Chronobiology: Isn’t it time to benefit from it?

For at least 60 years, the value of circadian rhythm in timing medications to the body's internal clock to improve their effectiveness and reduce side effects--chronobiology--has been studied. However, even though it is known that hormones and immune signals are produced rhythmically in 24-hour cycles, chronobiology has received little attention from physicians. Perhaps that is changing as, according to chronobiologist Dr. John Hogenesch, of the University of Pennsylvania, the idea “is not coming from left field any more.” He is referring to a 2014 study for which he was senior author. “Now we have the groundwork to precisely understand a person’s clock and leverage that information for better health,” he explains.

The human body undergoes daily cycles in gene expression, protein levels, enzymatic activity, and overall function. The suprachiasmatic nucleus (SCN), the seat of the brain’s timekeeping machinery, sets the pace for neuronal and hormonal signals that regulate body temperature, feeding behavior, rest or activity, immune cell functions, and other daily activities.

In the 2014 study of gene expression in mice, Dr. Hogenesch and colleagues found periodic expression in conserved mammalian genes targeted by 56 of the top 100 best selling drugs in the U.S. These included Abilify, an antipsychotic; Nexium, for heartburn; and Cymbalta, for depression. Most are not currently prescribed with suggested dosing times.

Clinical trials in 1985 found that antihistamines were most effective when taken at night instead of in the morning. Other studies showed that inhaling corticosteroids at bedtime, or using delayed-release prednisone formulations that allocated the medication to the body pre-dawn, were most effective at combating allergy symptoms.

Given the fact that blood pressure tends to decline at bedtime and rise early in the morning, some (not all) blood pressure medications are better taken at night. For example, a 2009 study showed that patients with high blood pressure were better able to control their blood pressure and cardiovascular symptoms by taking angiotensin receptor blockers at night instead of in the morning.

In 2007, AARDA Scientific Advisory Board member Maurizio Cutolo, M.D., of the University of Genova, Italy, wrote: “General clinical experience supports that disease-related symptoms in patients with chronic inflammatory disorders exhibit circadian, approximately 24-hour, rhythms.” He said that to develop a therapeutic advantage in rheumatoid arthritis management (and other forms of arthritis) from the respect of circadian rhythms, the best time for the corticosteroid replacement therapy should be around 2:00 or 3:00 a.m. Dr. Cutolo said that timed corticosteroid administration seems to lead to a really significant reduction of rheumatoid arthritis-related symptoms in the early morning.

A recently reported study from researchers at the University of Birmingham, UK, observed effectiveness of flu vaccinations in 300 healthy men and women over the age of 65. They received their vaccinations between either 9 a.m. and 11 a.m. or 3 p.m. and 5 p.m. Blood drawn a month later revealed that the participants had higher levels of anti-flu antibodies if they had received their vaccinations in the morning. The results suggested that daily rhythms of people’s bodies tweaked the vaccine’s effectiveness.

Experimental data have studied short-acting cholesterol drugs, such as simvastatin (most effective taken at bedtime); chemotherapy for ovarian, endometrial, or metastatic bladder cancer (best results, doxorubicin at 6 a.m. and cisplatin 12 hours later). But oncologist and biomedicine professor Dr. Francis Levi, at the University of Warwick, UK, says that circadian-based chemotherapy shows benefits for only approximately half of patients in trials. One possible influence is gender, he says.

Dr. Anna Phillips Whittaker, lead author of the University of Birmingham study, suggests that age may play a role. Also, a group of Israeli scientists suggest that another factor could be genetics.

It is generally agreed that synchronizing medications to the circadian clock is easier said than done since not everyone’s rhythms are the same. However, Dr. David Spiegel, a Stanford University psychiatrist, says, “We’ve learned enough now to know that there are relatively easy-to-do, low-risk things that may have an effect on disease outcomes.” He says, “If you normalize your circadian rhythms, you’ll certainly feel better, and you might just help your body.” Dr. Spiegel adds, “I’d be surprised if there were any disease that didn’t have some circadian component.”

Dr. Hogenesch says, “It’s very likely that drugs have failed not because they didn’t work or the mechanisms were wrong, but simply because time of administration wasn’t taken into account.” He says that a little timing could even rescue drugs that “fell off the path to the clinic somewhere along the way.”

To chronobiologists, time is an often-overlooked aspect of precision medicine’s mantra of finding the right drug for the right patient at the right dose. Dr. Hogenesch says, “Time offers another way to be precise, and now the groundwork exists to precisely understand a person’s clock and leverage that information for better health.”

