



Autoimmune Diseases Association

American Autoimmune
Related Diseases Association, Inc.

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

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Autoimmune disease and fatigue: What do patients say?

A recurrent theme in communication with autoimmune disease patients is the subject of fatigue--the bone-tired, always present, misunderstood drag of autoimmune-caused fatigue. Neither the fatigue nor the cries for help go away. What can we do? Step one: Show the extent of the problem. Thus was born the survey "Autoimmune Disease and Fatigue: Patients Speak."

As one autoimmune disease patient says, "Fatigue is probably the most debilitating symptom of having an autoimmune disease." Her comment is not surprising since in a recent survey conducted by the American Autoimmune Related Diseases Association (AARDA), 98 percent of respondents reported suffering from fatigue and 89 percent said that fatigue is a major issue for them. This fatigue is not simply "tiredness" that everyone experiences at various times but a life-altering state.

Of the 7,838 respondents whose survey forms were analyzed, 89 percent indicated that their overall quality of life was affected by fatigue; and 78 percent indicated that their career/ability to work and their romantic relationships were impacted by fatigue. Other areas impacted by fatigue were sense of self-esteem, 69 percent; professional relationships, 65 percent; finances, 61 percent; and parenting abilities, 47 percent. As one patient commented, "Life as I knew it no longer exists."

When asked whether they believe that others judge them negatively because of the fatigue, 70 percent of respondents said, "Yes."

A source of great concern for autoimmune disease patients is the lack of understanding by their support systems--families, friends, and health care professionals--for the depth of their fatigue. Although 90 percent of the respondents said that they had discussed the intense fatigue with their families and friends, only 23 percent said that their families and friends understood while 49 percent said that they did not take the fatigue seriously.

Receiving understanding and help from their doctors was a problem for many

autoimmune disease patients. While 87 percent of the respondents said that they had discussed with their doctors the fatigue they were experiencing, only 48 percent took their problem seriously and only 37 percent had prescribed or suggested treatment options for the fatigue. When asked whether their primary care doctor had suggested that they contact a mental health professional as a result of their fatigue, 80 percent said, "No"; and, in fact, only 29 percent said that they had sought professional mental health treatment as a result of their fatigue.

According to one autoimmune patient, "It's difficult for other people to understand our ongoing fatigue when it can't be seen by them. It's so hard just trying to get others to really, really understand how very tired you are sometimes--even our own doctors don't understand. One wonders if even our doctors may think we are for the most part just mental cases or whiners."

While family relationships, not the least of which includes parenting, are affected by the autoimmune-caused fatigue, the resulting economic hardship on many is a cause for very practical concern. When asked whether they or their family are in financial distress as a result of their autoimmune disease-related fatigue, 55 percent said, "No," while 37 percent said, "Yes"; and 21 percent said that fatigue had caused them to lose their job.

The sense of emotional well-being has been affected by the ongoing fatigue. Increased emotional stress has been experienced by 88 percent of the respondents; sense of isolation, 76 percent; anxiety, 72 percent; and depression, 69 percent, although, as previously

stated, only 29 percent reported that they had sought professional mental health treatment. The survey did not ask whether that treatment had proved helpful.

"One day at a time is what I'm learning to accept," wrote one respondent. "It's still so hard wanting to have our life the way it was. I am in a battle with the mind and emotions thinking about what has been taken and then being grateful for what I still have."

This AARDA patient survey of "Autoimmune Disease and Fatigue" was in the field for roughly four weeks from Saturday, February 7, 2015, through Monday, March 2, 2015. The first notice of the survey had been posted on AARDA's Facebook page in 2014 when its 65,000+ followers were asked to respond: "Autoimmune disease and fatigue, let's discuss. How has fatigue affected your daily life?" Within less than 36 hours, AARDA had received an overwhelming response from its followers. Fully 100 percent of those who responded said that fatigue was an issue for them.

AARDA conducted the survey online using Survey Monkey and promoted the link through its Facebook page, as well as the Autoimmune Awareness and Education Forum Facebook group and contacts with the 37 member groups of the National Coalition of Autoimmune Patient Groups (NCAPG).

A total of 7,874 responses were received, with a final total sample audience of 7,838 achieved after the removal of the fewer than .5 percent who had only chronic fatigue syndrome and/or fibromyalgia, neither of which is considered an autoimmune disease.

All patients surveyed reported having at

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



One of the really exciting happenings during Autoimmune Diseases Awareness Month in March was our Autoimmune Summit which we held at the National Press Club in Washington.

Working with several members of the National Coalition of Autoimmune Patient Groups (NCAPG), we welcomed researchers, patients, and policy makers. A presentation of great interest was the Autoimmune Fatigue Survey which I had mentioned in the March *InFocus* and which is included in this issue. We are hoping that we can use the results to serve as a springboard for work in that area. So much is not known!

This month, June, brings our annual 17th Autoimmunity Day at Johns Hopkins University under the guidance of Dr. Noel R. Rose, Director of the JHU Center for Autoimmune Disease Research and Chairman Emeritus of AARDA's Scientific Advisory Board. This gathering of researchers was the brainchild of the late Linda Otto, AARDA Board member, who also, along with AARDA, supported its work financially, and Dr. Rose. With attendance by invitation only, it has been a valuable source of sharing and learning among leaders in the field of autoimmune diseases.

