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. 3, September 2014**

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

As I write this, all of us at the AARDA office are getting ready for some changes that I want to share with you. Because of AARDA's growth, we are moving out of the traditional comfort zone and shifting things around a bit.

❖ We are finding an increased need for AARDA presence in Washington, DC, while still maintaining our national office in Michigan. Therefore, thanks to the generosity of another charity, AARDA will have a working office in DC. I shall be alternating between DC and Michigan on a biweekly basis or more often if needed.

❖ Heading the Michigan office will be longtime staff member **Patricia Barber** who takes on the mantle of Assistant Director. Pat has served AARDA since 1993, starting first as a volunteer member of AARDA's Corporate Advisory Board and then becoming a staff member as Patient Educator and Event Planner. She has been an AARDA representative and speaker at a number of state and national meetings and has joined AARDA and member groups of the National Coalition of Autoimmune Patient Groups (NCAPG) in lobbying Congress on behalf of autoimmune diseases and autoimmune research. Pat also has coordinated the work of the NCAPG and the development of a number of educational pamphlets and other printed materials.

With a veteran staff in the Michigan office working behind the scenes and the AARDA Board of Directors, led by Chair **Dr. Herbert G. Ford**, actively lending support, I am confident that AARDA has great potential for added growth for the benefit of the 50 million Americans who are depending on us.

❖ One sad note involves the passing of one of the founders of AARDA, **Jane Able Tado**. She was a tremendous support to me as we laid plans for AARDA, and she always had a view of the big picture. Our heartfelt tribute to Jane in this newsletter expresses only a small part of our gratitude and love for her.

❖ In other news, I am pleased to share with our readers another step forward. As many of you know, it has long been our goal to develop an autoimmune diagnostic and treatment center. Now, toward that goal, we are funding a grant for a pilot program with the MidMichigan Physicians Group, University of Michigan, in Midland, Michigan, for a clinic that will set out to determine whether such a focused facility would be effective in diagnosing particularly difficult-to-diagnose autoimmune diseases. **Abid Khan, M.D.**, will be in charge of planning and staffing the clinic. It is our hope that this clinic will serve as a springboard for a National Autoimmune Diagnostic and Treatment Center. We are committed to seeing this center become a reality, and we continue to work toward recruiting a major contributor or contributors.

❖ You will see elsewhere in this newsletter information about the Autoimmune Walk schedule. This event has become a significant means of fund raising, and I urge you to support this activity any way you can. If you can't walk, for whatever reason, consider organizing your own Virtual Walk--or simply donating to one of the scheduled walks. For that matter, I invite you to donate to my Virtual Walk and help me meet my goal. Simply go to www.autoimmunewalk.org, type in my name, and donate any amount. It's a good cause, yes?

❖ And on that fundraising note, I have been thinking about the tremendous success that ALS has had with its ice buckets project (and more power to them). With many people, including a number of celebrities, dumping buckets of ice over their heads for ALS (you have been watching the news, haven't you?), they have raised over $41 million for ALS as of this writing. **What would happen** if a majority of the 50 million Americans affected by autoimmune diseases chose to send $5 (or even $1) each to AARDA? We could jump start that National Autoimmune Diagnostic and Treatment Center. Possible? No doubt about it.

❖ I hope to see some of you in Midland, Michigan (September 27); Seattle, Washington (October 11); or Boston, Massachusetts (November 15) at one of our public forums "What Every American Needs to Know About Autoimmune Disease." There is always something to learn from our speakers, and it's a great way to share with others in a positive way.

On behalf of all of us here at AARDA, I thank you for your interest and support. Our successes couldn't be possible without you.

***With appreciation,***

*Virginia*

we are 50 million

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

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# What Every American Needs to Know About Autoimmune Disease

Autoimmune Diseases Association
American Autoimmune Related Diseases Association, Inc.

- AARDA Public Forums -

Have you been hoping to attend a patient-centered autoimmune disease forum in your area? Check out this schedule. You might find a forum right around the corner or within travel distance.

***Each program runs from 10:00 a.m. to 4:00 p.m. with time for lunch (included with $20 registration fee - scholarships available). Registration/gathering begins at 9:30 a.m.***

**Michigan**
**Saturday, September 27**
MidMichigan Medical Center,
4000 Wellness Drive
Midland
Towsley Auditorium
Register: http://midlandforum.eventbrite.com; or call 586-776-3900

**Washington**
**Saturday, October 11**
University of Washington,
850 Republican Street,
Seattle - UW Medicine
South Lake Union Campus - Orin Smith Auditorium
Register: http://seattleautoimmuneforum.eventbrite.com; or call 586-776-3900

**Massachusetts**
**Saturday, November 15**
Boston
Venue to be announced
Register: http://bostonadforum.eventbrite.com; or call 586-776-3900

***AARDA's public forums are open to autoimmune patients, their families, health care providers, and interested others. They feature nationally (or internationally) known speakers who are available for questions.***

AARDA's public forums are supported by a grant from Genentech.

# We're growing! Welcome extended to new NCAPG members

The Myasthenia Gravis Foundation of Illinois and the Relapsing Polychondritis Awareness and Support Foundation, Inc., are the newest members of the National Coalition of Autoimmune Patient Groups (NCAPG). This brings to 36 the total number of NCAPG members. From its first exploratory meeting in March 1998, when representatives of 12 national autoimmune disease groups met at AARDA President/Executive Director Virginia Ladd's invitation, the NCAPG has proved its collaborative strength through congressional briefings, national awareness campaigns, scientific symposia, and other joint programs. The NCAPG serves as a voice not only for the best known autoimmune diseases but also for the rare, relatively unknown diseases which otherwise would not have national representation.

