INFOCUS

American Autoimmune Related Diseases Association, Inc.

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

Vol. 26, No. 2, June 2018

The acorn has sprouted! National autoimmune center announced!

All of AARDA's Acorn contributors who put their dollars on the line with faith that "from tiny acorns grow mighty oaks" can rejoice with all AARDA friends that AARDA's dream of a place to send autoimmune patients for accurate diagnosis and proper treatment, plus facilities for cross-specialty autoimmune research, is becoming reality. This was a goal of AARDA founder Virginia Ladd at AARDA's very beginning, and AARDA's Board of Directors joined her in this goal in 2015 when they established a fund toward instituting such a center.

Virginia Ladd and the AARDA Board of Directors are proud to announce AARDA's collaborative partnership with Allegheny Health Network and its new Autoimmunity Institute, with its hub at West Penn Hospital, in Pittsburgh, Pennsylvania. The Institute, headed by Chair Joseph M. Ahearn, M.D., is focused on integrated multispecialty care and multidisciplinary research for patients with all autoimmune diseases. It will serve as an umbrella for multiple Centers of Excellence, modeled after its world class Lupus Center of Excellence, directed by Dr. Susan Manzi. Newly launched Centers for Excellence within the AHN Autoimmunity Institute now include those for rheumatoid arthritis, celiac disease, and inflammatory bowel disease, with more planned for 2019.

More than a dozen specialties care for patients in a single 16,000 square foot suite housing rheumatology, dermatology, cardiology, gastroenterology, pulmonary, psychiatry, psychology, endocrinology, cardiology, dietary, clinical pharmacology, and primary care. The patient care team is tightly integrated with clinical and translational research, education, training, and outreach for patients with any of the more than 100 autoimmune diseases.

AARDA is providing seed funds to initiate a critical major study on the costs of autoimmune disease and the obtaining of a diagnosis.

Representing AARDA at the ribbon cutting ceremony at the opening of the Autoimmunity Institute were Board member Michael Linn and President/Executive Director Virginia Ladd. Both will serve on the steering committee for the Institute. Mrs. Ladd said, "We are especially excited that the Institute will provide diagnostic triage as our study found that on average our patients see an average of four physicians over three years before receiving an accurate diagnosis, and over 62 percent were told that they are too concerned with their health or that their symptoms are 'in your head.'"

Speaking on behalf of AHN, Dr. Joseph M. Ahearn said, " ... We are delighted to be collaborating with AARDA, which shares our vision and has stepped to the plate to accelerate our mission."

Left to right: Dr. Joseph Ahearn, Chair, AHN Autoimmunity Institute; Dr. Susan Manzi, Chair, AHN Medicine Institute, and Director, AHN Lupus Center of Excellence; Virginia Ladd, AARDA President and Executive Director; Kyle Marcelli, winner, AHN Autoimmunity Institute/AARDA/Race for RP Autoimmune Disease Awareness Champion Award; and Michael Linn, member, AARDA Board of Directors Photo by Graeme Jenvey of Marcelli Motorsports

The AHN Autoimmunity Institute welcomes autoimmune patients from across the United States and other countries. The only other such national facility is located in Israel.

Laying the groundwork for this collaborative effort, in negotiation and planning meetings, were AARDA Board members Richard Hodge and Michael Linn, Board Chair the Rev. Dr. Herbert G. Ford, and AARDA President and Executive Director Virginia T. Ladd who met with AHN representatives, including Dr. Ahearn and Dr. Manzi.

A two-month national awareness campaign is being launched by AARDA to announce the AHN Autoimmune Institute partnership. Adding to the awareness is Kyle Marcelli, AARDA Ambassador, whose race car boldly carries "Allegheny Health Network Autoimmunity Institute" and AARDA's logo as he competes in major races around the country.

What happens to the acorn now? AARDA will continue to grow the Acorn Fund for the support of projects that will help autoimmune patients through awareness, research, and education.

In the meantime, CHEERS for those early believers who helped our little Acorn burst into a great oak! An unknown author said, "Always believe that something wonderful is about to happen." Yes! We believe. ■

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President/Executive Director's Message

— Virginia T. Ladd

Dear AARDA Friends,

Yes, it's been a busy time for AARDA over the past months--but would you expect anything different? Let me share some highlights with you.

♦ If you have read the first page of this newsletter, you know our BIG NEWS is that AARDA has formed a partnership with the Allegheny Health Network Autoimmunity Institute, West Penn Hospital, in Pittsburgh. With AARDA's support, this will be a national autoimmune diagnostic and treatment center--our long-awaited dream facility. Cheers!