Although my message to you will be brief this month because of a very full issue, I do need to call your attention to the Autoimmune Walks. They are a tremendous source of local

awareness and fundraising--plus, let's face it, camaraderie. The first is the annual DC Area Walk, scheduled for Saturday, June 27, in McLean, Virginia (see article in this issue). Also, the Tristate Autoimmune Walk takes place on September 20, at Clinton Cove Park, in Manhattan, New York. With enthusiasm, local support, and generous sponsors, the organizers always manage to have successful events.

Can you see an AARDA Autoimmune Walk in your own area? High school running tracks, local playgrounds, university activity areas, and city parks are possible locations. Planning and carrying out such an event is not easy (we'll be truthful!), but it really puts the local area in the autoimmune spotlight. Contact AARDA Assistant Director Patricia Barber to discuss the possibilities (pbarber@aarda.org; or 586-776-3900).

A last thought: Are you one of the 78 percent of respondents who said that they would contribute to supporting our goal of having a National Autoimmune Disease Medical Center in the United States? No? That's O.K. The fund is open and looking for contributions. The seed has been planted. Please take your place in making this Center a reality--in our lifetime!

On behalf of the 50 million Americans afflicted with autoimmune disease, I thank you for your interest and support.

*With appreciation,
Virginia*



Upcoming Education Events for 2015 Sponsored, cosponsored, or supported by AARDA

June 5 - 17th Annual Autoimmunity Day - Johns Hopkins University, Baltimore, MD

June 11 - Scientific Round Table - "Eosinophils, Type II Immunity and Autoimmune Disease" - Washington, D.C.

August 29 - "What Every American Needs to Know About Autoimmune Disease" Forum, 10:00am – 4:00pm (Registration begins at 9:30am) - This conference is open to autoimmune patients, their families, healthcare providers, and the general public. Henry Ford West Bloomfield Hospital, 6777 West Maple Road, West Bloomfield Township, MI 48322, <http://westbloomfieldforum.eventbrite.com>

Sept 11-13 - Scientific colloquium - "Neuropsychiatric Manifestations of Autoimmune Disease" - Mt. Washington Conference Center, Baltimore, MD

AARDA Board approves policy statement on biologics

With many questions surrounding the new biologic medicines and with requests concerning AARDA's view of biosimilars, the AARDA Board of Directors has written and approved in recent action a "Statement of Principles on Biologic Medicines." We are pleased to share this statement with our newsletter readers.

American Autoimmune Related Diseases Association Statement of Principles on Biologic Medicines

The past decade has brought about new treatments for many autoimmune diseases for the first time in over 50 years. These new therapies are biologic medicines which have revolutionized the treatment of many serious diseases, providing drugs that treat the underlying cause of a disease rather than just the symptoms. As many patients are aware, biologic medicines, like all treatments, can come with both benefit and risk; they also can be expensive. Biologics are large molecules made from living cells, so there is increased need to assure quality in the manufacturing process. Because they are usually injected or infused, there is greater need for vigilance to deal with potential adverse effects. And because of their complexity, they often come at a higher financial cost. Not surprisingly, as many of the first-generation biologic medicines come off patent, there is great interest in the reproductions of these originals as an opportunity to reduce costs. These reproductions are referred to internationally as biosimilars. In the United States, the Affordable Care Act (ACA) in 2010 provided the U.S. Food and Drug Administration (FDA) with authority to create a pathway for approving biosimilar biologic products for U.S. use. Under that pathway, FDA is poised to begin issuing U.S. approvals for biosimilars, perhaps as early as this year [2015].

The advent of biosimilars potentially may offer the prospect for lower-cost alternatives to original biologic medicines. Recognizing that biosimilar biologic products are not the same as generic copies of small-molecule chemical drugs, and consistent with the ACA, FDA has been working to establish regulatory guidelines for the development and approval of biosimilars. As companies work on research and development efforts on biosimilar products, and as FDA considers the criteria under which it will evaluate and regulate these products, we believe it is important for policymakers and other stakeholders to ensure that these efforts include guidelines for ongoing monitoring and other standards that will protect patients and facilitate the safe, efficacious, and cost-effective use of all biologics, including original innovator medicines as well as any biosimilars that receive approval from FDA. To those ends, and particularly in light of the current lack of long-term experience with biosimilars in the United States, we believe the following principles are essential to guide the introduction of biosimilars to our healthcare system:

1. Approval standards for a biosimilar product must meet the same standards of rigor and accountability as those for the innovator biologic.

Biologic medicines are made from living cells; and subsequent "copies" are—as the term "biosimilars" makes clear—*similar but not identical* to the innovator product. While a generic chemical drug is made from the same active ingredients and has the same structure as the original drug, for a biologic drug it is not only the chemical structure of the protein but also the way this structure is folded that determines how it works. The process by which a biologic is manufactured has as much influence on the final product as does the starting ingredients.

Because the manufacturer of the original, innovator biologic does not need to share its manufacturing process, the company making the replication needs to develop its own process. The standards set by the FDA for the approval of a biosimilar must be as rigorous and accountable as those for the innovator biologic to assure the same level of safety and effectiveness.