The **Myasthenia Gravis Foundation of Illinois** began in the Chicago area and has expanded to serve Iowa, the Quad Cities, and Northwest Indiana. The organization strives to provide programs and services that have a positive, direct impact on myasthenia gravis (MG) patients and their families. MG is a chronic autoimmune disease affecting the skeletal muscles. It is characterized by reversible fatiguability which is the result of a disturbance of neuromuscular transmission. Several forms of MG exist, and various clinical classifications have been suggested. One form, generalized myasthenia gravis (GMG), leads to a progressive loss of strength and wasting of the muscles. For information, go to www.myastheniagravis.org, or call 800-888-6208.

The **Relapsing Polychondritis Awareness and Support Foundation, Inc.**, headquartered in Minnesota, was founded to provide information and support to those afflicted with relapsing polychondritis (RP), a rare, chronic, multisystem autoimmune disorder. Relapsing polychondritis is characterized by recurrent, painful episodes of inflammation of cartilaginous tissues. The disease sometimes is referred to as the Red Ear Syndrome since a glaring red ear can trigger a diagnosis after the patient has endured months or years of a wide variety of undiagnosed symptoms. RP can be life threatening and debilitating. For further information, go to www.polychondritis.org, or call 612-296-1628.

National autoimmune disease groups interested in NCAPG membership may contact facilitator Virginia Ladd (vladd@aarda.org; or 586-776-3900). ■

## Autoimmunity--the digestion connection

Digestion, as defined by Merriam-Webster, is "the process by which food is changed to a simpler form after it is eaten." Every step of digestion breaks our food down into smaller and smaller parts until it eventually gets to a form that the body recognizes and can use. The whole process is highly coordinated, and each step in the digestive process prepares the body for the next step.

Our body's first line of defense is the cells that line our digestive tract. These cells, called epithelial cells, provide a strong barrier against anything crossing into the bloodstream that our body doesn't want there. Proteins cement these cells together, like building an impenetrable wall.

Our immune system makes up another one of our body's defenses against outside invaders. It's like an army that stands guard, ready to attack at the first sign of a foreign invader. With the thousands of viruses and bacteria we are exposed to in our world, we would not last a day without our immune system. Because of this risk, 80 percent of our immune system surrounds the gut.

In a perfect world, we would have no problems breaking down food and extracting the nutrients we need. Unfortunately, we live in a world riddled with pro-inflammatory foods, e.g., sugar, wheat, preservatives, various chemicals that work collectively to tear up our digestive system. Over time, these foods and chemicals chip away at our epithelial barrier and the proteins that hold those cells together. This leads to intestinal permeability, or "leaky gut." Large compounds of undigested proteins penetrate our protective barrier and are not recognized by our immune system. So the underlying immune system in the gut attacks and flags these proteins as "invaders."

Once our epithelial barrier has been penetrated and an inflammatory cycle has begun, our gut immune system gets up-regulated. This can cause an explosion of intestinal inflammatory cytokines to be released into circulation. These inflammatory cytokines have been known to activate immune cells in the brain, joints, blood vessels, heart, and many other tissues. This is the connection between eating certain foods and exacerbation of symptoms such as joint pain, headaches, brain fog, fatigue, etc. However, one of the most sinister plot twists in this story is the fact that the dysregulation of our gut immune system over time can lead to an overactive immune response. Eventually the body cannot recognize self from non-self, and autoimmunity develops.

New research is constantly revealing insights into how the immune system functions. This is necessary because autoimmunity is a growing epidemic in our world today, and the gut plays a significant role in the development and management of autoimmune conditions.

One quality of our immune system that makes it so effective is its ability to adapt to the outside environment. When exposed to new pathogens, the immune system has two major responses: the T-helper (TH1) response and the T-helper 2 (TH2) response. These responses each activate different cells to fight pathogens in different ways. Typically, in autoimmunity the balance of this system is thrown off, and the body shifts to a TH1 or TH2 dominate state. To provide a check-and-balance in the body, we also have T-helper 3 (TH3) cells, otherwise known as regulatory cells. These cells down-regulate the immune system and maintain tolerance to self.

The key with the immune system is balance. We need an immune response to protect us from invading pathogens, yet we need to keep the immune system in check so that it doesn't attack our own cells. Looking to a "natural" path, some suggestions for promoting balance are the use of vitamin D and glutathione, to support the TH3 cells and help maintain balance; turmeric (curcumin) and resveratrol, to balance TH17 cells and nuclear factor kappa-B (NF-kB); and L-glutamine, probiotics, and digestive enzymes, to repair the gut barrier.

Our food is our fuel, and we are blessed with much good food to nourish our bodies. The challenge is knowledge and balance. ■

*--Source: Adapted from "How Your Gut Affects Your Immune System...And Makes You Sick," Dr. Anne Zauderer, Health Hunters Newsletter, Riordan Clinic, Wichita, Kansas, August 2014*

## In memoriam...a tribute to AARDA's Founding Board Chair

Word has been received of the passing of a dear friend, Jane Able Tado, whose help was vital in the founding of the American Autoimmune Related Diseases Association (AARDA). She not only was the Founding Chair of the Board but also stayed on as Missouri Local Contact long after her retirement from the Board in 1994 because of her husband's failing health.

In a letter written to the Board of Directors in 1996, Jane stated:

> "As some of you may know, Virginia [Ladd] and I began to see the need for research in autoimmunity quite a number of years ago, as we worked with patients who had one or more autoimmune diseases. As our conviction grew, we began to dream of and discuss the possibility of founding an autoimmune association. Finally, in the early 1990s, we decided it was time to make our dream become reality, and we filed not-for-profit corporation papers. Virginia did more than 90% of the work, while I served as a "sounding board" and gave marginal assistance. Now this organization is on firm ground and growing so rapidly."