--Sources: “Circadian Rhythms Influence Treatment Effects,” Jyoti Madhusoodanan, The Scientist Magazine, April 1, 2017; and “Circadian rhythms in arthritis - what are the implications for RA Management,” Maurizio Cutolo, M.D., AARDA InFocus, June 2007
Dear AARDA Friends,

With hardly a pause, we have completed our 25th Anniversary acknowledgments and celebrations. Now we are heading into our 26th year with enthusiasm for projects underway, e.g., the start-up of ARNet, the first worldwide registry for autoimmune disease patients, and with gratitude for all of AARDA’s supporters who share our mission.

Education, research, awareness, and advocacy—all are intertwined in some way. The Autoimmune Summit at the National Press Club, in March, was a good example as we reached not only congressional staff members but interested patients and friends. We thank keynote speakers Haley and Barbara Ramm who very effectively presented the patient and family perspectives of coping with autoimmune diseases. We are grateful to them, and we also appreciate the active, very valuable involvement of our friends in the National Coalition of Autoimmune Patient Groups (NCAPG).

Another good example of a combined activity is the “AARDA Motor City Charity Fundraiser,” scheduled for June 3, before most of you see this newsletter. This event, being held at the Detroit Athletic Club, will be a gala evening introducing AARDA’s message to a wide audience during the Detroit Grand Prix which brings guests and participants from many countries around the world.

In the planning stage is the AARDA-sponsored scientific colloquium “Infection and Autoimmune Disease” to be held in Washington, DC, on Saturday, October 14. This is being organized by Dr. Noel Rose.

Not forgotten is the plan being designed to achieve major funding for a National Autoimmune Diagnostic and Treatment Center. The AARDA Board of Directors sees this as a major undertaking. In a running start, prompted by my own dream and initial donation, this is being encouraged by our members and friends who have been supporting the cause on an impromptu basis through contributions to our grassroots “Acorn’s Promise” (growing but not yet ready to burst into a tree!). I invite YOU to join us in our vision.

On a high energy note, a number of you are registering with your friends for participation in the Autoimmune Walks scheduled for several locations around the country (see article in this newsletter). If you can’t participate by walking, you may want to support a walker—or simply show up on Walk day for the camaraderie. Another idea: go to our Web site and participate in our Virtual Walk program (see article in this newsletter). These Walks provide an excellent source of funding for AARDA projects, not to mention the autoimmune awareness and education value. To our Walkers and organizers, I say “thank you” on behalf of the many autoimmune patients who will benefit from your dedication. Enjoy!

From all of us at AARDA, I send this note of appreciation to all of you who support AARDA’s mission in some way—large, small, all important.

Best wishes to all,

Virginia
Let food be your medicine. So goes an ancient maxim. But which food? Individuals with serious health issues, such as autoimmune disease, grasp hope offered by promising diet plans.

Perhaps one of the newest plans offered to autoimmune patients is the Autoimmune Protocol Diet (AIP), touted widely on the Internet as promising the reduction of intestinal inflammation, healing of intestinal mucosa, and lessening of inflammation throughout the body. It is a very restricted diet; and proponents recommend combining diet and gut-healing treatment for bacterial overgrowth of the small intestine, where indicated, plus supplements for boosting immunity. However, credentialed nutritionists caution against the AIP diet as well as other very limited eating plans which may be nutritionally unbalanced and need close dietary supervision.

In planning a healthful diet, counselors generally look first to a system of determining foods that may cause an adverse reaction. This may be a blood test to determine food sensitivities and allergies, or it may be an elimination diet in which the patient eats only those foods that are not likely to cause an adverse reaction and then gradually reintroduces certain foods to ascertain foods that are best tolerated. Elimination diets are difficult and sometimes harmful to follow without the help of a health professional.

Nutritionist Mindy Hermann, M.B.A, R.D.N, writes, “Increasingly, research is connecting bacteria in our body with health and illness. The microbiome, or microbiota, the bacteria living in the large intestine, plays a major role in immune function and health.” She points out that 70 percent of the body’s immune system is located in the intestinal tract and says that the microbiota form a protective layer or barrier in the intestine to protect the body from ingested allergens and harmful bacteria, viruses, and parasites.