2. All users (including patients and their healthcare providers) must have access to information that distinguishes the biosimilars from the innovator biologic for appropriate prescribing.

Even small differences between biologic products can have implications for autoimmune patients. In order for clinicians to prescribe appropriately, it is important that they have access to all product information. Moreover, we believe it is critically important that each biosimilar product must have a unique and distinguishable nonproprietary name and a distinct name under the International Non-proprietary Names (INN) Program of the World Health Organization (WHO). Unique names are essential for accurate prescribing, dispensing, and tracing of adverse events back to the source product.

3. Accurate tracking and tracing of biologics must be assured for purposes of monitoring safety and effectiveness.

Biologics are large, complex molecules, and the immune systems of people differ. Therefore, the same biologic drug may have different immunological effects in individual patients. Likewise, a patient may respond well to one biologic but have serious reactions to another version of that drug. Because small differences in the manufacturing process or the type of stabilizer can lead to significant differences in the final product, it is imperative that the FDA monitor all biologics, including innovators and biosimilars, once available to patients. A complete and accurate tracking system is required to make certain that a concern about efficacy or adverse events can be attributed to the specific product, manufacturer, and product lot. This will enable authorities to identify product-specific problems that develop after approval and to minimize patient risk.

4. Patients and their physicians must have the final choice on what product a patient receives.

Biologics treat serious and life-threatening conditions, and autoimmune patients often have multiple health challenges as well as a heightened immune response. Treatment decisions take into consideration the patient's unique health circumstances, history of treatment responses and sensitivities, economic circumstances, and other relevant factors. Because different versions of the same biologic, including the biosimilars, are not identical, the physician should be the one to decide which product best meets the patient's needs. Similarly, no patient should be switched from one medicine to another biologic or biosimilar without the treating physician's and the patient's advance notification and agreement with the switch.

In summary, all public policies, approval processes, and reimbursement practices involving biologics should be guided by

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the foregoing essential principles. The availability of biosimilars, once approved by FDA, has the potential to contribute meaningfully to overall public health if patient safety remains the utmost priority. Lower cost should not mean lower quality or additional risk to patients and the public health. Regulatory authorities play an essential role in realizing this potential. We urge these authorities to collaborate with relevant stakeholders to achieve these critical objectives of protecting patient safety, facilitating positive clinical outcomes, and promoting the public health.

NOTE TO OUR READERS: If you would like to receive a free booklet on biosimilars for additional information, you may contact AARDA: e-mail, aarda@aarda.org; or phone 586-776-3900.

Rheumatology textbook offered free to in-depth readers

Textbooks aren't the chosen reading for everyone, but rheumatology sufferers with a desire for in-depth information might want to access the 2015 edition of *Rheumaknowledgey*. Three professors of medicine have launched their textbook online for free (www.rheumaknowledgey.com).

Co-author John Cush, M.D., director of rheumatology for the Baylor Research Institute, says that he and his co-authors recognize that most students and trainees prefer to use online, accessible sources of learning. He says, "There is no advertising or funding for this. I have paid for it all."

Rheumaknowledgey is presented in three sections: clinical information, including diagnosis and treatment of rheumatic conditions; tests and procedures; and drugs. Dr. Cush says, "We are still updating some

chapters." He indicates that they plan to offer a free mobile app (although, as Dr. Cush explains, the site already is optimized for both desktop and mobile devices).

Each chapter will be reviewed annually but updated "on the fly," whenever there is a new and important advance.

Other co-authors are Arthur Kavanaugh, M.D., director of the Center for Innovative Therapy, Division of Rheumatology, Allergy, and Immunology, University of California-San Diego; and C. Michael Stein, M.D., associate director of the Division of Clinical Pharmacology, Vanderbilt University School of Medicine. ■

--Source: "Free for All: Rheumatology Textbook by Cush, Kavanaugh, and Stein," Lois Wingerson, *Rheumatology Network*, April 2, 2015

Some insect-borne diseases misdiagnosed and underreported

Just a little bug--but possibly bad news if it's a deer tick. With the summer outdoor recreation season being enjoyed again in many parts of the country, campers and others are advised to be especially vigilant about checking for deer ticks on their skin and in their hair. The bite of an infected blacklegged deer tick can result in Lyme disease, the "Great Imitator," as described by Dr. Elizabeth Maloney, Minnesota family physician, in her article for the September 2013 issue of *InFocus*.

To remove a tick: •Use fine-tipped tweezers to grasp the tick as close to the skin's surface as possible. •Pull upward with steady, even pressure. Don't twist or jerk the tick. If mouth parts break off and remain in the skin, remove the mouth parts with tweezers. •After removing the tick, thoroughly clean the bite area and your hands with rubbing alcohol, an iodine scrub, or soap and water. If you develop a rash or fever within several weeks of removing a tick, see your doctor.

Originally thought to be juvenile rheumatoid arthritis, in Old Lyme, Connecticut, Lyme disease may be misdiagnosed as a virus or "summertime flu," according to Dr. Maloney. Over a period of months, the disease can include headaches, stiff necks, pain in specific muscles and joints, and heart irregularities, to mention only a few of the symptoms of Lyme disease. In late Lyme disease, says Dr. Maloney, multiple symptoms are expected.

