



"Let My Doctors Decide" initiative launched

A new national initiative has been established to advocate for doctor-patient-led decisions vs. harmful "step therapy" interventions. Led by the American Autoimmune Related Diseases Association (AARDA), "Let My Doctors Decide" is driven by an advisory task force comprised, to date, of nine national patient advocacy and provider groups including AARDA, the American Behçet's Disease Association, American Gastroenterological Association, Coalition of State Rheumatology Organizations, Dermatology Nurses Association, International Foundation for Autoimmune and Autoinflammatory Arthritis, Lupus Foundation of America, National Organization of Rheumatology Managers, and Sjögren's Syndrome Foundation.

"We are bringing critical attention to step therapy and other restrictive practices that undermine the doctor-patient relationship and give insurance companies the ability to make treatment decisions," says Randall Rutta, chair of the Advisory Task Force, Let My Doctors Decide. "When recommended by doctors for medical reasons, step therapy can be the right choice. However, there is an important distinction between sound medical protocol versus economically driven decisions that do not take into consideration what is medically best for the patient."

Step therapy, also known as "fail first," has been criticized for the way in which it negatively impacts patients. Under this policy, patients are required to try--and fail on--medicines preferred by the insurer before their insurer will cover the cost of the drug that the individual's doctor initially prescribed. "Fail" is an ominous risk for the patient whose health--and possibly life--depends on timely, medically determined treatment.

In a study conducted at Emory University by researchers Kenneth E. Thorpe, Ph.D., and Manasvini Singh, "Impact of Prescription Drug Benefit Design on Access to Autoimmune Disease Medications under Medicare and Commercially Available Health Plans," key findings show that "people living with autoimmune disease in America face substantial hurdles in accessing medicines whether insured by commercial insurance or through Medicare, with few exceptions."

Most of the nation's top health insurers and pharmacy benefit managers (PBMs) receive a failing grade in providing access to medicines at the pharmacy counter for patients with autoimmune disease, according to a new report card from Let My Doctors Decide. The analysis, based on the research by Thorpe and Singh, highlights the extent to which private and Medicare health plans utilize coverage limitations on medications for five of the most serious autoimmune

diseases: Crohn's disease, multiple sclerosis, psoriasis, psoriatic arthritis, and rheumatoid arthritis. The coverage limitations evaluated include prior authorization, formulary status, tier placement, and step therapy--a practice whereby insurance companies mandate that patients, many of whom are seriously ill, try a series of drugs before covering the cost of doctor-recommended medicines.

The report card was released in conjunction with the Let My Doctors Decide initiative which will focus on three core areas: (1) educating patients and doctors about step therapy, (2) proposing solutions to prevent step therapy and other harmful practices from being used by health insurers and pharmacy benefit managers, and (3) providing tools and resources to help patients overcome these access challenges.

As policymakers in Washington consider proposals that would expand the use of step therapy within Medicare Part D's "six protected classes" and Medicare Part B, the report card released by the Let My Doctors Decide initiative demonstrates how the vast majority of private and Medicare health plans impose significant to severe restriction on access to the most appropriate medicines for the diseases evaluated in the study. According to the findings, 86 percent of Medicare Advantage and Part B received an "F" for access to medicines at the pharmacy. All plans within Medicare Advantage and Part B received an "A" for access to medicines that are administered in a doctor's office.

The five autoimmune diseases studied do not fall within Medicare Part D's "six protected classes." However, the findings do show how coverage for drugs within these therapeutic classes may change if reforms are enacted.

Patients who need medicines that fall within the "six protected classes" may see higher access restriction (similar to Part D).

Article continued on page 2

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President/Executive Director's Message - Virginia Ladd

Dear AARDA Friends,

A year ago, in the June 2018 *InFocus*, I mentioned that we were developing a task force to address the problems surrounding step therapy. While this advocacy issue started as a Michigan project, "Let MI Doctors Decide," one year later it is being launched nationally, "Let My Doctors Decide," as you have seen on the cover page of this newsletter. This is a doctor-patient problem that is beginning to spread as a cost-saving plan of insurers. As innocent as that might sound, step therapy generally overrides physicians' decisions and has been known to create severe, frequently life-threatening health problems through its "fail first" policy. What autoimmune disease patient can afford to risk failure in health care?

Looking at AARDA as a whole, we see advocacy, education, awareness, research, patient services, and collaboration; and sometimes it's difficult to see where one ends and another begins. That is especially true when we look at step therapy. Perhaps in this united plan to bring attention to the problems surrounding step therapy, we can educate the insurers (would they choose "fail first" for their own families?), bring awareness to the patients so that they can ask questions, advocate for doctors and patients who are caught up in this problem, encourage research into the process (as with the Emory University study), and seek collaboration among interested parties.

In the meantime, you, our AARDA friends, can stay alert to this problem as it affects you or your family members. Ask questions, be informed about your medications, make notes of any reactions (good or bad) that you might be having to a change in medications, ask about any variation from the prescription given by your physician. Be your own best advocate.

