INFOCUS

Autoimmune Diseases Association

American Autoimmune Related Diseases Association, Inc.

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

Vol. 22 No. 1, March 2014

March Is National Autoimmune Diseases Awareness Month

So...you know all about autoimmune diseases. Yes? Then, in honor of National Autoimmune Diseases Awareness Month, let's list some facts that you can share with friends.

❖ ***Autoimmune diseases are a major health problem.***

--Over 100 autoimmune diseases have been identified to date.

--The National Institutes of Health (NIH) states that 23.5 million people in the U.S. have an autoimmune disease, and prevalence is rising. (AARDA estimates 50 million because the NIH includes numbers from only about 24 of the over 100 known autoimmune diseases.)

--Autoimmune disease affects more people in the U. S. than cancer or heart disease.

--Autoimmune disease has a high prevalence in the pediatric and adolescent population (one of the top ten causes of death in children aged 1-14), and the prevalence is rising.

--Autoimmune diseases are one of the top ten causes of death in females in all age groups up to age 64.

--Treatment costs were estimated at over $100 billion in 1991 (almost twice as much as cancer) and are expected to increase to $500 billion in a few years.

--Autoimmune diseases can affect any part of the body, are chronic (usually lasting a lifetime), and can be life-threatening.

--Autoimmune diseases are a genetically interrelated family (like cancer), which explains observed disease clustering in individuals and families.

--A 2003 study in Finland estimates that the prevalence of celiac disease, triggered by gluten intolerance, is at least one in 99 children.

--Some ethnic groups as compared with others are more susceptible to certain autoimmune diseases. In lupus, for example, African American, Hispanic, Asian, and Native American women are two to three times more likely to develop the disease than Caucasian women.

❖ ***Autoimmune disease diagnosis and treatment need major improvement.***

--The search for a diagnosis averages four years, with a patient having seen four or five doctors during that search.

--Autoimmune diseases are perceived incorrectly as rare and often are misdiagnosed as psychosomatic ("all in your head"). An AARDA survey found that more than 45 percent of autoimmune disease patients have been labeled hypochondriacs in the earliest stages of their illnesses.

--Symptoms cross many specialties and can affect all body organs, confusing diagnosis as patients go from specialist to specialist.

--Specialists are generally unaware of interrelationships among autoimmune diseases or treatment advances outside their own specialties.

--No new treatments for the majority of autoimmune diseases have been introduced in over 40 years.

--Current treatments primarily suppress the immune system, thus increasing the risk of other diseases.

--Many of the current treatments have devastating long-term side effects.

Keep up with AARDA!

Sign up for our **ENews** on the front page of our Web site (www.aarda.org).

Help with awareness!

Like us on Facebook (www.facebook.com/autoimmunity)

❖ ***Genetic predisposition isn't everything.***

--Research attention is now focused on the complex and thus far poorly understood interaction between environmental exposures and genetic predisposition (only one-third of the risk).

--Occupational exposures, including silica, solvents, and pesticides, are associated with autoimmune diseases.

--Drugs are recognized as a non-infectious environmental exposure associated with autoimmunity.

--Streptococcal infections trigger pediatric autoimmune neuropsychiatric disorders associated with streptococcus (PANDAS), hallmarked by the presence of obsessive-compulsive disorder or a tic disorder.

--In about 60 percent of pediatric cases of immune thrombocytopenic purpura (ITP), there is a history of prior infection.

--An increased risk of immune thrombocytopenic purpura is associated with the MMR vaccination.

--Other exposures, such as those to foods, e.g., gluten in celiac disease, cigarette smoking, ultraviolet radiation, heavy metals, collagen implants, silicone implants, and stress, have been proposed as risk factors for autoimmune disease.

--Increasing incidence suggests that addressing environmental factors is critical in the study of autoimmune diseases as well as other health issues.

--The lack of epidemiology studies of incidence and prevalence of autoimmune disease is a major roadblock for research funding and the development of public policy.

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InFocus, *a quarterly newsletter of the Amercian Autoimmune Related Diseases Association, Inc. (DBA Autoimmune Diseases Association)*

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President/Executive Director's message — *Virginia T. Ladd*

Happy spring! I say that with great hope after experiencing the rigors of winter. Most of our readers will understand that. As for the rest of you, sitting under palm trees or whatever, I can assure you that the snow is beautiful as I write this--maybe too much, but beautiful nevertheless.

❖ First...our thanks to all of you who contributed to our Annual Appeal (and some whose contributions are "in the mail"). At latest count, the contributions total $39,113, compared to $38,767 in 2012. A number of first-time contributors joined our longtime supporters in giving generously, on all levels, toward AARDA's mission. We are grateful.

❖ With spring comes our 14th Annual Fund Raiser, the Derby Luncheon and Auction, being held this year on May 3, at The Henry Hotel, in Dearborn, Michigan. THANK YOU to the volunteers who make this major fund raiser possible. It raises over $50,000 each year.

❖ Our new Chair of the Board **Dr. Herbert G. Ford** took the gavel at the January 2014 Board meeting. Dr. Ford and all the Board members paid tribute to outgoing Chair **Dr. Stanley M. Finger** who had served in that position from November 2000 to September 2013 after having first joined the Board in June 1995. As announced in the December *InFocus*, Dr. Finger has assumed the position of Vice Chair of the Board. I feel confident that AARDA continues in good hands.

❖ Are you making use of AARDA's social networking opportunities? We continue to reach out via Facebook, Twitter, YouTube, and the AARDA video. We have 14,842 Facebook page members and 1,264 Twitter followers. These are tremendous awareness and education opportunities. Join us!