Jane gave more than "marginal assistance." She served on the organizational steering committee, assisted in the writing of the bylaws, helped to recruit the charter members of the Medical Advisory Board (later to become the Scientific Advisory Board), contacted hospitals nationwide with news of the founding of AARDA and its services, stepped into active leadership on the new Board of Directors, and, yes, did serve as a valuable sounding board.

Jane wrote, "This will always be a cause very dear to my heart." That loyalty remained throughout her life; and thanks to Jane's talents and dedication, thousands--no, millions--of autoimmune patients have been helped. One person--what a difference! ■

# From the archives: "Life with Lupus--A Male Patient's Perspective on Lupus"

*The following is an excerpt from an article by lupus patient Kenneth A. Windstein that appeared in the May/June 1992 issue of Lupus/Cope, the newsletter of the Michigan Lupus Foundation, a former chapter of the Lupus Foundation of America, Inc., courtesy of the LFA Central New York Chapter. Many of our readers with autoimmune diseases, not only lupus, will be able to appreciate the author's perspective.*

As a 30-year-old attorney with a general private practice, I'm rarely at a loss for words. But when I was asked to share my perspective on lupus, I did not realize what a difficult topic it would be. Let me begin by explaining briefly my background and experience with the disease so that you can understand my vantage point. Then I will try to weave together some of the common threads that many of us experience in living with lupus, bearing in mind at all times that enduring illness is an individualized matter.

My background enables me to speak from a dual perspective. As a child, I experienced lupus vicariously as I witnessed it afflict my mother. She struggled against her illness from the time of my early childhood until four years ago, when she finally succumbed to its complications at the age of 52. Even at the end, she astonished her excellent doctors with her courage and fighting spirit. This spirit survives and has instilled in my life a continuing source of inspiration.

Now I have experienced lupus directly as an adult. Two years ago, I reached a point where I couldn't shake hands, turn doorknobs, or open bottles. I had a rash, was tired, and felt pain when I breathed. I began to realize that I was experiencing something more than tennis elbow and fatigue from long hours of work. I grudgingly agreed to go to the doctor--for the first time in 15 years. After review of my medical history and a few blood tests, the doctor diagnosed systemic lupus erythematosus (SLE).

Before that time, I really had no scientific basis to believe that I would contract the disease. Prevailing medical wisdom was that it was not hereditary, and statistics disclosed that males are not usually affected. But I had experienced false positives on VD tests, even as a teenager. In addition to being rather incriminating, these tests afforded me a trace of a clue. Also the imprint of my mother's situation never really allowed me to accept the medical verdict that I didn't have to worry about lupus. Since my diagnose has been made, I've been on a steady diet of methotrexate and prednisone.

Philosophically I am a realist in that I accept the fact that not everyone with lupus will be cured. At the same time, I am optimistic that humankind has the capacity to overcome the disease and that all of us can lead quality lives with or without lupus.

Living with lupus, or any chronic disease, can become an overwhelming problem if we let it. To cope with the disease, I've found it useful to dissect some of the aspects of having lupus and analyze them separately. By categorizing problems associated with lupus, I've been able to deal with them more effectively. It's much easier to manage a lupus-related problem if it appears limited in its scope, rather than generalized and all-consuming. Also, I find that an analytical approach allows me to temper my emotional reactions to problems with the voice of reason. Let me categorize...

1. **Discovery that you have the disease** - The medical explanation of lupus is so all-encompassing that many patients continue to find it hard to understand even after it is identified and explained. The initial reaction is a feeling of bitterness, resentment, fear, and isolation. How can these feelings be resolved?

In my view, discovery of the illness enables us to deal with the illness in an enlightened way. We can seek appropriate treatment and support. We can locate similarly situated people and share information and concerns. After the initial emotions wind down, logic and reason can be invoked in coping with the discovery.

2. **Medication** - Most lupus patients manage their illness with prescribed medicine. Oftentimes the distinction between treatment of the illness and alleviation of symptoms is lost in the initial euphoria that accompanies starting a high dose of steroids. However, we soon learn that the disease process remains at work and that the medicine we're taking involves significant side effects over the long and short term.

In my case, at the outset I was very resistant to taking any medicine. I had seen what it did to my mother. I thought it was worse than the disease itself. Also, the pills represented a threat to my independence as a person.

I've now resolved these dilemmas by abandoning my absolutist approach to medication and invoking a new philosophy of maximum utility. I now view the illness and the medicine as two opposite points on a fulcrum. The ideal lies in the middle--no lupus and no medicine, while getting as close to the midpoint as possible. I believe that the best path is to work with my doctor to develop a medical plan involving the lowest dosage necessary to control the illness.

In dealing with medicine, I feel that a constant sense of vigilance needs to be established. Appetite and psychological outlook are particularly vulnerable. It's important to establish a balanced diet and stick to it. It's also important to monitor your psychological self and watch for mood swings that may impact on other people. I always try to stay on an even keel without sacrificing spontaneity.

3. **Pain and symptoms** - A peculiar aspect of lupus is that it appears to do its dirty work in cycles. In my case, I experience a round of pleurisy and pericarditis about every two weeks. It lasts a few days and then disappears until the next time. My joint stiffness and tendonitis are more constant and seem to correlate with stress and over-exertion. If I'm in the courtroom, it all seems to hit me the day after the trial is over.

Regular rest is important. Also, exercise and diet are important components, especially because medications can affect strongly the appetite and lead to a vicious circle of weight gain, fatigue, and high blood pressure.

When I experience pain, I know that my body is sending me a signal; and I try to use that signal to do what I can to put things back into some equilibrium. I try to help myself through rest, exercise, and nutrition before

*Life with Lupus continued from page 4*

complaining about pain. Do I ever complain? Yes, when the pain gets really bad, I do complain and try to muster some support from my wife. However, it's hard for others to understand how you could hurt so bad one day and feel so energetic the next. I don't know any way that they could understand through discourse alone. I'm more concerned that others believe me when I say I'm hurting rather than feel sorry for me.