Lyme disease now appears to be expanding outward from long-time refuges. Recent information from the Centers for Disease Control and Prevention (CDC) indicates that, while the annual incidence of Lyme disease in the U.S. had been 30,000 cases, that number has now jumped 10-fold. This new information is based on data gleaned from using a combination of insurance claims for a six-year period, clinical laboratory reports, and self-reports instead of the standard surveillance reports.

Early research tested the assumption that reducing deer populations would lower the risk of human infection, but some studies have reported that tick density is linked with numbers of white-footed mice or small mammalian predators. Tick abundance will increase at first in the absence of hosts, i.e., they accumulate on vegetation with no hosts for attachment. But later the abundance declines fast as the ticks die and are not replaced through natural reproduction--no hosts to feed adult ticks, no eggs.

In the meantime, protesters demonstrated in October 2014 during Infectious Diseases Week to ask physicians to update their guidelines for chronic Lyme disease. Protest organizer Josh Cutler, who has battled late-stage Lyme disease for nine years, said he wishes that clinicians would be slower to dismiss patients' symptoms. "Don't assume that people working in IT, like myself, or the Ph.D.candidate who drops out of grad school are pretending to play sick, as we are often accused of doing," he said. "We know they can't provide a cure, but their current guidelines prevent us from getting the right medical treatment, and they are telling us that it's all in our heads." ■

--Sources: Excerpted from "Lyme Disease, the Great Imitator," Elizabeth Maloney, M.D., *InFocus*, newsletter of AARDA, September 2013; "Lyme Disease Activists Protest at ID Week," Caroline Helwick, October 19, 2014, via *Medscape*; "An Epidemic of Epidemics," John G. Bartlett, M.D., February 28, 2014, via *Medscape*; "The Lyme Disease Debate," Sharon Levy, *Environmental Health Perspective 2013*, National Institute of Environmental Health Sciences (NIEHS); "A History of Lyme Disease, Symptoms, Diagnosis, Treatment, and Prevention," October 9, 2012, National Institute of Allergy and Infectious Diseases (NIAID)



Veteran team brings home a winner!

For the 16th year in a row, a dedicated team of AARDA volunteers planned and facilitated a winning fund raiser. With its traditional Victorian Tea having given way to a Derby Day for the past three years, AARDA continues to welcome guests to its popular annual luncheon and silent auction. Hats worthy of the most festive Derby brightened the dining room, and snap brim straw hats on a few gentlemen were seen as emcee Dr. Partha Nandi, of Channel 7's "Ask Dr. Nandi," and singer/impressionist Matt Walch encouraged audience participation. The result? Many happy guests and a profit to AARDA of \$50,731.



Hearty notes of thanks go to corporate sponsors Pfizer, Inc., Underwriter; Genentech, Gold Sponsor; and Detroit-based NECABA Management Group, Inc., Silver Sponsor. Also, a note of gratitude goes to Honorary Chairs Chuck and Susan Gaidica, longtime volunteers and supporters of AARDA. Chuck is well known in the Greater Detroit area as a former Director of Meteorology for Channel 4 and special events host.

Derby plans are alive and well as the committee already has met to concentrate on bringing in another winner in 2016. It's not too early to take your place at the starting gate. Call 586-776-3900 or e-mail aarda@aarda.org.

Belated "welcome" to celiac group

Somehow we failed to give recognition to the welcoming of the National Foundation for Celiac Awareness to the 37-group National Coalition of Autoimmune Patient Groups. We'll remedy that omission by a hearty "glad you're with us" in this newsletter.

Through empowerment, education, advocacy, and advancing research, the National Foundation for Celiac Awareness (NFCA) drives diagnoses of celiac disease and other gluten-related disorders.

NFCA is affiliated with leading researchers internationally and supports collaboration and partnership among scientists and institutions to optimize research potential with the goal of improving the quality of life for those who have celiac disease and other gluten-related disorders. For further information, go to www.celiaccentral.org or phone 215-325-1306.

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

A DVD to consider: experts in mind body medicine offer encouragement

A newly compiled DVD, *The Connection; Mind your body*, brings together ten leading experts in a documentary about the latest scientific research proving a direct connection between mind and body when it comes to health. The project was inspired by journalist Shannon Harvey after she was diagnosed with an autoimmune disease. Traveling the world in search of the missing link in healthcare, she interviewed world leading scientists and people with remarkable stories of recovery from a variety of illnesses--severe back pain, heart disease, infertility, cancer, and multiple sclerosis.

Featuring such internationally recognized experts as Herbert Benson, M.D.; Esther Sternberg, M.D.; Dean Ornish, M.D.; Alice Domar, Ph.D.; Andrew Weil, M.D.; David Spiegel, M.D.; Jon Kabat-Zinn, Ph.D.; and others, the DVD presents valuable information about the connection between meditation, mindfulness stress reduction, and the value of community. As Dean Ornish says, "We are creatures of community."

In the "ritual of medicine," although the mind body connection is beginning to be explored, to a certain extent, by a number of physicians, it still is not being considered in modern medicine; and patients tend to follow that lead. As one patient said when he found the mind body connection of dealing with stage 4 melanoma, "I never looked to myself; I looked to the medicine system."