And, yes, while step therapy is a vital topic, I want to make note of other happenings in AARDA.

◆ In March we sponsored, with members of the National Coalition of Autoimmune Patient Groups (NCAPG), a Congressional Briefing: "The Hidden Epidemic of Autoimmune Disease." It featured outstanding speakers, including Dr. Joseph Ahearn, chair, Allegheny Health Network Autoimmunity Institute, and AARDA Board member Lilly Stairs, head of growth and partnerships, Savvy Cooperative.

◆ In May, Dr. Noel Rose assembled an outstanding group of researchers in a scientific colloquium to discuss "Innate Immunity in Autoimmune Disease."

◆ Once more, we are supporting the Johns Hopkins Autoimmunity Day which was established 19 years ago through the efforts of Dr. Noel Rose with a grant from AARDA through an AARDA Board member, the late Linda Otto, and her husband Alan Landsberg.

◆ In this issue, you will see news of the upcoming Autoimmune Walk schedule and two public forums (Pittsburgh and Detroit area).

◆ The day before Mother's Day, we presented AARDA's 20th annual spring fund raiser, "Bound by a Common Thread." A report will be given in the September *InFocus*.

I hope that you enjoy this issue of the newsletter. As usual, it is written for YOU. It's always a pleasure to have this opportunity to reach out to you, our members and friends.

Thank you for your support--in giving, in participating, and in spreading the autoimmune story in your own community.

With appreciation,
Virginia



Let My Doctors Decide . . . continued from page 1

Furthermore, the "A" grade that Part B plans received would be jeopardized if step therapy were expanded and physician-administered drugs were treated more like Part D--as outlined in one of the Administration's proposals.

According to Thorpe and Singh, "In a recent American Medical Association survey, 78 percent of doctors reported that prior authorization 'sometimes, often, or always' leads to abandoning a recommended course of treatment. More than 90 percent of doctors indicated that prior authorization requirements had negatively affected patients' clinical outcomes."

To read the full results of the Report Card and learn more about this new Let My Doctors Decide initiative, visit letmydoctorsdecide.org.

Could a Charitable Distribution (QCD) be advantageous to you?

Are you over 70? Do you want to make a gift to AARDA? If you have an IRA, it can be advantageous to do so through a Charitable Distribution (QCD).



What is a QCD? Also known as “IRA Charitable Rollover Gifts,” Qualified Charitable Distributions (QCDs) are the most tax efficient ways for many to make charitable gifts. However, there are restrictions:

- ◆ QCDs are for those 70½, or older, with a traditional Individual Retirement Account (IRA). The 70½ threshold is due to the IRS requirement that IRA owners must start withdrawing money from their accounts in the year in which they turn 70½. These withdrawals are known as Required Minimum Distributions (RMDs).

- ◆ There is a large penalty--equivalent to half the RMD--for failure to withdraw enough money within the year. If the IRA owners

want to donate some or all of the distribution to one or more charities, they can deduct that amount from their taxes that year.

How does a donor make a QCD? The easiest way to make a QCD is for a donor to submit a request to the donor’s IRA custodian, such as, Vanguard, Fidelity, or Charles Schwab. The donor’s custodian then sends a check (or checks) directly to the nonprofit(s) of choice; or if the donor prefers, the check(s) can be sent directly to the donor who can send the contribution(s) to the charity (or charities). Some donors prefer this route to enhance donor relations.

A second, less common, method is to use an IRA checkbook.

What is the minimum amount that can be donated? QCDs have no minimum amount that can be donated, but the most that can be given annually is \$100,000. These gifts can be made year after year.

How does the IRS see other plans? Roth IRAs are eligible; but since they already are tax-free, there is not the same tax advantage.

It is worth noting that 401(k)s and 403(b)s are not eligible for QCDs.

Who wins? There is a clearly defined and very large group of people--those 70½, or over, with traditional IRAs--who will benefit from making Qualified Charitable Distributions. Their favorite charities will benefit as well--definitely a win-win situation. ■

Blood test for fibromyalgia holds promise

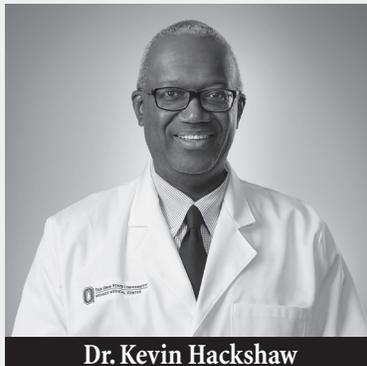
While not an autoimmune disease itself, fibromyalgia frequently brings its muscle pain, fatigue, headaches, and other problems to patients suffering from certain autoimmune diseases, such as, rheumatoid arthritis, lupus, and ankylosing spondylitis (spinal arthritis). The disorder affects 5 million Americans, age 18 or older, 80-90 percent of whom are women.

Because lab tests often appear normal in these patients, doctors must rely on patients’ symptoms, results from physical exams, and the exclusion of other diseases to reach a diagnosis of fibromyalgia. The existence of “tender points” on specific places on the body is one significant diagnostic lead.