4. **Limitations** - There's nothing worse in life than not being able to do something you want to do. But having lupus does not necessarily bar you from doing things--you just have to pick your sports. For example, it may hurt me to play tennis, but hurting helps me concentrate more. Since I'm giving up something to play the game, I want the win more than ever as a payoff for the effort. Maybe I'll play three sets instead of five, but I'll put more into the games I play and exert the best effort I can muster.

The same thing applies to vacations. Does your family want to go to the beach? Go off-season and avoid the beating sun and the crowds. Enjoy the local color of the place much better when it's not overrun by tourists.

The point is that there are silver linings to many of the stumbling blocks lupus creates. Some may even lead us into new areas of activities and expand our horizons. Sacrifices we make can make us better persons as a whole.

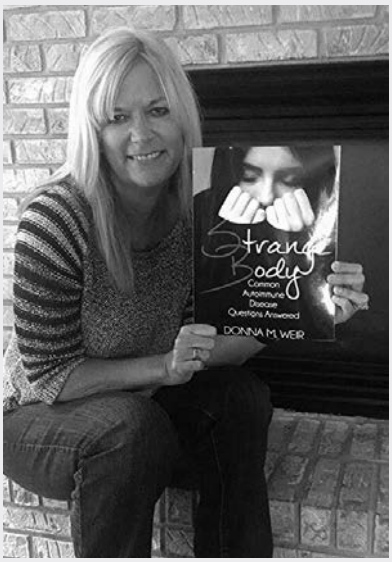
I urge this approach because I believe that, if positive, you still have a chance for remission. Yes, I know that lupus is a lifelong struggle. I really don't expect to be healed in some magical way. But with a positive outlook, we can fight the fight and live a productive life in the process. ■

## Grassroots fundraising...why? what?

Raising money for the fight against autoimmune diseases is usually the impetus for planning a fund raiser, whatever form it might take. But funny things happen along with fund raisers. Whether very lucrative or not, they reach beyond the wildly popular annual golf outings, children's birthday donations in place of gifts, high school fashion shows, personal CD sales, musical performances, bike tours, marathons, garage sales--to name only a few. These fund raisers offer opportunities to bring the news of "autoimmunity" to families and individuals whose lives will be saved through the AUTOIMMUNE AWARENESS introduced via even the most modest fund raiser.

**On behalf of all of us at AARDA, we say THANK YOU for the following recent projects:**

❖ Author Donna Weir: $500.00 from royalties, to date, on her book *Strange Body*, available through Amazon KPD, Barnes and Noble, and IBooks.




❖ Dominica Piscitelli Pavlik and crew: $2,100 from "Night Out at Archie's," an annual event in loving memory of Cara Lian Lebedda. Dominica reports that they had a great turnout again this year.

❖ Modropy - Modern Philanthropy: $504 from selling Modropy-created tee shirts and canvas bags in a week-long campaign.

❖ Marshal Gore: $1,650 from sponsors who donated money for every save he made in a two-month range for soccer tournaments. This was his Mitzvah project.

Is there a fund raiser/awareness opportunity in your future? For ideas, assistance, and a copy of the Grassroots Newsletter, contact AARDA Project Manager Sharon Harris (sharris@aarda.org) or phone 586-776-3900. ■

# Asbestos and autoimmune disease--what connection?

Who has not been exposed to asbestos and vermiculite, substances used in insulation and gardening? Who has not breathed in nanoparticles, ultrafine particles engineered for specific mechanical and biochemical properties? Long ignored, either through ignorance or intention, the dangers now are being brought to light--and a new autoimmune disease is being proposed. Because genetics and environmental exposures are recognized as causes or triggers for autoimmune diseases, scientists are systematically searching for ways to sidestep those dangers. To a certain extent, nature has its own way of dealing with those problems--survival of the fittest, etc. But that isn't much reassurance for individuals suffering from autoimmune diseases, cancer, or other life-threatening diseases or feeling concern for family members.

Graham Cliff, Ph.D., of the University of Manchester, England, has been a materials scientist for 40 years, specializing in the health hazards of minute particles, including asbestos. He suggests that the dangers of particle exposure extend far beyond asbestos. Nanoparticles are found in multiple products, e.g., sunscreens, cosmetics, bicycles, automobiles. Dr. Cliff says, "We should be warning people today about this. There's no regulation for these small particle exposures."

On the other hand, Andrew D. Maynard, Ph.D., Director of the University of Michigan Risk Science Center in Arbor, states, "But for most materials that people are being exposed to in consumer products, there is no clear evidence that they present a substantial risk." He adds, "That may change, new evidence may come to light, but there are not big warning signs at the moment."

Concerning environmental exposures, Dr. Maynard has stated, "Humans have developed as a species in the presence of airborne carbonaceous nanoparticles from combustion, and our bodies have evolved to handle exposure to such materials. Since before the industrial revolution, people have been exposed to airborne metal and metal oxide nanoscale particles from hot processes, and while these materials are rarely innocuous, we have an understanding of how they impact on human health."

Dr. Maynard points out that nanotechnology is relatively new. He says, ". . . one of the things we've found over the past 10 years is that we have already evolved being exposed to nanoparticles, and because of that our bodies have learned to adapt to them, manage them, and work with them. Our bodies are very adept at this."