❖ With spring comes the first of our 2014 public forums, "What Every American Needs to Know About Autoimmune Disease." This one is scheduled for Saturday, April 5, from 9:30 a.m. to 4:00 p.m., in Los Angeles, California. Members and friends in that area will receive a mailing; but if you will be visiting the Los Angeles area and want to attend, contact the AARDA office or go to www.laadforum.eventbrite.com.

❖ Washington DC area friends and/or visitors may want to visit the 3rd USA Science & Engineering Festival at the Walter E. Washington Convention Center, on April 26 and 27. The AARDA booth was very popular in the 2nd Festival, drawing many young students and their parents, and we hope to be even better this year. AARDA is an official partner of this event that hosted 258,000 visitors at the 2nd Festival over a two-day period. This included students and their parents, teachers, and 3,000 STEM professionals.

❖ Also, we are proud to be a sponsor, with the Society for Women's Health Research and the Immune Deficiency Foundation, of "The Microbiome and Autoimmune Disease," a scientific symposium to be held on May 16 through 18, at the National Conference Center, in Leesburg, Virginia.

The Human Microbiome Project (HMP) is a United States National Institutes of Health initiative with the goal of identifying and characterizing the microorganisms which are found in association with both health and diseased humans (their microbial flora). Launched in 2008, it is a five-year project best characterized as a feasibility study which has a total budget of $115 million. The ultimate goal of this and similar NIH-sponsored microbiome projects is to test how changes in the human microbiome are associated with human health or disease.

❖ We've also hit the printed pages. Perhaps some of you read "All About Autoimmunity - Ask the Expert: Dr. Noel Rose" in the August/September issue of *Irish America*. Also, an article in the *Hudson Valley Chronogram*, entitled "The Autoimmune Connection," referred to AARDA and utilized some of our information. See this issue of *InFocus* for excerpts from both articles.

❖ In the area of research, one of our projects is support of "existing scientific sessions" at the 9th International Congress on Autoimmunity to be held in Nice, France, at the end of March. We are proud that AARDA, a national organization, has an international outreach. Your dollars at work!

❖ All of us can thank AARDA's Ad Hoc Advocacy Committee as it continues its work on behalf of autoimmune patients. Some issues being tackled are in the areas of discrimination against autoimmune patients by the proposed removal of immunosuppressant therapies and the assurance of patient access to specialists and specialty medicines. We are fortunate to

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The many faces of dermatomyositis: an update

We thank volunteer Heather Kaiser for an update of the AARDA brochure on "Dermatomyositis." Here we present excerpts from the brochure and some adaptation for this newsletter. The complete brochure is available at no cost from AARDA.

Dermatomyositis, an inflammatory autoimmune disease that affects the muscles (myositis), skin (dermis), and blood vessels, is part of a group of diseases called "inflammatory myopathies." It can afflict people of any age, sex, and ethnic group--but like many other autoimmune diseases, it is found most often in women.

What causes dermatomyositis? Autoimmunity is generally accepted as the cause of dermatomyositis. Like other autoimmune diseases, it is caused by a combination of genes and environmental triggers. In a healthy immune system, cells called T cells help identify and destroy viruses, bacteria, and other foreign substances. In dermatomyositis, in typical autoimmune disease fashion, the T cells are more active than normal and begin attacking healthy tissues. This causes the tissues and muscles to become inflamed and damaged which leads to the symptoms of dermatomyositis.

Dermatomyositis is a complex disease. Current research suggests that there is a genetic component that may increase one's susceptibility to the disease. Although a specific gene has not been identified, researchers have identified mutations or alternative forms of genes that are thought to be known risk factors for the development of dermatomyositis.

Environmental factors also contribute to the development of dermatomyositis. Several research sources have observed that it may be triggered by a response to a virus, bacteria, or current infection. Several microorganisms are suspected of being involved in the onset of dermatomyositis. These microorganisms include Coxsackie B, echovirus, and Streptococcus pyrogenes. Also, some research has found that gastrointestinal and respiratory illnesses, with or without antibiotic use, have been reported within three months before a diagnosis of dermatomyositis is made. It has been found that the onset of dermatomyositis may be seasonal because a large amount of cases occur in spring and summer. Exposure to sunlight has been found to be a contributing factor in the progression of the disease.

What are the symptoms of dermatomyositis? Onset of symptoms can be sudden or may develop over a long period of time. The most common symptoms include the following: rash, known as heliotrope, that develops around the eyelids; rash or bumps, known as Gottron's papules, that can develop on the knuckles, finger joints, toes, knees or elbows; rough, scaly skin; muscle weakness, including muscles close to the trunk of the body; general fatigue or muscle pain; fever, swelling, weight loss, headache, and/or abdominal pain; difficulty swallowing or breathing; changes in voice or hoarseness; development of calcium deposits on soft tissues.

How is dermatomyositis diagnosed? While early diagnosis can be critical to limiting the progress and severity of dermatomyositis, reaching a diagnosis may take weeks, months, or even longer. It can be difficult to diagnose because the symptoms can be vague, may come and go, or can mimic other illnesses. Sharing with your doctor your complete medical history, family history, and a complete list of your symptoms, including how long the symptoms have persisted, is important.

The physical examination is the key to diagnosis. The exam may include testing of muscle weakness, laboratory tests, and nail fold (cuticle) examination. The laboratory tests will include blood tests for muscle enzyme measurements, complete blood count (CBC), and C-reactive protein (CRP) or erythrocyte sedimentation rate (ESR).

If recommended by your doctor, magnetic resonance imaging (MRI), electromyography (EMG), or a muscle biopsy may be needed to obtain an accurate diagnosis. The MRI can provide more in-depth information about the body when compared to x-rays, CT scans, and ultrasound.