Hermann says, “An unhealthy or unbalanced microbiota may contribute to inflammation and is thought to exacerbate the development of autoimmune diseases. Harmful bacteria carry and produce toxins that can damage the protective mucus layer in the intestine, make the intestine more permeable and possibly trigger autoimmune disorders.” However, researchers are still not sure whether harmful changes in the microbiome lead to autoimmune disorders and whether inflammation causes changes in the microbiome.

Maintaining gut health may be assisted in various ways. Prebiotics are important; they feed beneficial bacteria in the large intestine. Foods that contain prebiotic fibers include chicory root (its fiber is called inulin), Jerusalem artichoke, garlic, leek, onion, and dandelion greens. Resistant starch (from raw oats, potatoes, cashews, and supplements) functions as a prebiotic.

Prebiotics also feed probiotics, live bacteria that are beneficial bacteria strains not native to the human gastrointestinal tract that convey specific health benefits. These can be obtained from some foods, such as yogurt (be sure to read ingredients) or fermented foods. Also, probiotic supplements are available; but as Noel R. Rose, M.D., Ph.D., of Brigham and Women’s Hospital and Harvard Medical School, cautions, “None of these probiotics has yet been tested scientifically for safety and efficacy.”

Susan Blum, M.D., M.P.H, points out that when the amount of healthy bacteria in the gut is too low, a condition called dysbiosis occurs. The severity of dysbiosis can cause a lot of intestinal symptoms. Since these changes in gut flora have profound effects on the immune system’s first and second lines of defense, it is not surprising that an imbalance has been linked to autoimmune diseases. Researchers at the University of Arizona College of Medicine recently found good evidence that dysbiosis plays a role in rheumatoid arthritis and, in animal studies, multiple sclerosis.

A gluten-free diet may benefit some individuals who are sensitive to gluten, a protein found in wheat, barley, kamut, spelt, and rye (and oats unless labeled gluten-free). Kate Scarlata, a registered dietitian nutritionist, points out that some people are sensitive to components in wheat other than gluten, including glucose, fructans, or amylase inhibitors. Gluten may appear in many products, e.g., soy sauce (wheat) and beer (barley).

Omega-3 fatty acids, found primarily in fatty fish and fish oil as well as in a less potent form in walnuts, flaxseed, and chia seeds, have been shown in animal studies possibly to improve autoimmune disorders. The 2015 Dietary Guidelines for Americans recommends two weekly servings of fish, for an average of about 250 mg/day EPA plus DHA omega-3 fatty acids.

Also not proved but of interest is capsaicin (e.g., chili peppers and hot sauce) which activates the vanilloid receptor. This may enhance immune status and improve particular immune functions.

Scarlata advises moderation over extremes and suggests supporting immune health with food sources of omega-3s (nuts, seeds, leafy greens, fish, legumes, whole grains), less saturated fat, and fewer food additives. Blum strongly suggests eliminating sugar and white flour. Nutrients associated with a strong immune system include vitamins A, E, and possibly D, which still is being studied, as well as some trace minerals.

Certainly autoimmune diseases and their treatment can adversely affect nutrition; and in some cases, individual, multiple, or multi-nutrient supplements may be the best option for improving nutrient intake.

As Hermann points out, “The ultimate goal is to balance nutritional adequacy with gut comfort and, hopefully, immune benefits.”


**Quote to ponder and enjoy...**

“If we believe that what we know now is nearly all we will ever know, we will be unable to imagine the surprises tomorrow will bring.” -- Michael D. Lockshin, M.D.
We say “farewell” to Carolyn

Dear friend, beautiful person, and super volunteer Carolyn Ugval, one of the volunteers featured in our “#Autoimmune Heroes for March & April,” passed away suddenly from a stroke on April 25. Such a loss to all of us--but what memories she leaves!

Carolyn's love and enthusiasm reached out in all directions, usually with a bubbling, hearty laugh. Her family, her friends, her church, and, yes, even the local merchants who were charmed into donating items or money for fund raisers of her favorite charities are missing her.

Many AARDA members who never met Carolyn continue to benefit from the autoimmune awareness and financial support she generated through her years of work with AARDA’s annual fundraising committee. Guests at AARDA’s events may remember Carolyn’s energetic involvement as chair of the silent auctions during those years, and she cheerfully was gathering items for AARDA’s May 20 “Return to Downton” tea.

