

## AARDA shines at Motor City Charity Event

Hello, World! At the prestigious Detroit Athletic Club (DAC), with a Grand Prix race car on display, a delicious dinner, and music provided by the Simone Vitale Band, the Motor City Charity Event introduced (or re-introduced) AARDA to Detroit and some other locales on June 3. Sharing the honors and benefits with Grow Detroit's Young Talent program, AARDA members and friends mingled and shared AARDA awareness with a who's who of business leaders and other guests.

for the city's workforce. It is an important summer youth employment program that combines work readiness training with on-the-job experience.

AARDA was well represented, from the race car sporting a couldn't-be-missed AARDA logo (prompting many questions) to the strolling AARDA guests, staff members, and Board members who chose every possible opportunity to describe AARDA's work and autoimmune disease in general.



**Jim Barber; Patricia Barber; Virginia Ladd; Mary Yavor; Katie Simons; and Drew Yavor**  
(AARDA volunteers Jim Barber, Mary Yavor; Drew Yavor; AARDA staff Pat Barber, President/Executive Director Virginia Ladd, Katie Simons)

The gala evening was spearheaded by AARDA Board members Michael Linn and Scott Selby. Co-chairs were The Honorable Mike Duggan, Mayor of Detroit; Andrew Richner, Partner, Clark Hill PLC (also a benefactor); and Nancy Linn, Autoimmunity Advocate. Lively emcee for the evening was AARDA friend Neil Langberg.

Grow Detroit's Young Talent program prepares 8,000 young Detroiters, ages 14-24,

The AARDA exposure carried over to the Detroit Grand Prix as driver Kyle Marcelli zipped around the track with, again, spectators wondering about the pink and blue logo.

AARDA members and friends can be assured that autoimmunity was well represented all during the Grand Prix weekend, and we feel certain that we made some good friends. ■

## Job well done, Pat... now on to the future!



After 21 years with AARDA, Patricia Barber has now retired. Starting as a volunteer member of AARDA's Corporate Advisory Board while still a bank manager, she came upstairs--literally--after leaving her banking career of 26 years. Pat then volunteered in several areas with AARDA before becoming a staff member. She started as AARDA's Meeting/Events Planner, added Advocacy Coordinator and Patient Educator to her duties, and then became Assistant Director.

Many AARDA callers will remember her as the "voice" who provided a listening ear, helpful information, and good referrals as she answered the AARDA phone as Patient Educator. Also, Pat was right out front at many public and scientific meetings, representing AARDA and advocating for autoimmune patients and families. She (and sometimes husband Jim) enjoyed registering and greeting guests at AARDA's annual fund raisers held in the Greater Detroit area.

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22100 Gratiot Avenue, Eastpointe, MI 48021-2227  
Phone 586-776-3900; Fax 586-776-3903;  
E-mail: aarda@aarda.org; Web: www.aarda.org

~ Editor ~

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~ Editorial Reviewers ~

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**Cathleen Cruchon, Accounting/Database**

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## President/Executive Director's Message

— Virginia T. Ladd

Dear AARDA Friends,

As I write this, we still are experiencing a beautiful Michigan summer although all the “back to school” commercials remind us that our autumn schedule is beckoning. Autoimmune Walks, scientific meetings, public forums, and various other activities are on the calendar.

These past weeks have been somewhat challenging for me, the Board, and AARDA staff as we have concentrated on Strategic Planning and new staff recruitment.

The AARDA Board of Directors, with Advisors Dr. Noel Rose and Stephanie Hales along with AARDA staff, met to look back over the past five years--great view!--and look forward to the next five years at the Strategic Planning retreat. It's exciting to realize just how much we have accomplished in advocacy, patient services, education (patients, students, and health care/research professionals), and research support.

Awareness, tremendously important, received a big boost in an unexpected way when, thanks to Board members Michael Linn and Scott Selby, along with AARDA member/Autoimmunity Advocate Nancy Linn, we had the opportunity to be introduced (or, rather, re-introduced) to Detroit and beyond through exposure in a “Motor City Charity Event” (see article) in conjunction with the 2017 Detroit Grand Prix. Can you imagine AARDA's pink and blue logo emblazoned on the Chevy Camaro, car #96, for the Fields Racing Team, driven by 2016 Belle Isle (Detroit) winner Kyle Marcelli? It drew lots of attention. What's AARDA? What's autoimmune disease? What a great way to say, “Hello, Detroit,” and “Hello, Detroit visitors.” Serious business, that's awareness--but fun, too.

Back to AARDA business, telephone inquirers may hear some new voices. We have added four new staff members: Laura Simpson (Assistant Director), Sandra Cobb (Resource development and Community Outreach Manager), Katie Simons (Administrative Assistant), and Aricka Tuttle (Database Assistant).