How is dermatomyositis treated? Treatment goals include reducing and controlling the inflammation, preventing further complications, and improving the function of the patient. A treatment plan may include a team of physicians and other disciplines, including the primary care doctor, rheumatologist, dermatologist, and physical therapist.

Certain medications will be used, and the first line of treatment is a corticosteroid given orally, usually prednisone. The dose of prednisone usually is started as a high dose and tapered down as signs and symptoms improve. The dosage of prednisone and the symptoms of dermatomyositis will be monitored closely by the physician or team of physicians. Topical steroids, usually in a cream form, may be applied directly to the skin for any dermatomyositis symptoms present on the skin.

The administration of an intravenous steroid called methylprednisolone is being tested currently as an alternative treatment option. The intravenous route may be more beneficial for patients who have decreased absorption of medications given orally. The effectiveness of intravenous methylprednisolone is still being researched and is being considered currently only for patients in very serious condition.

If symptoms are not improving with prednisone only, immunosuppressant chemotherapy drugs, azathioprine and methotrexate, may be added to the treatment. Also, these medications may be added so that the prednisone can be tapered down if the side effects of prednisone become too troublesome for the patient.

Another medication, acthar, a preparation of adrenocorticotropic hormone (ACTH), may be administered either by injection under the skin or into the muscle. ACTH is a hormone that is produced naturally in the pituitary gland in the body. It stimulates the release of cortisol from the adrenal glands and mimics the effects of oral corticosteroid medications. It may reduce the autoimmune activity responsible for dermatomyositis by interacting with the receptors in the immune system.

Intravenous immunoglobulin (IVIG) is used in severe cases when the patient has not responded to steroid and/or methotrexate treatment. IVIG blocks the body's attack of the muscles and skin by introducing healthy antibodies from blood donors into the blood.

Many additional treatment options are being studied but not commonly used at this time. These include plasmapheresis, a blood purification procedure; cyclosporine, a type of immunosuppressant that has been used for cases of dermatomyositis that do not respond to the common treatments; cyclophosphamide, a drug more commonly used to treat cancer that is reserved for cases of dermatomyositis which include ulcerative skin disease, respiratory issues, or major organ involvement; and some biologic agents (vaccines, antibodies, interleukins).

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When is it time to find a new provider?

So...you're happy with your physician and the office staff. That's great. That's probably true of the majority of clients. But what are some of the warning signs that the patient/physician relationship isn't working? When might be the time to look for a new provider?

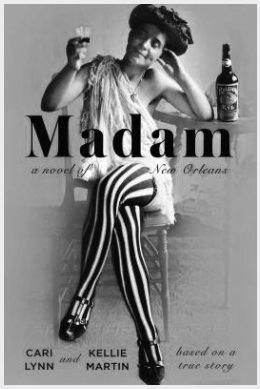
A good doctor/patient fit is important, and every individual has different expectations and preferences as to how he/she should be treated medically. Your gut feeling is often the best guide to follow, but other warning signs could include the following:

- ❖ Being "talked down" to (by physician and/or staff), especially as you age.
- ❖ Having your "chief complaint" dismissed or interrupted by blaming your age.
- ❖ Having your provider insisting that "nothing can be done" or, conversely, quickly referring you to a specialist, ordering a test, or giving you a prescription without "hearing you out"--particularly detrimental if you are a patient with multiple complex issues, as describes many autoimmune patients.
- ❖ Receiving the recommendation of treatments without consideration or discussion of your lifestyle.

Very important are ongoing communication problems with office staff, especially if you are unsuccessful in trying to rectify them with the office manager. Very possibly your provider is unaware of the issues; yet if the office is not organized enough to follow up on ordered tests or procedures, your provider's care may suffer. When you are not feeling well already, it may seem almost impossible to face this situation. You will need to decide whether the problem is worth trying to rectify for the sake of your own health needs. ■

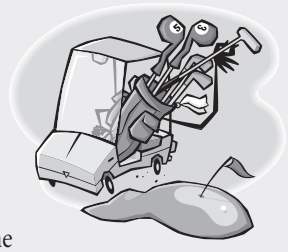
--Adapted from "Dear Sandy: Your health insurance questions answered," Sandy Beiter, RN, BSN, Vanguard, Michigan Association of Retired School Personnel, January/February 2014

Just a note....



AARDA spokesperson Kellie Martin and friend Cari Lynn are announcing the publication of their first novel, ***Madam: A Novel of New Orleans***. The well researched book weaves fact and fiction into the rise of nondescript Mary Deubler, who plied her trade in late 19th century New Orleans in its infamous "Storyville" red light district, to become influential Madame Josie Arlington. It is described as "...a fantastic romp through The Big Easy and the irresistible story of a woman who rose to power long before the era of equal rights." The book is available at major book sellers. ■

Calling all golfers in the Greater DC area!



The 16th Annual Brave Dave Open, a fund raiser in support of AARDA and all autoimmune diseases, has been scheduled for Friday, June 13, at the Blue Mash Golf Club, in Gaithersburg, Maryland. This is a traditionally great day for "all the regulars" plus a welcoming experience for newcomers. Dinner and an auction follow the tournament.

The tournament honors Dave Gearing who was jokingly termed "Brave Dave" a number of years ago. However, he now can wear the title for real as he refuses to surrender to the multiple sclerosis which afflicts him. Surrounded by friends and possessing an indomitable spirit, Brave Dave continues to inspire others.

For information about the golf tournament, contact Tom Branthover, the Brave Dave Open (phone, 301-949-6101; Web, www.bravedave.org; e-mail, tbranthover@comcast.net). ■

Are Autoimmune Walks coming to your area?

