

# INFOCUS



**American  
Autoimmune**  
Related Diseases Association, Inc.

*A nonprofit association bringing a national focus to autoimmunity, the major cause of chronic diseases*

**Vol. 27, No. 3, September 2019**

## **President/Executive Director's Message** - Virginia Ladd

Dear AARDA Friends,

This October will be an exciting, somewhat anxious beginning for me as I step out of my 28-year role of AARDA President/Executive Director and transition to the new position of Advisor to the President. In this part-time role, I'll still be active in autoimmune awareness, resource development, advocacy, education, and perhaps other areas--just enough to keep the autoimmune cause and AARDA in my life.



While I knew that I eventually would see a new person in the AARDA president and CEO role, I wondered who that person would be. Then, within the AARDA government relations area of our work, the Board of Directors and I saw a well-informed and enthusiastic individual with the dedication and leadership qualities necessary to continue AARDA's mission. And, thus, we welcome Randall ("Randy") Rutta to the position of AARDA President and Executive Director (CEO).

I am pleased and, quite honestly, very relieved, to know that such a capable, experienced, knowledgeable, and personable individual as Randy is assuming the position that I have held dear over the years. I hope that many of our members and friends will have the pleasure of meeting Randy and welcoming him to AARDA.

In recent weeks, Randy has been busy getting acquainted with AARDA staff and some--not all!--of the paperwork and documents necessary in understanding his new role and the organization itself although, through his advocacy and government relations work, he has had a good introduction to AARDA.

In the meantime, life goes on at AARDA-- choosing the recipients of AARDA's "Young Investigator" grants, arranging for the translation of 16 AARDA brochures into Spanish, coordinating the very important national doctor-patient advocacy campaign "Let My Doctors Decide," providing written and oral response, including our concerns, to the U.S. Department of Health and Human Services for its proposed "Nondiscrimination in Health and Health Education Programs or Activities Proposed Rule," and other projects too numerous to mention here. Also, the usual activities continue (see articles in this newsletter).

As I hand over my role to Incoming President/Executive Director Randy Rutta, I must say "thank you" to YOU for your support through the years. In so many ways, I have had reason to be grateful to you--for your messages, your words of encouragement, your personal concerns, your active support through volunteer work and financial contributions as you have been able to give. It truly has been a great run.

I leave the role of AARDA President and Executive Director in good hands and look forward to my less demanding role with AARDA.

To all of you, I send my best wishes to you for much joy and success.

With appreciation,  
*Virginia*



## **Welcome, Randy Rutta!**



In August, the AARDA Board of Directors selected Randall Rutta to succeed Virginia Ladd as AARDA President and Executive Director (CEO), effective October 1, 2019. Randy has been serving as AARDA's Federal Policy Consultant in Washington, DC, promoting to Congress, the Administration, federal agencies, patient health advocates, and other stakeholders the policy priorities benefiting people living with autoimmune conditions. He is a seasoned health care executive with a long and extensive background in strategic and operational leadership across the nonprofit health policy and service and delivery sectors.

AARDA Board Chair Dr. Herbert Ford says, "We are fortunate to have found such a person as Randall Rutta to step into this transition process within AARDA as he becomes AARDA's new President and Executive Director. Randy not only has a strong nonprofit background but also has a firm understanding of AARDA's mission and its historical background." Dr. Ford adds, "Randy and outgoing President/Executive Director Virginia Ladd have a good working relationship which has been well established in Randy's role in promoting AARDA's advocacy and government relations programs. We are pleased to welcome Randy into this AARDA leadership role."

Much of Randy's career was based at Easterseals, a global nonprofit service and advocacy organization dedicated to the health, well-being, and success of people with disabilities, veterans, seniors, and families. He served as Easterseals' President and CEO, Chief Strategy Officer, Executive Vice President for

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**Welcome Randy Rutta . . . continued from page 1**

Public Affairs, and other positions over three decades, managing increasingly significant responsibilities in all aspects of the organization's mission, impact, brand, governance, finances, sustainability, and growth. Additional career experience includes acute care, health care quality assurance, and long-term care policy and programs.

In 2017, Randy established ConnectHealth, LLC, a Washington, DC-based, consulting services company providing senior health executives with strategic insight and support in achieving objectives across the healthcare ecosystem. As Principal, his portfolio emphasizes the experiences of patients, their families and communities, and the role of diverse stakeholders in chronic conditions, age-related impairments and disabilities. Client partners include: patient advocacy groups, coalitions, associations, service providers, consultants, and investment firms.

Randy serves as Board Chair of the Partnership to Fight Chronic Disease (PFCD), a national coalition of nearly 100 patient, provider, and community organizations, business and labor groups, and health policy experts committed to raising awareness of chronic disease in America and globally. He joined the PFCD Board early in its inception some 11 years ago and recently has served as its Chief Patient Advocacy Officer to extend PFCD's reach and impact.