A voice that you won't be hearing is long-time employee Pat Barber, outgoing Assistant Director, who decided that retirement was a good idea. We know that she was a great source of information and encouragement to many of our AARDA members and friends over the years, and all of us miss her--but she still is a great AARDA advocate and a dear friend to all of us.

To those who missed the “Acorn's Promise” update in the June InFocus: Yes, we still need donations and encouragement (see article). We in AARDA make the impossible possible.

On behalf of all of AARDA and the 50 Million whom we represent, I say “thank you” to you for all you do--pass the message along, give financially as you can, and support each other. It's been a great 26 years--with more great years to come--yes?

With appreciation,  
**Virginia**



### Well done Pat continued from page 1

Pat's time with AARDA, both as volunteer and staff member, allowed her to utilize her financial knowledge, volunteer commitment, people skills, interest in learning as much as possible about autoimmune diseases, and creative abilities for supporting both the organization and many autoimmune patients and families. Job to be done? Pat was there.

With Jim and fuzzy little rescue dog Samantha, Pat now embarks on her new life--retirement! Those of us who know Pat are sure that “retire” won't mean “quit.” Her enthusiasm for life simply will send her in a different direction, full speed ahead, of course. It's been a great 21 years of service to autoimmune patients and to AARDA.

From all of us at AARDA, we send Pat on her way with love and many blessings. ■



## AARDA Downton Tea brings funds, awareness, and graciousness

AARDA's annual spring fund raiser, held on May 20, brought "Return to Downton," an afternoon tea and auction, to The Whitney, a Romanesque-revival mansion, in Detroit. More than 100 guests, many in their favorite Downton-style attire, gathered to lend support to the AARDA mission and to learn about AARDA as President/Executive Director Virginia Ladd spoke of her passion over the past 26 years.

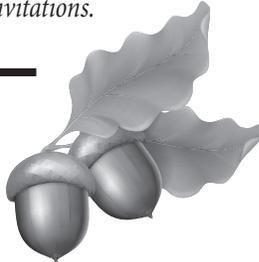
Guests were greeted by Lord and Lady Grantham and the Dowager Countess (actors Jenni Clark, Doug Clark, and Ruth Crawford); enjoyed authentic period music from pianist Will Bennett (with impromptu dancing from some of the guests!); and participated in a lively live auction, raffle,

and silent auction. Proceeds from the event raised nearly \$50,000 for AARDA's programs.

We gratefully acknowledge the support of our sponsors: Pfizer, NECABA Management, and Hour Media LLC. We also thank Grosse Pointe Theatre and Meadow Brook Theatre for their lively assistance.

*In the planning...AARDA's 2018 Spring Fund Raiser, "Food, Fun, Fashion!" scheduled for Saturday, April 28, 2018, in the Crystal Ballroom of the majestic Masonic Temple, Detroit. Those on the AARDA mailing list for the Greater Detroit area will receive invitations. Other interested persons should contact the AARDA office (586-776-3900; or aarda@aarda.org) to receive invitations.*

## The Acorn's Promise: Thanks for asking



Yes, the Acorn's Promise for AARDA's dreamed-for, planned-for National Autoimmune Diagnostic and Treatment Center continues to draw contributions--some small, some large, and all welcome. AARDA members and friends are a jump ahead of a major donor who still hasn't come forward; but we of great faith know that the individual or foundation is out there, just checking all details.

In the meantime, the AARDA Board of Directors has tapped Board member Michael Linn and President/Executive Director Virginia Ladd to lead the

investigative process. Virginia Ladd, with her heartfelt determination to see a National Autoimmune Diagnostic and Treatment Center in the United States, was the initial contributor; and she continues to add to the fund for the Center--affectionately dubbed the Acorn's Promise.

While we don't have the oak tree yet, we know that the Promise grows. This Center is desperately needed. AARDA members, friends, InFocus readers, share the dream!

We can do it. ■

## AARDA welcomes new Assistant Director



Joining AARDA as Assistant Director is Laura Simpson who comes to AARDA with a strong background in nonprofit organization work, both as volunteer and staff member.

Laura most recently served as Interim Executive Director for the River Rec Teen Zone, in Marine City, Michigan. Past positions have included Program Director and then Executive Director with Wish Upon a Teen, in Birmingham, Michigan; Senior Customer Advisor, World at Work, in Arizona; and Assistant Director of Admissions, Education Management Corporation, Arizona.

