend baseball games or travel. Simply put, there is no reason for celiac disease to stand in the way of enjoying life.

ANDREA LEVARIO
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In The Kitchen p. 10 Stocking up is key in the gluten-free Sitchen

Celiac Research p. 15
Dr. Alessio gives hope for medical advancements

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We make our readers succeed!
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This birthday you can finally stop wishing for the same thing.


Question: Can athletes with celiac disease keep up grueling schedules and stay true to their diets?
Answer: With a little ingenuity, these two successful athletes have all the right moves.


# Growing up with celiac disease 

## HOW WE MADE IT

Growing up following a gluten-free diet need not be difficult-even for on-the-go teens and young adults. Even young athletes can maintain their diets despite grueling practice and competition schedules.

Celiac disease doesn't stop 18 -yearold skiing sensation A.J.Clemens from eating at McDonald's with his friends. He just orders his hamburger without the bun, and makes sure the fries are
cooked in separate oil from the Chicken McNuggets.
With his eyes on the Olympics, Clemens, who has been gluten-free since he was six, spends part of the school year at Waterville Valley Academy in New Hampshire, where he combines ski instruction and tutored lessons from home.The cafeteria chefs happily dabble in recipes for him. "One came up with making breaded chicken using crushed non-gluten pretzels," said the busy teenager, who competes in

"I love the celiac diet."
A.J. Clemens Junior Olympian Athlete
dozens of ski events a year and also plays high school football and runs track. His family now makes the meal for him at home.
LPGA golfer Sarah-Jane Smith, 25, has tricks for eating on the road too."It is pretty simple to do once you know what to avoid," said Smith, who developed the disease only two years ago. "The golf courses put in beautiful meals for us, but they don't always cater to celiac, so I always pack food -gluten-free bars, lots of fruits and
snacks like rice crackers, which I can make sandwiches with.I bring glutenfree cereals with me, too," said Smith. "If a hotel room doesn't have a refrigerator, I will store foods in a bag of ice in the sink or bathtub."

Both athletes say their diet is a healthier way to live. Smith says she has, "tons more energy."

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editoria@mediaplanet.com

## (Cunahmastero (a) <br> Great Taste. Zero Gluten.




## PROFILE

A.J. Clemens, Jr.

## - Age: 18

- Position: Competitive Skier

NFCA Athlete for Awareness - Other: A Junior at Radnor High School in Radnor, Pennsylvania. Also a member of the New Hampshire Alpine Racing Association and United States Ski and Snowboard Association.

## PROFILE

Sarah-Jane Smith

## - Age: 25

$\square$ Position: Professional Golfer NFCA Athlete for Awareness - Other: A native of Australia. A member of the LPGA tour, who turned pro in 2005.
"I never felt 100 percent before. Now I have tons more energy and my golf improved pretty much instantly!"

## - Sarah-Jane Smith



# What it really means to live gluten-free 

## - Question:

How can a celiac diet be both tasty and healthy?

## - Answer:

Balance gluten-free treats with fruits, vegetables, and vitamins.

A diagnosis of celiac disease is serious because it means you must alter your diet to avoid glutens. Even a tiny morsel of gluten can have serious side effects."The first thing I tell people is to relax and don't think of what you can't have; but rather what you can," said Bob Levy, the founder of Bob \& Ruth Gluten-Free Dining and Travel Club.

## Choices Are Abundant

Today, the more than two million celiacs in the United States can have more foods than ever. Greater knowledge and understanding of celiac disease has unleashed products from pizzas to cookies that are safe for glutenfree diets. Restaurants are adding gluten-free items to their menus. There's even gluten-free beer!

## Gluten-Free Is Not

## Dangerous To Your Health

"A gluten-free diet is not void of nutrients if patients eat a well-balanced diet covering dairy, lean proteins,greens, low fat dairy
and fruits," advised Emma Fogt R.D. and consultant to Dietz \& Watson.For those who may struggle to eat properly, there are glu-ten-free vitamins.

## A Bright Future

Hope is on the way for easier ways to manage celiac disease, perhaps in the form of injections and pills. Research brings promising news of answers to a myriad of autoimmune diseases such as type 1 diabetes and rheumatoid arthritis.

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## Bon Appétit!