Since 2008, Randy has served on the Board of Directors of the American Eagle Lifecare Corporation, an Ann Arbor-based nonprofit organization providing assisted and independent living services in multiple communities nationwide.

Randy holds a Bachelors of Arts degree in Sociology and a Masters of Arts degree in Politics, focusing on international health policy. He resides in Washington, DC.

Randy says, "Close collaboration with Virginia and AARDA over the years has helped me understand the many challenges facing people with autoimmune disease, their families and practitioners, and the compelling need for increased research, awareness and education, and advocacy. I am energized to join AARDA at this critical time, to contribute my expertise and talent to advancing the important goals of this great organization and the autoimmune disease community."

## Opportunities for local advocacy--read on....

Have you been wishing for autoimmune advocacy and awareness in your own community? Perhaps the answer is YOU. Be an AARDA Local Contact, by yourself or with a friend--or if you already have a Local Contact in your area, you may want to volunteer your help.

A detailed training manual is provided to assist Local Contacts, and personal support is available through the AARDA office.

The purpose of an AARDA Local Contact volunteer is to represent AARDA locally in one or more of the following core areas:

- Patient Services: Answer general questions by phone.
- Education: In partnership with AARDA staff, plan local education meetings featuring doctors or other credible, appropriate speakers.
- Community Outreach/Awareness: Identify venues, such as local hospitals, churches, libraries, community agencies, etc., to distribute AARDA literature to the public.
- Fund Raising: Suggest/help coordinate fundraising opportunities with AARDA staff guidance.

**To explore this volunteer opportunity**, you may contact Sandra Cobb, Resource Development and Community Outreach Manager, by email ([scobb@aarda.org](mailto:scobb@aarda.org)) or by phone (586-776-3900). Sandra will be pleased to hear from you. ■

## It's been a great run!

At the end of AARDA's fiscal year, September 30, AARDA Founder, President and Executive Director (CEO) Virginia T. Ladd will enter a new phase with AARDA. After 28 years of founding and leading AARDA, Virginia has chosen a new AARDA path, with full approval of the Board of Directors.

As of October 1, Virginia Ladd, still a member of the AARDA staff, will assume the position of Advisor to the President. In this role, she will continue some of the work that she has been carrying out, but on a more limited basis. Also, with the wealth of experience and knowledge she has gained over the years, Virginia will serve as an advisor on association and organizational matters as requested by the incoming President and CEO.

Virginia and husband Jerry were pioneers in the autoimmune disease movement, starting in 1975 with the fledgling Michigan Lupus Foundation; continuing in 1976 with the Lupus Foundation of America; and then, in 1991, founding the American Autoimmune Related Diseases Association (AARDA).

Virginia says, "In founding AARDA, I nurtured the vision of having **autoimmune disease** recognized as a category of disease. I was convinced that this would make possible increased advocacy for funds, and it would open up studies of the genetic background of autoimmune disease." This is proving to be true.

The Ladds' original involvement arose out of necessity, a need to find life-saving advice and medical care for the newly diagnosed lupus being experienced by Virginia. Perhaps serendipitously, information from a lupus volunteer in Texas led them to a Detroit physician whose counsel not only very likely saved Virginia's life but eventually led to his becoming a Board member and medical advisor of AARDA--many years after Virginia had first consulted him.

As Virginia often declares, "When needs have arisen in AARDA, somehow the right person or opportunity always has appeared."

While heading AARDA, Virginia has been active nationally and internationally in the nonprofit community as an educator

and patient advocate for autoimmune patients and others. She was instrumental in the formation of the International Alliance of Patients' Organizations (IAPO); is a past Board member of the National Health Council; is the founder and facilitator for the National Coalition of Autoimmune Patient Groups (NCAPG); and was significantly involved in the World Health Organization (WHO) debate on the draft global strategy and plan of action on public health, innovation and intellectual property. As an IAPO representative, she made presentations to patient groups in Osaka, Japan; and Buenos Aires, Argentina.

Virginia was an invited speaker to the Fourth International Conference on Health Promotion, in Jakarta, Indonesia; and serves, or has served, on several committees of the National Institutes of Health (NIH) as a patient group representative. She represented AARDA as a member of the NIH Autoimmune Diseases Coordinating Committee which was commissioned by Congress to develop a comprehensive strategic Research Plan for NIH-funded autoimmune research with the goal of reducing the impact of autoimmune disease.