Laura, a graduate of Brigham Young University, in Provo, Utah, has a Bachelor of Science degree, Economics. In applying to AARDA for the Assistant Director position, she wrote: "I would be honored to join in the movement you have created to provide awareness, education, and research for autoimmune diseases."

Already Laura has become an active member of the AARDA team as she takes over from outgoing Assistant Director Patricia Barber and establishes a working relationship with staff members and the Board of Directors through its recent Strategic Planning retreat.

*Welcome, Laura.*

## Upcoming Autoimmune Walk schedule announced. Join the fun! Coming soon...

- September 10 - New York Walk - Hudson River Park's Clinton Cove (West 55th St. & 12th Ave.)
- September 16 - DC Metro Walk - Bluemont Park, Arlington, VA
- September 16 - Missouri Walk - Washington University, St. Louis
- September 30 - Metro Detroit Walk - Lake St. Clair Metropark & Activity Center, Harrison Twp.
- November 11 - 3rd Los Angeles Walk - Culver City Park, Culver City
- Any Day, Any Time - Virtual Walk - Anywhere you choose!

To register for an Autoimmune Walk near you: Visit [AutoimmuneWalk.org](http://AutoimmuneWalk.org). Like us on Facebook at [www.Facebook.com/AutoimmuneWalk](http://www.Facebook.com/AutoimmuneWalk). Tweet us [@AutoimmuneWalk](https://twitter.com/AutoimmuneWalk). If you have questions: Call 855-239-2557 or e-mail [walk@aarda.org](mailto:walk@aarda.org).

### Top 5 reasons to participate in an AARDA Autoimmune Walk:

1. Honor/support someone you love.
2. Raise \$\$ for autoimmune research.
3. Meet and network with people going through what you are experiencing.
4. Gather new information and resources.
5. Tell your autoimmune story.



### Meet one of our AARDA Autoimmune Walk leaders:

Linda Vanthournout coordinated AARDA's first Bowling Green, Kentucky, Autoimmune Walk this past July, despite challenges faced by having been diagnosed, in 2015, with relapsing polychondritis, a rare autoimmune disease characterized by recurrent, widespread inflammation of cartilage and other connective tissues, such as the nose, ears, tracheal bronchial tree, eyes, joints, kidneys, and heart. She wanted to build awareness in her state--and she was a natural.

Linda wrote her story, which was published in *SOKY (South Central Kentucky) Happenings*; she asked for and received auction items and in-kind donations, billboard space for free, and found a band who donated their time. She posted frequently on Facebook and managed the logistics of the Walk.

This first-time Bowling Green, Kentucky, Autoimmune Walk raised nearly \$8,000 for autoimmune research!

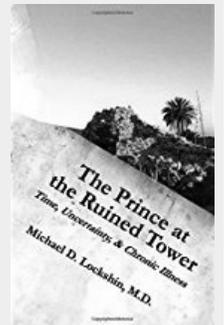
All of us in AARDA thank you, Linda, for a job well done! ■



Walk Coordinator Linda Vanthournout is pictured second from the left.  
Credit: Photo courtesy of John Cipolla

## A book worth considering...

In *The Prince at the Ruined Tower: Time, Uncertainty, & Chronic Illness*, author Michael Lockshin, M.D., takes the reader on a journey through certainty and uncertainty in the world of medicine. What do those terms mean for the medical student? the new physician? the seasoned physician? and, yes, the patient? How does the teacher share uncertainty with the student?



Dr. Lockshin asks, "Do we talk about our uncertainties with the patient, or do we keep them to ourselves?" He says, "In this book, I pose the question to you. We will have a conversation and decide together what to do."

Dr. Lockshin points out that in an acute illness, physicians do certain things--order blood tests or an x-ray; prescribe antibiotics, antidepressant, or water pill; perhaps perform surgery--and the problem abates. For chronic illness, doctors do tests that may or may not provide answers. He says, "Treatments do not cure chronic illness--the illness would not be chronic if it did. Physicians who treat patients with chronic illnesses accept uncertainty. It is part of the job." He says, "The defining feature of chronic illness is uncertainty."

In his book, Dr. Lockshin presents various instances of working with chronic illness patients, of teaching and observing medical students as they encounter chronic illness, and the effect of the "certainty" or errors involved in medical coding. Dr. Lockshin comments on the "compliant" and "non-compliant" patient. Why might the patient be non-compliant? Is money a problem? Is there a lack of mutual trust? He writes, "The social and economic factors of illness affect outcome at least as much as does a misbehaving gene."

One of the final chapters, "A note to Administrators: A diagnosis is not an answer" is a thoughtful message.

*The Prince at the Ruined Tower* speaks to patients and physicians alike. This is a book with questions, compassion, wisdom--and great respect for uncertainty. As to the title of the book, enjoy the author's explanation!