When Guenter Oberdorster, Ph.D., of the University of Rochester, was asked whether one type of particle, carbon nanotubes, might pose a particular hazard, he responded, ". . . nanoparticles of fibrous shape and dimensions and of high biopersistence, resembling asbestos, may induce adverse effects similar to those known to be caused by asbestos exposure, i.e., lung fibrosis, lung carcinoma, and mesothelioma." He commented that most engineered nanomaterials with a potential for human exposure may turn out to cause "an asbestos-type disaster" if uncontrolled.

Dr. Maynard agrees that many questions remain, including the possibility of disturbances of immune function. He observes, "There are subtle perturbations to the body, which begin to express themselves over time, and it's not that easy to find the link between causative agent and actual response."

An outstanding, tragic example of failing to recognize or maybe admit a vital link between cause and effect started in Libby, Montana, in 1916, with the mining for vermiculite, called Zonolite, which was shipped across the continent for use as insulation and various commercial products. Unfortunately the mine and vermiculite contained asbestos. By the 1980s, hundreds of the miners and their family members had sickened and died of asbestos-related diseases at rates 40 times higher than the U.S. as a whole.

It was not until 1999 that the problem was widely exposed when *Seattle Post-Intelligencer* reporter Andrew Schneider wrote about the cluster of diseases in Libby. He stated: "First, it killed some miners. Then it killed wives and children, slipping into their homes on the dusty clothing of hard-working men. Now the mine is closed, but in Libby, the killing goes on."

A group of researchers from Idaho State University and the Center for Environmental Health Sciences, University of Montana, are suggesting that a further health concern for the Libby residents should be added--autoimmune disease, including an as-yet undescribed autoimmune condition affecting the lungs.

Libby asbestos contained a variety of serpentine, or "amphibole" fibers. One of the Idaho researchers, Jean C. Pfau, Ph.D., explains that the various types of asbestos fibers appear to have quite different effects on the immune system. She says, "Exposure to the common chrysotile asbestos [serpentine] most often has been associated with cancer, possibly because it suppresses the immune response and the ability of the immune system to destroy the cancer." But she further explains that the amphibole asbestos in Libby doesn't suppress the immune response; instead, it appears to activate the immune system which leads to the production of autoantibodies.

A screening program was conducted in Libby in the early 2000s by the Centers for Disease Control and Prevention (CDC). In questioning more than 7,000 Libby residents, the researchers found that 6.7 percent of the population had experienced lupus, rheumatoid arthritis, or systemic sclerosis. This far exceeded the expected prevalence of less than 1 percent for these conditions.

The researchers found that 24 percent of serum samples of Libby residents contained antibodies to extractable nuclear proteins which are commonly found in patients with systemic lupus erythematosus. This was in contrast to serum samples obtained from residents of Missoula, Montana, an area where no asbestos had been mined. Only 4 percent of the Missoula samples contained these antibodies.

Now Dr. Pfau's group is focusing on a specific subgroup of patients in Libby who have developed an unusual very severe and progressive pulmonary illness in which many of the patients succumb to infections. She says, "These patients are in terrible pain and lose their lung function because their lungs aren't elastic enough for them to breathe in and out, as though there's wrapping of scar tissue around their lungs." This appears similar to what the researchers found following amphibole exposure in their earlier mouse studies: the production of autoantibodies was followed by an increase in scarring in the connective tissues surrounding the lungs.

Dr. Pfau says, "We are proposing that this is a novel autoimmune disease, and we're now working on the data that might actually show cause and effect, rather than just an association."

What is beyond Libby? Studies of one mine operation show that 9,780,000,000 pounds of vermiculite ore was mined from 1960

*Article continued on page 10*

## Atherosclerosis: an autoimmune disease?

A recently published study led by Dr. Eiji Matsuura, of the Okayama University (Japan) Graduate School of Medicine, Dentistry, and Pharmaceutical Sciences, points out that, in the past decades, it has become apparent that patients with systemic autoimmune diseases develop premature and, quite often, severe atherosclerotic cardiovascular disease (CVD). These systemic diseases are characterized by chronic inflammation and immune dysregulation which may produce such effects as platelet and vascular pathology, arterial lesions, and enhanced autoantibody production.

Given the similarities with autoimmune-mediated atherosclerosis, which emphasizes the active inflammatory, complex or multifactorial and long-term nature of the disease, it is not surprising that investigators have generally accepted an autoimmune nature for atherosclerosis which is seen as an inflammatory disease of the arterial vessel. For that reason, it also is not surprising that the chronic inflammatory disorder rheumatoid arthritis, an autoimmune disease, is associated with an increased cardiovascular risk.

Dysregulation of inflammatory responses and adaptive immunity are important pathologic mechanisms underlying the clinical manifestations of systemic lupus erythematosus (SLE) and antiphospholipid syndrome. According to the authors, these patients may develop venous thromboembolism and premature cardiovascular disease. As systemic autoimmune diseases and atherosclerosis share common pathogenic pathways, it is not surprising that systemic lupus erythematosus (SLE) is associated with an increased cardiovascular risk.

Dr. Matsuura and colleagues state that "whether atherosclerosis is an auto-inflammatory disease, an autoimmune disease, or both is still debatable, with sound arguments supporting each position." They feel that understanding the nature and inter-relationship of auto-inflammatory mechanisms in atherosclerosis might provide new concepts with possible impact not only on early and accurate diagnosis but also on preventive programs and perhaps more effective therapeutic interventions than presently are available. ■

*--Source: Excerpted from "Is atherosclerosis an autoimmune disease?" by Eiji Matsuura, et al, BioMed Central Ltd., via BioMed Central 2014, published March 18, 2014*

## Upcoming Education Events for 2014

***Sponsored, cosponsored, or supported by AARDA***

**September 6 - Full Day Seminar, "How to Dance in the Rain, Rxs for Mind, Body and Spirit,"** Scleroderma Foundation Michigan Chapter and other groups - Grand Rapids, MI - Information: 248-595-8526; ldyas@scleroderma-mi.org