Virginia has testified on numerous occasions at FDA panels regarding a patient's right to have a voice and choice in decisions regarding therapies that might pose serious side effects or have valuable benefits, and in decisions concerning FDA reform. She was instrumental in the creation of the Johns Hopkins University Center for Autoimmune Disease Research (now the Noel R. Rose and Deborah Rose Center for Autoimmune Disease Research).

Virginia has received many awards for her volunteer work on behalf of patients. To mention some, she was a 1995 Jefferson Award Honoree of the American Institute for Public Service with recognition at the national level in honor of her many years of volunteer service, and she received the Heritage Award of the Johns Hopkins University Alumni Association. Virginia was the first non-medical recipient of the AESKU Award for Life Contribution to Autoimmunity at the 7th International Congress of Autoimmunity, in Lubljana,



Slovenia, in May 2010. She was a recipient of the 2016 Research & Hope Award for "Advocacy and Activism," presented by the Pharmaceutical Research and Manufacturers of America (PhRMA).

What does AARDA's "fearless leader" do after stepping down as leader? Naturally she remains active with AARDA, but she also looks to having special times with her children, grandchildren, and friends. The "children and grandchildren" include a very dear Indonesian family who became part of the Ladd family as a result of the Ladd's meeting and providing education and a Michigan family experience for a 15-year-old boy whom they met on a beach in Bali. Now, back in Bali with a family of his own and with an administrative hospital position, he and a physician are establishing a local clinic, as he "pays it forward."

Virginia also has volunteer involvements, including the nonprofit organization founded by her and husband Jerry, the Global Orphans Assistance Foundation (GOAF). This began as support for orphaned children and others in Uganda, a number of whom have now gone on to higher education, including medical school, thanks to scholarships funded by GOAF members. GOAF also has contributed money and supplies to children in other third world countries as well as here in the United States.

So...watch out, World! It's been a great run, but it's a good bet that Virginia Ladd will continue as a force for good in the autoimmune fight, in children's causes, in patients' rights, and in who knows what else?

For all of us in AARDA, we'll just end this: Thank you, Virginia (aka Ginger). You've made a difference to all of us--and to the millions who never will have the pleasure of meeting you. ■



## Dr. Noel Rose receives prestigious award

Congratulations to AARDA's Scientific Advisory Board Chairman Emeritus Noel R. Rose on being granted a 2019 Golden Goose Award along with his mentor, professor and researcher Dr. Edward Witebsky.

Why is the Golden Goose Award significant? Sometimes research that sounds odd can turn out to be extremely important, even have a major impact on society. Thus, two decades ago, the Golden Goose Award was founded to recognize groups of researchers whose work has led to critical advances in biomedical research, medical treatments, and computing and communications technologies. Winners are honored every year at an award ceremony in Washington, D.C., where Members of Congress speak to the importance of the award and of federal funding for scientific research.

When Dr. Noel Rose, early in his medical career, joined the laboratory of Dr. Ernest Witebsky, the aim was to learn more about molecules specific to certain organs of the body. Surprisingly, during the course of his experiments involving a substance produced by the thyroid gland known as thyroglobulin, Dr. Rose found evidence that the body can form an immune response to its own tissues, not just foreign substances. This went against the predominant scientific understanding at the time.

Dr. Rose followed the unexpected evidence where it led, working with Dr. Witebsky's guidance to back it up with solid science. The results were seminal to scientists' understanding of autoimmunity today. Science now recognizes scores of autoimmune diseases affecting tens of millions of Americans and others throughout the world, and thus we celebrate our own Golden Goose Award winner! ■

## "Go Green" - Are you interested?

AARDA is pleased to announce that, in an effort to "go green," we are launching an electronic version of our *InFocus* newsletter during the fall of 2019. The *E-InFocus* will be available to current and future subscribers via email for the same subscription membership contribution of \$34 USD (International \$44 USD).

Please contact the AARDA office at (586) 776-3900 or email at [aarda@aarda.org](mailto:aarda@aarda.org) if you would like to receive an electronic newsletter in place of your printed quarterly newsletter. We will be happy to assist you with your request in becoming an electronic newsletter subscriber.

For those subscribers who look forward to seeing their *InFocus* dropped into the mailbox, we'll see you there! ■



## Women and autoimmune disease-- again, the question

The million dollar question: Why do women suffer much higher rates of autoimmune disease than men do? In the United States alone, women represent approximately 80 percent of all cases of autoimmune disease. Women are 16 times more likely than men to develop Sjögren's syndrome, for example, and nine times more likely to have Hashimoto's thyroiditis, the disease that caused tennis star Venus Williams to withdraw from the U.S. Open in 2011.

Some scientists now think that the placenta itself might be the reason that women are so disproportionately affected. Some researchers at Arizona State University have put forward an explanation called the "pregnancy-compensation hypothesis." It suggests that women's immune systems are engaged in a fierce tug of war with placentas, even when the organs aren't actually present.