--*The Prince of the Ruined Tower: Time, Uncertainty, & Chronic Illness*, Michael D. Lockshin, M.D., March 2017, 195 pp., \$14.99, available through Amazon, Barnes & Noble ■

### Keep up with AARDA!



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youtube.com/  
AARDAtube

## Know your nutrients: let's look at C

Vitamin C is a water-soluble compound that human bodies cannot produce and, hence, must be included in our diets or supplements. It resists degradation in acid solutions but is considered the least stable vitamin. It is very sensitive to oxygen; and exposure to light, heat, and air will reduce its potency.

Sources for vitamin C include sweet red peppers, kale, broccoli, cauliflower, Brussels sprouts, citrus fruits, guava, persimmon, strawberries, potatoes, and papaya, to name a few.

Primary functions of vitamin C include the following: manufacturing of collagen (a protein necessary for the formation of connective tissue, tendons, and cartilage); serving as an antioxidant with anti-viral, anti-bacterial, and anti-cancer properties, plus protection of thiamin, riboflavin, folic acid, pantothenic acid, and vitamins A and E through its antioxidant properties; promoting the absorption of iron, calcium, and manganese (protects against the toxic effects of heavy metals, such as mercury and cadmium); providing an antihistamine effect--necessary for the conversion of tryptophan to serotonin in the brain; and manufacturing of adrenal gland hormones (concentrations of vitamin C in the body are highest in adrenal glands and brain).

Each person's need for vitamin C differs because of genetics and individual biochemistry. Further, our bodies undergo different stresses, and we all eat different foods. When we are challenged with a viral infection, our need for vitamin C can rise dramatically, depending on the body's immune function, level of injury, infection, or environmental toxicity, such as cigarette smoke.

Nobel prize winner Linus Pauling, Ph.D., writing in the *Antioxidant Cookbook*, by Cory SerVaas, M.D., of the Saturday Evening Post Society, said, "Vitamin C is a valuable substance. A mixed diet of raw natural plant foods would provide an adult with over 2,000 milligrams of this valuable substance each day. Modern diets, un-supplemented, provide far less. The deficit may be made up by taking extra vitamin C..." Dr. Pauling stirred vitamin C crystals into his orange juice each morning.

The daily amount of vitamin C to maintain health for an adult seems constantly under debate; and opinions of the use of intravenous vitamin C, long recognized in much of the integrative and orthomolecular medicine community, range from useless to almost miraculous. Further research and clinical studies are warranted in finding the effect of ascorbic acid (vitamin C) on the boosting of the immune system.

Clearly this article provides only a smattering of information about vitamin C (ascorbic acid), but perhaps it will inspire readers to expand their own knowledge of vitamin C, its value to their health, possible avenues for supplementation, and intelligent food storage and preparation to protect the vitamin.

Dr. SerVaas suggests adding vitamin C crystals (or powder) to recipes (at the end of cooking usually). She cautions against using copper or iron utensils unless they are coated with something else. She says, "Having a vitamin C shaker on the table instead of a salt shaker might be a healthier habit for all of us."

Unfortunately the *Antioxidant Cookbook* is out of print; but who knows, dedicated book hunters may find it online or in a local library or charity book sale. It's worth the search. ■

--Source: Adapted/excerpted from *Health Hunters Newsletter*, Riordan Clinic, Wichita, KS, February 2014; and *Antioxidant Cookbook*, Cory SerVaas, M.D., Saturday Evening Post Society, 1995 pp., 1995



### Quote to ponder and enjoy...

Now and then it's good to pause  
in our pursuit of happiness and  
just be happy. -- Unknown



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## Autoimmune advocate: My reason for being

AARDA Board member Lilly Stairs shares her autoimmune experience. She is Head of Patient Advocacy Relations, Clara Health, Cambridge, Massachusetts, a web and mobile platform working to empower patients by connecting them to clinical trials with breakthrough treatment options. She is also a motivational speaker inspiring others to make a difference in the world.

Have you ever had one of those dreams where you're trying as hard as you can to run away but you can't seem to break out of slow motion or are simply stuck in your tracks? I have. Except for me, it wasn't a dream. It was my life.

Five years ago, after an onslaught of testing and doctor's visits, I was diagnosed with psoriatic arthritis, an autoimmune disease that resulted in total body arthritis and paralyzing pain that made even the slightest movement excruciating. I was indefinitely unable to break out of slow motion. The diagnosis turned my life upside down. Every day was a battle against my joints, fatigue and my self-confidence.

