



KRISTINE BULS/EXAMINER

As director of the University of Maryland Center for Celiac Research, Dr. Alessio Fasano studies the long-misunderstood illness that affects about 3 million Americans. The disease is more complicated than just an allergy to gluten, and proper diagnosis is essential. "This is the only autoimmune disease from which we know the trigger," he says.

Doctor unraveling mystery of celiac disease

Each week, as part of Power Friday, The Examiner profiles researchers, scientists and health care professionals who are making a difference in the everyday lives of Marylanders.

By Sara Michael
Examiner Staff Writer

Dr. Alessio Fasano is director of the University of Maryland Center for Celiac Research, which is part of the School of Medicine, where he studies a long-misunderstood illness that affects about 3 million Americans. Celiac disease causes gastrointestinal symptoms such as bloating and diarrhea, as well as anemia, joint pain, fatigue and skin disorders. In recent years, research and awareness has grown, as has the popularity of gluten-free foods, the only treatment for celiac disease.

Celiac disease is more than just an allergy to gluten, isn't it an autoimmune disease?

For many years [people] were under the impression it was a food allergy. The understanding of it as an autoimmune disease changes a series of paradigms. It has been revolutionary. From a patient's standpoint, knowing it is an autoimmune disease implies you are not going to grow out of it.

Is treatment a lot different?

Treatment is more than saying, "You have to avoid the food that contains the material that offends you. But if you by any chance are exposed to it, it's not a big deal because you will pay the price on the spot. You will feel bad, and it will go away."

An autoimmune disease will have a cumulative effect over time. You can end up in a very unpleasant situation [with] possible co-morbidities [such as rheumatoid arthritis]. Because it's an autoimmune disease, there is the genetic component, and then there is an environmental component that is the trigger that is mismanaged by the immune sys-

tem.

What is revolutionary is that this is the only autoimmune disease from which we know the trigger. And this has created tremendous turmoil because our [response] is that if you have an autoimmune disease there is nothing you can do about it. But celiac disease suggests otherwise.

Because you know the trigger?

We know the trigger. The treatment of a gluten-free diet allows you to take one of the two elements out of the picture. These people go back to normal. The symptoms go away, and damage in the intestine that is the autoimmune insult goes away.

How do you know it's celiac disease and not an allergy to gluten?

It is a very important question. We see roughly 1,100 people a year, and a fraction have celiac disease. All of them come claiming they are sick from eating and when they go on a gluten-free diet they feel better. As a matter of fact, there is a spectrum. A reaction to gluten on one end, and the worst-case scenario is the autoimmune reaction of celiac disease. But there is a lot in between.

Are there other symptoms that help you know it's celiac disease?

No, because some of the symptoms of allergies overlap with celiac disease. The situation becomes even more complicated when you talk about gluten sensitivity. That's a condition where the vast majority of people [have].

What is that?

It's an immune reaction to glu-

ten, but it's not an allergic base and not an autoimmune base like celiac disease. But definitely there are different machineries involved in that. And there are specific ways to diagnose celiac disease and specific ways to diagnose an allergy. There are not yet ways to diagnose a sensitivity.

Is the treatment more than a gluten-free diet?

For all of them the basic [treatment] is a gluten-free diet. But the rules of engagement are different for where you are on the spectrum. That is why a proper diagnosis is extremely important. Celiac disease is an all-or-none proposition. If you go on a 99.9 percent gluten-free diet, that 0.1 percent is perceived by the immune system as something dangerous there. It can't distinguish between a crumb and an entire bread loaf. It's a different story with gluten sensitivity and allergy. Some people can't tolerate a crumb, and others have a threshold that is such that you can tolerate a piece of pizza.

Why are we hearing more about it and seeing more gluten-free products?

When we started this process the general wisdom about celiac disease was that it was a pediatric condition, it has only [gastrointestinal] symptoms and involves only Caucasians. That's what we had in mind, and indeed when you look in that direction the disease is rare. The real celiac disease, we see now, is not confined to pediatrics, not confined to GI symptoms, and not confined to Caucasians. What you see now is the entire picture, and [we've] come up with this 1 percent [of the population].