When the placenta grows during pregnancy, the organ sends signals to the mother's immune system to change its activity so that the mother's body doesn't eject the placenta and the baby. This might mean turning down the immune system in some ways, or for a certain amount of time. Turning down the immune system too much, however, risks leaving women sensitive to pathogens, which would be bad also for the developing baby. So, instead, the mother's immune system ramps up in other ways throughout adulthood, suggests evolutionary biologist Melissa Wilson and her Arizona State colleagues, and remains vigilant against germs even when some of its parts become dormant during pregnancies.

Things get complicated when those pregnancies don't actually occur. Women today tend to have fewer children than in previous decades--fewer than two on average in the US, according to the Centers for Disease Control and Prevention (CDC). Dr. Wilson reasons that without a more or less constant pushback from placentas during pregnancies--the pushback that women's immune systems have evolved to anticipate--the immune system can get too aggressive. It starts looking for things to attack that aren't dangerous, which is how autoimmune diseases set in.

Many theories have been put forth about why women suffer from more autoimmune disease than men do. The way Dr. Wilson sees it, the pregnancy-compensation hypothesis synthesizes many of the previous theories into one and provides the evolutionary explanation behind them. She says that, so far, no one has come forward to attack her for being wrong, despite the seeming boldness of this theory.

Dr. Nikolaos Patsopoulos, assistant professor of neurology at Brigham and Women's Hospital, in Boston, says that "this theory puts together a lot of things we know that are true and some that we're still trying to understand."

Dr. Wilson says that the hope is to learn eventually what it is in the immune system that's trying to respond to the placenta and to target "that thing" with vaccines or treatments. ■

--Source: Excerpted from "A Breakthrough in the Mystery of Why Women Get So Many Autoimmune Diseases," Olga Khazan, *The Atlantic*, June 18, 2019



## Behind-the-scenes treatment decisions: Should we care?

*The following opinion/editorial is written by Kenneth Thorpe, Ph.D., the Robert W. Woodruff Professor and chair of the Department of Health Policy and Management in the Rollins School of Public Health at Emory University.*

As many as 50 million Americans are living with some kind of autoimmune disease illnesses in which dysfunctional immune systems attack healthy tissues and organs, leading to painful, life-affecting conditions like psoriatic or rheumatoid arthritis, multiple sclerosis and Crohn's disease. These diseases are difficult to diagnose, complicated to treat and usually involve painstaking work by physicians to determine just the right medication, or combination of medications, that will bring the autoimmune sufferer some level of relief and the ability to live as close to a normal life as the illness will allow.

Many of these patients are unaware that their health insurance companies are restricting access to the treatments their doctors have deemed most effective. A disturbingly high number of health plans are geared to override the judgment of physicians and give patients the medicines that they--the insurers--want them to take. For those with complex autoimmune challenges, the ramifications of taking the wrong medicine can be severe.

A research team from Emory University evaluated the formularies of thousands of private health plans and Medicare coverage plans, specifically looking at the access they provide to medicines for five serious autoimmune conditions. The results are both startling and distressing.

The vast majority of private health plans and insurance options in the Medicare Part D prescription drug program impose significant to austere restrictions on access to treatments for these autoimmune conditions. In fact, fewer than 3 percent

of plans nationwide offered what we would define as meaningful access to medicines at the pharmacy. Interestingly, these plans offer much broader access to medicines administered in a hospital or physician's office.

It's at the pharmacy counter where these access restrictions have the greatest detrimental effect on patients.

Some plans require the cumbersome, time-consuming process of prior authorization before patients can begin taking the medicines their physicians deem essential. Some require higher out-of-pocket spending for certain drugs in an effort to drive patients toward therapies that are better for the insurer's bottom line. And then there is the particularly insidious policy known as step therapy, or "fail first," in which patients are forced to try insurer-preferred medication options first until they have proven to be harmful or ineffective, at which point, they can finally transition to the medications their doctors initially ordered. Needless to say, these delays are significantly more harmful for individuals already suffering from a serious illness.

Patients also run into what is known as the "rebate wall." Health insurers and pharmacy benefit managers negotiate sizable rebates on particular drugs and then direct their patient-customers to use those drugs because greater utilization means more rebate dollars going into their bank accounts.

Just because certain treatments haven't achieved volume in the marketplace doesn't mean that patients shouldn't have access to them. Oftentimes,

these medications--which can include less costly generics and complex biosimilars for autoimmune diseases--are the catalysts for future innovation. Restricting access can equate to less R&D investment over time, which slows the pace of innovation.