Now researchers at Ohio State University Wexner Medical Center have biologic evidence of fibromyalgia through a new experimental testing method that can quickly and accurately diagnose fibromyalgia while differentiating it from other chronic pain conditions. This lab test appears to diagnose the disease with near 100 percent accuracy.

Lead author of the study Dr. Kevin Hackshaw, associate professor of rheumatology at Ohio State University, says, “Being able to see the biological differences in the blood of those with fibromyalgia compared to those with other conditions like lupus, osteoarthritis and rheumatoid arthritis finally gives patients validation of their symptoms.” He adds, “Not only does this help us direct treatment, but also prevents the use of unnecessary medications, like opiates, that don’t alleviate fibromyalgia pain and can lead to addiction.”

“When you look at chronic pain clinics,” says Dr. Hackshaw, “about 40 percent of the patients on opioids meet the diagnostic



Dr. Kevin Hackshaw

criteria for fibromyalgia. Fibromyalgia often gets worse, and certainly doesn’t get better, with opioids.”

Dr. Luis Rodriguez-Saona, co-author of the study and professor of food science and technology at Ohio State, says, “Each patient’s blood is unique, like a fingerprint, and this test can show us the intricate details of that fingerprint. Now we can see that certain patterns in those fingerprints indicate fibromyalgia, while different ones signal other conditions.”

In addition to identifying fibromyalgia, the researchers found evidence that the metabolic fingerprinting technique has the potential to determine the severity of fibromyalgia in an individual patient.

Identifying the biological characteristics may help experts develop novel therapies to treat fibromyalgia. Dr. Rodriguez-Saona says that, eventually, this work could lead to identification of a particular protein or acid--or combination of molecules--that’s linked to fibromyalgia.

Researchers hope that as future research validates the test further, it will lead to a widely available blood test that can be used in doctors’ offices so that patients can receive a diagnosis in minutes with just a finger prick. Dr. Hackshaw says that his goal is to have a test ready for widespread use within five years. ■

--Sources: Excerpted from “What Is Fibromyalgia?” NIH National Institute of Arthritis and Musculoskeletal and Skin Diseases; “First Blood Test for Fibromyalgia Could Provide Answers and Validation,” The Ohio State University Wexner Medical Center; and “Experimental Blood Test Accurately Spots Fibromyalgia,” Misti Crane, The Ohio State University Wexner Medical Center Media Relations, March 18, 2019



Can autoimmune diseases be slowed?

Researchers at the University of Utah say that they are “taking treatment for autoimmune disease in a new direction.” The treatment, immunostasis, offers a more precise alternative than most current treatments which target both the healthy and unhealthy cells. By exclusively targeting non-functional white blood cells, the new treatment can turn off an overactive immune response, all the while leaving protective immune cells intact. Immunostasis is critical for the immune system to defend against infections and cancer without causing autoimmune disorders

The key is a protein called programmed death 1 (PD-1). The treatment is based on a protein molecule, engineered in the lab, that targets only those immune cells with malfunctioning PD-1. This engineered molecule comes in three parts: an antibody fragment, a toxin, and a binder. Depletion of PD-1-positive alleviated autoimmune diseases in two animal models, type-1 diabetes and experimental autoimmune encephalomyelitis. The treatment was able to delay the onset of diabetes in mice by 10 weeks, and the depletion even reversed disease progression in autoimmune encephalomyelitis.

Researcher Mingnan Chen, Ph.D, assistant professor, Department of Pharmaceutics and Pharmaceutical Chemistry, University of Utah, says, “To make similar therapeutics for people, we would need to find the anti-human PD-1 antibody, like the anti-mouse PD-1 antibody.”

Certainly there are reasons to be hopeful about the new approach. Only a single dosage was needed to suppress autoimmunity completely, and this dosage was able to target both T cells and B cells--two common factors in autoimmune diseases. Also, there was no long-term impact on healthy immunity in the mice studies.

Dr. Chen says, “In summary, the depletion of PD-1-positive cells may become a therapeutic approach that selectively and specifically suppresses autoimmunity.” ■

--Source: Excerpted from “Scientists Have Found an Entirely New Way to Slow Autoimmune Diseases,” Carly Cassella, *Nature Biomedical Engineering*, March 7, 2019; and “Selective suppression of autoimmunity through depletion of programmed death-1 (PD-1)-positive cells,” University of Utah, Mingnan Chen, Ph.D.

What’s the harm in social stress?

In 1936, Hungarian-Canadian endocrinologist Dr. Hans Selye coined the term “stress” in reporting his studies of stress and its biological effects on the body. Now, 83 years later, researchers at the Bar Ilan University, in Israel, with their study of stress, have shown that continued social stress can negatively affect the gut microbiota, or the microorganisms, which then triggers different harmful immune responses.

The researchers found that mice under social stress-related conditions increase the reduction of effector T helper cells, a type of cells which performs the function of autoimmunity in the body. Lead study author and immunologist Orly Avni, Ph.D., says, “We know that there’s a strong crosstalk between the immune system and the microbiota.” She and her research team found that continuous stress not only poses a threat to genes expression of the gut bacteria in the mice but also changes their composition. Dr. Avni explains that the “consequent immune response to that threat jeopardized the tolerance to self.”

