

# Autoimmune Diseases

Professional cyclist  
**Mandy Marquardt**  
on how she keeps  
Type 1 diabetes from  
slowing her down.

## DISCOVER

how patients are  
advocating for their  
health and better  
treatment options  
on Capitol Hill.

## BROWSE

more stories  
online including a  
conversation about  
the benefits of a  
gluten-free diet.



# 30 Million Women

Have one or more autoimmune disease



**Autoimmune  
Diseases  
Association**

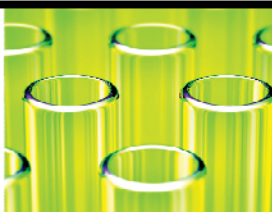
Learn more at [www.aarda.org](http://www.aarda.org)

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The CEO of the Celiac Disease Foundation weighs in on how to transition to a gluten-free diet. [Page 6](#)



Learn how new research is helping scientists better understand and treat autoimmune diseases. [Page 7](#)



Type 1 diabetes experts share advice on living with autoimmune diseases, and what to do when first diagnosed. [Online](#)

# Widespread, but Poorly Understood

More than 100 serious chronic illnesses comprise the category of autoimmune disease, including Grave's disease, rheumatoid arthritis, lupus, and multiple sclerosis. However, autoimmune disease remains one of the most poorly understood and poorly recognized group of illnesses. Why?

**A**lthough autoimmune diseases affect an estimated 50 million Americans, targeting women three times more often than men, they can be difficult to diagnose — and patients have reported seeing five physicians, over a period of three or four years before receiving an accurate diagnosis. To complicate the issue, once an individual develops an autoimmune disease, the odds of developing another are increased. While autoimmune disease was identified more than 60 years ago, it has been slow in taking its place among early-considered, identifiable illnesses.

## Spotlighting symptoms

Autoimmune diseases occur when the immune system's normal responses go awry. In autoim-

mune diseases, the immune system attacks what it is designed to protect: the body's own healthy cells and tissue. These diseases can affect almost every part of the body, from skin and eyes, to the brain, to the gastrointestinal and endocrine systems. Some of the symptoms shared by many autoimmune diseases include functional exhaustion, joint and muscle pain, low-grade fever, low blood counts, dry mouth, skin rashes, extreme hair loss and gastroenterology issues.

Where does one start in getting an accurate diagnosis? What questions should a patient ask? A good place to start would be to inquire whether the doctor has considered an autoimmune disease. Most intake forms ask about specific diseases, such as stroke, cancer, or arthritis; few ask about a family history of autoimmune diseases—one of the most important steps in diag-



**Virginia T. Ladd**  
President & Executive Director,  
American Autoimmune Related  
Diseases Association

nosis leading the doctor to consider an autoimmune disease.

## Beyond blood

If a person has unexplained symptoms that might point to an autoimmune disease, a good idea is to start with an internist who can refer to a specialist for treatment.

Many blood tests can screen for autoimmune disease, but sometimes tests can be negative when an autoimmune disease is present or positive when it is not.

Diagnosis should be based on clinical findings (medical history, physical findings, test results, and current symptoms), not a simple blood test. To complicate diagnosis, sometimes an autoimmune disease will be in the beginning stage and not yet diagnosable. It often takes time and monitoring of the patient to make a diagnosis.

According to the American Autoimmune Related Diseases Association, finding a correct diagnosis can be frustrating for both the patient and doctor. The search may require both patience and persistence, but that search can prevent organ damage and lead to life-saving treatment, certainly worth the effort. ■

## UPCOMING EVENTS

**Celiac Disease Foundation National Conference & Gluten-Free Expo**  
Pasadena, CA, May 5–6

**33rd Annual National Alopecia Areata Foundation International Conference**  
Scottsdale, AZ, June 28–July 1

**International Immunology Conference**  
Dubai, UAE, August 6–7

**Metro Detroit Autoimmune Awareness Walk**  
Detroit, MI, August 26

**11th Annual Congress on Immunology & Immunotechnology**  
Zurich, Switzerland, September 13–14

**New York Autoimmune Awareness Walk**  
Washington, DC, September 29

Publisher **Maureen McCarthy** Business Developer **Jessica Berman** Managing Director **Luciana Olson** Content and Production Manager **Chad Hensley** Senior Designer **Celia Hazard** Production Coordinator **Josh Rosman** Designer **Eric Marquard** Copy Editor **James Diabri** Contributors **Kristen Castillo, Marilyn Geller, Stephen Katz, Cynthia Kupper, Virginia Ladd, Marie Robert, Gary Sherwood, Jay Skyler, Katlin Smith** Cover Photo **David Bracetty Photography** All photos are credited to Getty Images unless otherwise credited. This section was created by Mediaplanet and did not involve USA Today.