❖ The DC Metro Autoimmune Walk is set for Saturday, June 21, at McLean Central Park, 1468 Dolley Madison Boulevard, McLean, Va--same location as last year. This is a popular venue and the Walk should be a winner again this year.

❖ The California Autoimmune Walk is looking for a home, with planners searching for an April 6 location in the Pasadena/Glendale areas.

❖ The Louisville, Kentucky, area Walk is being planned, possibly for a September date. The planners are looking for a good, highly visible location. Two companies have committed for sponsorships.

❖ Groundwork is being laid for a renewal of the TriState (Greater NY Area) Autoimmune Walk, probably the last Sunday in August (same as last year).

❖ Our friends in St. Louis, Missouri, are planning another Autoimmune Walk at Washington University. The students, very supportive in 2013, hope to draw the interest of the larger community.

Autoimmune Walk

LINKING TOGETHER FOR A CURE

So...heads up, AARDA walkers! You're not a walker? Remember--you have a chance to collect your family and friends for a Virtual Walk. Use your imagination in naming your team and deciding how and when you will "walk." These events are tremendous awareness events along with the obvious goal of fund raising. And, would you believe, they are FUN!

Need inspiration or information? Visit AARDA's Walk Web site (www.autoimmunewalk.org); call our Walk phone line (855-239-2557); or e-mail (cpottenger@aarda.org). ■

Interdisciplinary Autoimmune Summit convenes

AARDA President Virginia Ladd is a member of the steering committee planning a unique educational experience that will bring together experts and specialists from across the rheumatic autoimmune disease spectrum. AARDA is proud to be one of the active partners of this event, the Interdisciplinary Autoimmune Summit 2014.

Keynote speaker will be the "father of autoimmunity," Noel R. Rose, M.D., Ph.D., director of the Johns Hopkins University Center for Autoimmune Disease Research and Chair Emeritus of AARDA's Scientific Advisory Board.


Noel R. Rose, M.D., Ph.D.

With the goal of improving the understanding of how to treat and collaboratively care for patients with interrelated disease, the two-day conference, to be held at The Mirage Hotel, in Las Vegas, Nevada, is designed for rheumatologists, dermatologists, gastroenterologists, nurse practitioners, nurses, physician assistants, and other health care professionals involved in the management of patients with autoimmune diseases. The agenda will include 20 one-hour CME/CNE-accredited sessions (North American Center for Continuing Medical Education (NACCME).

A variety of exhibits will be on display to enhance the educational offerings of the conference.

For additional information, go to www.joinias.com. ■

Place your bets! It's Derby Day!

AARDA's 14th Annual Fund Raiser once more offers, by popular request, its Derby Luncheon and Auction--but in a different location. On Saturday, May 3, at 11:30 a.m., Derby guests will gather at The Henry Hotel, in Fairlane Plaza, 300 Town Center Drive, Dearborn, Michigan. Known for its elegance, gracious hospitality, excellent cuisine, and splendid contemporary art, The Henry promises to be a perfect venue for the afternoon's program.

Once more Silent Auction Chair Carolyn Ugval and her committee are assembling a tempting array of one-of-a-kind silent auction items, the menu is being chosen, and the program committee has arranged for entertainment by The Satin Dolls, featuring music of the 40s, 50s, and 60s. Emcee Chuck Gaidica stands ready to lead the way, and the mystery judge will be looking for award-winning outfits, especially hats worthy of the Derby.

Last year's Derby Luncheon netted $57,739 in support of AARDA's mission. Can we do better this year?

AARDA friends and members in the Greater Detroit area will receive invitations. Other interested friends may contact the AARDA office (e-mail, aarda@aarda.org; phone, 586-776-3900). ■

Myasthenia gravis patient turns disease into action

It's one thing to be afflicted with an autoimmune disease. It's another thing to turn the affliction into a help for others. That's what autoimmune patient Courtney G. Smith has done with the myasthenia gravis attacking her body.

Obtaining her bachelor's degree in communication in May 2000 from Michigan State University, Courtney returned to Chicago where she became a substitute teacher for the Chicago Public Schools. Life was good. However, in 2001, she began to notice that her speech was slurred at various times. Then, at dinner with come college friends, she suddenly felt her facial muscles become so weak that she could not chew her food or speak without extreme difficulty.

After being referred to a neurologist, Courtney was diagnosed with myasthenia gravis, an autoimmune disease characterized by great muscle weakness and progressive fatigability. Some cases are mild while others are life-threatening.

Following a strong desire to promote autoimmune education and awareness, Courtney's new passion turned to pursuing a master's degree in Health Communication which she was unable to complete because of myasthenia gravis complications. Returning to work in the Chicago Public Schools, she still felt the need to educate and spread awareness of autoimmune diseases. That could be done utilizing her communication skills.

Based on the fact that people with autoimmune disease often appear healthy despite suffering devastating and debilitating physical and emotional tolls caused by the disease, Courtney set about writing and producing an award-winning documentary. The lives of seven women living with various forms of autoimmune diseases, including lupus, multiple sclerosis, Sjögren's syndrome, pernicious anemia, and myasthenia gravis are told in *Beauty Does Lie: The Untold Stories of Autoimmune Diseases*.

Courtney presented *Beauty Does Lie* at the 2012 Myasthenia Gravis Foundation's national conference in Las Vegas; and she will raise public awareness of autoimmunity, autoimmune diseases, and AARDA through screening and promotion of the film at upcoming Alpha Kappa Alpha sorority regional meetings in March. These are being held in Dallas and Chicago.