♦ I am happy to tell you that our Autoimmune Disease Patient Registry Research Network (ARNet) is capturing the interest of patients and researchers alike. Since ARNet's launch in February 2017, we have gained 2,600 registrants and are averaging about 80-120 new registrants per month. This project has great potential for enabling autoimmune disease investigators around the world to enlist patients in clinical research studies.

♦ Also in the area of research, we once again are sponsoring students in the Summer Diversity Internship Program at Johns Hopkins University. Each of the three students has one or more mentors to oversee the chosen autoimmune disease research project.

♦ As you know, our various programs need funding; and one of the surprisingly effective fundraising means has been Facebook which now allows fund raisers to do matching gifts. Since we started the program in March 2017, this Facebook effort has raised $34,807.97; and since January 2018 through April, Facebook fund raising has brought $19,310.90, with an average increase of 30 percent each month. Amazingly, donations have arrived in Australian, Canadian and American dollars, Euros, Great Britain pounds, Hungarian forints, and Japanese yen.

♦ In support of the AARDA mission, our annual fundraising event, held in Detroit, with a theme of "Bound by a Common Thread," was another success. It was not only a fundraising event but also an outstanding autoimmune awareness opportunity.

♦ As mentioned in our March newsletter, step therapy has become a real doctor-patient education issue; and we are excited about the development of a task force comprised of several patient groups and a rheumatologists association. We anticipate that more groups will join. You can read about the topic in this newsletter. While this initiative is based currently in Michigan ("Let MI Doctors Decide"), there is every reason for this to spread across the country. Voices need to be heard!

I can say that once a patient encounters step therapy (see article) and overpaying for prescriptions and "clawback" (see article), our education efforts on the subjects become highly relevant!

I hope that you will enjoy this issue of InFocus. It is written for YOU, and it is one way that we can say THANK YOU for your support in whatever way you choose.

With appreciation,
Virginia

Announcing...New York AARDA Public Forum

What Every American Needs to Know About Autoimmune Disease
New York University Langone Center
Saturday, September 15, 2018
For information: Sandra Cobb, 586-776-3900 or scobb@aarda.org

Jon Jordan and Je Donna Dinges

Fashion with a Focus

AARDA's 18th Annual Fund Raiser "Bound by a Common Thread" welcomed guests to luncheon, fashion, and spirited auction bidding in the Detroit Masonic Temple's Crystal Ballroom. The event brought together fashion show program participants sharing the common thread of autoimmunity.

Je Donna Dinges, owner of Margaux & Max Boutique, in Ferndale, Michigan, has spent the past 18 years dealing with an autoimmune disease, sarcoidosis--her reason for being one of three local retailers providing fashions. Je Donna sent four high-end looks down the runway.

Similarly inspired was event emcee Jon Jordan, WDIV Local 4 style editor who was diagnosed in 2015 with HLA-B27 (human leukocyte antigen) which is associated with certain autoimmune and immune-mediated diseases, including ankylosing spondylitis. Jon, charming the audience with humor and grace, took care to highlight AARDA's patient education, outreach, and advocacy efforts.

Others adding to the success of the fashion show were Roloni's of Southfield Boutique (Veronica Hood), Simply Casual, Detroit (Rufus Bartell), TSK Boutique, Eastpointe (Barbara Covington), and MTM Model and Talent Management.

"Bound with a Common Thread" welcomed new sponsors Health Alliance Plan (HAP), MidMichigan Health, and Michigan Health and Hospital Association, and returning sponsors Pfizer, NECABA Management, and *HOUR Detroit*.

In the spotlight were AARDA's 2018 Champion Award honorees, Pfizer, Inc., whose award was accepted by Barbara GJurgjovski, and outstanding AARDA volunteer Jaclyn Selby.

AARDA's thanks go to all the program participants, silent auction and raffle donors, sponsors, volunteers, and guests. This event raised nearly $80,000 for AARDA's mission. ■

2018 AARDA Champion Award Winners Honored

Joining Dr. Noel R. Rose, 2016 AARDA Champion Award Honoree, in the Winners Circle are two 2018 Champion Award recipients--one, a corporate supporter; and one, an outstanding individual. They were presented at AARDA's 18th Annual Fundraising Event, "Bound by a Common Thread," held on April 28, at the Masonic Temple, in Detroit.

Pfizer, Inc., received recognition for its 18 years of invaluable support to AARDA through underwriting AARDA's annual spring fund raiser and providing educational funding. Pfizer has been a staunch supporter of the AARDA mission--particularly our advocacy on behalf of autoimmune patients. Through this 2018 AARDA Champion Award, we recognize the longevity and generosity of Pfizer as a corporate partner and extend our thanks to the Pfizer representatives who have encouraged us in our work along the way.