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Partnering with pharma for needle-free drug delivery





# Empowerment for today. Hope for tomorrow.

**There is no single solution or approach to identifying effective treatments and cures.**

It takes dedication, innovation, collaboration and research. Our organizations partner to empower you to be a part of the solution by providing you with the education and resources you need.



Engagement and empowerment  
at the point of care.

[infusioncenter.org](http://infusioncenter.org)



Patient engagement and clinical trial  
participation in autoimmune research.

[nolupus.org](http://nolupus.org)



Empowerment through disease tracking  
and patient-centered research.

[arthritispower.org](http://arthritispower.org)



Education and resources for chronic  
illnesses and pain management

[uspainfoundation.org](http://uspainfoundation.org)



## Charging Capitol Hill to Discuss Alopecia Areata

Professionals and patients are joining forces to raise awareness and effect change for those living with alopecia areata.

In September 2017, the U.S. Food and Drug Administration held a patient-focused drug development meeting focused exclusively on the autoimmune condition alopecia areata. The goal was to collect patient perspectives on current and potential treatment options and learn about the ways alopecia areata impacts the patients' everyday lives. Obtaining this important meeting was made possible by the tireless advocacy efforts of the National Alopecia Areata Foundation (NAAF) in which we urged our lawmakers to speak on our behalf to the FDA. And the centerpiece of those efforts is our Hill Day.

Each year, NAAF brings a contingent of our most active patient advocates, the Legislative Liaisons, to Capitol Hill for meetings with their congressional representatives and senators. In these meetings, we discuss the need for increased funding for the National Institutes of Health, and because the Affordable Health Care Act still faces possible repeal we request that any replacement legislation maintain these four pillars of patient protection: maintain the prohibition against pre-existing condition discrimination, allow dependents to stay on family insurance until age 26, continue to prohibit lifetime and annual caps on insurance coverage, and limit out-of-pocket costs for patients in a meaningful way.

We're also asking House members to co-sponsor H.R. 2925 which would re-categorize cranial prosthetics (i.e. wigs) as durable medical equipment and allow Medicare to provide coverage if a doctor certifies that they are medically necessary. Unfortunately, most insurance plans do not cover the cost of a cranial prosthetic for those with alopecia areata and with the passage of this legislation, we hope to reverse that inequity with the end goal that private insurers will follow suit.

The importance of patient engagement in the research process cannot be understated. As the scientific community and pharmaceutical companies begin to develop treatments, it is essential that patient voices and experiences are heard and understood so that the treatments that are developed are meaningful to those living with alopecia areata. We want to increase the number of successful ongoing research studies for the benefit of patients with alopecia areata. And for that we need patient involvement.

**Gary Sherwood, Communications Director,  
National Alopecia Areata Foundation**

# Meet Mandy Marquardt: A Pro Cyclist with Type 1 Diabetes

Ten years ago, track cyclist Mandy Marquardt was diagnosed with Type 1 diabetes but she hasn't let the illness slow her down.

**H**er mission has always been to get back on her bike. As of February 2018, the 26-year-old is ranked in the top 20 of the 336 female sprinters in the world.

Marquardt, who was born in Germany and moved to the U.S. with her family when she was six, started cycling when she was a kid. She loved being outdoors and soon she realized her passion for cycling was more than a hobby. She started to race around the country and eventually the world.

"It's always been there, that competitive drive," says Marquardt, who's competitive with herself. "I've always wanted to do better than I could have the last time and beat my time."

### A shocking diagnosis

While racing with the German national team, Marquardt took a routine physical and found out she had diabetes.

[A doctor] "told me I'd never be able to compete at a high level," she

says. "I believed it for a moment and I just knew I wanted to get back on my bike because that's what I love to do."

Marquardt was in the hospital for two weeks getting testing, and meeting with endocrinologists and nutritionists.