Five months after my diagnosis, I was in and out of the ER three times over the course of one weekend with stomach pain that made even drinking water unbearable. While many of the doctors were convinced it was all in my head (even though I was on 90 milligrams of morphine and it didn't even come close to taking away the pain), a camera study proved otherwise when bleeding ulcers were discovered in my small intestine. It was at this point I was diagnosed with yet another autoimmune disorder: Crohn's disease.

At the ripe age of 19 I had received back-to-back diagnoses of serious, life-long chronic illnesses. I endured countless failed treatments, debilitating fatigue, strained relationships and more pain than I could have ever imagined. But I am now blessed to have just celebrated three years of remission because of the life-saving therapy I receive every two months--therapy that treats the symptoms of both my autoimmune diseases. I now live a relatively "normal" life and I couldn't be more thankful.

I firmly believe that everything happens for a reason.

While my autoimmune diseases caused me to endure the most difficult trials of my life, I am still thankful for them. Why? Because they gave me a purpose. It is my life's mission to support autoimmune patients as they march through their journey.

There are 50 million Americans battling more than 100 autoimmune diseases, from Crohn's and arthritis to lupus, celiac, and type 1 diabetes. As a society, we tend to recognize autoimmune diseases individually. We must begin to view these diseases as an umbrella category like we do cancer and heart disease to ignite change, raise awareness and catalyze research. As the root cause of these illnesses is one in the same, a treatment for one has the potential to mean a treatment for many.

My autoimmune diseases have shaped the course of my life ultimately for the better. And I hope my story will raise much needed awareness for autoimmune diseases and inspire fellow patients to draw strength from adversity and remember that everything happens for a reason. ■

--Source: Stanford Medicine, Scope blog, Inspire, April 18, 2017



Lilly Stairs lower center and friends

## Autoimmune encephalitis receiving much needed attention

Out of Henry Ford Hospital, Detroit, Michigan, comes encouraging research that sheds increasing understanding of autoimmune encephalitis, which was described in *Brain on Fire*, an autobiography written by *New York Post* journalist Susannah Cahalan. The disease is actually a diverse group of neuropsychiatric disorders that can trigger psychosis, memory impairment, and seizures. The scope of autoimmune encephalitis, an important cause of new-onset altered mental status, has only recently begun to be recognized in the medical literature.

Autoimmune encephalitis is very difficult to diagnose since it looks similar to other illnesses. Henry Ford Hospital researcher Brendan P. Kelley, M.D., MSc., has pointed out that behavioral changes can start out as subtle or not specific, and patients can become aggressive, delusional, or confused. Patients may start developing stroke-like systems, blindness, or other issues that can't be explained by a psychiatric diagnosis.

The good news, according to Dr. Kelley, is that research has shown clear guidelines on how to diagnose and treat this illness. Treating autoimmune encephalitis is a challenge because the disease alters how the body's immune system functions. Patients can make full recovery in some cases when the disease is caught early enough. Early diagnosis of this and all autoimmune disease can be crucial. ■

--Sources: Excerpted from "Doctors Close To Understanding Disease Behind *Brain on Fire*," Andrew Follett, *The Daily Caller News Foundation*, February 10, 2017; "Autoimmune Encephalitis: Pathophysiology and Imaging Review of an Overlooked Diagnosis," B.P. Kelley, et al., *American Journal of Neuroradiology*, February 9, 2017

## It's all in your head...really?

Those of us in the autoimmune disease world like to think that "It's all in your head" is a comment of the past, but is it? A recent article in the *Los Angeles Times* suggests that we may need to be alert to such a quick dismissal from some physicians.

TV personality Maria Menounos was fortunate when symptoms of her nonmalignant brain tumor quickly caught the attention of a physician. The operation was successful and she has had a good recovery.

However, *LA Times* writer Emily Dwass was not so fortunate. It took four years and several doctors before she was diagnosed with the same condition experienced by Menounos. The delay caused permanent problems and made surgery more dangerous than it would have been with earlier attention. Also, after surgery, she still met with "dismissive, condescending doctors." When she was experiencing muscle spasms, a doctor said, "We don't know what's wrong with you--but we think the problem is all in your head." A nurse correctly suggested that Dwass was having a bad reaction to post-surgery steroids given to reduce brain swelling.

Doctors may fail to appreciate women's symptoms partially because medical research has focused historically on men. A 2014 Johns Hopkins University study found that women having a stroke were 30 percent more likely than men to be misdiagnosed in the emergency room.

In a study conducted by the American Autoimmune Related Diseases Association (AARDA), the number one concern among women with autoimmune disease is that doctors don't listen to them. AARDA President/Executive Director Virginia Ladd states that some 40 percent of women who eventually are found to have a serious autoimmune disease have been told by a physician that they are complainers or simply too concerned with their health.