Jaclyn Selby, an AARDA volunteer, was acknowledged as an AARDA Champion Award Honoree for her exceptional efforts on behalf of AARDA and those we serve, including raising awareness and sizable funds toward AARDA's mission. Always supportive at AARDA events, Jaclyn stepped up to chair AARDA's 25th Anniversary Dinner at Bouley Botanicals, in New York City. Using her many talents and connections, Jaclyn created a memorable event that brought many new friends to AARDA.

Virginia Ladd and Jaclyn Selby

A graduate of Northwestern University, Jaclyn is an experienced advertising professional currently employed as the Director of Sales, at Pathmatics, a digital marketing intelligence company based in New York. Jaclyn started her career at Hearst Communications, Inc., working for *Harper's Bazaar*. In addition to volunteering for AARDA, Jaclyn is a member of the genLOVE Host Committee supporting God's Love We Deliver, part of the Boys & Girls Club of Greater Flint (MI) Golf Committee, to support its annual outing.

Jaclyn lives in New York City with her husband Scott, a member of AARDA's Board of Directors.

We in AARDA count ourselves fortunate to have these loyal supporters who give generously and selflessly to the AARDA mission. ■

Let's look at...autoimmune pancreatitis

Sometimes confused with pancreatic cancer, autoimmune pancreatitis is a rare, newly recognized disease that is thought to be caused by the body's immune system attacking the pancreas. There is no established association between autoimmune pancreatitis and cancer.

Two subtypes of autoimmune pancreatitis are now recognized. Type 1 autoimmune pancreatitis, also called IgG4-related pancreatitis, is part of a disease called IgG4-related disease (IgG4-RD) that often affects multiple organs, including the pancreas, bile ducts in the liver, salivary glands, kidneys, and lymph nodes.

Type 2 autoimmune pancreatitis, also called idiopathic duct-centric pancreatitis, seems to affect only the pancreas. About one-third of people with type 2 autoimmune pancreatitis have associated inflammatory bowel disease, such as ulcerative colitis.

Type 1 autoimmune pancreatitis responds rapidly to treatment with steroids but is likely to relapse if treatment is discontinued. People with type 1 autoimmune pancreatitis are likely to be males over the age of 60. People with type 2 autoimmune pancreatitis are often over age 40. They are as likely to be female as male.

Autoimmune pancreatitis is difficult to diagnose since often it doesn't cause any symptoms. The most common sign of autoimmune pancreatitis, appearing in about 80 percent of the affected people, is painless jaundice, which is caused by blocked bile ducts. Unexplained weight loss can occur, and there may be abdominal pain. Many people with autoimmune pancreatitis have masses in the pancreas and other organs, which can lead to a misdiagnosis of cancer. It is important to see a physician when any of these symptoms are present.

Pancreatic insufficiency is a possible complication as autoimmune pancreatitis may affect the ability of the pancreas to make enough enzymes. Signs and symptoms may include diarrhea, weight loss, metabolic bone disease, and vitamin or mineral deficiency. Other possible complications include diabetes and/or pancreatic calcifications or stones. Also, long-term treatment with steroids can cause complications. However, even with these complications, people who are treated for autoimmune pancreatitis have a normal life expectancy. ■

--Source: "Autoimmune pancreatitis, symptoms and causes," Mayo Clinic, 1998-2018 Mayo Foundation for Medical Education and Research

AARDA represented in Florida Muscle Car Challenge

AARDA Board Member Michael Linn (left) and Kyle Marcelli

In the April 15 Trans Am Series TA2 Muscle Car Challenge, held in Homestead, Florida, AARDA was represented by driver Kyle Marcelli whose Chevrolet Camaro carried the AARDA logo. He survived a penalized unavoidable contact by another driver to complete the race in the TA2 top five. In total, the competition spanned 45 laps, 102.15 miles around the 2.27-mile, 10-turn modified road course at Homestead-Miami Speedway.

Marcelli, winner in the 2016 Detroit Grand Prix, sported AARDA's pink and blue logo on his Chevy Camaro in the 2017 Detroit Grand Prix. A number of future competitions will give Marcelli opportunities to spread AARDA's autoimmune awareness message. ■

Diagnosing lupus: Chinese researchers develop new method

Using DNA methylation detection to find lupus-specific information in genes, Chinese researchers announce a new testing method which could improve the accuracy rate for diagnosis by over 90 percent. Lu Qianjin, a professor with Central South University, says that this is the first time that researchers have been able to elevate the diagnosis of lupus to the genetic level.

Lupus, systemic lupus erythematosus or SLE, is an autoimmune disorder that can damage the joints, kidneys, heart, lungs, brain, and blood. It reportedly affects 40 to 70 out of 100,000 people worldwide.