Grabbing a bite to eat takes on new meaning if you are a celiac who must avoid all forms of wheat, rye and barley in order to maintain your health.
"To eat or not to eat?" is the question every person with celiac disease must answer every time we eat anything or have to take a pill.

Currently no medication exists. The treatment for celiac disease is a major lifestyle adjustment requiring strict avoidance of any andallglutenfromthetoxicgrains. Avoiding all gluten is a major lifestyle change. It is not a fad diet, we have no option-gluten-free foods are our "drug of choice." We do not take eating gluten-free for granted; it is how each one of us controls our condition. We are
grateful for the bounty of choices we have that keep us healthy.
Currently the Food \& Drug Administration (FDA) is working on establishing a standard for glu-ten-free. This will enable food manufacturers to effectively test their products to label them glu-ten-free and will give assurance to the quality and safety of our foods. Bon Appétit!
May is Celiac Disease Awareness Month internationally and CDF is celebrating its 20th anniversary of advocating for and raising awareness of celiac disease in the United States.

ELAINE MONARCH
Founder/Executive Director Celiac Disease Foundation editorial@mediaplanet.com


## BEST TIPS

Mediterranean and Asian diets that can turbo charge your gluten-free diet:
$\square$ Carbohydrates form the base of these diets, so choose mainly whole gluten-free grains like brown rice or quinoa instead of cous cous(unless it's gluten-free) Eat lots of vegetables, fruit, beans and nuts daily
Focus on plant based fats like olive oil
$\square$ Rotate dairy, fish, eggs and poultry weekly as your sources of protein, and minimize red meat

Courtesy of Christine Doherty, N.D www.glutenfreevitamins.com
$\square$


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## Whether it is school time or summer recess, kids shouldn't have to fret about sticking with their gluten-free regimen.



ublic schools must make reasonable accommodations for children on glu-ten-free diets under the Americans with Disabilities Act, however, the quality of those lunches does vary.
"There are school lunches that mimic the mainstream meal. If it is a corn dog on the menu, there is a gluten-free option," said Pam Cureton, RD, at the University of Maryland Center for Celiac Research.

Other schools, unfortunately only serve up minimal options.
In the meantime, lunches don't have to be an uphill battle, according to Emma Fogt, RD a nutritionist, dietician and consultant for Dietz \& Watson. There are deli meats that are clearly gluten-free for sandwiches on wraps or glu-ten-free bread. With celiac disease becoming more recognized, there are myriad foods including glu-ten-free cookies, crackers,candies, soups, pizzas and pastas.
Cynthia Kupper, CRD, executive director of the Gluten Intolerance

Group of America suggested children need to know how to explain their diet to friends and to adults. "Kids also should be proactive and learn at a very young age to read labels," she said. GIG has a teen support group (TAGS) for kids to help other kids. "Every time a teen tells me how nice it is not to feel alone and know they have some one that understands what they're going through, I know I have a purpose. My celiac is a strength, and I wear it proudly," said Mari Cleven, the 16 -year-old president of TAGS. Camp is also accessible thanks
to GIG which sponsors two glutenfree summer camps. "Even a tiny crumb can make me sick," said Kelsey LeBard, a Seattle teen who has camped since she was eight at both the Seattle and the North Carolina locations. "At camp, I don't have to worry.There's even glutenfree s'mores for campfires."
"Kids also should be proactive and learn at a very young age to read labels" -Cynthia Kupper GIG

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## GLUTEN-FREE SPOTS

## Restaurants!

$\square$ There's no need to pass up a chance to eat out! These restaurants serve up gluten-free options. Note: It often helps to check ahead with the manager or chef to ensure meals are prepared without cross contamination.
P.F.Chang's China Bistro

Legal Sea Foods
Maggiano's Little Italy
Uno's Chicago Grill
Outback Steakhouse
Carrabba's
Smokey Bones
Capital Grill
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# MOMMA DIETZ SAYS: <br> "TO MAKE MY MEATS GLUIEN-FREEIDID SOMEHHNG RAPEEYDO: NOTHING: 



# THE KEY TO CREATING A GLUTEN-FREE KITCHEN 

The availability of more glu-ten-free products is making it easier than ever to stock a pantry for those with celiac disease. A quick trip to the grocery store or a few clicks online yield everything from gluten-free brownie mixes to pizzas safe for celiacs.Improved labeling makes sure the products are right for a gluten-free diet.