DAVID BRACETTY PHOTOGRAPHY

At the time, the cyclist didn't know of any other athlete with Type 1 diabetes but she was determined to stay on track for her health and her sport.

### Overcoming challenges

Nowadays, Marquardt, who spends a lot of time in the gym as well as on her bike, knows lots of athletes with the disease. She's racing with

Team Novo Nordisk, a global all-diabetes professional cycling team, which is dubbed "Team Type 1."

"It should never stop you," says the USA Cycling Olympic hopeful with for the 2020 games in Tokyo.

Marquardt gets inspiration from her fans and they inspire her too. "I got this really cool note and it really made me cry because it was super cute," she says, explaining a girl with T1D sent her a card that read, "I don't really believe in superheroes, but you're my superhero." Marquardt keeps that card and a few others in her backpack as good luck charms.

The toughest part for the cycling star is adjusting to the inconsistent schedules she has while traveling for her sport.

"Each day is different," says Marquardt, who wears a glucose monitor to keep tabs on her blood sugar and makes sure she gets proper rest and eats healthy, especially while traveling.

"If I'm happy, I race my bike really well." ■

**By Kristen Castillo**



## JOIN US AT THE 33RD ANNUAL National Alopecia Areata Foundation International Conference

**June 28 - July 1 in Scottsdale, Arizona**  
Hyatt Regency Scottsdale Resort & Spa at Gainey Ranch

Learn to be a more effective patient advocate when you attend the Conference Advocacy & Awareness Workshop!

[naaf.org/programs/  
annual-naaf-international-conference](http://naaf.org/programs/annual-naaf-international-conference)

NAAF also urges young people with alopecia areata to participate in our Youth Mentor Program.  
[naaf.org/Youth-Mentor-Program](http://naaf.org/Youth-Mentor-Program)



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FROM AN AUTOIMMUNE DISEASE.

AND EACH COULD HAVE  
THE ANSWER ALREADY  
INSIDE THEM.



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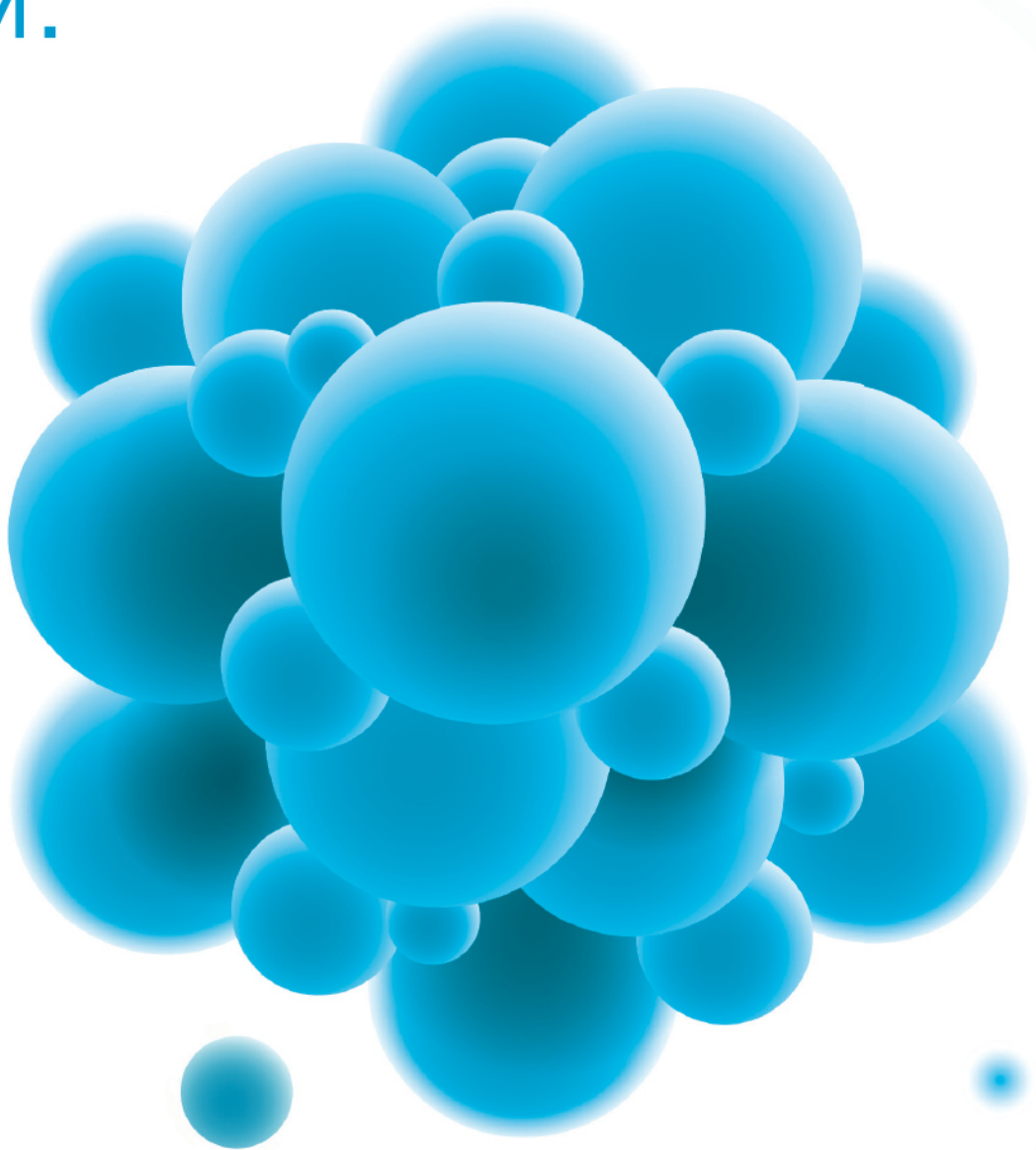
The result is clear — lasting relief from symptoms of autoimmune diseases such as **multiple sclerosis, rheumatoid arthritis, dysautonomia, lupus and diabetes**, as well as degenerative and vascular conditions.