The change in the expression of these genes can increase the chances of the gut microbes to travel outside the gut to the nearby lymph nodes where they initiate immune responses. The mice of the stress group had increased concentration of pathogenic bacteria as well as effector T cells. This included the myelin-autoreactive cells which researchers find in multiple sclerosis (MS), an autoimmune disease.

Researchers believe that by understanding this deep connection between gut microbiota and stress, one day they will be able to discover various gut microbe treatments for autoimmune disease which are triggered by stress.

Dr. Avni says, “It is not enough to study the composition or the increase or decrease of a species. We also have to understand how the microbiota sense us and how they change their ‘behavior’ accordingly.” ■

--Source: Excerpted from “Are You at Risk of Autoimmune Diseases due to Persistent Social Stress?” Emma Colleen, *Ask Health News*, May 20, 2019

Thank you for awareness

A big **thank you** goes to all of you who requested AARDA materials to distribute in your own communities during Autoimmune Disease Awareness Month (ADAM). It was terrific outreach.

To request AARDA brochures for your local libraries, doctors’ offices, churches, community groups, or friends, contact AARDA Resource Development and Community Outreach Manager Sandra Cobb at scobb@aarda.org. Awareness saves lives.

Gut microbiome linked to autoimmune disease

Recently reported research studies in Ireland and the United States have shown detailed evidence of a link between an abnormal mix of bacterial imbalances in the gut and various diseases, including autoimmune diseases.

Researchers at the New York University School of Medicine state that their experiments are the first detailed evidence of a link between bacterial imbalances in the gut and potentially life-threatening forms of systemic lupus erythematosus (SLE). The new study showed that 61 women diagnosed with SLE had roughly five times more gut bacteria known as *Ruminococcus gnavus* than 17 women of similar ages and racial backgrounds who did not have the disease and were healthy.

Study results showed that disease flares, which can range from skin rash and joint pain to severe kidney dysfunction requiring dialysis, closely tracked major increases in *R. gnavus* bacterial growth in the gut, alongside the presence in blood samples of immune proteins called antibodies, specifically shaped to attach to the bacteria. Study participants with kidney flares had especially high levels of antibodies to *R. gnavus*.

Study Senior Investigator and immunologist Gregg Silverman, M.D., says that their results also point to leakages of bacteria from the gut as a possible immune system trigger of SLE. The study results suggest that perhaps internal gut

environment may play a more critical role than genetics in renal flares of the disease.

If the study team's results are validated, then some current treatments may actually be causing harm if they impair overall immune defenses against infection. Current approaches to treating the disease focus on immune-suppressing anticancer medications to relieve symptoms and injury to the kidneys.

Dr. Silverman says that future treatments could include inexpensive probiotics or dietary regimens that impede *R. gnavus* growth and prevent flares. New treatments also could be used to promote growth of *Bacteroides uniformis*, bacteria thought to hinder growth of *R. gnavus* in the gut. Experts say that over 1,000 different types of bacteria make up the human gut microbiome.

Meanwhile, researchers at Queen's University in Belfast, Ireland, have revealed findings from a recent study showing that some patients with autoimmune disorders--such as, multiple sclerosis (MS), rheumatoid arthritis, and ulcerative colitis--display higher-than-normal levels of a "mimic protein" produced by *Bacteroides fragilis*, a member of the human gut microbiome.

Study author Sheila Patrick, Ph.D., professor at Queen's University, says that this specific microbe in the gut pumps out protein molecules that mimic a human protein, causing the human defense

system to turn on its own cells by mistake, contributing to autoimmune deregulation.

Dr. Patrick says, "When we carried out the first complete genome sequence of the reference type strain of the gut bacterium *Bacteroides fragilis* in the early 2000s, we were astonished to discover that it produces a homologue of mammalian ubiquitin." She explains, "Ubiquitin is found in all eukaryotic cells but is not found in bacteria. *B. fragilis* is therefore unique among bacteria."

Dr. Patrick says that the research proves that *B. fragilis* ubiquitin can cross the human gut lining and generate an immune response. The researchers found that people with autoimmune diseases, such as lupus and rheumatoid arthritis, are more likely than healthy volunteers to have antibodies to BfUbb (a bacterial mimic of ubiquitin).

Future studies on the topic will be aimed at discovering the relationship between the stage of disease and antibody levels to the bacterial mimic in individual patients. This can assist in the development of a rapid test which will aim to detect antibodies to the bacterial ubiquitin and provide insight into a person's predisposition to an autoimmune disease.

--Sources: "Lupus Strongly Linked to Imbalances in Gut Microbiome," NYU Langone Health, February 13, 2019; and "Common Gut Bacteria Linked to Autoimmune Diseases," Keith Loria, February 1, 2019

Have you read this book?