The new testing method has been adopted by 23 hospitals in China, Lu reports; and he has applied for patents in both China and abroad. ■

--Source: "Chinese researchers developed new method for diagnosing lupus," PanArmenian.Net, January 10, 2018

What do graying hair and vitiligo have in common?

Researchers from the University of Alabama at Birmingham (UAB) set out to find the science behind graying hair, but the study also may explain why approximately 1 percent of the world's population develop vitiligo or other pigmentation diseases.

Hair's graying can be caused by activation of the inborn immune system, according to the UAB researchers. The study looked at the negative effects of innate (inborn) immune activation on hair pigmentation cells, called melanocytes, suggesting a connection between viral infection and graying of hair.

"Our research looks primarily at how stem cells are affected by age," says Melissa Harris, Ph.D., corresponding author and assistant professor in the Department of Biology at UAB. She explains, "The stem cells we study are the melanocyte stem cells in the hair follicle, which are the stem cells that are essential for producing melanocytes."

Dr. Harris further explains, "Using current genomic tools, we are able to look at the whole genome to gain a better understanding of which genes are expressed and when, and this allows us to better address the question of why we age the way we do."

Melanocyte stem cells serve as a reservoir for the melanocytes that produce the pigment that give hair its visible color. The loss of these stem cells leads to the growth of non-pigmented, or gray, hairs. In animals that have a predisposition for hair-graying, artificial elevation of the innate immune response, either through a genetic mechanism or via exposure to a virus mimics results in significant melanocyte and melanocyte stem cell loss and leads to the production of an increased number of gray hairs.

Dr. Harris says, "Perhaps, in an individual who is healthy yet predisposed for gray hair, getting an everyday viral infection is just enough to cause the decline of their melanocytes and melanocyte stem cells leading to premature gray hair."

Study co-author Dr. William Pavan, chief of the Genetic Disease Research Branch at the National Institutes of Health (NIH), says "These results may enhance our understanding of hair graying. More importantly, discovering this connection will help us understand pigmentation diseases with innate immune system involvement like vitiligo."

Vitiligo is an autoimmune disease, caused by an immune attack on melanocytes, that leads to the loss of natural skin color. This action results in milk-white patches surrounded by normal pigmentation, as cells lose the ability to produce melanin.

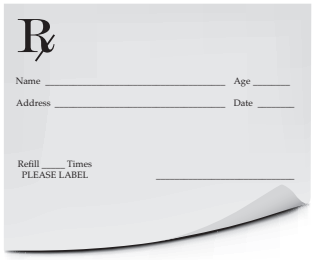
Dr. Harris says that gray hair itself is not a definitive indication of infection, but this study highlights just one mechanism that gives a better understanding of biological contributions to the visible signs of aging--and, one might add, to vitiligo and other pigmentation diseases. ■

--Source: "Study explains one reason hair can turn gray," Alicia Rohan, UAB News, University of Alabama at Birmingham, May 3, 2018; and "Graying Hair Linked To Immune Response, Study Finds," Sadhana Bharanidharan, Medical Daily News, May 6, 2018

Are you overpaying for prescriptions?

A recent study published in *Kaiser Health News* shows that patients overpay on their prescriptions 23 percent of the time. The trap is a system called "clawback" in which a middleman, known as a pharmacy benefit manager (PBM) who handles claims for an insurance company, "claws back" extra dollars from the pharmacy, causing patients to pay more than they should pay for the medication.

The University of Southern California Schaeffer Center researchers concluded, after a study of millions of prescriptions, that close to a quarter would have been cheaper if consumers had skipped the health insurance card and the copay and simply paid cash. For example, the average overpayment among claims with clawbacks involved some of the following: levothyroxine, $6.12; simvastatin, $6.33; amoxicillin, $6.21; Ventolin HFA, $19.95; metropolol succinate, $13.21; and Crestor, $14.56. Brand-name drugs had the highest clawbacks--an average overpayment of $13.45 per prescription. Clawbacks on generic drugs were $7.32 on average. However, in one case, a patient was charged a $42.60 copay for a generic version of simvastatin when he could have paid $18.59 out-of-pocket.



The USC researchers, analyzing prices paid for 8.5 million prescriptions in the first half of 2013, showed that overpayments totaled $135 million during that six-month period.

How does it work? After taking your insurance card, your pharmacist says that you owe a $10 copay, which you pay, assuming that the drug costs more than $10 and your insurance company is covering the rest. However, the drug actually costs only $7.00. The pharmacy benefit manager claws back the extra $3.00. If you had paid out-of-pocket, you would have saved that $3.00 for yourself.