Pharmaceuticals are not tossed out in mind body medicine. They take their place in the total picture that includes not only drugs and surgery but also self-care which includes nutrition, exercise, and stress-relieving aspects of the mind body connection. However, physicians incorporating this "new" philosophy into their practices find skepticism among not only patients but also colleagues. As one physician was cautioned in introducing meditation into his practice, "Your career is in jeopardy."

The Connection, Mind Your Body, Elemental Media 2014, www.theconnection.tv ■



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.)

Grassroots fundraising brings fun and profit

AARDA friends continue to turn talent into support for AARDA's mission. They dance, they bring laughter, they inspire caring, and they spread autoimmune awareness. Here are some of the most recent events.

- **Lilly Stairs and her "50 Cents for 50 Million (50c50m)"** group raised \$2,265 in their "Laugh for Immunity Comedy Show," held in Boston, in March. Lilly and a couple of her close friends created the 50c50m campaign after Lilly, a recent Northeastern University graduate, was diagnosed with Crohn's disease, psoriasis, and hypothyroidism. The campaign has included partnering with Boston-based restaurants, conducting t-shirt and jewelry sales, and seeking online donations. In total, the campaign has netted more than \$11,500 for autoimmune disease research!

- **College of the Holy Cross Dance Team**, in Worcester, MA, generated \$126.50 for AARDA through its annual "Dancing with the Stars" competition.

- **AcrobatAnt**, in Tulsa, OK, celebrated Valentine's Day with a Share the Love Week and chose to honor employee Shannon O'Connell with "Spoonful of Hearts" as a fun way to collect donations. This brought \$708 to AARDA--and made quite a statement in Shannon's office as colorful hearts almost obliterated her desk.

- **Enterprise Holdings, Inc.**, of Orlando, FL, awarded AARDA with a \$1,000 donation when employee Allison Dufresne wrote a personal story and completed an application to the company foundation.

- Students and the professor in Speech 275, Public Speaking, at the **DeVry University Chicago Campus** choose AARDA

as the recipient of their class donations in the amount of \$61. Working in groups, the students presented speeches about a nonprofit organization whose mission and work they felt helped to solve a serious social problem.

Based on the groups' arguments, the class voted to select AARDA.

- The office of the law firm of **Troutman Sanders LLP**, in New York, was the scene of a very successful fund raiser, "Denims and Donations," which raised \$1,910 for AARDA. The inspiration for this day came via attorney Simon Cices, husband of AARDA Board member Althea Cices. Denim, in the form of jeans and other types of apparel, has proved to be an effective vehicle for fundraising (maybe because it's a symbol of wellbeing and relaxation?).

- Previously mentioned in *InFocus*, March 2014, the documentary *Beauty Does Lie: The Untold Stories of Autoimmune Diseases*, produced by autoimmune patient **Courtney Smith**, of Chicago, continues to educate and bring contributions to AARDA. Diagnosed with myasthenia gravis when she was 22, Courtney underwent treatment that ultimately made her illness worse. Her road to healing included her documentary, Reiki, and yoga. She also is being featured in the May 2015 issue of *Self* magazine.

Way to go, AARDA friends! You are reaching out effectively and creatively. Thank you, thank you, thank you.

Note: If you have an idea for a fund raiser that you would like to discuss, you may contact AARDA Project Manager Sharon Harris (sharris@aarda.org; or 586-776-3900). ■



FAS molecule, thumbs up. Rogue germinal center B cells, thumbs down

Australian researchers at Sydney's Garvan Institute of Medical Research believe that they have discovered a group of cells that trigger autoimmune diseases, as well as the molecular "trigger guard" that holds them in check. While germinal center B cells make the "high affinity" antibodies required for long-term immunity, previously undetected rogue germinal center B cells trigger autoimmune disease.

During a normal immune response to an infection, vaccination, or other attack, B cells that encounter the foreign "antigen," e.g., virus or bacteria, migrate to germinal centers which are transient microstructures that form in lymph nodes and tonsils. Once inside, B cells mutate their antibody genes randomly until they produce an antibody with high affinity to the invader. At that point, successful B cells transform into small antibody factories known as "plasma cells." These cells multiply to flood the system with new antibodies.

The urgency and speed at which B cells mutate, as well as the random nature of the process, sometimes create B cells with high affinity autoantibodies that happen to match the "self." These cells must be inactivated in order to avoid autoimmune disease. The FAS molecule, a "death receptor" present at high levels in these cells, has been a prime suspect in their control. Now the Garvan Institute research team led by doctors Danyal Butt, Tyani Chan, and Robert Brink demonstrates that FAS has a very important, but entirely unexpected, role in preventing autoantibody production.

Professor Brink says, "In very simple terms, we believe FAS prevents rogue germinal centre B cells from developing, and we suspect that is its primary role."

Patients with a mutation in FAS develop an autoimmune disease known as autoimmune lymphoproliferative syndrome (ALPS) in which the body cannot control the number of immune cells (lymphocytes). This results in enlargement of the lymph nodes, liver, and spleen. Professor Brink and his colleagues, through collaborators at the National Institutes of Health, found that over 25 percent of ALPS patients have abnormally high levels of IgE (immunoglobulin gamma E)

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Attention, Walkers: Time to "link together for a cure"

The 4th Annual Washington DC Metro Area Autoimmune Walk takes place on Saturday, June 27. Location is McLean Central Park, 1468 Dolley Madison Boulevard, McLean, Virginia. Registration begins at 9:30 a.m., at the gazebo, and walk-off begins at 10:00 a.m. Parking is available at Dolley Madison Library, 1244 Oak Ridge Avenue.