Carolyn is survived by her four sons Tony, Tom, Jon, and Mike; her daughters-in-law Kristin and Anne; and grandchildren Evelyn, Jack, and Tommy. She also leaves behind siblings Deanna Radtke, Sharon Dettmer, and Tom Nix as well as other dear family members and many friends, including her AARDA family.
The quandary of modern medicine vs. natural therapies

Both the physician and the patient may struggle with the challenge of choosing preferred treatment when the patient wants to try an alternative route while the physician is certain that to delay conventional treatment will lead to further damage. What to do?

Sharon Lolasinski, M.D., a rheumatologist and specialist in complementary and alternative medicine at the University of Pennsylvania, says that if a patient is committed to pursuing non-traditional therapies, he/she should be educated about the potential consequences of the choice, including possible adverse reactions with medicines. Especially in the case of an autoimmune disease, such as rheumatoid arthritis, Dr. Lolasinski points out that patients have received a life-long diagnosis. They want to have some control which they believe is promised by natural therapies.

Dr. Lolasinski advises that a timeline be established. No natural therapy should be implemented indefinitely. Decide upon an appropriate time frame—a week, a month or several months. Then evaluate whether the natural therapy has been successful. Dr. Lolasinski says, “If a patient’s outcomes aren’t different after the test period, then they need to stop trying it.”

It is true that some standard treatments can be associated with adverse effects in some patients. However, irreversible damage due to uncontrolled rheumatoid arthritis, for example, can be the consequence of delaying treatment with established and proven therapies.

In the meantime, researchers continue to explore the benefits of alternative and complimentary therapies. For example, studies show that tai chi and yoga are effective in improving physical function in many adults with rheumatoid arthritis and fibromyalgia. Another study shows that the combination of chondroitin sulfate and glucosamine hydrochloride supplements is comparable to celecoxib in reducing knee pain in osteoarthritis.

Patients must be warned that few herbal supplements or natural therapies have been tested and vetted through the clinical trials process. That’s not to say alternative therapies shouldn't be used as adjuvant therapies approved by the attending physician; in fact, some have proven therapeutic effects.

Dr. Lolasinski advises physicians to avoid being judgmental about the patient’s choice. Try to find common ground that will address the patient’s concerns and wants while effectively controlling the disease.

--Source: Adapted from “When the Patient Insists on Natural Therapies,” Whitney L. Jackson, Rheumatology Network, March 17, 2017

AARDA Memorial / Tribute Program
Write or call us for full details of this program. It can be handled by mail or by phone using Visa, MasterCard, or American Express. Memorial and Tribute contributions bring great satisfaction to donors AND to the recipients (or their families). They also help greatly in our ongoing fight against all autoimmune diseases.

American Autoimmune Related Diseases Association
22100 Gratiot Avenue, East Detroit, MI 48021-2227 Phone: (586) 776-3900 • www.aarda.org

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.

Autoimmune Walk
LINKING TOGETHER FOR A CURE

Yes! AARDA friends are walking. Here is the current schedule. These are great friend-building events that raise local autoimmune awareness while raising needed funds in support of AARDA’s mission. What can you do? Form your own team, join a team (receive a warm welcome), or bring your chair, cheer the walkers, and maybe contribute a dollar or so in support of a walker.

• Bowling Green, KY - Saturday, July 8 - Ephram White Park
• New York (Manhattan), NY (formerly Tri-State) - Sunday, September 10 - Hudson River Park
• Arlington, VA (DC Metro) - Saturday, September 16 - Bluemont Park
• Detroit, MI (Metro Detroit) - Saturday, September 30 - Lake St. Clair Metro Park
• Los Angeles, CA - Saturday, November 18 - Culver City Park

Want more information? Go to www.AutoimmuneWalk.org or call the AARDA office at 586-776-3900 and ask for Walk Coordinator Deb Patrick.

P.S. - Have you heard of a Virtual Walk? Even if you can’t join an on-site walk, you can join the fun. Collect a few friends into your own Virtual team (you have the right to be the Captain, of course), let Deb Patrick know that you are forming a team (don’t forget to choose a name), and then look for your Virtual Walk Kit from AARDA. Deb will send you a T-shirt, Walk bibs for your team members, registration forms for off-line registrants, and “Linking for a Cure” wristbands for your team members.

Online registration allows individuals and teams to participate whether they’re sitting in their living rooms, working out at the gym, or having coffee at the local bistro.

One spectacularly successful Virtual Walk team, Vanessa’s Warriors, raised more than $2,000. Even though Hashimoto’s thyroiditis and Sjögren’s syndrome kept Vanessa Caine from walking, it didn’t stop her and her friends from participating.