We initiated and are sharing this research because this trend warrants closer examination and concern. There are currently proposals being considered at the federal level that would expand coverage restrictions to more patients dealing with serious illnesses. The CMS is considering changes that would allow Medicare Part D plans to cover fewer medicines and use approaches like step therapy for more therapeutic classes of medications. These changes would apply to Medicare beneficiaries who are already stable and doing well on the medications they are currently taking, forcing changes that could disrupt their care and undermine their health.

This research and countless patient case studies should prompt a discussion of how we define health insurance and as how we, as a nation, strive to improve population health and responsibly reduce health care costs. Making people sicker by manipulating the medicines they take for financial gain would seem to be a flawed strategy if our goal is indeed to have a healthier America. ■

--Source: "Commentary: Behind-the-scenes decisionmaking limits doctor-recommended treatments for sickest Americans," Kenneth Thorpe, Ph.D., *Modern Healthcare, CareerRx, Crain Communications, Inc.*, August 19, 2019

## Have you missed your September InFocus?

Because of the special timing for the announcement of the transition of AARDA leadership from President/CEO Virginia Ladd to Incoming President/CEO Randall Rutta, *InFocus* patiently awaited the go-ahead for publication. The time is now! Enjoy. ■

## From raceway to runway-- Awareness championed at AARDA fund raiser



*Fashions & Models with Emcee Jon Jordan*

What do race car drivers and fashion designers have in common? At AARDA's annual spring fund raiser "Bound by a Common Thread," held at the Detroit Athletic Club, in May, it was a desire to raise autoimmune disease awareness.

Race car driver and past Grand Prix winner Kyle Marcelli was presented the AARDA Champion Award for reaching new audiences nationally through lending his name and celebrity, since 2016, to bring attention to the trailblazing work of autoimmune organizations.

On the event runway, four talented young people enrolled in the Wayne State University (WSU), Detroit, Fashion Design and Merchandising Program showed stunning collections: Gauri Jaiman, Kelsey Tucker, Mason Andrew Williams, and Amber Williams-Ryan. The students' participation was made possible through a partnership between AARDA and WSU. Another partner, I Catch Management, headed by Shubhra Shukla, provided volunteer models. AARDA friend and style icon Jon Jordan, of Channel 4 WDIV-TV, generously donated his time as emcee.

Bound by a Common Thread was sponsored by Pfizer, "Hour Detroit" magazine, and our Community Partners, Level One Bank, MidMichigan Health, and the Michigan Health & Hospital Association. The event raised more than \$50,000, including \$2,300 for minority student research scholarships.

Joining AARDA staffers Cathy Cruchon, Eula Hoover, Virginia Ladd, Deb Patrick, and Katie Simon as event planners were outstanding volunteers Erica Copeland, Ebony Dooley, Tracy Holloway, and Carrie Ryckman.

Mark your calendars and Save the Date for AARDA's 20th Anniversary Spring Fund Raiser to be held Saturday, May 9, 2020, at the Skyline Club, in Southfield, Michigan. Call 855-239-2557 or email [dpatrick@aarda.org](mailto:dpatrick@aarda.org) to reserve your seats. ■

### Quote to ponder & enjoy...

"The only thing that is truly in my control is my reaction to the things and the people around me. Calm is a superpower."

~ Jamie Lewis, Process and Data Manager, Michigan Nonprofit Association links, summer 2019

## Marcelli receives 2019 AARDA Champion Award



*Kyle Marcelli and wife Amy Marcelli*

The AARDA  
Champion Award is  
bestowed upon

individuals or organizations who have made significant contributions to AARDA's mission--in science, awareness, volunteerism, or other areas. In May, at AARDA's annual spring fund raiser, Grand Prix winner and international award-winning race car driver Kyle Marcelli was awarded the title of 2019 AARDA Champion.

A native of Canada, Kyle has served over the past two years as AARDA's Brand Ambassador, carrying the AARDA logo on his race car, his helmets, and race suits. He also has spoken on behalf of AARDA and autoimmune patients. Because of Kyle's very visible support of AARDA's mission, autoimmune patients have achieved representation to large groups of race spectators and other audiences who might never have known the autoimmune story.

To Kyle Marcelli, the 2019 AARDA Champion, we say, "Job well done. Thank you." ■



## Available to watch now--AARDA's webinar recordings

Thanks to a generous grant, AARDA has been offering a series of webinars. Ranging from 30 minutes to one hour, topics such as diagnosis tips, clinical trials, doctor-patient relationships, and ARNet are presented. View them all at your leisure on our YouTube channel, [youtube.com/AARDAtube](https://www.youtube.com/AARDAtube).