So we just weren't looking at it the right way?

[In 2004, the National Institutes of Health] concluded the disease is indeed a public health problem in the U.S. involving almost 3 million people. And it's even more of a pub-

Dr. Alessio Fasano

- » **Career:** Director of the University of Maryland Center for Celiac Research, which is part of the School of Medicine
- » **Age:** 52
- » **Hometown:** Salerno, Italy
- » **Current home:** West Friendship
- » **Education:** University of Naples (Italy) School of Medicine; Hopkins Business of Medicine graduate from Johns Hopkins University School of Medicine
- » **Family:** Companion Jo Anne and three children, ages 10, 19 and 22
- » **What he's reading:** Hemingway, Pirandello
- » **Philosophy:** Discovery is to see what everyone else has seen and to think what no one else has thought.

lic health problem if you consider that of this 1 percent, a ridiculous fraction is diagnosed.

So we have changed how we approach it because we understand it better?

Yes, and the other major work we had to do once there was the flag on the ground. [There] was a tremendous effort to educate health care professionals, to change the paradigm. It was a tremendous effort. Celiac disease was put on the map, and we started this awareness campaign.

Are people still self-diagnosing and cutting out gluten?

Absolutely. But the hazard is ... once you go on a gluten-free diet, the tools we use for the diagnosis are not available anymore. The tests will test negative once you go on a gluten-free diet. You lose the ability to make a diagnosis. It's like you say, "I am peeing a little too much, and I am lightheaded, so let me take 20 units of insulin and see if I have diabetes." For celiac disease, a gluten-free diet is like insulin for diabetics.

smichael@baltimoreexaminer.com

Celiac sufferers adjust to life without gluten, wait for a cure

By Sara Michael
Examiner Staff Writer

As a teenager, Anna Quigg was tested for Lyme disease and lupus. She was told she had juvenile rheumatoid arthritis, irritable bowel syndrome and persistent anemia.

None of the diagnoses seemed to fully explain her gastrointestinal symptoms and joint pain.

"I went to a lot of different doctors," said Quigg, 33, of Catonsville.

It wasn't until years later that she was tested for — and diagnosed with — celiac disease.

People with celiac disease can't eat foods with gluten, which is found in wheat and other grains, because it causes an autoimmune reaction that destroys parts of the small intestine. Symptoms include gastrointestinal problems such as abdominal pain and diarrhea, irritability, joint pain, anemia and fatigue.

Quigg shared office space with someone who worked with Dr. Alessio Fasano, head of the University of Maryland Center for Celiac Research. Her co-worker suggested the symptoms that were keeping Quigg from enjoying lunch out was celiac disease.

In the five years since her diagnosis, Quigg has watched awareness of the disease grow — and her own life change.

After starting a gluten-free diet, she could actually go out to a movie after dinner with her husband, where before she often went home early feeling sick.

"It's amazing," she said. "In the first three weeks, I thought, 'This is what normal feels like.'"

Getting used to a gluten-free diet is one of the hardest parts of being diagnosed with celiac disease, said Rachel Williams, a volunteer for the national Celiac Disease Foundation, which offers support for the newly diagnosed.

"I try to focus on what you can have," said Williams, of Finksburg, whose son was diagnosed when he was about 15 months old. "I try to focus on corn, rice and potatoes. It's all about knowledge."

For a while, Williams kept a four-page printout from support Web site www.celiac.com that listed foods and ingredients her son couldn't eat.

The gluten-free food market in the United States is estimated at about \$700 million and could reach about \$1.7 billion by 2010, according to research by Packaged Facts.

"The quality and quantity is astonishing," said Fasano.

Despite the abundance, a gluten-free diet is restrictive, and patients are anxious for a cure, he said.

Fasano said researchers are "darn close" to finding a cure. Clinical trials are centered on a feature of autoimmune diseases called a leaky gut, where molecules that cause the disease can break through the barrier of the gastrointestinal tract. Results from one phase of the trials should be available soon, he said.

"Fixing the barrier dysfunction," Fasano said, "is what we are focused on."

smichael@baltimoreexaminer.com