Need help getting started? Contact Walk Coordinator Deb Patrick at 855-239-2557 or dpatrick@aarda.org for directions.
Anorexia nervosa and celiac disease--a connection?

Even though celiac disease (CD), a condition requiring a gluten-free diet, and anorexia nervosa (AN), an eating disorder, have different origins, Swedish scientists have found an unexpectedly strong link between the two illnesses. A recently published study shows that women with celiac disease are at an increased risk of being diagnosed with anorexia, either before or after the celiac diagnosis is made. The researchers point out that although the vast majority of anorexia occurs in women, the disease can occur also in men.

Celiac disease is an autoimmune disorder in which ingesting gluten damages the small intestine, whereas anorexia is an eating disorder in which patients severely restrict their food intake and experience distorted body image. Either disease, if allowed to progress, can be life-threatening.

Stanford University pediatricians Neville Golden, M.D., and K.T. Park, M.D., note that since both diseases have similar gastrointestinal symptoms, patients with one condition may be misdiagnosed initially with the other. Also, certain genes may confer susceptibility to both diseases, or some element of one disease may increase the risk for the other.

Both diseases focus on some element of eating. Dr. Golden writes, “Not infrequently, an eating disorder begins with well-meaning, self-imposed attempts to ‘eat healthily’ by eliminating foods perceived to be unhealthy. The present study suggests that excessive focus on diet in patients with celiac disease may lead to anorexia nervosa in susceptible individuals.”

Doctors Golden and Park remark on the new wave of interest in gluten-free diets. They say, “Interest in going gluten-free is increasing, particularly in adolescent female subjects, with one in five Americans attempting to restrict daily gluten intake. The interaction between gluten-free diets and eating disorders is an even larger issue.” They note that this important study is “only the tip of the iceberg.”

Swedish researchers state, “This nationwide study found a positive association between CD and AN both before and after CD diagnosis. This bidirectional association should encourage physicians to closely monitor these patients and calls for heightened understanding of factors that contribute to their co-occurrence.” They point out that an English study including hospitalized anorexia patients found a significant threefold increased risk of later celiac diagnosis and a twofold risk increase for anorexia in celiac patients.

The researchers indicate that the two diseases can complicate each other. Having anorexia nervosa makes it hard to follow a gluten-free diet, and some anorexia patients knowingly consume gluten-containing products to lose weight.

The Swedish researchers emphasize that as the two illnesses may mimic each other, the misdiagnosis of either disorder likely causes “protracted and unnecessary morbidity.” They caution, “The bidirectional association between diagnosis of AN and CD warrants attention in the initial assessment and the follow-up of women [and men] with these illnesses.”


A book to consider...

For those wanting a view of real-life lupus battles, this is a book of choice. Author Kayrene Mimms, in her book Fighting Lupus Battles: Hope For A Cure, presents “True Stories From Lupus Warriors.”

While this is a book about lupus, the stories offer real-life views of the challenges and victories of dealing with the uncertainty met in the treating and living with autoimmune diseases.

As a family member wrote, “That’s the thing about lupus and other autoimmune diseases--the symptoms can be so subtle and unpredictable that you don’t know what’s happening. As a family member or someone watching from the outside, it’s easy to be dismissive because the symptoms are often hard to see.” She said, concerning her sister, “I remember jokingly calling her a hypochondriac because it seemed like there was always something wrong. In hindsight, it was likely the disease manifesting itself over a longer period of time than any of us realized....”

Starting with her own first experience with one of the 100+ autoimmune diseases, lupus, Mimms then gives a general view of the disease: What is lupus? What causes lupus? Is there more than one type of lupus? What are the most common symptoms? Is lupus easy to diagnosis?

The opening explanation is followed by stories written by individuals affected by lupus, through having lupus attack them or afflict dear ones. They describe shock, disbelief, pain, searches for correct diagnoses and proper medical care, and eventual acceptance and plan of action.

As one man wrote, “After leaving the hospital, the journey of learning how to cope and adjust to life with lupus began.” He said, “It took me quite some time to find the balance of how to function in the world while dealing with lupus flares.”

One of Mimms’ doctors said, “As a primary care doctor, it’s hard, yet quite rewarding and challenging in a good way, to take care of patients with rheumatologic disorders like lupus because (a) it affects nearly every organ system, and (b) just about everybody has multiple systems that need to be waded through. Certain symptoms can be followed, whereas, other ones need to be looked into and treated aggressively.”