Is there a subject in which you are interested? Please let us know via email ([aarda@aarda.org](mailto:aarda@aarda.org)). ■

## Step therapy: One woman's story

*Sandra Cobb describes her own experience with the "fail first" policy of step therapy for an autoimmune disease.*

Last year, Medicare announced new policies that will allow Part D Prescription drug plans, as well as the Part B benefit for provider and hospital administered drugs, to use a policy known as "step therapy," in which patients must first try a cheaper prescription drug before being allowed to use a potentially more expensive version that their doctor believes is better for them. This happened to me when I was diagnosed with an autoimmune condition; and since it scares me that other patients might be forced to endure what I had to go through, I'm sharing my story to help people understand that cost-saving measures like step therapy policies have a very real human cost.

About three years ago, around Thanksgiving of 2016, I began to experience extreme, chronic fatigue. I quickly lost the energy to do just about anything other than rest. It was physically challenging, but just as difficult was the emotional challenge of being involuntarily checked out of my own life. Perhaps the most difficult part was losing the ability to play with my grandchildren. I couldn't pick them up and hug them anymore, and I certainly didn't have the energy to baby-sit them as I had previously.

I went from doctor to doctor and appointment to appointment seeking answers. They constantly came up short. Specialist after specialist told me, "We still don't know." Finally, one day I got a call from my doctor after the latest test. "We have good news--it's not cancer, but we think you have an autoimmune condition called sarcoidosis," he told me. I had never heard of sarcoidosis, but I had recently started a job at the American Autoimmune Related Diseases Association (AARDA) and I immediately went over to grab their brochures describing various autoimmune conditions.

Sarcoidosis is an inflammatory disease that affects multiple organs, but primarily the lungs and lymph glands, in which an overactive immune system creates masses of inflamed tissue that interfere with the organ's structure and function. As with many autoimmune diseases, the first thing that my doctors tried was to put me on prednisone. It helped raise my energy levels, but it also caused me to put on excess weight--a common side effect of such steroids. Following an MRI scan in which my doctors found inflammation in my brain, they further increased my prednisone dose. This worried me, as the excess weight gain can lead to diabetes and other serious



negative consequences.

That was around July 2018. In November, my doctor came to me and said, "OK, Sandra, I have good news. I can get you on a newer, advanced medication that I've always wanted to put you on, but we had to go through this process with the prednisone before your insurance company would pay for it."

Because of my work at AARDA, I immediately knew that he was talking about "step therapy," also sometimes known as "fail first." And I was livid when I found out there was a better drug I could have been on this whole time that would have treated my sarcoidosis more effectively and without all the negative side effects of prednisone.

My doctor, with his decades of training and experience, had been forced by bureaucrats at my insurance plan to provide me with care that he knew was less than optimal. While I was overjoyed at knowing that I would now be getting a medicine that

was much more effective, I couldn't believe that insurance companies could have more say over someone's health care than their own doctor.

And while I've since learned that private insurance plans have been making doctors and patients jump through these hoops for many years--as awful as that is--many more Americans soon will be facing the possibility of step therapy. In May, the federal agency which oversees Medicare and Medicaid announced that Medicare Advantage and Medicare Part D plans would be allowed to implement step therapy policies, potentially exposing tens of millions of seniors to new bureaucratic hurdles in accessing vital medical care.

While I personally do not believe anyone other than a patient's own physician should be deciding which medicine that patient should receive, I hope that these new policies will include a swift and robust appeals process--one that doesn't make doctors give up in frustration at the amount of paperwork required--so that more patients aren't forced to endure months of sub-optimal treatment when their doctor knows exactly what is best for them.

I was blessed to finally be able to get on a medication that has my sarcoidosis well controlled. And the good news is that more seemingly miraculous new treatments are being approved all the time. I just hope that politicians and insurance companies will let doctors--not financial considerations--make decisions about which patients need which treatment and when they need it. Patients deserve no less. ■



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## Autoimmune Walk Ambassadors--a rare breed

In each Autoimmune Walk location, we try to find an AARDA Walk Ambassador, a volunteer who has created an especially effective way to represent AARDA. Here we present three new AARDA ambassadors.

### New York Walk Ambassador Nika

**Beamon** has IgG4, a rare autoimmune disease in which inflammatory cells cause fibrosis, the deposition of connective tissue, in one or more organs. Nika says, "For years I wondered if there was anyone else like me; chronically sick, tired, in pain and overwhelmed. I was living in a fog of doubt about my mortality and functionality. All of that changed once I got the correct medical diagnosis and sought out doctors who could treat me using leading-edge procedures."



Nika continues, "But, the biggest change in my attitude came when I began sharing my story and found out I wasn't alone. There are millions of people, just like me, living and thriving with an autoimmune disease. I am now one of them. I rely on my Triple A plan to get through the obstacles posed by my condition: accept, adapt, and achieve. With it, I confront my limitations, find ways around them and succeed at nearly everything I tackle."