The Tristate Autoimmune Walk takes place on Sunday, September 20, at Clinton Cove Park, in Manhattan, New York.

For more information about the walks, pre-registration, or creation of your own online fundraising page, visit www.autoimmunewalk.org.

Still needed: Other Autoimmune Walk locations and local volunteer support. Contact Pat Barber, Assistant Director, at AARDA (pbarber@aarda.org; or 586-776-3900). ■

What is ARNet?

AARDA Informatics Director and Board Advisor Aaron Abend has been overseeing, with the cooperation of several member groups of the National Coalition of Autoimmune Patient Groups (NCAPG), the development of a much needed new resource designed to assist in finding treatments for autoimmune diseases. In this article, Mr. Abend presents an introduction to ARNet.

Today there is one approved treatment for lupus. For some autoimmune diseases, there are no approved new treatments. AARDA's Autoimmune Research Network (ARNet) is a new resource that will help find new treatments for all autoimmune conditions. We believe that drugs which work on one autoimmune disease may work on others and that new drugs are needed for all of these diseases.

To develop new drugs, medical researchers and pharmaceutical companies need patient volunteers to conduct research. Volunteers play a critical role in research. There are some benefits to participation--volunteers get to play an active role in the research on their own health, they may gain access to new research treatments before they are widely available, and they help others by contributing to medical research.

ARNet is a network that helps patients with autoimmune disease find research opportunities. ARNet is a network of independent databases representing individual patient advocacy groups. Today, in addition to AARDA's own database, we have databases from seven NCAPG members: Celiac Disease Foundation, International Foundation for Autoimmune Arthritis, Myasthenia Gravis Foundation of Illinois, National Adrenal Diseases Foundation, National Alopecia Areata Foundation, National Foundation for Celiac Awareness, and Relapsing Polychondritis Awareness and Support Foundation, Inc.

How does ARNet work? Several steps are involved:

1. Patients answer survey questions about their health, symptoms, and other factors that may qualify them for participation in research.
2. All data is anonymized--names, e-mails, and contact information are removed and replaced with a random number that is not connected to the patient in any way.
3. Researchers can query the anonymized data to see how many volunteers are qualified for their research. If you are one of them, and if we approve their research, we will contact you to tell you about the research. Then, if

you are interested, you decide whether or not to contact the researcher. All research must meet the National Institutes of Health (NIH) guidelines and standards for medical research.

Research may include any of the following:

- Responding to an online survey on lifestyle and quality of life
- Providing blood or saliva that can be used for DNA research
- Participating in the clinical trial of a new drug

Any time patients decide to contact a researcher about their study, they are entitled to additional information on the potential risks of participation. It will be different for each research project.

The most important things to understand about ARNet are the following:

1. ARNet does not store any patient data. Your data is stored and protected by the autoimmune patient group to which you belong. Data is not moved to a central location.
2. Researchers do not contact you--you contact the researchers--if you want to.

How do patients participate in the new AARDA survey?

Patients can participate in ARNet by filling out the AARDA survey which is being updated for release in June. The new survey will collect information on the patients' background, health, disease, and other factors that might qualify them for participation in research. This survey includes general questions about health as well as disease-specific questions.

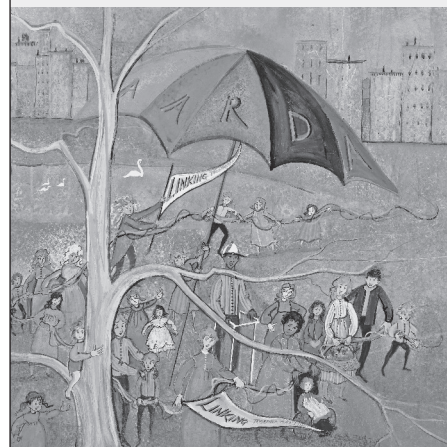
To fill the database with consistent information, the new survey will use questions being used by the Patient Centered Outcomes Research Institute (PCORI). Patient advocacy groups participating in ARNet will use those same questions. Most important, the survey can be filled out more than once so that we can have data that can help researchers understand the impact that autoimmune diseases have on diseases over the long term. Look for an invitation to participate in June!

Special print honors autoimmune patients

AARDA is proud to present a specially commissioned giclee print, "Linking Together for a Cure," by the famed artist P. Buckley Moss who has created a delightful image depicting autoimmune disease patients "Linking Together for a Cure."

Ms. Buckley has captured many of the elements that link autoimmune disease patients. Can you identify them? The 10" x 10" reproductions are \$85 each. If you are interested in purchasing one for yourself or as a gift for someone special, or you may want to see the print in full color, visit www.aarda.org.