Arizona research center explores possible autoimmune triggers

The National Institutes of Health (NIH) has awarded a five-year, $1.73 million grant to the University of Arizona Steele Children’s Research Center to determine what triggers autoimmune disease. While the research is focused on inflammatory bowel disease (IBD), which includes Crohn’s disease and ulcerative colitis, the research is relevant not only to IBD but to many other autoimmune diseases.

Dr. Pawel Kiela, associate professor, Department of Pediatrics, at the Steele Center, says, “In this study, we essentially are asking what happens during the very early stages of an autoimmune disease. How does autoimmune disease develop?”

Dr. Fayez K. Ghishan, professor and head, Department of Pediatrics, and director of the Steele Center, explains that the study will explore the role of immune cells known as dendritic cells, specialized cells of the immune system. They make the immune system “tolerate” harmless antigens, an action known as “immune tolerance” which is necessary to keep the body from making an immune attack on itself.

Dendritic cells also instruct the immune system to respond to and destroy foreign pathogens, and the researchers are curious about what triggers those cells to launch an immune response against normal cells, resulting in autoinflammatory disease, rather than maintaining tolerance. They hope that their research will identify new targets for potential therapeutic approaches that could restore tolerance in patients with autoimmunity or for disease prevention in patients with clear genetic predisposition.

“Steele Children’s Research Center Receives $1.73M Grant,” Dr. Fayez K. Ghishan, December 6, 2016

New drug for pemphigus vulgaris in trials

Genentech has announced that the Federal Drug Administration (FDA) has granted Breakthrough Therapy designation status to Rituxan (rituximab) for the treatment of pemphigus vulgaris, an autoimmune disease. The designation was based on data from a Phase II study, and Genentech is currently enrolling a Phase III study in pemphigus vulgaris.

FDA Breakthrough Therapy designation is intended to expedite the development and review of medicines with early evidence of potential clinical benefit in serious diseases and to help ensure that patients receive access to medicines as soon as possible. The current standard of care includes high doses of corticosteroids taken for several weeks and corticosteroids in combination with the off-label use of corticosteroid-sparing immunosuppressive drugs for many months. These can cause significant long-term side effects.

Pemphigus vulgaris is the most common type of a group of autoimmune disorders collectively called pemphigus. It is a painful, disfiguring, and potentially fatal disease characterized by progressive blistering of the skin and/or the mucous membranes. Pemphigus vulgaris affects women and men equally and occurs primarily in adults ages 40-60. It is estimated that from 0.1 to 2.7 people out of 100,000 are diagnosed with pemphigus vulgaris.

“FDA Grants Breakthrough Therapy Designation to Rituxan for Life-threatening Skin Disease,” Kyle Owens, Centron Public Relations, March 27, 2017; and “FDA Grants Breakthrough Therapy Designation for Rituxan (Rituximab) in Pemphigus Vulgaris,” Allison Neves, Genentech, March 23, 2017

Annual Report FY 2016 available

To obtain a copy of the AARDA Annual Report FY 2016, go to www.aarda.org.
For those who don’t have access to the Web, you may call the AARDA office (586-776-3900) to request a copy.

New treatment announced for giant cell arteritis

Adults with giant cell arteritis (GCA), also known as temporal arteritis, now have, for the first time in 50 years, an advancement in the treatment of the disease as the Federal Drug Administration (FDA) has approved the medicine Actemra (tocilizumab). Until now, the most common way to treat giant cell arteritis has been with a high-dose, long-term steroid regimen.

Vasculitis is an autoimmune condition in which the body’s blood vessels become inflamed. In giant cell arteritis, blood vessels throughout the body, including behind the eyes, can be affected. In fact, as many as 20 percent of people with the disease may suffer permanent vision damage.

Giant cell arteritis is often difficult to diagnose because of the wide and variable spectrum of signs and symptoms. It can cause severe headaches, jaw pain, and visual symptoms. Due to the variability in symptoms, complexity of the disease, and disease complications, people with giant cell arteritis often are seen by several physicians, including rheumatologists, ophthalmologists, and neurologists.

An estimated 228,000 Americans over the age of 50 have giant cell arteritis, and women are three times more likely than men to be affected with the disease.