**September 27 - AARDA Public Forum, "What Every American Needs to Know About Autoimmune Disease"** - Midland, MI - Registration: http://midlandforum.eventbrite.com; or call 586-776-3900

**October 11 - AARDA Public Forum, "What Every American Needs to Know About Autoimmune Disease"**- Seattle, WA - Registration: http://seattleautoimmuneforum.eventbrite.com; or call 586-776-3900

**November 14-16 - 2014 American College of Rheumatology Annual Meeting** (AARDA display booth) - Boston, MA

**November 15 - AARDA Public Forum, "What Every American Needs to Know About Autoimmune Disease"** - Boston, MA - Registration: http://bostonadforum.eventbrite.com; or call 586-776-3900 ■

Autoimmune Walk

LINKING TOGETHER FOR A CURE

## Chicago area walkers: Change your calendars!

Two down and three to go--that's AARDA's Autoimmune Walk commitment for 2014. Only the **Chicago area** date has been changed. The new date is **Saturday, October 25**. Location remains the same: Volunteer Park, Tinley Park, Illinois.

Both the Washington DC Metro (McLean,Virginia) and the Marietta, Georgia, walks added generously to AARDA's coffers. Georgia walkers, brave souls that they were, walked in pouring rain. Better luck next year!

What's scheduled for the rest of 2014? The **Greater New York Area Tristate** Autoimmune Walk is scheduled for **Sunday, September 7**, at Hudson River Park's Clinton Cove, in Manhattan, New York. The **Missouri** Autoimmune Walk is scheduled for **Saturday, September 27**, at Washington University, in St. Louis. And, of course, the Virtual Walks (where no one really walks!) are ongoing for any teams who choose to determine their own schedules and participants. Register for any of these walks at www.autoimmunewalk.org.

Would you like to have **your own** AARDA Autoimmune Walk, either actual or virtual? It's a great way to raise funds to combat autoimmune diseases, to spread autoimmune awareness, and to experience camaraderie among kindred spirits.

Do you need help in setting up your walk, or do you have questions? Go to www.autoimmunewalk.org or contact the AARDA office at 586-776-3900 or aarda@aarda.org.

Kellie Martin, AARDA's National Spokesperson and Autoimmune Walk Ambassador, says, "Together we will step closer to a cure!" ■

## Research Bits...

❖ **Fibromyalgia** - Whole-body vibration exercise on physical function and pain severity in patients with fibromyalgia was discussed in the May 2014 meeting of the American College of Sports Medicine Annual Meeting, in Orlando, Florida. A pilot study by Indiana University researchers found that while regular exercise participation is one of the best known therapies for patients with fibromyalgia, whole-body vibration exercise may reduce pain symptoms and improve aspects of quality of life in individuals diagnosed with fibromyalgia. According to Tom Kaleth, associate professor in the School of Physical Education and Tourism Management, Indiana University-Purdue University Indianapolis, studies have reported improvements in strength, muscle spasticity, and pain "in select populations." Fibromyalgia is a disorder characterized by widespread musculoskeletal pain and fatigue. It may involve difficulties with sleep, memory, and mood. *Source: "Vibration Exercise Study Finds Some Relief for Fibromyalgia," Indiana University, via Newswise, May 26, 2014*

❖ **Influenza and respiratory virus** - According to researcher Sang-Moo Kang, at Georgia State University's Institute for Biomedical Sciences, red ginseng extract improves the survival of human lung epithelial cells infected with influenza virus. He found that treatment with the red ginseng extract reduced the expression of genes that cause inflammation. Dr. Kang also found that Korean red ginseng extract improved the survival of human lung epithelial cells against respiratory syncytial virus (RSV), the leading cause of inflammatory bronchiolitis pneumonia and viral death in infants and in some elderly adults. The red ginseng inhibited the RSV from replicating, or multiplying, in the body. Kang's test results suggest that Korean red ginseng extract has antiviral activity against RSV infection. *Source: "Ginseng Can Treat and Prevent Influenza and RSV," Georgia State University, via Newswise, April 21, 2014*

❖ **Celiac disease** - Although current guidelines from the American Gastroenterological Association (AGA) and the American College of Gastroenterology (ACG) recommend routine celiac screening in patients with chronic gastrointestinal symptoms suggestive of malabsorption, new data suggests that fewer than half are being screened. Dr. Heba Iskandar, of Emory University School of Medicine, in Atlanta, Georgia, says, "The data suggest a gap in patient care and a target for future quality assurance initiatives." She says that raising awareness is important; but other initiatives, such as programming EMR systems to generate reminders, may result in testing of a greater number of candidates.

Dr. Alberto Rubio-Tapia, of Mayo Clinic, says that his own recent data support the flaws in the case-finding method. He comments, "Only 5 percent of residents of Olmsted County [Minnesota] with positive serologies consistent with undiagnosed celiac disease, followed for a period of five years, get a clinical diagnosis."

Celiac disease, a disease of gluten intolerance, is among the most common causes of chronic malabsorption. The heterogeneous presentation of celiac disease makes it easy to miss; but the substantial health risks posed by celiac disease, including inadequate nutrient uptake and an impaired quality of life, generally can be greatly reduced with a gluten-free diet. *Source: "Candidates for Celiac Disease Detection Go Unscreened," Ted Bosworth, Gastroenterology & Endoscopy News, July 2014*

❖ **Alopecia areata** - Not life-threatening but life-altering, this autoimmune disease involves the loss of hair, sometimes circular bald spots on the scalp and sometimes loss of all body hair. A research team at Columbia University Medical Center, New York, has been able to restore the hair of three patients using an FDA-approved drug. The research team identified the immune cells responsible for destroying hair follicles and tested a drug called ruxolitinib. The results were dramatic--three participants saw complete hair regrowth within four to five months of starting treatment, with the cells responsible for the hair loss also disappearing. Ruxolitinib currently is approved by the U.S. Food and Drug Administration as a

*Article continued on page 10*

~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.