In *Mostly Sunny, How I Learned to Keep Smiling Through the Rainiest Days*, author Janice Dean, senior meteorologist for *Fox News* and morning meteorologist on *Fox & Friends*, has written a book that weaves her experiences in TV-land with her multiple sclerosis (MS) experience. Dean's book is a journey punctuated by laughter, tears, searches for compassionate physicians, and encounters with abusive and sexist executives. She jokes to other MS patients that "finding your doctor is kind of like dating: you have to go on a few of them until you find your match."

Perhaps most of all, for autoimmune patients and MS patients in particular, *Mostly Sunny* is a sharing of the challenges of accepting a diagnosis of MS and fitting it into one's life-- dating, marriage, motherhood, climbing the career ladder, etc. "There have been trying moments, painful situations, and moments of feeling sorry for myself. However, being diagnosed with MS has also made me

realize the important things in life." She says, "Embrace the unknown rather than fear it."

Dean shares the need to find necessary support--family, friends, child care, doctors who look you in the eye, and perhaps a therapist. Dean says that her therapist "was a personal trainer for my brain to strengthen my mental muscles."

A writer of children's books, Dean has written *Freddy the Frogcaster* books to help children understand storms and how to prepare and be safe. Freddy has covered thunderstorms, a big blizzard, a terrible tornado, a huge hurricane, and a flash flood. Dean says that many families have reported getting emergency preparedness kits for their homes and cars after reading the stories in the "Freddy" books.

--HarperCollins Publishers, New York, 244 pages, hardcover, \$26.99 US, \$33.50 Canada



AARDA supports undergraduate researchers



Young researchers in the 2018 Johns Hopkins Diversity Summer Internship Program, including three students sponsored by AARDA, gather to celebrate the completion of their projects.

Looking to the future, AARDA is proud to sponsor undergraduate students each year in the Diversity Summer Internship Program (DSIP), in the Bloomberg School of Public Health, at Johns Hopkins University (JHU). Established in 1995, the program provides graduate level, independent research experience in biomedical and/or public health research to undergraduate students under the direct mentoring of established Johns Hopkins researchers. AARDA has a particular interest in students who choose to study some aspect of autoimmune disease.

Opportunities in the program are granted to students interested in careers in science and public health, including those from underrepresented minority groups and economically disadvantaged backgrounds. All of this year's participants are eligible to receive a partial tuition scholarship upon matriculating into a qualified graduate program in the JHU Bloomberg School of Public Health.

For the summer of 2018, AARDA was assigned the following students: Austin Castellanos, a graduate of Haverford College, Haverford, PA, "Identification of Novel Self Antigens in Patients with Secondary Hypophysitis Pre and Post"; Brianna Celix, a graduate of Pacific Lutheran University, Tacoma, WA, "The Impact of Prenatal and Early Life Arsenic Exposure on TLR Signaling"; and Christine Okemkpa, a graduate of Morgan State University, Baltimore, MD, "Pathogenic relevance of BCR-encoded autoantigen in type 1 diabetes subjects."

It has been interesting to hear from some of the students as they have entered their various fields of medicine, including those involving autoimmune research. The most recent to come to our attention is a researcher whose NIH-funded research has uncovered the driver in inflammatory arthritis severity (see *InFocus*, September 2018). Another former student currently is researching gene therapy approaches for early onset inflammatory bowel disease (Crohn's disease and colitis). Both have expressed gratitude to AARDA; and the arthritis researcher wrote, "I would say that the AARDA made a good investment in supporting the early stages of my career..."

AARDA contributions to research take many paths. Certainly the steps these young researchers are taking along the autoimmune path are very promising to our future--a "good investment," indeed. ■

AARDA Autoimmune Walks and Public Forums scheduled



Do you live in the general areas of Greater Detroit, New York City, or Greater Pittsburgh? Here is your chance to support AARDA while meeting some great AARDA members and friends.

Come to walk (maybe even push a stroller along the way), visit (chairs available), and enjoy speakers and entertainment. To date, here is the schedule. If you've ever been to an AARDA Autoimmune Walk, you know there are no age limits.

Here is the 2019 schedule to date:

- ◆ **Metro Detroit Autoimmune Walkabout and Public Forum** - Saturday, August 24, VisTaTech Center, Schoolcraft College, Livonia, Michigan
- ◆ **New York Autoimmune Walk** - Sunday, September 15, Hudson River Park, Pier 45, New York City
- ◆ **Pittsburgh Autoimmune Walk and Public Forum** - Public Forum: Saturday, September 28, Autoimmunity Institute; and Walk: Sunday, September 29, Schenley Plaza
- ◆ **5th Los Angeles Autoimmune Walk** - Sunday, November 3, Culver City Park, Culver City, California
- ◆ **Virtual Walk** - Any day, Anytime, Anywhere, your choice

To register for an Autoimmune Walk or receive more information, you may visit www.autoimmunewalk.org. Like us on Facebook at [www/Facebook.com/AutoimmuneWalk](https://www.facebook.com/AutoimmuneWalk) or tweet us @AutoimmuneWalk. Also, you may call the AARDA office (586-776-3900). ■

Team approach enhances MS treatment

The diagnosis of multiple sclerosis (MS), a neurological autoimmune disease, can create a sense of doom in a patient; but Dr. Cary Twyman, a neurologist at Penn State Health, says that with proper treatment and management, patients can manage the disease's often unpredictable nature.