Newsworthy links:
- Genentech (www.facebook.com/Genentech)
- Genentech (www.twitter.com/Genentech)
- Genentech (www.youtube.com/Genentech)
- AARDA (www.facebook.com/AARDA)
- AARDA (www.twitter.com/AARDA)
- AARDA (www.youtube.com/AARDA)

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YouTube (www.youtube.com/AARDA)
Celiac disease: what triggers it?

New research at the University of Chicago and the University of Pittsburgh School of Medicine suggests that a common but otherwise harmless virus can trigger the immune system response to gluten and lead to celiac disease. This prompts the possibility that vaccines could be used in the future to prevent the development of autoimmune disorders such as celiac disease and type 1 diabetes.

Celiac disease is an autoimmune disorder that affects 1 in 133 people in the U.S. although it is believed that only 17 percent of those have been diagnosed. In The Autoimmune Connection, authors Rita Baron-Faust and Jill Buyon, state that, in the United States, the low rate of diagnosis is “partly because some physicians may not be aware of celiac and because the symptoms are so varied.” They state, “While men and women are affected, women are diagnosed three times more often than men, partly because the symptoms are similar to irritable bowel syndrome and partly because women tend to visit doctors more often, so there’s more opportunity for a diagnosis.”

Celiac damages the small intestine, causing a state of chronic inflammation, and interferes with absorption of nutrients. Celiac is generated by an improper immune response to the protein gluten found in wheat, rye, barley, spelt, kamut, rye, and sometimes oats (unless labeled gluten-free). The only effective treatment (no cure) is a gluten-free diet.

Study senior author Bana Jabri, M.D., Ph.D., in referring to the newly reported research, says, “This study clearly shows that a virus that is not clinically symptomatic can still do bad things to the immune system and set the stage for an autoimmune disorder, and for celiac disease in particular.” He adds, “However, the specific virus and its genes, the interaction between the microbe and the host, and the health status of the host are all going to matter as well.”

Terence Dermody, M.D., working in collaboration with Dr. Jabri and colleagues, says, “We are now in a position to precisely define the viral factors responsible for the induction of the autoimmune response.”

The study suggests that infection with a reovirus, one of the viruses found in the respiratory and digestive tracts of apparently healthy persons, could be a key initiating event for developing celiac. For example, babies who are given their first solid foods, often containing gluten, and weaned from breastfeeding around six months of age have immature immune systems that make them susceptible to viral infections at this stage. For those genetically predisposed to celiac disease, the combination of an intestinal reovirus infection with the first exposure to gluten could create the right conditions for developing celiac.

The researchers are investigating the possibility that other viruses can trigger development of complex immune-mediated diseases. This raises the possibility that vaccines targeting viruses infecting the intestine could be used to protect children at risk for celiac and other autoimmune disorders.

Dr. Jabri says, “...once we have more studies, we may want to think about whether children at high risk of developing celiac disease should be vaccinated. ■

--Sources: Adapted from “Seemingly Innocuous Virus Can Trigger Celiac Disease,” University of Chicago Medical Center, April 3, 2017, via Newswise; and The Autoimmune Connection, Rita Baron-Faust, MPH, CHES, and Jill P. Buyon, M.D., McGraw-Hill Education

Autoinflammatory or autoimmune?

Autoinflammatory diseases represent a relatively new category of conditions which shares with autoimmune diseases the fact that both kinds of diseases happen when the immune system attacks the body’s own tissues. However, they occur by different processes.

The immune system has two parts, the acquired and the innate immune systems. The acquired (or adaptive) component develops over time. It produces antibodies that “remember” invaders and can fight them if they return. The more primitive innate (or inborn) immune system causes the heat, redness, and swelling that are associated with acute inflammation. In autoinflammatory diseases, the innate immune system reacts uncontrollably and for unknown reasons.

Researchers from the National Institutes of Health (NIH) and from around the globe played a vital role in differentiating between the two groups of diseases, discovering the molecular causes for autoinflammatory disease and identifying and testing treatments. Research findings in 1997 and 1999 led the NIH investigators to propose the term “autoinflammatory disease” to distinguish these diseases from autoimmune diseases. Since then, investigators around the globe have uncovered the genetic basis for approximately three dozen autoinflammatory diseases.

Studying autoinflammatory diseases has revealed the inner workings of the innate immune system, and rare autoinflammatory diseases are teaching about the innate immune system’s role in more common diseases. For example, the study of one disease targeting children is providing insights about lupus, an autoimmune disease.