Patients often aren't told that they could pay less without using insurance cards unless they ask; but even then, some insurance plans prohibit pharmacists from telling patients due to gag clauses. Six states have prohibited gag clauses, and 20 more are considering similar legislation. ■

--Source: "Paying Cash for Prescriptions Could Save You Money 23% of the Time, Analysis Shows," Sydney Lupkin, Kaiser Health News, March 13, 2018

The microbiome: Let's get acquainted

Microbiome, another word for gut, is inching its way into our health vocabulary as researchers uncover new understanding of its influence on our lives.

Dr. Carolyn Hwang, gastroenterologist, University of Southern California Keck School of Medicine, explains that the human gut contains trillions of microorganisms that aid in our long-term survival by doing everything from metabolizing our food to fighting disease. In trying to determine a healthy microbiome, researchers are comparing the microbiome in ill people and in healthy ones.

Dr. Hwang says that each person's gut is as unique as a fingerprint. Much of our microbiome is created the moment we begin the journey down the birth canal. Swallowing fluids along the way, the baby populates its gut with bacteria provided by its mother.

The process of birth can have other influences. In Cesarean births, some studies show that babies have higher rates of allergies than those born vaginally. Also, a Cesarean birth can put a baby's gut at risk if the mother is given antibiotics during the procedure.

Some studies show that stressed-out mothers can pass their anxiety onto their babies through the birth canal, tending to pass on less of the healthy bacteria, such as lactobacilli, important to calming anxiety.

Dr. Hwang says that breastfeeding has been shown to influence a person's autoimmunity as breastfed babies tend to have lower rates of autoimmune diseases, such as Crohn's disease or colitis.

A variety of illnesses have been blamed on the gut. People who have trouble shedding pounds might blame it on the gut. When researchers took microbiome bacteria from obese subjects and transplanted it into healthy subjects, those subjects gained weight. Also, researchers are looking to determine whether alcoholics have different gut bacteria than non-drinkers. Perhaps bacteria from a non-drinker could help the alcoholic.

Some research shows that the gut can be tied to mental health. A Norway study found that certain bacteria could be connected to depression in patients. Another study found that the bacteria bifidobacterium was as effective as the antidepressant Lexapro.

Researchers suggest that autism could be tied to gut bacteria; about three-fourths of autistic people have some type of gastrointestinal issue.

To an extent, the microbiome could be retrained. Dr. Hwang says that the two big things to pay attention to are diet and antibiotics. There's evidence that exercise helps, too. As to currently popular probiotics, many physicians and others say that they are still an experiment. While capsules, pills, and liquids are available, many probiotic advocates choose naturally fermented products like yogurt, kefir, and sauerkraut that contain "good" bacteria for a healthy microbiome.

"To get benefits, you've also got to give the probiotics something to live on," says registered dietitian Heidi Turner, Seattle Arthritis Clinic, Northwest Hospital. "Prebiotics, non-digestible carbohydrates that act as food for probiotics, are found in whole grains, asparagus, garlic, onions and other fiber-rich vegetables."

--Sources: Adapted from "Do probiotics work? Answers to this and other gut-wrenching questions," Joanna Clay, Science-Technology, USC News, February 14, 2018; and "Foods that fight arthritis," Emily Delzell, Arthritis Today, May/June 2018

AARDA Autoimmune Walks = Awareness! Support! Education! Fun!

Gather a team or come on your own. You'll be welcomed by AARDA staff, volunteers, and like-minded AARDA friends of all ages. Walk or simply sit and enjoy--something for everyone.

Autoimmune Walk
LINKING TOGETHER FOR A CURE

- **Metro Detroit Walk** - Sunday, August 26 - Milliken State Park & Harbor, 1900 Atwater Street, Detroit
- **New York Walk** - Sunday, September 16 - Hudson River Park, Pier 45, Greenwich Village - Walk Ambassador: Author/Journalist Nika Beamon
- **DC Metro Walk** - Saturday, September 22 - Bluemont Park, Arlington, VA
- **Virtual Walk** - Any day, anywhere - You and your friends and/or family - Be part of the fun while supporting the autoimmune cause--wherever you are.

♦ To register for an Autoimmune Walk or to find more information, visit **www.AutoimmuneWalk.org**. Like us on Facebook at **www.Facebook.com/AutoimmuneWalk**, or tweet about us at **@Autoimmune Walk**.

If you have questions or suggestions, or you want to schedule a walk, call **855-239-2557** or email **walk@aarda.org**.

Special note to our New York area friends...