Dr. Twyman says, "The immune system of someone with MS has lost its sense of self. Cells that protect the body from disease can't detect what is dangerous and what isn't, so they attack the brain, optic nerve and spinal cord."

While scientists still don't know what causes MS, they believe that the disease is triggered by an unidentified environmental factor in a person who is genetically predisposed to respond. Common symptoms include numbness or tingling in the face, body or arms and legs, pain, fatigue, walking difficulties, muscle spasms, general weakness, vision problems and dizziness or vertigo. Most people with MS find it diagnosed between the ages of 20 and 50, and it affects twice as many women as men.

Dr. Twyman says that over the years, diagnosing MS has become clearer. More than 800,000 individuals have been diagnosed in the U.S. alone, with approximately 10,000 new cases

Article continued on page 9

Congenital Lyme disease rare but real

In December 2018, when 55 entries were undergoing final review for the International Classification of Diseases (ICD), published by the World Health Organization (WHO), one diagnosis--congenital Lyme disease--was dropped from the list. The condition occurs when a pregnant woman infected with the tick-borne disease passes the *Borrelia burgdorferi* bacterium, a spirochete, to her developing baby.

In response to questions about the removal of the diagnosis, WHO spokespersons said, "(T)here is not sufficient evidence to justify a separate statistical category for congenital Lyme disease." It was stated that when newborns are found to harbor Lyme spirochetes, other diagnostic codes can be used; but patient advocates fear that this does not give the condition the recognition it deserves.

Jane Marke, M.D., a New York City psychiatrist who treats Lyme patients, advises, "For babies riddled with spirochetes, there needs to be a way to describe them to simply have the discussion."

Cases of Lyme spirochetes crossing the placenta have been documented since the 1980s. According to the United States Centers for Disease Control and Prevention (CDC), "Lyme disease acquired during pregnancy may lead to infection of the placenta and possible stillbirth; however, no negative effects on the fetus have been found when the mother receives appropriate antibiotic treatment." Also, according to the CDC, "In general, treatment for pregnant women with Lyme disease is similar to that of non-pregnant adults, although certain antibiotics, such as doxycycline, are not used because they can affect fetal development."

Can Lyme disease be transmitted through breast milk? According to the CDC, "There are no reports of Lyme disease being spread to infants through breast milk." Mothers with Lyme disease are advised to consult their doctors to receive a prescription for an antibiotic that is safe for breastfeeding babies.

Questions remain on the consequences of Lyme disease infection in utero, but the pathogen has been found in the damaged bodies of babies who could not have been bitten by a tick.

The on-again, off-again status of congenital Lyme borreliosis is most certainly an outgrowth of the large issues that plague Lyme disease. Each year, approximately 30,000 cases of Lyme disease are reported to CDC by state health departments and the District of Columbia. However, cautions the CDC, this number does not reflect every case of Lyme disease that is diagnosed in the U.S. each year.

The infection is difficult to diagnose and the pathogen difficult



to culture. This certainly inhibits identification in babies and mothers. Treatments also fail many patients for unknown reasons; and research funding has been scant, leaving questions unanswered about congenital and other forms of Lyme disease.

Physicians in prime Lyme disease areas say that the standard diagnostic test fails often, and scientific studies back them up. According to the CDC, "...the accuracy of the test depends on the stage of the disease." Also, according to the CDC, "Several weeks after infection, currently available ELISA, EIA and IFA tests and two-tier testing have very good sensitivity."

In an effort to assess the risk of Lyme disease during pregnancy, the state and territorial epidemiologists and the CDC have established a registry to enroll cases of Lyme disease in pregnant women before the outcome of pregnancy is known. Information from the CDC states, "Since transplacental transmission of *B. burgdorferi* has been documented, it will be important to determine whether maternal infection with *B. burgdorferi* is associated with an increased risk of adverse pregnancy outcome." This would suggest that every obstetrician should be highly aware of this threat. ■

--Source: Excerpted and adapted from "When Lyme Disease Strikes an Unborn Child," Mary Beth Pfeiffer, *Scientific American Blog Network*, January 25, 2019; "Current Trends Update: Lyme Disease and Cases Occurring during Pregnancy--United States, Centers for Disease Control and Prevention (CDC); "Lyme Disease Frequently Asked Questions (FAQ)," United States, Centers for Disease Control and Prevention (CDC), May 6, 2019 (<https://www.cdc.gov/>)



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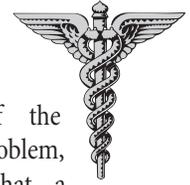
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Sjögren's, Hashimoto's, Graves'--What connection?

All three autoimmune diseases-- Sjögren's syndrome, Hashimoto's thyroiditis (hypothyroidism), and Graves' disease (hyperthyroidism)--share common genetic and environmental risk factors. In these autoimmune diseases, and all autoimmune diseases, the immune system which is designed to eliminate invading viruses or bacteria becomes misdirected and attacks the very organs and tissues it was designed to protect.