Beauty Does Lie: The Untold Stories of Autoimmune Diseases is now being distributed through Courtney's production company. It will have national, and very likely international, distribution. For additional information, go to **cgsmith@courtneygsmith.com** or call Courtney G. Smith at 866-944-9549. ■

Autoimmune disease: still a misunderstood health problem

According to the National Institutes of Health (NIH), autoimmune diseases affect 23.5 million Americans although the American Autoimmune Related Disease Association (AARDA) estimates 50 million. Of those, 75 percent are women. Annual healthcare costs for autoimmune diseases are in the range of $100 billion. To date, slightly more than 100 autoimmune diseases have been identified--but 80 percent of Americans can't name one of them. That response is alarming because most of these same Americans are well acquainted with autoimmune diseases--but by specific names, such as, multiple sclerosis, rheumatoid arthritis, lupus, Crohn's disease, celiac, vitiligo, thyroiditis, and type 1 diabetes--all autoimmune diseases. Why does it matter that the average American doesn't recognize them as autoimmune diseases?

AARDA promotes "Know Your Family AQ," that is, "autoimmune quotient." So, for example, you have rheumatoid arthritis in your family. If you know that rheumatoid arthritis is an autoimmune disease, you will be aware that, within families, there is both the chance of passing on specific autoimmune diseases and of inheriting a general predisposition to developing an autoimmune disease.

Dr. Noel R. Rose, Director of the Center for Autoimmune Disease at Johns Hopkins University and Chairman Emeritus of AARDA's Scientific Advisory Board, says, "The first thing you look for [within a family] is either the same or a closely related disease. So, if the patient has, for example, thyroiditis, which is a disease of an endocrine organ, you look for diseases in other endocrine organs, such as type 1 diabetes, Addison's disease, or diseases of the parathyroid or pituitary gland." He adds, "But then they also may have some more distant autoimmune diseases, like lupus or rheumatoid arthritis."

Dr. Rose points out that, as significant as genes can be in autoimmunity, they are really the minor part of it. He says, "All of the many genes together make up about only 1/3 of the risk. The other 70 percent of the risk is something external, usually something we encounter in the environment."

Kenneth Bock, M.D., who practices integrative medicine in Rhinebeck, New York, observes, "You can't control your genes, but you need to be aware of them. Then you can be more preventive in your family about things that may contribute to the autoimmunity." He says that, depending on the disorder, one treatment approach might involve identifying and eliminating a toxin--whether a dietary allergen contributing to inflammation, such as wheat or dairy, heavy metals from fish, or even a virus or bacterial infection, such as strep throat.

With most autoimmune disease, the environmental factor that triggers the immune system's response is not only difficult but also often impossible to pinpoint. It can be exposure to a certain medication, toxin, or other substance. Some triggers are now well known. For example, gluten is recognized as a trigger for celiac disease. "Also, smoking tobacco is not only bad for heart disease and cancer," according to Dr. Rose, "but it's bad for many forms of autoimmune disease, including disease of the thyroid and for rheumatoid arthritis."

Dr. Rose comments, "Interestingly, the gluten-free diet may also be helpful for people who don't have celiac disease but who have other forms of autoimmune disease." He says, "It's just speculative, but as gluten-free diets become more available, other people are trying them and often feel better."

Another proactive measure, according to Dr. Bock, may be adhering to a regimen of supplements that are known to help regulate the immune system. "I call it the holy trinity: probiotics, omega 3s, and vitamin D. This combination enhances a beneficial group of lymphocytes in the blood called T-regs, which can reduce inflammation."

For reasons not fully understood, autoimmune diseases are increasing worldwide. Dr. Bock says, "We're seeing more autoimmunity, there's no question about it." Among the disorders he's encountering more frequently is Hashimoto's thyroiditis, a self-attack of the thyroid. He says, "It's so common now, it's incredible."

Autoimmunity is not only multifactorial but also cumulative. Dr. Bock refers to what he calls "the immune kettle." In the kettle are many things--heavy metals, BPAs, plastics, trans fats, vitamin D deficiency, and even, according to a recent study, salt (or the iodine in it). Then there are the genetic factors.

Dr. Bock says, "When you get all these factors, then the kettle will overflow and boil over. That's when immune imbalances and clinical symptoms appear, and ultimately you get these disorders and the diseases."

Leaders in the battle against autoimmune diseases, including Dr. Rose and Virginia Ladd, president and executive director of AARDA, see the need for autoimmune diseases to be recognized as one entitity. Dr. Rose's hope is that more medical centers and doctors dedicated to autoimmune disease as a whole will emerge. He says, "From a patient point of view, it would be very helpful if there were critical autoimmune disease centers where patients who have multiple autoimmune disease could be treated in the same place, by the same group of physicians."

With the establishment of such centers for research, diagnostic triage, and treatment, patients would benefit greatly and an economic advantage would be seen. Mrs. Ladd says, "We have cancer centers all over the country, but not one autoimmune center."

If Mrs. Ladd, Dr. Rose, and other AARDA leaders are successful, that situation will be corrected within the next few years although, as Mrs. Ladd points out, fundraising for autoimmunity as a disease category on its own is a challenge. She observes, "Philanthropists and donors are very loyal to their particular disease, whether it's MS, diabetes, or another." She suggests, "What the people writing these checks ought to consider is that we might need to support research in autoimmunity as a whole in order to make progress in the fight against any one of these diseases individually." ■

--Sources: "All About Autoimmunity--Ask the Expert: Dr. Noel Rose," Sheila Langan, Irish America, August/September 2013; and "The Autoimmune Connection," Wendy Kagan, Hudson Valley Chronogram, December 2013

Quote to ponder and enjoy...

"Never follow anything that you can't see around or over."