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# How to Maintain a Gluten-Free Diet With Celiac Disease

Living with celiac disease and its diet necessities has become easier with more gluten-free food and beverage options available.

Although celiac disease was once thought to be a rare disease that only affected children, we now understand that it is a common and serious genetic autoimmune disease that can develop at any age. When people with celiac disease eat gluten, a harmful immune reaction occurs in the small intestine, damaging the villi, which are fingerlike projections that aid in absorbing nutrients. Although celiac disease can be diagnosed through a blood test and intestinal biopsy, it is estimated that only one in five Americans with the disease are diagnosed.

**Transitioning to a gluten-free diet**  
Transitioning to the gluten-free diet may seem overwhelming and challenging at first, but it is a medical necessity. Untreated celiac disease can lead to additional serious complications, including other autoimmune disorders, osteoporosis, infertility, miscarriage, and even cancer. Gluten is most commonly found in breads, pastas, baked goods, crackers and cereal, but it can also be hidden in foods like gravies, soups, dressings and soy sauce.

When you go gluten-free, it's important to focus on what you can eat rather than what is now off limits. Thanks to the popularity of the gluten-free diet in the U.S., there are also a growing number of delicious gluten-free

substitutes for nearly all traditional breads, pastas and baked goods.

**Breaking bread**  
If you are sticking to a gluten-free diet, you can enjoy eggs, breakfast meats, fruit and yogurt in the mornings. If you prefer cereal for breakfast, you can find cereals labeled "gluten-free" in most grocery stores. Gluten-free waffles and pancakes are also widely available, or you can make your own using a gluten-free baking mix.

Gluten-free bread, bagels or tortillas can be used to make sandwiches for lunch, or you can choose to eat salad without the croutons or other wheat-based toppings. There are also plenty of delicious gluten-free snack options,

like gluten-free pretzels, popcorn and crackers to satisfy your cravings. Naturally gluten-free and cost-effective dinner options might include meats, poultry, fish, tofu, veggies, beans, rice, potatoes and corn. Fruit is also naturally gluten-free, as are most dairy products, nuts and seeds.