A portion of the proceeds from the sale of "Linking Together for a Cure" will benefit the American Autoimmune Related Diseases Association (AARDA). AARDA's mission includes medical research, patient outreach, and public advocacy on behalf of autoimmune patients. ■



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Health varies with seasons...not your imagination

Cold weather means less exercise for arthritis sufferers. Is that the reason for aching joints? Do the gray skies of winter bring on the blues in seasonal affective disorder (SAD)? Why are cardiovascular risk factors higher in winter than in summer? What's going on here? "Seasonal immunity" may be a clue.

Gene expression in human immune cells varies by season, according to a study led by investigators from the Juvenile Diabetes Research Foundation (JDRF)/ Wellcome Trust Diabetes and Inflammation Laboratory in the Department of Medical Genetics, Cambridge University Institute for Medical Research. The international team examined samples from over 16,000 people living in both the northern and southern hemispheres--in countries including the UK, USA, Iceland, Australia, and The Gambia. These samples included a mixture of blood samples and adipose (fat) tissue.

The researchers found that in immune cells of the blood, the expression of genes that promote inflammation tends to rise in the winter and dip in the summer. The seasonality also affects immune cells and the composition of blood and adipose tissue (fat). Ghislain Breton, who studies circadian rhythms at the University of Texas

at Houston (but not involved in the study), says that the researchers' results indicate "sort of a molecular signature of the seasons in humans."

Nikolas Cermakian, who studies circadian rhythms at Douglas Mental Health University Institute and McGill University, in Montreal, Canada, states, "We now know that all immune cell types have their own circadian clocks..." He says, "Moreover, the immune responses, controlled by the circadian clocks, vary according to the time of day." Cermakian observes that the new study conducted at Cambridge indicates that timing information--not only in the daily time scale, but also according to the time of year--must be taken into account when assessing gene expression and immune-related information.

Professor John Todd, of the Cambridge Center, indicates that an outstanding question is whether expression levels of pro-inflammatory genes rise in the winter as an offensive measure against pathogens or as a response to heightened pathogen exposure. "That's the 'chicken and egg' argument," says Todd.

A particularly surprising finding was that a set of genes associated to an individual's response to vaccination was more active in

winter. This suggests that some vaccination programs might be more effective if carried out during winter months when the immune system is ready to respond.

Knowledge of seasonal gene expression potentially could help researchers better understand and treat seasonal diseases, but Cermakian says that it is too soon to consider the clinical utility of these findings.

Professor Todd says, "In some ways, it's obvious--it helps explain why so many diseases, from heart disease to mental illness, are much worse in the winter months--but no one had appreciated the extent to which this actually occurred." He adds, "The implications for how we treat disease like type 1 diabetes, and even how we plan our research studies, could be profound." ■

--Sources: "Seasonal immunity: Activity of thousands of genes differs from winter to summer," *University of Cambridge*, via *Science Daily*, May 12, 2015; and "Seasonal Genes," Ashley P. Taylor, *The Scientist Magazine*, May 12, 2015, from X. Castro Dopico et al., "Widespread seasonal gene expression reveals annual differences in human immunity and physiology," *Nature Communications*

New NIH resource may help identify mechanisms of immune-related diseases

Researchers from the National Institutes of Health (NIH) National Institute of Allergy and Infectious Diseases (NIAID) Vaccine Research Center and colleagues from King's College London have developed an extensive database identifying immune traits, such as how immune cell function is regulated at the genetic level in healthy people. By studying healthy people, the researchers have created a reference resource for other scientists.

While many genetic risk factors have been linked to various diseases, including autoimmune disease, it is not always clear as to how a genetic change causes susceptibility to a disease. The research team analyzed blood samples collected from 669 female twins and developed a screening method that could differentiate approximately 78,000 subsets of immune cells, or immune traits. By using twins, the researchers identified which immune traits were most likely to be heritable and, thus, regulated at the genetic level. They discovered 19 immune traits that were regulated by more than 240 genetic changes clustered within 11 areas of the human genome.

The results of this study have far-reaching implications, especially for researchers studying autoimmune disorders like multiple sclerosis, lupus, type 1 diabetes, and inflammatory bowel disease. For example, genetic changes in the *FCGR2* gene are known risk factors for several autoimmune disorders, including those just noted. However, it remains unclear how *FCGR2* influences such a range of disorders. Now researchers can use this new database to see how a change in *FCGR2* or another gene affects components of the immune system and, subsequently, incorporate this information in the design of future studies. ■

--Source: "NIH researchers develop database on healthy immune system," NIH National Institute of Allergy and Infectious Diseases, March 12, 2015 (Media Contact: Linda Huynh, niaidnews@niaid.nih.gov; 301-402-1663)

Autoimmune research support involves young investigators

AARDA research dollars continue to support various autoimmune research projects, and we are especially pleased when we can stimulate interest among young investigators. One of those investigators is Dr. Heather Torrey, who works with Dr. Denise Faustman in the immunobiology laboratories at Massachusetts General Hospital and has a portion of her salary paid by AARDA. This support is made possible by funds contributed by the Brave Dave Foundation.

Dr. Faustman describes some of Dr. Torrey's work: "She is doing wonderful work on human autoimmunity, multiple sclerosis, diabetes and Sjogren's. She is a basic scientist but tests all her ideas across multiple autoimmune diseases and only in human lymphocytes.... Her project is to map and identify the specificity of newly created monoclonal antibodies to TNFR2 for the expansion of human Tregs...the regulatory T cells in autoimmunity that are needed to stop the abnormal autoimmune reaction."