~ Unknown

It's in the genes!

Numerous studies have reported that certain diseases are inherited; but genetics also plays a role in immune response, our ability to stave off disease. This information comes from a team of international researchers who took blood samples from 1,629 Sardinians. The new findings, from the "SardiNIA Study of Aging," were supported in part by the National Institute on Aging (NIA) at the National Institutes of Health.

Why Sardinians? According to team leader Francesco Cucca, M.D., Director of the National Research Council's Institute of Genetic and Biomedical Research in Italy, "The lineage of most Sardinians goes back approximately 20,000 years, to the Mediterranean Island's original settler population--an ideal group for this type of research." He added, "We have learned that in case after case, findings in Sardinia have been applicable worldwide."

The SardiNIA researchers found 89 independent gene variants on the genome associated with regulating production of immune system cells. Five of these sites for the gene variants coincide with known genetic contributors to autoimmune diseases and extend previous knowledge to identify the particular cell types that are affected by these genes.

"We know that certain diseases run in families. From this study, we wanted to know the extent to which relative immune resistance or susceptibility is inherited in families," said David Schlessinger, Ph.D., chief of the NIH National Institute of Aging (NIA) Laboratory of Genetics. "If your mother is rarely sick, for example, does that mean you don't have to worry about the bug that's going around? Is immunity in the genes?" According to the researchers' findings, the answer is "yes"--at least, in part.

Understanding the genes affecting immune system cells and risk for autoimmune disease is the first step in developing therapies that are personalized according to an individual's needs. However, as the researchers point out, more research is needed to characterize further the role that genetics plays in the complex dynamics of the immune system which has evolved to reject pathogens--harmful germs--and even some cancers; but also high levels of immune function can make the body prone to autoimmune disease.

The number of adaptive immune system cells available to attack a pathogen or, in the case of autoimmune disease, attack healthy cells, is what appears to be regulated by genetics. Small variations in genes naturally occur throughout the DNA code and are generally without effect on any specific trait. However, in some instances, researchers find that a particular variant is more common among people with a trait or disease.

In the analyses, researchers identified 89 independent variants and 53 sites associated with immune cell characteristics. Most of these associations were previously undiscovered. In comparing their findings with data in public repositories, the researchers found, in some cases, that these genes already had been associated with autoimmune disease.

The researchers noted that understanding the genetics behind immune system response and autoimmune disease may have future implications on therapeutic targets, especially in the treatment of autoimmune disease. ■

--Excerpted from NIAMS Update, November (2013) issue, NIH National Institute of Arthritis and Musculoskeletal and Skin Diseases

Upcoming Education Events for 2014 — *Sponsored, cosponsored, or supported by AARDA*

March 26-30 - 9th International Congress on Autoimmunity - Nice, France

March 29-31 - 6th Global Patients Congress, "Better access, better health: A patient-centered approach to universal health coverage" - International Alliance of Patients' Organizations - Ascot, UK - www.globalpatientscongress.org

April 4-6 - 22nd Annual Congress, "Women's Health 2014" - Academy of Women's Health - Washington, DC - www.academyofwomenshealth.org/conference

April 5 - AARDA Public Forum, "What Every American Needs to Know About Autoimmune Disease," 9:30 a.m.- 4:00 p.m. - Holiday Inn, 9901 S. La Cienega, Blvd., Los Angeles, CA 90045 - To register: www.laadforum.eventbrite.com

April 26-27 - 3rd USA Science & Engineering Festival, "Celebrate Science" - Founding and Presenting Host, Lockheed Martin - Walter E. Washington Convention Center, Washington, DC - Information: www.usasciencefestival.org

May 16-18 - "The Microbiome and Autoimmune Disease," Sponsored by AARDA, Society for Women's Health Research, and Immune Deficiency Foundation - National Conference Center, Leesburg, VA

June 20-22 - Interdisciplinary Autoimmune Summit, North American Center for Continuing Medical Education (NACCME)- The Mirage Hotel, Las Vegas, NV

November 14-16 - 2014 American College of Rheumatology Annual Meeting - Boston, MA

Is there a link between intestinal bacteria and arthritis?

In the first demonstration in humans that rheumatoid arthritis, a chronic autoimmune joint disease, may be mediated in part by specific intestinal bacteria, researchers at New York University School of Medicine have linked a species of intestinal bacteria, *Prevotella copri (P. copri)*, to the onset of the disease. The new findings add to the growing evidence that the trillions of microbes in our body play an important role in regulating our health.

Studying stool samples, the researchers found that 75 percent of samples from newly diagnosed rheumatoid arthritis patients carried *P. copri*, compared to 21.4 percent of samples from healthy individuals; 11.5 percent from chronic, treated patients; and 37.5 percent from patients with psoriatic arthritis.

Why *P. copri* growth seems to take off in newly diagnosed rheumatoid arthritis patients is unclear, according to the researchers. As rheumatoid arthritis is treated with an assortment of medications, including antibiotics, anti-inflammatory drugs like steroids, and immunosuppressive therapies that tame immune reactions, "It could be that certain treatments help stabilize the balance of bacteria in the gut." This is according to Jose U. Scher, M.D., director of the Microbiome Center for Rheumatology and Autoimmunity at NYU Langone Medical Center's Hospital for Joint Diseases and author on the new study. "Or," he adds, "it could be that certain gut bacteria favor inflammation." Also, it is possible that environmental influences such as diet and genetic factors can shift bacterial populations within the gut, and this may set off a systemic autoimmune attack.