JUJAMCYN Theaters offer AARDA fundraising opportunities through the use of Broadway group tickets in their Givenik program. Most shows require only 10-12 tickets for "HUGE" discounts. For group pricing and the way to get started, contact **kfreidus@jujamcyn.com or jwooden@jujamcyn.com.**

Let doctors decide care, not insurance bureaucrats

-An editorial by AARDA President and Executive Director Virginia T. Ladd

As Executive Director of the American Autoimmune Related Diseases Association (AARDA), I hear many heartbreaking stories from patients who have difficulty dealing with autoimmune illness while experiencing the stress of finding medical care. One patient's experience was so appalling that I knew that our association had to become involved.

Heather, a young Michigan woman, received a devastating diagnosis of multiple sclerosis (MS). During this difficult time, she encountered an additional obstacle: accessing prescribed treatment to control the MS.

When Heather's doctor prescribed a new, expensive oral treatment, her insurance company denied the prescription in favor of "step therapy," a health insurance policy seen as cost-containment strategy. This practice requires the patient to first try older, less expensive therapies before the insurer agrees to cover the doctor's prescribed treatment. Because of step therapy, Heather was assigned an injectable drug, which she tried for six weeks. The drug works for many but was inappropriate for Heather.

Over the following months, Heather's insurance company continued to require her to try drugs that, according to available evidence, likely wouldn't be effective for her. Heather talked with her doctor weekly and eventually obtained a new prescription for the original oral treatment. Even then, her insurer required extensive efforts on the part of Heather and her doctor to approve the treatment, including blood tests, imaging scans, and phone calls from the doctor.

This process consumed a great deal of Heather's time as she acquired "a notebook full of names and information" of insurance company contacts. She missed six months of work, including a period when there was opportunity to earn significant overtime pay and her company had to hire someone to assume her responsibilities.

The result of all these delays was that it was five months between Heather's diagnosis and the initiation of the proper treatment, despite doctor recommendations to start therapy as soon as possible after diagnosis. This has permanently impacted Heather's health and mobility.

Heather's story illustrates the concerns many have with step therapy. While all sectors of health care seek ways to reduce spending, it will be essential to implement policies that improve patient outcomes without causing harm.

Intruding on the doctor-patient relationship or denying patients necessary treatments ultimately will prove counterproductive and often result in added medical expenses in the future. That's why my association has initiated a campaign, "Let MI Doctors Decide," to arm patients and doctors with the knowledge and resources to navigate step therapy and secure the right treatment at the right time.

To learn more about this issue and obtain information for how to submit an appeal when faced with step therapy, visit **www.letmidoctorsdecide.org** or call **586-776-3900**. We must work to advocate for all patients who are being affected by insurance policies that not only burden the patient and the doctor but also jeopardize the patient's health. ■

AARDA's community outreach efforts continue

For National Women's Health Week, an AARDA representative made a presentation regarding autoimmunity at the Metro-Detroit Chapter of the Coalition of Labor Union Women (CLUW) annual Women's Health Week Forum, on May 8.

AARDA has scheduled "What Every American Needs to Know About Autoimmune Diseases" presentations at the Lunch & Learn series being conducted by the Health Alliance Plan (HAP). Upcoming events are scheduled in the Greater Detroit area: June 5, Detroit; June 7, Southfield; and June 12, Flint. ■

Recently recognized autoimmune disease worth noting

Autoimmune encephalitis (or autoimmune encephalopathy) refers to a group of conditions that occur when the body's immune system mistakenly attacks healthy brain cells, leading to inflammation of the brain. People with autoimmune encephalitis may have various neurologic and/or psychiatric symptoms.

Neurologic symptoms may include impaired memory and cognition, abnormal movements, seizures, and/or problems with balance, speech, or vision.

Psychiatric symptoms may include psychosis, aggression, inappropriate sexual behaviors, panic attacks, compulsive behaviors, euphoria, or fear. Symptoms may fluctuate, but they often progress over days to a few weeks. Symptoms can progress to loss of consciousness or even coma.

Autoimmune encephalitis may be associated with antibodies to proteins on the surface of nerve cells, or within nerve cells. Some of these proteins are involved in passing signals between nerve cells. In some cases, it occurs in association with cancer (a paraneoplastic syndrome).

Research regarding why specific antibodies attack the body's healthy cells is ongoing. Autoimmune encephalitis generally occurs sporadically in people with no family history of the condition.

Treatment may involve intravenous immunosuppressive therapy (IVIG) and, when necessary, tumor removal. Other treatments include first line steroids, and second line Rituximab and Cyclophosphamide, followed in many cases by steroid-sparing agents in the long term. Early treatment decreases the likelihood for long-term complications, speeds recovery, and reduces the risk of recurrence (relapse). If not treated, the condition can lead to progressive neurologic deterioration and loss of life. ■

--Source: "Autoimmune encephalitis," NIH Genetic and Rare Diseases Information Center, October 26, 2017; Wikipedia

Drug compound may dial down inflammation in multiple disorders

A report from Washington University School of Medicine in St. Louis reveals that researchers have designed a new drug compound that dials down inflammation. This suggests possible future uses against autoimmune disorders, such as rheumatoid arthritis.