As Dwass points out, "Elderly women have to contend with ageism on top of sexism." Her mother-in-law, in her 80s, went from doctor to doctor, trying to find an answer to severe abdominal pain, which eventually turned out to be widespread cancer. One doctor, making a note of her age, had flippantly asked, "What do you expect?" It should be pointed out that the ageism/sexism sometimes occurs with young females whose complaints may not be taken seriously.

Is there a perfect answer to this problem? What can we do? Remember "the patients themselves." We are individuals first, patients second. As such, we need to take charge of our health as much as possible.

- ◆ Observe and chart your symptoms. It's easy to forget some symptoms on a good day. Prepare an organized list to take to the physician. Even the seemingly insignificant, easily forgotten symptom may be the important one.
- ◆ Dress the part. Studies have shown that a neatly groomed person gains the respect of physician and office staff alike--the whole team.
- ◆ Act the part. See yourself as the "client," not the "patient." You are paying for professional advice, not begging. Be polite but self-respecting.
- ◆ Keep your mind on the reason for your visit. It's easy to be too chatty--probably nerves! Write your questions down in advance.
- ◆ Be honest. Don't say, "Just fine," when the physician asks how you are. Look at your symptoms list.
- ◆ Take an advocate with you if you are likely to be forgetful or shy. Let that person see your lists of symptoms and questions, but emphasize that he/she should be a silent observer unless you ask for help. That friend could take notes for you.
- ◆ Expect the doctor's attention. If he/she is concentrating on the laptop instead of giving you full attention, try to find a way for eye-to-eye contact. Many doctors still are not comfortable entering information on their computers.
- ◆ Ask questions. Make sure they are answered before you and the doctor leave the room. Don't let the "one hand on the door knob" intimidate you.
- ◆ Remember your mother's advice to say "thank you" at the end of your visit--which YOU have ended!
- ◆ If all else fails, seek a second opinion or change doctors.

These are not foolproof suggestions but ones that may help you to avoid the "all in your head" flippancy. It's hard to take charge when you are feeling really bad, but forming a bond of mutual respect with your physician--two adults working together--can benefit both of you. ■

--Source: Includes excerpts from op-ed "The 'it's all in your head' diagnosis is still a danger to women's health," Emily Dwass, *Los Angeles Times*, July 26, 2017

## New guidelines published for medication in joint replacement

The risk of joint infection, a potentially devastating complication, has remained a threat in joint replacement. Now an expert panel of rheumatologists and orthopedic surgeons has developed guidelines for the management of anti-rheumatic medication, occurring immediately before, during and immediately after surgery (perioperative

guidelines), in patients undergoing total hip or knee replacement.

Susan Goodman, M.D., co-principal investigator and a rheumatologist at the Hospital for Special Surgery, in New York City, pointed out that patients with rheumatic diseases who have joint replacement surgery are at increased risk for joint infection. She said, "As infection

risk is linked to the use of anti-rheumatic medication, our goal was to develop recommendations on when to stop medication prior to joint replacement and the optimal time for patients to restart treatment after surgery."

The study included traditional disease-modifying anti-rheumatic drugs  
 ————— Article continued on page 10

## Children, celiac, and type 1 diabetes: what connection?

A new study of young people with type 1 insulin dependent diabetes and celiac disease shows that celiac disease is more common in young people with type 1 diabetes than in diabetes-free children; but how often the two conditions occur together varies in different countries.

In type 1 diabetes, a chronic autoimmune condition typically diagnosed in children and young adults, the pancreas produces little or no insulin, a hormone the body needs to help convert blood sugar into energy for cells. In celiac disease, also an autoimmune disorder, consumption of the protein gluten in wheat, barley, rye, and non-gluten-free oats leads to damage of the small intestine that interferes with absorption of nutrients from food. About 5

percent of people with type 1 diabetes have celiac disease, compared to about 1 percent of the overall population, reports the study's lead author Dr. Maria Craig, from University of New South Wales Medicine, Kensington, New South Wales, Australia.

The researchers looked at the prevalence of celiac disease in four different registries of type 1 diabetes patients in Germany/Austria, the U.S., the UK, and Australasia. The analysis included data from 2013 and 2014 on 52,721 children and teens under the age of 18. Overall, 3.5 percent of the young people with diabetes in the study had celiac disease, and the prevalence ranged from 1.9 percent in the U.S. to 7.7 percent in Australia. Girls were more likely to have celiac disease than

boys, at 4.3 percent versus 2.7 percent, respectively.