Since gut flora can vary across geographical regions, the researchers plan to validate their results in regions beyond New York and investigate whether the gut flora can be used as a biological marker to guide treatment. They hope to study people before they develop rheumatoid arthritis to see whether overgrowth of *P. copri* is a cause or the result of autoimmune attacks. ■

--Source: "Study Links Intestinal Bacteria to Rheumatoid Arthritis," New York University School of Medicine, November 5, 2013

Special protein may have role in AD

What causes inflammation in autoimmune diseases? Researchers from the University of Copenhagen have identified a special protein, TL1A, that may have a role in autoimmune diseases, such as inflammatory bowel disease (IBD), rheumatoid arthritis, psoriasis, and perhaps more. The study results may reveal what causes inflammation to lead to autoimmune diseases that develop when the immune system becomes misdirected.

The researchers found that TL1A induces pro-inflammatory cytokines that are linked to certain autoimmune diseases. They suggest that targeting the TL1A protein with biological therapies could potentially help treat inflammatory bowel and other diseases.

Researcher Kirsten Reichwald, Ph.D. student at the Department of Veterinary Disease Biology, Faculty of Health and Medical Sciences, at the University of Copenhagen, notes that while biological treatments can stop rheumatoid arthritis from advancing, more information is needed on the exact processes that cause inflammation in order to deliver targeted treatment. She says, "Through analysing blood cells, we have observed that a particular protein called TL1A can get healthy cells to behave like those we see in chronic inflammation. This is bringing us closer to unlocking the mystery of inflammation." ■

--Source: "Blocking this special protein could help treat IBD, arthritis and more," Kathleen Blanchard, PLOS ONE, January 8, 2014

~ 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.

An oil that smells good and may be good for you!

The newest superstar of oils, organic virgin coconut oil, is a highly saturated fat--but not from an animal source. It is rich in lauric acid, which stimulates thyroid function while increasing metabolism to trigger natural weight loss. The oil's increased popularity is evident by its presence on most grocery store shelves, in health food stores, and on line. Make sure to purchase the USDA certified organic, extra virgin unrefined oil, which contains 6.2g of lauric acid, 1g of caprylic acid, and 800 mg of capric acid.

Organic virgin coconut oil is derived from the meat of matured coconuts. It is mild in flavor and is an extremely stable oil, making it most suitable for cooking and appropriate in medium to high heat to 350 degrees. One tablespoon has 130 calories and 12g of saturated fat, with zero trans fats and no cholesterol. It is gluten, sodium, and sugar free. It should be stored in a cool, dry place; no refrigeration is necessary. The coconut oil remains in a solid state but will transform quickly to liquid at temperatures around 75 degrees. All health and nutrition properties remain the same in either the solid or the liquid state.

Coconut oil can be used for cooking, simply substituting it for margarine, butter, shortening, or any other cooking oil that can be used for baking and frying. It is also delicious used as a spread, in salad dressing, or added to a smoothie or any blended natural "green drink."

A number of studies have shown that coconut oil can help moisturize skin and treat skin infections. It can be used safely for cleansing, moisturizing, and keeping hair healthy with no worries that it will get into one's body and raise cholesterol levels. It has deep penetrating antibacterial and antimicrobial characteristics. However, as a facial moisturizer, it should be used cautiously because coconut oil can block the pores of susceptible people. ■

--Source: Excerpted from "Three Ways to Feed Your Thyroid Coconut Oil," Laurie Roth-Donnell, Master Herbalist and Holistic Health Practitioner, Riordan Clinic Health Hunters Newsletter, January 2014, using sources: www.herbs-info.com; Dr. Andrew Weil (http://www.drweil.com); The New Optimum Nutrition Bible, Patrick Holford; Kathi Keville of HowStuffWorks.com; "Aromatherapy: An A-Z," Patricia Davis, 1999.

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With Special Thoughts...

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The Barry S. Elkin Family – Congratulations Red Sox !!! – Ann Randolph Schmid

Rusty Flocken & Tanya Alexander - In honor of their marriage - Kevin Dawson

Joseph McGlynn, Jr. – For being a great dad – Joseph McGlynn

Cecilia Hudson – Recently diagnosed with lupus – Mercedes Barris

Colette Hughes - A birthday gift – Mary Hughes

Kelli Spachtholz - In memory of Kelli, Rusty Flocken's cousin, – Kevin Dawson

Jamie McAndrews - In honor of Jamie's birthday – Hank & Johanne Maguire

Cornelia Wegner - In her honor – Suzanne Durbin of GV Financial Advisors, Inc.

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Amy Foley – Peggy Bucklin Family

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Special Seasons Greetings

Christmas gifts from Gail & John Maloney - to **Mr. & Mrs. James Keeter, Rachel Keeter, Mrs. John Maloney, Mr. & Mrs. Michael Maloney, Lt. Paul Maloney, Mr. & Mrs. David Price, Michael Price, John Price, Mrs. Richard Price, Captains J. & A. Tetrault**

Christmas gift from Michael & Erica Przybylski - to **Mariah Zebrowski Leach**

Christmas gift from Carol Thomas - to **Cindy Reynolds**

Christmas gift from Betsy Griffin - to **Vinny Sciplini and Mother**

Article continued on page 10

March AD month continued from page 1

❖ ***Ignorance of autoimmune disease is still widespread, according to a 2013 AARDA survey that was based on 1,005 telephone interviews.***

--Only 19.3 percent of Americans could name at least one autoimmune disease (up from 12.8 percent in 2008).

--Nearly 35.9 percent say they don't know the names of any autoimmune diseases.

--On the plus side, only 20 percent of Americans continue to name AIDS as an autoimmune disease (down from 31.9 percent in 2008).

--Only 17.4 percent of Americans say they or a family member has an autoimmune disease.