## Minority populations needed in clinical trials

National Institutes of Health (NIH) Director Dr. Frances S. Collins has said, "The ability to recruit the necessary number of volunteers is vital to carrying out clinical research that leads to health and medical advances." Ideally this process should take into account the patient populations that eventually will use the medications that are approved. However, that doesn't appear to be happening.

According to the Food and Drug Administration (FDA), although African Americans represent 12 percent of the U. S. population, they represent only 5 percent of clinical trials participants. Hispanics comprise 16 percent of the U. S. population, but they represent only 1 percent of clinical trials participants. To address this lack of involvement, a collaboration of the Pharmaceutical Research and Manufacturers of America (PhRMA) and the National Minority Quality Forum has created "I'm In."

I'm In is a fully integrated advocacy, media relations, and digital media campaign designed to encourage participation in clinical trials through raising awareness not only about the importance of clinical research but also about the need for increased diversity in clinical trials, particularly among traditionally under-represented populations.

The I'm In campaign is a contributor and supporter of the Clinical Trial Engagement Network which provides a secure Internet-based environment connecting patients, clinical trial sponsors, clinical investigators, health care professionals and their institutions, and advocacy organizations across the nation. The Network gives authorized users the capacity to identify simply and quickly, by both demographic and geographic characteristics, potential clinical study participants who meet specific protocol requirements. Simultaneously it identifies points of care and community resources that can assist with site locations, investigators, and patient recruitment.

More information about I'm In is available on www.JoinImin.org. A reminder: It is always best to discuss with one's physician the suitability of a clinical trial volunteer involvement. ■

*--Source: Adapted from news article by Emily W. Read, APR, Senior Director, Moore Communications Group, July 21, 2014*

## Control mechanism discovered for immune system

Researchers at the Salk Institute report that they have discovered a key control mechanism on regulatory T cells (Tregs) that determines whether they do or do not send a halt signal to killer T cells during a pathogenic attack on the immune system. Without this signal, killer T cells continue their activities and turn on the body. This causes inflammation and disorders such as allergies, asthma, and autoimmune diseases, e.g., rheumatoid arthritis, multiple sclerosis, and type 1 diabetes. According to the scientists, the new research could help develop treatments for autoimmune disorders as well as some types of cancer.

When faced with a pathogen, an agent causing disease, the immune system summons a swarm of cells made up of Tregs and killer T cells. Tregs are like the surveillance system of the immune response, notes report senior author Ye Zheng, Ph.D, assistant professor and holder of the Hearst Foundation Developmental Chair. He adds that this surveillance system is "key to healthy immune reactions, but it can be kicked into overdrive or turned entirely off."

For about a decade, researchers had known that the key to Tregs' peacekeeping ability was the Foxp3 gene; but they were not sure how exactly it worked. They knew that under certain conditions, Tregs can go rogue--they transform into killer T cells and join in the immune system battle, losing the ability to send a "halt" signal and, unfortunately, adding to inflammation.

The new paper, produced by Dr. Zheng and colleagues, reports that a particular genetic sequence in Foxp3 is solely responsible for the stability of a Treg. If the scientists removed the sequence, dubbed CNS2, Tregs became unstable and often morphed into killer T cells. The result was autoimmune disease in animal models.

The researchers report that conserved noncoding sequence 2 (CNS2) helps maintain immune homeostasis and limit autoimmune disease development by protecting Treg identity in response to signals that shape mature Treg functions and drive their initial differentiation.

Dr. Zheng points out that recent new drugs on the market or in clinical trials are attempting to disable Tregs in tumors to help the body's own immune system fight cancer. He says, "Now we can try to target this region of Foxp3 either to enhance or reduce the impact of Tregs for treatment of autoimmune disease or cancer, respectively." ■

*--Source: Excerpted from "Critical Immune System Control Mechanism Discovered," GEN News Highlights, Genetic Engineering & Biotechnology News, August 15, 2014*

## Researchers confirm rare autoimmune disease

Achalasia, a rare disease affecting 1 in 100,000 people, is characterized by a loss of nerve cells in the esophageal wall. Without these cells, the esophageal sphincter in the lower esophagus fails to relax as it should, causing food to accumulate in the esophagus. This results in swallowing problems, regurgitation, vomiting, nighttime coughing, chest pain, and weight loss. Current treatments are limited to stretching the esophageal sphincter endoscopically with a balloon or surgically cutting the sphincter. These treatments can help alleviate the disease's symptoms but do not address its cause.

Following a possible lead that achalasia involves an autoimmune response lying at the root of the disease, researchers in Belgium, Germany, and other European countries have studied the DNA of 1,506 achalasia patients and 5,832 healthy volunteers. The researchers genotyped 196,524 tiny differences called single-nucleotide polymorphisms (SNPs, pronounced "snips") in the immune-related DNA of people with achalasia. They compared the results with the DNA of the healthy volunteers and found 33 SNPs associated with achalasia. All 33 were located in the so-called "major histocompatibility complex" (MHC) region of chromosome 6, the most gene-dense region in the human genome, a region known to be associated with other autoimmune disorders, e.g., multiple sclerosis, type 1 diabetes, and lupus. This evidence was enough for the researchers to confirm that achalasia is an autoimmune disease.