For more information, go to http://www.niams.nih.gov/Health_Info/Autoinflammatory/

--Source: "Rare Autoinflammatory Diseases Research: Saving Lives, Giving Hope to Families," National Institutes of Health, Office of Science Policy

Patient Resource List available

While AARDA doesn’t have resources to provide funds for patient or prescription assistance, a list of organizations that may be able to provide help has been compiled. The list is not extensive, but it may be a good starting point for those looking for resources. Please note that AARDA is not affiliated with any of these organizations and it does not provide any endorsements.

To receive a copy of the list, contact the AARDA office via phone (586-776-3900), e-mail(aarda@ aarda.org), or Web site (aarda.org/ who-we-help/patients/patient-prescription-assistance/). ■
Researchers at Oregon State University College of Science conducted a study on triclosan, an antimicrobial and antifungal agent found in many consumer products ranging from hand soaps to toys to toothpaste and to kitchen utensils, to name a few. It is found to be easily absorbed through the skin and gastrointestinal tracts and has shown up in breastmilk.

As one of science’s answers to the concern of microbial pathogens, triclosan was used first as a hospital scrub in the 1970s and continues to be used in medical settings. Now it is one of the most used antimicrobial agents in the world.

The study of triclosan and its effects has shown that it can rapidly disrupt bacterial communities found in the gut. Is that a totally good thing? A growing awareness of the importance for human health of the bacteria in our gut microbiome and the concern for the overuse of antibiotics that lead to the rise in our gut microbiome and the concern for overuse of these agents are valid.

The researcher said that while some chemicals, metals, preservatives, microbes, and nutrients to which humans are exposed are beneficial, or perhaps just innocuous, others are harmful. Part of the strength of the present study is developing improved ways to more easily determine which compounds may be acceptable and which are toxic.

--Source: “Common Microbial Agent Rapidly Disrupts Gut Bacteria,” Oregon State University, May 23, 2016, via Newswise

Another reason for vitamin D supplementation?

Acute respiratory tract infections are responsible for approximately 10 percent of ambulatory and emergency room visits in the United States; and in 2013, an estimated 2.6 billion deaths internationally were attributed to acute respiratory tract infections. A study conducted at Queen Mary University of London, UK, reveals the value of vitamin D in the fight against these infections.

The research team, led by Adrian Martineau, Ph.D., says, “Our study reports a major new indication for vitamin D supplementation.” He says, “Our results add to the body of evidence supporting the introduction of public health measures such as food fortification to improve vitamin D status, particularly in settings where profound vitamin D deficiency is common.”

To date, observational studies have shown an association between low serum levels of 25-hydroxyvitamin D and risk of developing acute respiratory infections. It is recognized that 25-hydroxyvitamin D supports induction of antimicrobial peptides in response to bacterial and viral stimuli.

In the study, which included in the final analysis 11,321 participants ages 0 to 95, it was found that baseline vitamin D status and dosing frequency modified the relationship between vitamin D supplementation and acute respiratory tract infections. Age was not a factor.

Does everyone need vitamin D supplementation? A blood test can determine one’s current vitamin D level, and consultation with a health care professional can give guidance as to the amount of supplementation needed.

--Source: Adapted from “Can Vitamin D Prevent Respiratory Tract Infections?” Aisha T. Langford, PhD, MPH, Rheumatology Network, February 27, 2017

Cow’s milk and thyroid medication a poor mix

A recently reported study shows that taking levothyroxine with cow’s milk interferes with proper absorption of the medication. Levothyroxine is prescribed for patients with hypothyroidism, an underactive thyroid, to replace the natural thyroid hormone thyroxine (T4) that is too low or for patients with thyroid cancer in order to suppress their thyroid stimulating hormone levels.

Principal investigator Deborah Chon, M.D., commented, “These findings support previous research showing that calcium supplements can interfere with levothyroxine absorption.” Although it makes sense that milk, which contains calcium, might interfere with levothyroxine absorption, no study prior to this latest study has proved that it does, according to Dr. Chon who is an endocrinology fellow at the University of California Los Angeles David Geffen School of Medicine and the Veterans Affairs Center, Greater Los Angeles Healthcare System.

The manufacturer of a brand of levothyroxine recommends that the medication be taken preferably on an empty stomach, 30 to 60 minutes before eating food or taking other medications or vitamins.

--Source: “Cow’s Milk Interferes with Absorption of Thyroid Supplement Levothyroxine,” Endocrine Society, March 31, 2017, via Newswise

~ EDITOR’S NOTE ~

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