While blood sugar control was just as good for the children with celiac disease as for those without celiac disease, the study found that children with celiac disease were likely to be shorter. Dr. Craig remarked, "While the overall difference was modest, some children demonstrated important differences in height, highlighting the importance of early diagnosis and treatment." Dr. Craig said, "Celiac disease is not uncommon in type 1 diabetes, and regular screening is important." ■

--Source: "Higher risk for celiac disease in diabetic children," Anne Harding, Reuters Health News, July 28, 2017



## Parkinson's and autoimmunity connection revealed

Researchers at Columbia University Medical Center and the La Jolla Institute for Allergy and Immunology have found the first direct evidence that autoimmunity plays a role in Parkinson's disease, a neurodegenerative movement disorder. This discovery raises the possibility that the death of neurons in Parkinson's could be prevented through therapies that dampen the immune response.

Co-leader of the study, David Sulzer, Ph.D., professor of neurobiology (in psychiatry, neurology, and pharmacology) at Columbia, says that the study shows that two fragments of alpha-synuclein, a protein that accumulates in the brain cells of people with Parkinson's, can activate the T cells involved in autoimmune attacks.

Another co-leader, Alessandro Sette, Dr. Biological Science, professor in the Center for Infectious Disease at La Jolla Institute, states, "It remains to be seen whether the immune response to alpha-synuclein is an initial cause of Parkinson's or whether it contributes to neuronal death and worsening symptoms after the onset of the disease." He indicates that the findings of the study could provide a much-needed diagnostic test for Parkinson's disease and could help identify individuals at risk or in the early stages of the disease.

Dr. Sulzer hypothesizes that autoimmunity in Parkinson's disease arises when neurons are no longer able to get rid of abnormal alpha-synuclein. He says, "Young, healthy cells break down and recycle old or damaged proteins." He points out that the recycling process declines with age and with certain diseases, including Parkinson's. Dr. Sulzer says, "If abnormal alpha-synuclein begins to accumulate and the immune system hasn't seen it before, the protein could be mistaken as a pathogen that needs to be attacked."

Dr. Sette suggests, "Our findings raise the possibility that an immunotherapy approach could be used to increase the immune system's tolerance for alpha-synuclein, which could ameliorate or prevent worsening symptoms in Parkinson's disease patients." ■

--Source: "Parkinson's is partly an autoimmune disease, study finds," Columbia University Medical Center, June 21, 2017, via Science Daily

## Clinical trials continuing for scleroderma medication

Enrollment has been completed for a Phase III clinical trial investigating the use of Actemra (tocilizumab) in patients having scleroderma (systemic sclerosis). The aim of the study, as announced by Genentech, is to assess the efficacy and safety of Actemra compared to placebo for the treatment of scleroderma.

Lead study investigator is Dinesh Khanna, M.D., M.S., Frederick G. L. Huetwell Professor of Rheumatology and Professor Internal Medicine in the Division of Rheumatology, University of Michigan, and also director of the University of Michigan Scleroderma Program.

Scleroderma, or system sclerosis, a rare and life-threatening autoimmune disease with no current FDA-approved therapy, affects approximately 75,000 to 100,000 people in the U.S. More than 75 percent of scleroderma patients are women, primarily ages 30 to 50. Scleroderma causes thickening and scarring of the skin and abnormalities in respiratory function. It also can lead to degenerative changes and scarring in the joints and internal organs.

Article continued on page 10

## Global researchers scramble to understand the celiac trend

The growing number of gluten-sensitive individuals in the United States are joining the rising number of gluten-sensitive individuals around the world while researchers and medical observers struggle to address the problem. A Denver study showed that the prevalence of celiac disease was 3 percent by the age of 15--compared with the 1 percent for the United States that was being quoted. Sweden has a rate of just over 2 percent for children born in 1997, and blood tests suggest increasing numbers of people are developing celiac disease in wheat-eating areas of northern India, with a prevalence in children of around 1 percent.

What causes people to develop the ailment in the first place remains unclear. Almost all diagnosed patients have mutations in at least one of the two genes coding for HLA-DQ, a membrane receptor on antigen-producing cells that helps the immune system distinguish self from non-self and coordinate T-cell activity--but not everyone who has such risk gets celiac.

Gastroenterologist Edwin Liu, working on clinical and genetic data, says, "Around 40 percent of people have the genes predisposing them to celiac disease. The big question is why some people get it and others don't." While many hypotheses are considered, evidence to support these ideas remain far from conclusive.

One thing researchers seem to agree on is that the direct cause of the rise in the disease likely lives outside our DNA. Dr. Liu says, "We have to assume that this is based on environmental factors." But which ones? Examples are the rising incidence of celiac disease in South Asia with the widening adoption of Westernized diets; and in Sweden, the consuming of more than 5 grams of gluten per day (equivalent of about one slice of whole wheat bread) by Swedish infants before two years of age showed them to be up to two times more likely to develop celiac disease than those consuming less than that amount.