The researchers also identified a specific string of amino acids inserted in the DNA of people with achalasia. The researchers plan to examine the functional effects of these extra amino acids in the hope of finding the cause and eventually the cure of this puzzling disease. ■

*--Source: Excerpted from "Mysterious esophagus disease is autoimmune after all," Medical Xpress, July 22, 2014*

## Know your nutrients: what about vitamin C?

Rumor has it that, if you look hard enough, you'll find vitamin C in french fries. Don't bet on it. Let's take a serious look at this vitamin that plays such a vital role in our well-being on many levels.

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

What are some sources of vitamin C? A variety of fruits and vegetables are high on the list: sweet red peppers, kale, broccoli, cauliflower, Brussels sprouts, citrus fruits, guava, persimmon, strawberries, and papaya.

What are some of the advantages offered by vitamin C?

❖ Vitamin C is vital to the manufacturing of collagen, a protein necessary for the formation of connection tissue, tendons, and cartilage.

❖ Vitamin C is an antioxidant with antiviral, antibacterial, and anti-cancer properties. Plus it offers the protection of thiamin, riboflavin, folic acid, pantothenic acid, and vitamins A and E through its antioxidant properties.

❖ Vitamin C promotes the absorption of iron, calcium, and manganese. It protects against the toxic effects of heavy metals, such as mercury and cadmium.

❖ Vitamin C has an antihistamine effect, necessary for the conversion of tryptophan to serotonin in the brain.

❖ Vitamin C is used in the manufacturing of adrenal gland hormones. Concentrations of vitamin C in the body are highest in adrenal glands and the brain.

This look at vitamin C offers a great reason for increasing the family's per day servings of fruits and vegetables. Yes, creativity may come into play with convincing the children in the family. It's worth a try. ■

*--Source: Adapted from "Bio-Center Lab: Know Your Nutrients," Health Hunter Newsletter, Riordan Clinic, Wichita, Kansas, February 2014*

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Contributions in this category are too numerous to mention, but we would like to say "thank you" again for the many donations that have been made. Each one is noted with appreciation.

***Asbestos continued from page 6***

to 1990--and it was shipped to 563 different addresses in the U.S. and another 187 in six Canadian provinces. It was used as insulation in millions of homes and other construction sites--including the World Trade Center. The airborne debris from the Center covered lower Manhattan and blew across the region.

Libby isn't the only source of potential amphibole contamination. Another group of mineral experts has reported high levels in samples of soil and airborne dust obtained in the vicinity of Las Vegas.

Dr. Pfau warns, "A lot of people think asbestos is an outdated occupational exposure that's not occurring anymore. But that's not true. There are a lot of exposures happening right now, and we want physicians to be aware and watching for this."

A new autoimmune disease? Perhaps. ■

*--Source: Adapted from "Asbestos Revisited: A New Autoimmune Disease," Nancy Walsh, MedPage Today, July 29, 2014; and "Beyond Asbestos: Autoimmunity, Pollution, and Particles," Nancy Walsh, MedPage Today, August 13, 2014*

***Research bits continued from page 8***

treatment for a bone marrow disorder. Thus, while doctors could prescribe it for alopecia, it would be considered an "off-label" use--which means pharmaceutical companies wouldn't be able to promote their drug as a treatment for this autoimmune disease.

One of the researchers, Angela M. Christiano, Department of Genetics and Development, at Columbia University, suffers from alopecia areata herself. She says, "Over six million people in the U.S. also suffer from some forms of alopecia areata, so this is a tremendously large and motivated population in patients who have no other treatments available." ■

*--Source: "Researchers find potential treatment for autoimmune disease hair loss," Jesse Tahirali, CTV News.ca, August 17, 2014*

# With Special Thoughts...

### *Tributes*

**Catherine & Vance Brown** – In their honor - Ann Coxe
**Douglas Church** - In his honor for Father's Day – Bradley Church
**Eileen & Merton Greenstein** - In honor of their 40th Anniversary
**Lisa Smith & Howard Miller** - In honor of their wedding – Claudia Pecor
**Lynzie Munsell** – In her honor - Ward Pimley
**Dr. Irvin Pollin** - In honor of his 89th birthday – Steffi Bokser
**Taylor Wainwright** – In his honor - Kelly DenHartog

### *Memorials*

**Donna Crist** – Sarah Gameros; Dan, Deborah, Julie, Anne Hinojosa
**Donald Brauner** – Joe & Annette Hillring
**Louise Ettere** – Joe & Linda Showah
**Karen Seaman Gainey** – Nancy & Michael Christian
**Bernie Gottlieb** – Ruth Kiviat
**Theresa Grace** – Kathleen Roberts
**Amanda Hollowell** – Ric & Deb Wrye
**Bindiya Jaswal** – Priya Jaswal
**Diana Marie Martinez** – Lisa & Steven Clough, Lori Miller, Liz & Janice Redwine, Sherry & Julian Romero
**Eric Newman** – Debra Newman
**Massoud Nooralian** – Karen & Mark Skibicki, BECO Management, Bernie Burns & Mark Lopez, Cafferty Commerial Real Estate Services, Kyoung & Moonja Kim, Hosein Nematbakhsh, David Abrams, L.F. Jennings, Inc.
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**Sandra Porter** – Tracy Parks
**Nora Root** – Stuart, Shelly & Kyle Wilcox
**Lawrence Shufeldt** – Lorrie & Chuck Beer & Family, Angie & Mike Bookout & Family, Greg & Becky Butts & Family, Children of O.B. & Pauline Butts, Rodney Butts & Barb Phillips & Family, Paulette & Gary Huddlestun & Family, Laura & John Van Houtin & Family
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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.

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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.)

# AARDA Scientific Advisory Board



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- ~ You receive notifications of any AARDA-sponsored meetings in your area.
- ~ You make a tax deductible contribution to a worthwhile cause (AARDA is a 501(c)(3) organization).
- ~ You contribute to a membership count which is significant in our applying for grants and other support.


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