One of the current therapies, a protein called p38MAPK, when working properly, is responsible for helping tissue remain healthy. However, if the protein becomes chronically switched on, it creates collateral damage, attacking the body's own tissues. Thus, autoimmune disorders, such as rheumatoid arthritis and psoriatic arthritis, can result.

Because p38MAPK drives inflammation in many disorders, several drug companies have developed anti-inflammatory compounds that block its signaling. The down side is that, after a period of time, the body recalibrates and inflammation returns. The next step was to develop drugs to block p38MAPK. Again, the effect was temporary. Senior author Gabriel Mbalaviele, Ph.D., associate professor of medicine, said, "We wanted to develop a compound that is more precise, just blocking the portion of the pathway that we now understand drives inflammation and nothing else." The result? A new compound called CDD-450.

Studying mice, rats, and human cells, the researchers showed that CDD-450 reduces levels of inflammatory signaling molecules. The scientists further showed that CDD-450 prevents the destruction of bones and joints in a rat model of rheumatoid arthritis.

Dr. Mbalaviele, in comparing some current treatments with CDD-450, observes that the relatively new anti-inflammatory treatments, biologics, are made of short protein sequences. Consequently, the body's immune system may recognize biologics as foreign and eliminate them, resulting in a buildup of resistance. Biologics must be injected into the blood stream while the CDD-450, the new inhibitor, is a small molecule bearing no resemblance to proteins. It is a chemical compound that could be taken by mouth and could avoid an immune response, therefore maintaining its effectiveness, according to Dr. Mbalaviele. He says that the company developing CDD-450 is moving toward early clinical trials to test the safety of the new inhibitor (now called ATI-450) in humans. ■

--Source: Excerpted from "Drug compound shows promise against rheumatoid arthritis; may dial down inflammation in multiple disorders, studies show in mice, rats," Julia Evangelou Strait, Washington University School of Medicine in St. Louis, March 27, 2018

Current study offers hope for future in autoimmune and inflammatory diseases

A new study, carried out by an international group of researchers, shows promise for autoimmune patients and others. The researchers, led by Professor Savvas Savvides, of The Flanders Institute for Biotechnology and the University of Ghent Center for Inflammation Research, Belgium, joined by research groups at the University of California at Davis, have unraveled a crucial aspect of the molecular basis of autoimmune and inflammatory diseases, such as psoriasis, rheumatoid arthritis, and Crohn's disease, through their focus on cytokine IL-23.

Cytokines, a group of extracellular factors that may be produced by a variety of cells, are important in controlling local and systemic infections but have remained something of a puzzle. Since the first description of cytokine IL-23 about 15 years ago, the structural and molecular basis for the mechanisms underlying its pro-inflammatory activity has remained unclear. However, this new study has shed light on the unique way that IL-23 interacts with one of its receptors. Cytokines generally activate receptors; but in the current study, the opposite appears to be true.

Prof. Savvides says, "What we have now discovered about the pro-inflammatory complex mediated by IL-23 appears to be a new paradigm in the field."

Prof. Savvides offers hope for autoimmune patients as he says, "…our insights are expected to fuel the development of new therapeutic strategies against IL-23." ■

--Source: Adapted from "Scientists shed light on a key molecular mechanism of autoimmune and inflammatory disease," The Flanders Institute for Biotechnology, via ScienceDaily, January 17, 2018

~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.

Gut bacteria and antibiotics, the good and the bad

Out of Washington University in St. Louis comes the warning that killing gut bacteria with drugs weakens immune response. Researchers at the University, studying the wide range of effects of the West Nile virus, from life-threatening brain infections to no signs of infection at all, reported that one reason for different outcomes may lie in the community of microbes that populate the intestinal tracts of those infected.

Senior author of the study Michael S. Diamond, M.D., Ph.D., said, "The immune system is activated differently if the gut does not have a healthy microbiome." He said that while someone who is sick with a bacterial infection "absolutely should take antibiotics," it is important to remember that there may be collateral effects, such as perhaps altering the immune response to certain viral infections.

Dr. Diamond, first author Larissa Thackray, Ph.D., and colleagues at Washington University set out to determine whether antibiotic use could help explain why some people get very sick and others do not. They considered that since antibiotics kill off members of the normal bacterial community and allow some harmful ones to overgrow, and since a healthy immune system depends on a healthy gut microbiome, it stands to reason that antibiotics may be hobbling the immune system. This leaves the body unprepared to fight off a subsequent viral infection.