Other AARDA-supported research is being carried out at the Feinstein Institute for Medical Research by Principal Investigator Dr. Myoungsun Som. She is responsible for designing and performing the studies in the project.

Dr. Som writes: "Despite notable progress that has been made in controlling inflammation in many chronic autoimmune diseases, systemic lupus remains a challenging disease to treat. In order to develop a way to better regulate tolerance, we will focus on the regulation of High-mobility group box-1 (HMGB1)-mediated inflammation in myeloid cells. HMGB1 functions as a chaperone which helps transport extracellular toll-like receptor (TLR) ligands into the cytosol where they

bind the appropriate receptor." Dr. Som says, "We believe that this proposal will provide both new biological insights into [systemic lupus erythematosus] and a potential new therapeutic."

At the Johns Hopkins University School of Medicine, Dr. Jobert G. Barin, Research Associate, is studying the contribution made by neutrophils in heart disease. Dr. Barin writes, "Dilated cardiomyopathy is a major cause of heart failure in humans--often having no clearly identifiable congenital or injurious cause." He states, "Part of the inflammatory process in these diseased hearts involves the infiltration of neutrophils, a cell specialized for host defense to infectious microbes"; and he adds, "Our preliminary data indicate that neutrophils are important in eliciting and sustaining autoimmune T cell responses in the heart."

"We will examine a novel paradigm of neutrophil activity and function--the formation of extracellular traps (NETs). Dr. Barin states, "...these data will provide novel insights into the contributions of neutrophils to inflammatory heart disease processes." He says, "In this project, we will address how NETs contribute to the disease-causing activation of self-reactive T cells in culture in vitro, and in in vivo experiments in a mouse model of heart disease."

In 2010-2012, Dr. Barin's research was funded partially by the AARDA-sponsored O'Leary-Wilson Fellowship in Autoimmune Disease Research.

Autoimmune disease research wears many faces, each giving hope to the 50 million Americans who know the disease so well. We in AARDA are grateful that generous donors make possible our contributions to research. ■

Knee replacement patients find relief

Arthritis patients who undergo knee replacement surgery may find postoperative pain relief through a new treatment announced by physicians at Henry Ford Hospital, Detroit. The physicians have found that injecting a newer, long-acting numbing medicine called liposomal bupivacaine into the tissue surrounding the knee during surgery may increase recovery time and provide increased patient satisfaction.

"The pain scores for this injection technique averaged about 3/10, which is similar to the pain scores seen with our traditional method," reports Jason Davis, M.D., Henry Ford West Bloomfield joint replacement surgeon and the study's senior author. He says that patients given the liposomal bupivacaine injection at the site of the surgery had pain relief for up to two days after surgery and better knee function compared with the traditional method which causes some leg weakness and "makes patients somewhat tentative when walking during their hospital stay." Dr. Davis says that many patients receiving the liposomal bupivacaine injection were able to walk comfortably within hours after surgery. ■

--Source: Excerpted from "Study: An Alternative for Pain Control After Knee Replacement Surgery," David Olejarz, Henry Ford Health System, December 22, 2014, via Newswise



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~ EDITOR'S NOTE ~

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Quote to ponder and enjoy...

Worry does not empty
tomorrow of its sorrow. It
empties today of its strength.

– Corrie ten Boom

Autoimmune disease and fatigue continued from page 1

least one autoimmune disease (of the total of 82 autoimmune diseases reported). Half, 49 percent, reported having one autoimmune disease; two autoimmune diseases, 29 percent; and three or more autoimmune diseases, 22 percent.

Almost all of the survey respondents were female (95 percent), and 46 percent were in their childbearing years.

In this busy, busy world, it's normal to be tired; but the kind of fatigue autoimmune disease patients suffer is anything but normal. For too long, this problem has been ignored; yet through its overwhelming response, the AARDA survey shows without a shadow of doubt that fatigue in autoimmune disease is not an elusive complaint—it's real.

What is the hoped-for outcome of this online public opinion survey? The survey results should prompt fruitful conversation about autoimmune-caused fatigue, not only among the patients themselves but also among researchers--and financial supporters--who will see this as a cause for academic research. In the view of AARDA representatives, the subject of the debilitating effects of fatigue in autoimmune disease has not been properly addressed. For too long, it has been ignored and/or misunderstood by the medical community and the public at large.

Clearly, if 89 percent of respondents to this recent AARDA survey, involving almost 8,000 respondents, have indicated that fatigue is a major issue for them, the time is NOW for addressing this issue. It's a bone that AARDA will not release!

FAS molecule, thumbs up continued from page 6

in the blood. He says, "High levels of IgE antibodies are being found in other autoimmune diseases, such as lupus, and IgE is becoming increasingly associated with severe disease."

Dr. Brink comments, "We do not yet know how rogue B cells arise--mutation of FAS is certainly one way, but there are likely to be others." He says that defining the mechanisms promises to point the way to new diagnosis and treatment strategies. ■

--Source: Excerpted from "A trigger that likely unleashes autoimmune disease," Garvan Institute of Medical Research, Australia, via EurekAlert!, May 12, 2015

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