--Women are more likely than men to say they either have an autoimmune disease themselves or have a family member who has one (21.4 percent, women; 13 percent, men). ■

President's Message continued from page 2

have gained very recently the pro bono services of a legal firm to handle AARDA public policy issues as agreed upon by both the firm and AARDA.

❖ While space limits me in my writing to you, I do want to express my thanks to all of the grassroots fundraising volunteers who have contributed to AARDA over the past year. The most recent check came from the results of the 2013 Brave Dave golf outing ($15,000). Whether small amounts or large, they all join, like raindrops, to fill the bucket. If you have an idea, contact Sharon Harris in the AARDA office (586-776-3900 or sharris@aarda.org).

❖ Enjoy this newsletter as we keep in touch with all of you who share our autoimmune concerns. THANK YOU for your support. It would be a less effective struggle without you.

With appreciation,
Virginia

Dermatomyositis continued from page 3

What is some additional care to consider? Some cases of dermatomyositis have been known to occur when other conditions, such as lupus, diabetes, celiac disease, or arthritis, are present. Also, some studies have found that dermatomyositis may be associated with an increased risk of developing cancer. It is important to discuss these conditions with your physician to determine whether further testing is needed.

Because dermatomyositis can be a chronic condition, it is important to maintain good health practices, such as eating a well-balanced diet, maintaining a healthy weight, participating in regular exercise, having regular physician check-ups, and managing any additional illnesses or conditions.

It is important always to use sunscreen or sunblock that decreases exposure to both UVA and UVB light, wear a hat and protective clothing when out in the sun, and perhaps avoid sunlight during the hours of the day when it is strongest.

Physical therapy is thought to be important in dermatomyositis. The therapy is directed at preventing muscle wasting and stiffness, and it is particularly necessary in patients with calcium deposits (calcinosis) and muscle involvement.

Since the muscles used for swallowing and chewing may be affected by juvenile dermatomyositis, a speech therapist can help the patient adapt to these changes while a registered dietitian can assist in choosing and preparing foods that are safe to eat.

Resources for support and information, in addition to the American Autoimmune Related Diseases Association (www.aarda.org, 800-598-4668), are The Myositis Association (www.myositis.org; 800-821-7356); American College of Rheumatology (www.rheumatology.org; 404-633-3777); and National Institute of Arthritis and Musculoskeletal and Skin Diseases (www.niams.nih.gov; 301-496-8190). ■

With special thoughts continued from page 9 —

Christmas gifts from Kristian Graham - to **David & Karen Barrett, Rosemary Bertrand, Camden & Crystal Carey, Ronn & Martha Cunningham, John & Deena Ellington, Kevin & Amy Graham, Ralph & Sharon Graham, Chris & Christi Green, Terry & Merri Lynn Henderson, Don & Liz Hobson, Roxanne Johnson, Dolores Jones, Mike & Sherrie Jones, Brandon & Misty Keaton, Chris & Shannon Lipscomb, Cecil & Liesel Miller, Paul & Lauren Pilcher, Joe & Rachel Roy, Cal & Kay Seaton, Mike & Brenda Slone, Frances Suderman, Katie Walsh & Jon Moffit**

Christmas gift from Lindsay Morris - to **Bob & Maria Kuehn**

Christmas gifts from Keith Murphy - to **Leigh Anne Clark, Alison Starr-Moss, Kate Tsai of Dept. of Genetics & Biochemistry**

Merry Christmas from Courtney Ramsey - to **Mimi**

Happy Hanukah from Jan Fleckner - to **Beth & Adam Chandler**

Happy Holidays! from the The Eibschutz Family - to **Carol Arigo, Dr. Margaret Baumann & Family, Dr. Joseph Bettencourt, Dr. Roman Bukachevsky, Lori Bustamante & Family, Central Coast Chest Consultants, Central Coast Hematology, Lance Cowart, CPA, Dr. Sean Devine, Dr. Jeffrey Eidelman, Barry Epperson, Dr. Ramona Friedman, Pam Gillette, Dr.s H. & E. Hayashi, Mr. Gary Kaplan, Kay & Ohan Kerkarian, Dr. James Lawler, Dr.s Lemm & Breytenbach, Dr. James Longabaugh, Bob & Laurie Neumann & Family, Dr.s John & Kathy Norris, Mary Pagel, Dr. Richard Prier, Dr. Dewey Sandberg, Dr. Robert Schingler, Dr. Hal Segal, Dr. John Siebenlist, Dr. William Sima, Dr. Robert Steele, Dr. Ping Tsao, Dr. Ken Tway, Dr. Patrick Vaughan, Patrick & Carola Von Hahn, Dr. Elaine Yirt**

Happy Holidays from Judy Payne - to **Linda Nastick**

Happy New Year gift from Barbara Burrell - to **Karen Ninehan**

Happy New Year gift from Glenice Naslung - to **Erik & Shawna Naslund**

Happy New Year gift from Yolanda Walker - to **Vanessa Hamler**

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

If you belong to a Service Organization or Fraternal (or other) group which provides financial contributions to charitable organizations, please ask them to consider the AARDA as a potential recipient. Your thoughtfulness could provide a vital link in helping our efforts to promote autoimmune research, education and awareness. (The AARDA is a fully accredited IRS 501 (c) (3) tax exempt organization.)

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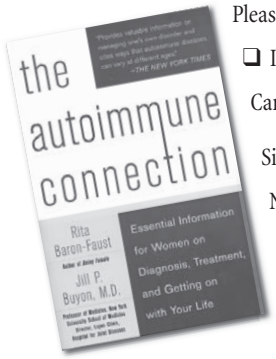

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*If you would like to join but cannot afford the full membership donation, please enclose a note and any amount.

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