Consumer product goods companies have websites to help consumers find local resources for gluten-free products, as well as numerous recipes. Liveglutenfreely.com offers a product box to help those get started on the diet,
and gfreecuisine.com offers an automatic grocery list creator.
Beth Hillson, a celiac, founded The Gluten-Free Pantry in 1993 (she sold the business but remains a consultant to the new owners).

## Stocking Up

The pantry should never be empty so a hungry celiac isn't tempted to grab the first thing he or she sees. Must haves include cookie mixes, gluten-free snack bars, special snack mixes, glutenfree pizzas, corn tortillas for wraps, potatoes, peanuts,fruit and yogurt. Most recipes can be easily con-
verted using cornflower or ricea few ingredients gluten-free followers should always have on hand.Another trick of the trade is xanthan, a gum which can be used in baking and other recipes. Plastic wrap can be used to offset the tacky texture the gum creates.

## Keep 'Em Separated

Contamination is a concern in households where some members need to eat a gluten-free diet and others don't. While it is crucial to keep foods separated, it need not be an ordeal. "One good idea is a separate cupboard and bright,
clearly-marked labels so that kids especially know what foods they can eat," explained Hillson whose son was diagnosed with celiac disease six months after she started her business.
There's no need for separate pots, pans and serving tools, as long as everything is washed thoroughly. However, if using wood cutting boards, a separate one for gluten-free is advised. Since bread can stick in the toasters, a good idea is to have two toasters.

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NEWS IN BRIEF

## cosmetcs

## Kiss and Tell

Can lipstick be dangerous？ Ann Whelan，editor and pub－ lisher of Gluten－Free Living and a celiac，believes that＇s a personal choice．There are arguments for both sides．Her opinion is that lipstick is not typically ingest－ ed and should be safe．Howev－ er，her magazine recently listed some lipsticks that are totally gluten－free such as Afterglow and Lancome．The magazine concludes that 86 percent of all lipstick product is made from gluten safe ingredients．

## FOOD ALLERGIES <br> Confusion Swirls Around Gluten

A new nationwide survey re－ veals that much of America has some knowledge of food aller－ gies，but are confused between food allergies and celiac disease． A Harris Interactive Poll spon－ sored by HomeFree found that three out of four Americans can correctly identify at least one food allergen from a list in－ cluding cinnamon，dairy，gluten， bananas，nuts，wheat and eggs． Forty three percent incorrectly identify gluten as an allergen．

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"There's nothing more rewarding than seeing kids eat things like cookies, pizza and pasta they've never tasted before."

## Safe haven for travelers

Bob Levy was relaxing on a beach when an idea hit him like a bolt of lightning. A celiac, he loved to travel but often worried about staying true to his gluten-free diet. Why not, he reasoned, create a travel group where he could guarantee all gluten-free meals in enticing locales. "Then a spouse or travel companion wouldn't have to worry while on vacation or give up something they wanted," he explained.

In 1998, he and his wife founded Bob \& Ruth's Dining \& Travel Club. What started as informal dinners in Baltimore restaurants evolved into trips of both large and small groups to venues ranging from Alaska to Africa and Club Meds to cruises. Especially popular now is a Romantic Rhine River Boat Cruise, said Levy, although many of the journeys allow children so families can vacation together. "There's nothing more rewarding than seeing kids eat things like cookies, pizza and pasta
they've never tasted before," Levy explained. Many travelers are so happy they return for more sojourns.
A self-proclaimed picky celiac, Levy personally inspects the facilities and meets with chefs to ensure meals fit his requirements. "We check everything to make sure it meets our needs, even issues like making sure spoons on buffets don't go from one food to another or to confirm there are new or clean toasters to avoid contamination." Those who have traveled joke they can't eat until Levy okays the food.
Levy, who was diagnosed in 1995, advises those new to glutenfree diets to relax. "Life goes on and you can do just about everything you did before, just glutenfree," he added. And with Levy on their side, celiacs can now have worry-free vacations.