"As the New York Walk Ambassador, I say, you can too! Start with small tasks like walking to raise money for research to help eradicate the diseases that influence our lives. Every unified step towards a cure will inspire hope in others who desperately need it."

### Los Angeles Walk Ambassador Dayna

**Caddell** agrees with Nika. "Spreading the word about autoimmune disease is crucial. The number of people suffering from an autoimmune disease is constantly rising and affects



families and friends in a way that you can't understand unless you're in that number.

"I know what it's like to live with an autoimmune disease. I've lost track of how many times I have been pricked, poked, and hospitalized. I've gained weight, lost weight, look great and, at times, unrecognizable. To not have a definite diagnosis for eight years has been quite frustrating. However, I push, pray and take one day at a time. ...

"It's a privilege to be this year's Los Angeles Walk Ambassador to further create awareness and to shine a light on this debilitating disease."

### Pittsburgh Walk Ambassador

**Dominica Pavlik** walks in honor of her cousin Cara Lian Lebedda, who passed away in 2008 as she suffered from ITP/TTP (sometimes called ATP), a rare blood disorder. "When I lost my cousin at the age of 20," says Dominica, "I needed to find a purpose, a reason to celebrate her." Dominica found AARDA. And ever since, she has held an annual event to raise awareness in the Pittsburgh area. Through that "Raising Awareness in Honor of Cara Lian Lebedda" event, Dominica and her friends have raised more than \$25,000 for ITP research.



Dominica says, "I am beyond happy to have been working with AARDA for the past 10 years and to be the Walk Ambassador for the inaugural Pittsburgh Autoimmune Walk."

We in AARDA invite you to Walk with Nika, Dayna, or Dominica if you can--or simply make a donation to AARDA in support of one or more of them as they Walk. Register or donate at [www.AutoimmuneWalk.org](http://www.AutoimmuneWalk.org). Or contact the AARDA office, 586-776-3900. ■

## Walk for a cause! Or maybe don't walk?

Either way, walk or not, it's a win for AARDA. An AARDA Autoimmune Walk is for all ages, from babes in arms to seniors, with dedicated walkers vying to meet their pledge goals. Registration includes Walk T-shirt, refreshments, giveaways, speakers, and more.

As one newcomer remarked, "I went to this walk and here were all these people, wearing AARDA T-shirts and sharing their experiences and uplifting each other. It was exciting."

The goal? To have fun while raising funds in support of AARDA's mission. It's an AARDA family thing. We walk for each other and for the 50 million nationwide in need of a cure.

The AARDA Autoimmune Walk schedule for 2019, to date, includes the following:

- ◆ **Los Angeles Autoimmune Walk** - Sunday, November 3 - 1:00 to 5:00 p.m. - Culver City Park, 9910 Jefferson Blvd., Culver City, CA. Enjoy speakers, information and resources, snacks, and music. Walk Ambassador: Dayna Caddell  
<http://autoimmunewalk.org/locationpage.asp?BranchID=125>
- ◆ **Virtual Walk** - Any day. Any time. Anywhere. "Virtual Walkers" choose a circle of friends with whom they set a time and a place--or maybe their individual homes, perhaps miles away from each other--to share pledges and sip tea or whatever. What a great way to work together, apart!

To register for an Autoimmune Walk or receive more information, see the Web sites listed above, visit [www.autoimmunewalk.org](http://www.autoimmunewalk.org), or call the AARDA office (586-776-3900). You can like us on Facebook at [www/Facebook.com/AutoimmuneWalk](http://www/Facebook.com/AutoimmuneWalk) or tweet us @AutoimmuneWalk. ■



## Sjögren's syndrome, not just a dry mouth

Sjögren's syndrome, an autoimmune disease, often is identified with dry mouth or dry eyes; but as a rheumatic disease, it can create other problems as well. In Sjögren's syndrome, the disease targets the body's moisture-producing glands: tears, saliva. It also targets moisture-producing tissues--including mucous membranes in the nose, vagina, and lungs.

Paula Marchetta, M.D., president of the American College of Rheumatology explains, "Typical symptoms are fatigue and dry mouth or eyes although those with Sjögren's may experience muscle aches, joint pain, and inflammation of major organs." She says, "Often symptoms such as fatigue or muscle aches start to affect daily life, and that's when a patient seeks help."

A variety of aids are available--eye drops, some containing androgen for women developing low levels of testosterone, common in Sjögren's; mouth washes and swabs for dry mouth; medications to reduce vaginal dryness; and others.

Rita Baron-Faust, MPH, CHES, co-author of *The Autoimmune Connection*, says, "Sjögren's is actually the second most common rheumatic disease after rheumatoid arthritis."