Also now under scrutiny is humans' usage of antibiotics and, consequently, the

composition of bacteria making up the gut biome. For example, while the bacterium *Helicobacter pylori* has been associated with protection from celiac disease, declines in the number of adults carrying this microbe in their guts appear to have coincided with increases in the number of celiac cases in the U.S.

With so many factors being investigated, Dr. Liu says, "I don't think we're going to be able to find a single environmental trigger. It's going to be a combination."

Dr. Murray comments, "There are so many things going on, so many moving parts. The challenge for us as scientists is to reduce it down to testable hypotheses." He also says that it's worth remembering that celiac is a lifelong condition. "The immune system has changed."

Confusing the situation is the fact that while "gluten-sensitive" has generally been applied to those accurately diagnosed with celiac disease, the relatively new category of "non-celiac gluten sensitivity" (NCGS) is far less understood than the more familiar celiac. In fact, many scientists argue that the "gluten" in NCGS is misleading; instead, they prefer non-celiac wheat sensitivity.

Gastroenterologist Detlef Schuppan, of the Johannes Gutenberg University Mainz, Germany, and his colleagues found that another component of wheat, amylase trypsin inhibitors (ATIs), can trigger an innate immune response in humans and mice. This result, the researchers noted, could explain gastrointestinal symptoms in people with "so-called gluten sensitivity," as well as potentially exacerbating celiac disease itself.

In the meantime, while scientists and researchers test hypotheses and experiment with various drugs, parasites, etc., where does this leave the celiac and other wheat-sensitive sufferers? University of Sheffield, UK, celiac researcher Dr. David Sanders remarked, "Every single day, this problem is right in front of [them]." And so the challenge remains.

--Source: Excerpted from "The Celiac Surge," Catherine Offord, *The Scientist*, June 1, 2017

## Nanomedicine study reported from Calgary

The search for cures for autoimmune disease is exploring the field of nanomedicine. Researchers at the University of Calgary, Alberta, Canada, say that their work in nanomedicine could lead to cures for type 1 diabetes, multiple sclerosis, and many more diseases. Researcher Dr. Pere Santamaria, professor of immunology at the University of Calgary, says that the process involves "nanoparticles," thousands of times smaller than a typical human cell, that could be used to stop the body from attacking itself as it does in autoimmune disease.

Dr. Santamaria says, "There are no drugs that can do that today." He adds, "Other drugs that are being used to treat chronic inflammatory disorders impair the ability of the immune system to do its job, so there are secondary effects and long-term complications...our drugs don't do that."

Dr. Santamaria says that the nanoparticles were discovered during an experiment years ago, and the initial test results "made no sense whatsoever." Since that day, the nanomedicines have been in development, and he credits the progress to curiosity. He comments that the process of taking a discovery from the research laboratory to the marketplace is enormously complex, and the drug has yet to go through preclinical trials. "Our nanomedicine is a new class of drug...so we're basically blazing the trail." ■

--Source: Excerpted from "Blazing the trail: University of Calgary research could lead to cures for autoimmune diseases," CBC News, August 2, 2017

### ~ EDITOR'S NOTE ~

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#### New guidelines continued from page 7

(DMARDs), biologic agents, tofacitinib, and glucocorticoids. The panel developed guidelines on when to continue, when to withhold, and when to restart these medications, as well as the perioperative dosing of corticosteroids.

Main recommendations included that (1) non-biologic DMARDs may be continued throughout the perioperative period in patients with rheumatoid arthritis, spondyloarthritis, juvenile idiopathic arthritis, and lupus, undergoing elective hip or knee replacement; and (2) biologic medications should be withheld as close to one dosing cycle as scheduling permits prior to elective hip or knee replacement and restarted after evidence of wound healing, typically 14 days, for all patients with rheumatic diseases.

--Source: "Expert Panel Publishes Guidelines for Medication Management in Rheumatic Disease Patients Having Joint Replacement," *Hospital for Special Surgery*, June 16, 2017

#### Clinical trials continued from page 8

Jeffrey Siegel, M.D., global head of Rheumatology and Rare Diseases at Genentech, comments, "We hope the Phase III trial results will show that treatment with Actemra not only shows improvement in skin thickening over time, which is crucial for these patients, but also the preservation of lung function." ■

--Source: Excerpted from "Genentech Completes Phase III Enrollment for Study of Actemra in Systemic Sclerosis," *Nina Wahl, Centron, for Genentech*, August 9, 2017

## With Special Thoughts...

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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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