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Despite being only 17,California resident Haley Anne Nelson had traveled to six continents. Diagnosed at age 12 with celiac disease, she was faced with sticking to a gluten-free diet in a world with tempting foods-especially in her travels.
An accomplished member of a ski team and a 4.5 GPA student, she had "intellectual brilliance, but exuded beauty from inside out," explained Yvonne Williams, president of StoreHouse Foods who could relate to Nelson's challenges since several of her family members are also celiacs. "She lived to explore and soar to the highest levels in everything that she set out to accomplish."
Williams created a line of gourmet gluten-free meals from The Gluten-Free Personal Chef line with hopes Nelson could serve as an unbiased test marketer. Williams recognized the difficulty of maintaining an active lifestyle while desiring the flexibility and the ability to have the same privileges of food both socially and from a convenience factor that
non-suffering celiacs enjoy.
"The inspiration of Haley touching my life confirmed my mission and life's desire to deliver versatile, delicious, portable instant gluten-free cuisine into the mainstream market," explained Williams. "Our company's mission statement is to bring a product of hope and comfort to know that now as a celiac you can travel through your life, be it simply for a quick meal at home, the office, in schools or University campuses, traveling the globe or attending a social event and be safe."
Sadly, Nelson never had the opportunity to test the products. She passed away last year stemming from complications of celiac disease. "I personally know," said Williams," that although Haley never tasted our products she has been guiding and inspiring me to stay on task with this project and it is with great honor that I dedicated this story to Haley Anne Nelson and the Nelson family."

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Peter HR Green, MD
Professor of Clinical Medicine Columbia University Medical Center Director, Celiac Disease Center at Columbia University

Question: What is the most pressing issue that medical professionals need to be aware of when it comes to celiac disease?
Answer: The realization that celiac disease is common and easy to diagnose. The difficulty seems to be recognizing that the patient needs to test for the disease. The clinical manifestations are extremely diverse and the symptoms common. Several studies have shown a long delay in diagnosis, and being physician-based rather than a delay with the patients seeking healthcare.

Question: What do you foresee could be the biggest medical advancement yet for celiacs?
Answer: The development of specific non-dietary therapies. This comes from a great advance in research in celiac disease that has allowed determination of the mechanism of disease, hence allowing development of specific therapies. This "medicinalization" of celiac disease will allow the pharmaceutical and biotechnology industry to have a role in the management of the disease. This in turn will increase investment in all aspects of the disease especially physician education and allow for more patients to be diagnosed.


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# Living social: embracing the lifestyle 

## - Question:

Does going gluten-free mean social seclusion?

## Answer:

No, not with a little help from family, friends and innovative new products.

When Debra Hazel of Jersey City, N.J. was finally diagnosed with celiac disease in 2000, she immediately read everything she could.
"Thank God for the Internet," said Hazel, who had been told her problems were everything from stress to a serious stomach condition. She easily managed dining at home, but found it more challenging to tackle social engagements and travel.
"You have to figure the odds of having something you can eat are slim to none at a party. I usually pick at the veggies and cheese. And I am sure to eat before so I'm not tempted," she explained.
One thing celiacs all point out is
that despite good intentions, not all hosts understand the complexities of their diet. A friend might make a special salad and then top it off with a big crouton. "People don't realize that even putting something on the plate and then taking it off is harmful," added Hazel.

When it comes time for a cocktail, Hazel said she'd "kill for a Guinness." However, thanks to several brewers, there are beer

## PARTY POINTERS

Offer To Bring: If you bring food to a barbecue, you'll know there is something you can have

- Make Your Own: Invest in an item such as Bready, a baking robot that produces non-contaminated, gluten-free breads and cakes
Call Ahead: When traveling or dining out, call ahead to make sure gluten-free is an option
options such as Bard's Tale Beer Company. Founded by two celiacs, Bard's has no wheat, barley, rye or oats and is naturally-gluten-free. "It is such a great beer, that we don't think just celiacs will drink it," explained Brian Kovalchuk, chief executive officer of Bard's who said he's received fan mail from celiacs who said they "hadn't had a beer in 15 years."
There's no doubt there is social anxiety about functioning in a


## Establish A Support Sytem:

Associations can help you find
a local group where you can share your story and get advice

!Publisher's Picks:
Nature's Path Crunchy Vanilla Sunrise Cereal
Pure Market Express' Lasagna Natasha's Cranberry-Orange Health Nut Cookies
world of wheat for adults. Imagine the strain for teenagers who already struggle in general with "fitting in."
Beth Hillson, the founder of the Gluten-Free Pantry used to put gluten-free pizzas in chain pizza boxes so her celiac son could feel like part of his crowd. Teenager Kelsey LeBard keeps to her diet by baking brownies to take to her social gatherings that everyone can eat.
Many companies have been formed out of a need to give kids gluten-free choices such as 1-2-3 Gluten-Free. When her two nieces and one nephew were diagnosed, Kimberlee Ullner, company founder, went to work to create a biscuit recipe so they could have pigs in a blanket like non-celiac kids. "Now you can have your cake and eat it, too," she said.