The researchers gave mice a placebo or a cocktail of four antibiotics for two weeks before infecting the mice with West Nile virus. About 80 percent of the mice that received no antibiotics survived the infection; only 20 percent of the antibiotic-treated mice survived. Subsequent experiments showed that the mice stayed at high risk for more than a week after the antibiotic treatment ended, and just three days of antibiotic treatment was enough to raise the mice's risk of dying from West Nile infection.

"Once you put a dent in a microbial community, unexpected things happen," Dr.Thackray said. "Some groups of bacteria are depleted and different species grow out. So increased susceptibility may be due to both the loss of a normal signal that promotes good immunity and the gain of an inhibitory signal."

When the researchers tested immune cells from mice treated with antibiotics, they found that they had low numbers of an important immune cell known as killer T cells. Normally during an infection, T cells that recognize the invading virus multiply to high numbers and play a key role in controlling the infection; but the mice treated with antibiotics generated fewer such T cells.

The weak T cell response was likely a by-product of the changes to the bacterial populations caused by antibiotics, not a direct effect of the drugs on the immune cells, as the mice still had trouble fending off viral infections a week or more after they stopped receiving antibiotics. Also, transferring gut bacteria from mice given antibiotics to other antibiotic-treated mice made the recipients even more vulnerable to viral infection. This suggested that something in the bacteria was undermining the mice's immune response.

Dr. Diamond commented, "If your immune system doesn't get activated because your microbiome is perturbed by antibiotics or anything else--diet, other infections, underlying medical conditions--you may be at higher risk of severe viral disease." ■

--Source: "Antibiotic Use Increases Risk of Severe Viral Disease in Mice," Washington University in St. Louis, March 23, 2018, via Newswise (published March 27, 2018 in Cell Reports)

What's the connection between Epstein-Barr and autoimmunity?

Epstein-Barr virus, the cause of infectious mononucleosis ("mono" or the so-called "kissing disease"), is not an autoimmune disease but may be a culprit in the development of some autoimmune diseases, particularly lupus. Researchers at the Center for Autoimmune Genomics and Etiology, at Cincinnati Children's Hospital Medical Center, have developed a new computational and biochemical technique known as the Regulatory Element Locus Intersection algorithm, or RELI, to study whether genetic analysis could further explain the relationship between Epstein-Barr infection and lupus.

Epstein-Barr virus is omnipresent worldwide. Usually acquired in early childhood, the virus may present as a brief cold-like illness. It seems mild enough, but it stays with the infected individual throughout life while remaining asymptomatic. However, when Epstein-Barr virus infection occurs in the teen years or young adulthood, it can lead to infectious mononucleosis which is characterized by prolonged fever, sore throat, swollen lymph nodes, and fatigue. It generally resolves with rest.

When Epstein-Barr infects human immune cells, a protein produced by the virus--EBNA2--recruits human proteins called transcription factors to bind to regions of both the Epstein-Barr genome and the cell's own genome. Together, EBNA2 and the human transcription factors change the expression of neighboring viral genes.

In the current study, the researchers found that EBNA2 and its related transcription factors activate some of the human genes associated with the risk for lupus and some other autoimmune diseases, such as multiple sclerosis, rheumatoid arthritis, inflammatory bowel disease, type 1 diabetes, juvenile idiopathic arthritis, and celiac disease. The team used RELI to identify regulatory regions in genes associated with the risk of developing lupus that also bound EBNA2 and its related transcription factors.

Daniel Rotrosen, M.D., Director of the Division of Allergy, Immunology and Transplantation at the National Institute of Allergy and Infectious Diseases (NIAID), says that avoiding infection with the Epstein-Barr virus is practically

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Epstein-Barr Article continued from page 9

impossible. He states, "However, now that we understand how EBV infection may contribute to autoimmune diseases in some people, researchers may be able to develop therapies that interrupt or reverse this process."

Researchers caution that Epstein-Barr infection is not the only factor contributing to the development of the seven autoimmune conditions discussed in the research paper. ■

--Source: "Epstein-Barr virus protein can `switch on' risk genes for autoimmune diseases," National Institutes of Health (NIH) National Institute of Allergy and Infectious Diseases (NIAID, April 16, 2018

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 necesarily reflect the views of the American Autoimmune Related Diseases Association or its Scientific Advisory Board.

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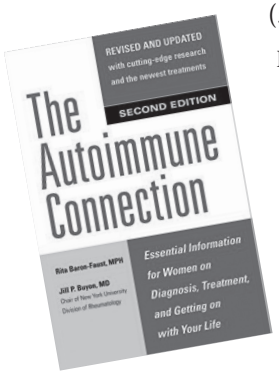

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