The thyroid gland, located in the front of the neck just below the larynx, is part of the endocrine system which controls the body's metabolism and other physiological functions. Metabolism is the rate at which the body converts food into energy. The thyroid uses iodine to make its hormones. Sjögren's syndrome is an autoimmune disorder that targets the body's moisture-producing glands: lacrimal, that produce tears; and sublingual, parotid, and

submandibular salivary glands. Sjögren's syndrome also targets moisture-producing tissues, including mucous membranes in the nose, vagina, and lungs.

Because both Sjögren's syndrome and thyroid disease increase with age, researchers believe that the two conditions might be caused by age-induced damage to the immune system. While studies have shown a higher prevalence of autoimmune thyroid disease in Sjögren's syndrome patients (autoimmune), they have produced inconsistent results regarding non-autoimmune thyroid disease.

In an attempt to address this inconsistency, researchers at China's People's Hospital of Liaoning Province reviewed clinical data from studies on Sjögren's syndrome and thyroid disease. The researchers not only found that Sjögren's syndrome patients were 3.3 times more likely to develop thyroid disease than

controls, regardless of the nature of the thyroid problem, but also discovered that a similar association was found in autoimmune and non-autoimmune patients, with 3.4 and 2.9 times, respectively, more likely to have these conditions.

The researchers suggest that since the risk of thyroid disease is shown to be increased in patients with Sjögren's syndrome, they should be screened for thyroid disease. ■

--Source: Excerpted and adapted from "Sjögren's Patients More Likely to Develop Thyroid Disease, Review Shows," Alice Melao, *Sjögren's Syndrome News*, via *BioNews Services, LLC*, April 16, 2019; "Hashimoto's Disease: The Facts," AARDA free brochure; and *The Autoimmune Connection, Second Edition*, Rita Baron-Faust, MPH, and Jill P. Buyon, M.D., McGraw Hill Education, 2016, 508 pp., softcover

Researchers study ways to promote some self-healing

The body's innate ability to heal itself is often overlooked or undervalued in our haste to use medications. One of the newest studies in "helping cells to help themselves" in multiple sclerosis (MS) is taking place at Charité-University of Medicine, Berlin.

Diseases such as MS are characterized by damage to the myelin sheath, a protective covering wrapped around nerve cells, like insulation around an electrical wire. The research team at Charité has discovered how the body initiates repair mechanisms which will limit the extent of any damage to this sheath, and their findings provide a basis for the development of new drugs to treat MS.

MS patients experience vision and sensory problems, as well as impaired coordination or even paralysis. These symptoms are caused by the disruption of nerve impulses in either the brain or the spinal cord. This disruption occurs when the body's immune system attacks the myelin sheath. When the myelin sheath is no longer intact, communication between nerve cells is impaired.

Knowing that under certain circumstances, the central nervous system is capable of repairing damage to the myelin sheath, Charité's research team decided to look closely at the body's innate ability to heal itself.

Specific molecular signals enable stem cells to differentiate

into myelin repair cells (oligodendrocytes) which reside in a small stem cell niche in the brain. Leaving this niche, these repair cells migrate to where myelin damage has occurred in order to restore the affected nerve cells' electrical insulation.

The researchers found that a protein, Chi313, plays a central role in the body's capacity to produce new myelin-forming repair cells. The study's first author, Dr. Sarah-Christin Starossom, explains, "The Chi313 protein initiates the differentiation of neural stem cells into myelin repair cells, which restore the electrical insulation around damaged nerve cells."

Using a mouse model, and later during an in vitro experiment using human cells, the researchers were able to show that a reduction in Chi313 levels in the brain significantly impairs the body's capacity for myelin repair cell production, while a Chi313 infusion leads to an increase in the production of myelin repair cells.

Dr. Starossom says, "We hope to use this knowledge to develop a new generation of drugs that can be used in the treatment of multiple sclerosis." ■

--Source: Excerpted and adapted from "Multiple sclerosis--helping cells to help themselves," Charité-Universitätmedizin Berlin, January 15, 2019

~ 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.

What's up with women and autoimmune disease?

Why are women three times more likely than men to acquire autoimmune diseases? It's a question with many guesses but no answer--although perhaps researchers at the University of Michigan can solve the puzzle.

New evidence points to a molecular switch called VGLL3 which appears in the skin of women in greater amounts than in men. The researchers have discovered that having too much VGLL3 in skin cells pushes the immune system into overdrive, leading to a "self-attacking" autoimmune response. This response extends even beyond the skin, attacking internal organs as well.

According to lead researcher Johann Gudjonsson, M.D., Ph.D., "VGLL3 appears to regulate immune response genes that have been implicated as important to autoimmune diseases that are more common in women but don't appear to be regulated by sex hormones." He says, "Now, we have shown that overexpression by VGLL3 in the skin of transgenic mice is by itself sufficient to drive a phenotype that has striking similarities to systemic lupus erythematosus, including skin rash and kidney injury."