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## Watch for signs

$\rightarrow$ Think celiac disease if you are doing everything "right" but not feeling really well. Persistent symptoms such as fatigue, anemia, joint or muscle pain, headache, itchy skin rashes, constipation, bloating, diarrhea,foggy brain, weakness, infertility or miscarriages, go away with a diet change if the cause is celiac disease. Is your diet working for or against you? Instead of providing energy, do meals leave you weak? Is your diet full of grains based products? Think celiac disease. Common vague ongoing symptoms are warning signs to discuss with your physician. For more information visit the Celiac Sprue Association website www.csaceliacs.org.

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The nation's estimated three million celiacs have a champion in the search for answers in Alessio Fasano, MD, professor of pediatrics, medicine and physiology at the University Of Maryland School Of Medicine where he's also director of the Mucosal Biology Research Center and the Center for Celiac Research.
Celiac research: a road of hope for other disorders

$\square$asano ushered in new ways to look at celiac disease.

## Debunking the Myths

Fasano's research shattered celiac disease fallacies such as that it only affects children or certain heritages. Celiac disease has been diagnosed in adults and in all backgrounds. Celiac disease is not a true food allergy, rather an autoimmune disease inherited or triggered by a breakdown in the immune system. Research into root of causes indicates the disorder develops when a person exposed to gluten also has a genetic susceptibility to celiac disease and an unusually perme-
able intestinal wall or "leaky gut."

## Better Testing

For many years, it was a hit and miss strategy to identify celiac disease. Starting in 2000, a blood test that screened for specific antibodies was developed to effectively validate celiac disease."Once you are diagnosed, you should seek medical advice rather than put yourself on a gluten-free diet," Fasano advised.

## Finding Magic Pills

While removing gluten from the diet heals intestinal damage, a lifelong adherence isn't always easy. Research points to a molecule that can be given orally to disrupt the events that trigger celiac disease. Fasano is exploring


Alessio Fasano, MD
Dr. Fasano ushered in new ways to look at celiac disease that could lead to not only a cure, but a key to unlock the mys teries of other autoimmune disorders.
the value of Larazotide (a zonulin inhibitor) which has been tested in human trials with celiacs who ate gluten without an excess of side-effects. While not a cure, Larazotide could greatly reduce the negative reactions celiacs have with gluten.

## The Tip Of The Iceberg

Knowledge about celiac disease could have far flung results since the same perfect storm of "an environmental trigger, a genetic susceptibility and a leaky gut," seems to underlie other autoimmune disorders which could lead to treatment of other conditions like type 1 diabetes, multiple sclerosis and rheumatoid arthritis.


## Celiac \& Reproductive

 HealthThereislittle that can compare to the tragedy associated with losing a baby, or not being able to have one. It happened to me. I suffered multiple miscarriages and a full-term stillbirth as a result of my undiagnosed celiac. Studies show up to 50 percent of womenwith celiac, diagnosed and undiagnosed, face problems such as miscarriages and unfavorable outcomes of pregnancy. Men with celiac are also affected, as almost 19 percent will face infertility caused by severe nutritional deficiencies.
Fortunately, the solution can be simple. A proper celiac diagnosis and gluten-free diet may hold the key to helping moms and dads have healthy babies and happy families!

## Center for CELIAC RESEARCH <br> 

The Center for Celiac Research (CFCR) is recognized as a world leader in the field of celiac disease covering clinical care for children \& adults, support services, education, and scientific research relating to celiac disease.

## The Center for Celiac Research www.celiaccenter.org

14 years of discovery
university of maryland school of medicine

## Boar's@Head

## All Boar's Head meats, cheeses and condiments are

$100 \%$ GLUTEN FREE.

We congratulate the following organizations for facilitating research and raising awareness of Celiac Disease:

Celliac Sprue Association
National Foundation for Celiac Awareness
Gluten Intolerance Group
Cellac Disease Foundation American Celiac Disease Alliance