It's important that people with celiac disease or non-celiac gluten sensitivity maintain a strict diet, as even trace amounts of gluten can trigger severe and prolonged reactions. Fortunately, gluten-free food and beverage options are becoming more diverse, more delicious and less expensive. ■

**By Marilyn G. Geller, Chief Executive Officer of Celiac Disease Foundation**

## Sprout Up, Snack On.

### Sprouted Seed Crackers

OUR ALL-STAR SEED LINEUP



SUNFLOWER SEEDS



CHIA SEEDS



FLAX SEEDS



HEMP SEEDS









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# Advances in Biomedical Research Offer Promise for Patients with Autoimmune Diseases

**T**he immune system is a powerful force for protecting the body from infections. It fights germs when we catch them, but sometimes the immune system can cause disease when it attacks our own bodies, which is called autoimmunity. The autoimmune diseases are different depending on which tissues and organs are damaged. Collectively, these conditions affect those of all ages and touch virtually every part of the body, often with devastating consequences. Many autoimmune diseases occur more frequently in women than in men. Some are more common or more severe in certain minority groups.

## Treatment and understanding

Over the past several decades, research has improved understanding of the immune system and its role in autoimmunity. We have identified fundamental similarities among autoimmune conditions: abnormalities in immune cells, inflammation, and organ damage. Additionally, we now know that genetic, environmental, and other factors affect the risk and severity of autoimmune disease. This knowledge has led to a number of treatments that block harmful immune responses. These advances have increased life expectancy and significantly improved quality of life for affected patients.

Despite considerable progress, safer and more effective therapies are needed. Some individuals do not respond to treatments or eventually stop responding. Furthermore, most therapies are not specific to a particular disease or affected organ; they broadly dampen the immune system, which can interfere with the body's overall ability to protect against infections.

Our goal is to develop treatment options that precisely target disease-causing immune responses without compromising the properly functioning parts of the immune system. We are developing new approaches to identify specific targets in affected tissues, for example, the lining of the joints in patients

with rheumatoid arthritis, the skin or kidney in lupus patients, or hair follicles in patients with alopecia areata. This research will enable the development of treatments that target disease-causing molecules in the affected tissues. Long-term, we hope to understand the roots of autoimmunity, which might allow us to stop autoimmune conditions from progressing or even prevent them entirely.

## New frontiers

Four years ago, the National Institutes of Health began the Accelerating Medicines Partnership in rheumatoid arthritis and systemic lupus erythematosus, a public-private partnership with several pharmaceutical companies and non-profit organizations to overcome challenges of drug and diagnostic development for autoimmune diseases. While this effort began with a focus on two autoimmune diseases, rheumatoid arthritis and systemic lupus erythematosus, its results may shed light on many others. Over time, we hope this promising approach will improve the health and quality of life for millions of individuals with these diseases. ■

**By Stephen I. Katz, M.D., Ph.D., Director, National Institute of Arthritis and Musculoskeletal and Skin Diseases National Institutes of Health**



"People suffering with auto-immune diseases have to give up so many types of foods to stay healthy. Pizza no longer has to be one of them."



**AMY** Owner | Founder

## THE ORIGINAL CAULIFLOWER PIZZA CRUSTS

Cali'flour Foods was created in 2016 by founder Amy Lacey two years after a Lupus diagnosis forced her to change her eating habits. Missing pizza, she sought out to create a crust that would be good for her and anyone else suffering with an autoimmune disease. Cali'flour Food's cauliflower pizza crusts are now rated the healthiest pizza crusts in America! Each 9" crust has only 180 calories, 15 grams of protein, and 6 carbs (3 net).

**These gluten free crusts have only 4 simple fresh ingredients:**

Cauliflower • Cheese • Egg • Spices

**THE BEST PART? THEY TASTE INCREDIBLE.**





## Did you know **1 in 10** people has an **Autoimmune disease?**

Autoimmune disease happens when your immune system, which normally protects you, instead attacks your body's healthy cells.

You may be familiar with rheumatoid arthritis, lupus, colitis and Crohn's. But there are more than 80 autoimmune diseases. Early symptoms can often be common and overlooked.

Routine annual testing may not uncover these diseases. Fortunately, our advanced diagnostics combined with clinical evaluation can detect them with greater accuracy.

Early detection can make a difference. It's important to tell your doctor whether anyone in your family has an autoimmune disease, since they may occur in families.

Learn more at [QuestDiagnostics.com/EarlyAutoimmune](https://QuestDiagnostics.com/EarlyAutoimmune).

**1 in 10**  
Americans



..... has an .....  
**Autoimmune disease**