A recently published study, "Gut microbial dysbiosis in individuals with Sjögren's disease," indicates that people with Sjögren's syndrome have significant alterations in the composition of gut bacteria compared to healthy individuals, some of which seem to be directly associated with eye dryness.

The researchers, a team of investigators from the University of Miami (Florida), explain, "The association between gut bacteria and autoimmune disease is likely a two-way street. On one hand, gut microbiome abnormalities can lead to systemic inflammation and, conversely, systemic inflammation can preferentially deplete beneficial gut bacteria and promote the growth of commensal bacteria with potential pathogenic properties."

The researchers say that their studies set the foundation for modulating the gut microbiome as a potential therapeutic approach in Sjögren's. They suggest that there are several ways to modulate the gut microbiome, including dietary intake, probiotics, and fecal microbial transplantation. They add, "More studies are needed to translate the findings to Sjögren's patients." ■

--Sources: "Alterations in Gut Bacteria May Be Linked to Eye Dryness in Sjögren's, Study Says," *Joanna Carvalho, MSc, Sjögren's Syndrome News*, July 30, 2019; "Venus Williams Opens Up About Rare Autoimmune Disease As She Prepares for the U.S. Open," *Nicole Natale, Prevention*, July 30, 2019; *The Autoimmune Connection*, Rita Baron-Faust, MPH, CHES, and Jill P. Buyon, M.D., McGraw Hill Education, 2003

## When is a gut feeling more than a gut feeling?

Relatively new in the research world is the interest in the amazing world of the gut. The ability to profile bacterial species inhabiting the gut--the microbiome--could have important implications in understanding conditions that affect, and are affected by, the intestinal microbiome, according to researchers at Tufts University, in Massachusetts. To that end, the researchers have developed a 3D printed ingestible pill that samples bacteria found in the gut as it passes through the gastrointestinal tract (GI).

The Tufts University researchers say that this 3D printed pill represents the first non-invasive diagnostic tool capable of providing a profile of microbiome populations throughout the entire GI tract. The pill has been studied extensively and found to provide accurate identification of bacterial populations and their relative abundance. While the pill has been tested in pigs and primates, clinical trials will be needed to determine whether the pill can be used routinely in humans for clinical care.

The vast majority of the more than 1,000 species of bacteria inhabiting the healthy gut have a beneficial, supportive role in

digestion and protection against disease. However, when the natural balance of the microbiome is disturbed, a condition called "dysbiosis" occurs. This can be associated with inflammation, susceptibility to infections, and even the exacerbation of other diseases, such as cancer.

"We are learning quite a lot about the role of gut microbiome in health and disease. However, we know very little about its biogeography," states Dr. Sameer Sonkusale, corresponding author of the study. He says, "The pill will improve our understanding of the role of spatial distribution in the microbiome profile to advance novel treatments and therapies for a number of diseases and conditions."

The researchers see this technology as bridging an important gap in understanding the complexity of the ecosystem of the gut. ■

--Source: Excerpted from "3D printed pill samples gut microbiome to aid diagnosis and treatment," *Tufts University, Medford/Somerville, Massachusetts*, July 24, 2019, via *Newswise: News for Journalists*

## ~ EDITOR'S NOTE ~

The information on these pages is provided without implied recommendation, solely as a service to those who may be interested. As with all research projects, interested parties should thoroughly question and have a complete understanding before considering participation.

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**To our readers:** Autoimmune diseases are conditions in which the body's own immune system can (among other things) cause damage to the skin, joints, and internal organs. Although most autoimmune diseases are not yet preventable or curable, most can be controlled to varying degrees. It is because of the wide variance and severity that **the individualization of medical management** is so important. It is vital that persons diagnosed with (or suspected of having) an autoimmune disease consult with their physician or with the appropriate division at a major teaching hospital to assure proper evaluation, treatment, and interpretation of information contained in this newsletter. Opinions expressed in this newsletter do not necessarily reflect the views of the American Autoimmune Related Diseases Association or its Scientific Advisory Board.

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## With Special Thoughts...

### Tributes

**Jacob Cartmill** - In honor of his new home purchase - Jonathan Wilson  
**Billie Johnson** - In honor of her birthday - Judy Udove  
**Rebecca Linn** - In honor of her wedding - Laura Ludwig  
**Jill & Nat Linhardt** - In honor of their anniversary - Aileen & Steven Sirkin  
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**Ralph W. Pysick** - In honor/memory for his birthday and Father's Day - Hal Pysick  
**Kerry Wahl** - In her honor for being an autoimmune disease warrior - Community Bank N.A.  
**Grandpa Wisler** - In his honor and the celebration of his life - McKenna Soards  
**Rachael Wisler-Keller** - In her honor - McKenna Soards

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