The skin of mice became scaly and raw with the gene expression changes caused by excess VGLL3. Immune cells thrived, filling the

skin and lymph nodes. The mice also produced antibodies against their own tissues, including the same antibodies that can destroy the kidneys of lupus patients.

The researchers don't know what causes female skin cells to have more VGLL3 to begin with, and they also don't know what triggers might set off extra VGLL3 activity. They do know, however, that in men with lupus, the same VGLL3 pathway seen in women with lupus is activated.

Finding the key factors downstream of VGLL3 may identify targets for new, and potentially safer, therapies that could benefit patients of both sexes. Many of the current therapies for lupus come with unwanted side effects from steroids, including increased infection risk and cancer.

The researchers are recruiting patients with lupus for a study sponsored by the A. Alfred Taubman Medical Research Institute, University of Michigan, Ann Arbor. Recruits will contribute skin and DNA samples. ■

--Source: Excerpted from "Why Women Get Autoimmune Diseases Far More Often Than Men," Kara Gavin, *Michigan Medicine*, University of Michigan Ann Arbor, April 25, 2019

New autoimmune study projects set for Michigan Medicine

While new treatments for autoimmune conditions may help patients with some of their symptoms, they often lead to impairment of normal immune system functions. This leaves patients with increased susceptibility to infections. Michigan Medicine, at the University of Michigan, Ann Arbor, has assembled a new research team to study how molecular targets affect autoimmune inflammation and damage and how to avoid impairing the immune system's ability to fight infection.

Researchers will lead projects on scleroderma, lupus, and a collaborative study of a broad range of other autoimmune diseases.

In the scleroderma project, the drug elotuzumab will be tested. It already has been approved by the U.S. Food and Drug Administration (FDA) for treatment of the blood cancer multiple myeloma.

For the lupus project, in cutaneous lupus, the drug tofacitinib which has been approved to treat rheumatoid and psoriatic arthritis will be tested.

In the final project, the researcher will explore new molecular targets in a range of autoimmune diseases, including rheumatoid arthritis, multiple sclerosis, lupus, scleroderma, and autoimmune eye diseases.

Researcher Dr. David Fox says, "This project will be an opportunity to take new discoveries related to rheumatoid arthritis and apply this progress to the study of many other autoimmune diseases that affect multiple organs and tissues in our patients, with the ultimate goal of safer and more effective treatment."

Dr. Dinesh Khanna, who will lead the research on scleroderma, states, "Grants, such as this one, help us take our work from the lab and translate it into tangible benefits for the patients we see each day in clinic." ■

--Source: Excerpted from "Exploring New Treatments for Autoimmune Diseases," *Michigan Medicine*, University of Michigan, May 7, 2019, via Newswise

MS... continued from page 6

diagnosed each year. A combination of methods can be used to diagnose MS. These include a careful study of the patient's medical history, a neurologic exam, and various tests including MRIs, evoked potentials, and spinal fluid analysis.

Dr. Twyman says that finding a treatment to alter the immune system should happen immediately after diagnosis. Currently 15 drugs are available to treat MS patients. Which is best? According to Dr. Twyman, there is no standard way to choose a drug to treat MS. It depends on such things as how far along the disease has progressed, what the patient's tolerance to the drug is, cost of the drug, and how closely the patient needs to be monitored on the drug.

Who helps the patient? Dr. Twyman says that it's no longer a physician-only approach to treating MS. It's a team approach, medical and non-medical, that helps with wellness. In addition to medication, the team approach may involve specialists in physical therapy, occupational therapy, speech therapy, and cognitive and behavioral management. Identifying and creating lifestyle habits, such as staying physically fit, reducing stress, and not smoking will help a patient's quality of life.

"As a comprehensive team, we are able to help our patients with MS look at their life conditions and see what improvements are needed, and then we help them make those improvements together," explains Dr. Twyman. ■

--Source: Excerpted from "The Medical Minute: Taking the Reins on Multiple Sclerosis," Dr. Cary Twyman, *Penn State Health*, March 14, 2019

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Inside this issue

Let My Doctors Decide initiative launched	1
Autoimmune Research Network, ARNet	1
President/Executive Director's message.....	2
Could a Charitable Distribution be advantageous?	3
Blood test for fibromyalgia holds promise	3
Can autoimmune diseases be slowed?	4
What's the harm in social stress?	4
Thank you for awareness.....	4
Gut microbiome linked to autoimmune diseases ...	5
Book review - Mostly Sunny	5
AARDA supports undergraduate researchers.....	6
AARDA Autoimmune Walks and Public Forums scheduled.....	6
Team Approach enhances MS treatment	6
Congenital Lyme disease rare but real	7
Sjögren's, Hashimoto's, Graves' -- connection?.....	8
Researchers study ways to promote self-healing	8
What's up with women and autoimmune disease?	9
New autoimmune study projects for Michigan Medicine	9
AARDA says "Thank you" to donors	10
With Special Thoughts - Tributes & Memorials...10	