AARDA continues its salute to #AutoimmuneHeroes

In the June 2016 Infocus, we announced the launch of a yearlong Autoimmune Heroes campaign in celebration of AARDA’s 25th Anniversary. Readers were introduced to the Heroes for March and April. In this issue, AARDA’s Heroes for May, June, and July are featured.

Who are #AutoimmuneHeroes? They are individuals, foundations, and organizations who have assisted AARDA in the advancement of the autoimmune disease agenda in the areas of research, patient safety, advocacy, public education, awareness, service, and volunteerism.

With gratitude, we are pleased to introduce the May, June, and July #Autoimmune Heroes. And so we begin...

AARDA’s May Autoimmune Heroes are the private family foundations and individuals whose personal experience with autoimmune disease has led them to be incredible research fundraisers.

Barbara Wilson Gómez - AARDA salutes Barbara Wilson Gómez as AARDA’s patron, one of the first and most significant donors, contributing nearly 25 years of consecutive financial support for AARDA and autoimmune disease research.

Mrs. Gómez provided the initial funding support to AARDA and the Johns Hopkins University which resulted in the creation of the Center for Autoimmune Disease Research in the Johns Hopkins University Bloomberg School of Public Health.

Again Mrs. Gómez stepped forth with an endowment in honor of her parents to establish the O’Leary-Wilson Postdoctoral Research Fellowship in Autoimmune Disease Research at Johns Hopkins University.

The Scobys say, “We are dedicated to AARDA because we believe that individuals can make a difference by supporting research projects and spreading awareness in their community.”

Dave Gearing, Tom Branthover, and The Brave Dave Foundation - Channeling Dave’s multiple sclerosis diagnosis into an annual charitable golf outing has raised more than $500,000 for research since 1998.

Dave Gearing contracted multiple sclerosis (MS) shortly after graduating from law school in 1979. Despite having to deal with the chronic progressive form of MS, Dave pursued a successful career in business and government before retiring in 1998.

But Dave wasn’t really finished working. Together with his friend Tom Branthover, and supported by other dear friends, Dave began the Brave Dave Open, a charitable golf tournament which combined his love of golf together with his desire to fight back against the disease afflicting him.

Today, 18 years later, the Brave Dave Open continues its work through the Brave Dave Foundation, a year-round charity working to help coordinate all autoimmune research being done in the hopes that an advance in one area of autoimmune research will have benefit in another. Like AARDA, their goal is eventually to bring about a cure for the millions of Americans who suffer from autoimmune disease. (For more information, visit www.bravedave.org.

Jay and Joseph Scoby and the Scoby Family Foundation - Using their eldest child’s autoimmune hepatitis diagnosis as the catalyst for wanting to make a difference for all those afflicted with autoimmune liver disease, Jay and Joseph Scoby set about raising funds for autoimmune liver research at Johns Hopkins University.

Shortly after their child’s diagnosis, they were introduced to AARDA. Then, in addition to their research fundraising activities, Jay also joined AARDA’s Board of Directors to help facilitate awareness of autoimmune disease in general.

The Scobys say, “We are dedicated to AARDA because we believe that individuals can make a difference by supporting research projects and spreading awareness in their community.”

Lila B. Zuckerman and The Gail I. Zuckerman Foundation - In memory of their young daughter Gail who passed away from autoimmune liver disease in 1967, the Zuckermans established The Gail I. Zuckerman Foundation that grants funds for research into children’s chronic liver diseases.

Marking the Foundation’s 25th anniversary in the early 90s, the family was frustrated by the paucity of knowledge in regard to diseases of the liver and too many unsolved mysteries in regard to this vital organ.

In 1998, after exploring possibilities for hepatitis as an autoimmune disease, Lila Zuckerman was put in touch with AARDA President and Founder Virginia Ladd. It was a fateful meeting that has resulted in years of significant funding to the Johns Hopkins University Center for Autoimmune Disease Research to study autoimmune liver disease under Director Dr. Noel Rose.

Article continued on page 3
Greetings! Now that summer vacations are ending, it's no surprise that neither autoimmune diseases nor the AARDA mission took a vacation. Well, yes, there were a few stops along the way--picnics, fireworks, and family get-togethers where we, not to waste an opportunity, shared our family A.Q.s (Autoimmune Quotients, aka family autoimmune histories). Yes?

During those vacation months, our Scientific Advisory Board Chairman Emeritus Dr. Noel R. Rose, of Brigham and Women's Hospital, Harvard Medical School, was organizing a September 24 scientific meeting, “Novel Cellular Pathways in Autoimmunity.”

Also, AARDA has invited members of the Autoimmune Partnership Council and the National Coalition of Autoimmune Patient Groups--now 38 members strong--to a meeting in Washington DC to become acquainted with each other as they share topics of mutual interest for the benefit of autoimmune disease patients.

Still in the areas of education and research, we are pleased that once again we have been able to provide $24,000 in sponsorships for five young medical students in the Johns Hopkins University Diversity Summer Internship Program. The AARDA Board also has approved to continue funding of the “autoimmune young investigators grants” which are awarded in order to stimulate interest in future autoimmune research. The Board will fund five young investigators for a total of $100,000.

On the organizational side, the AARDA Board of Directors reviewed AARDA’s Strategic Plan and found that we are pretty much on target for both accomplishments and finances.

The Board members expressed the need for increased public and corporate awareness that could bring an expansion of patient services, growth of volunteer involvement, and donor support. They also felt a strong need to reach out with additional informational programs to physicians and other health and medical professionals.

Celebration of AARDA’s 25th Anniversary is continuing. As a result of news releases and interviews, we have had a number of opportunities to send out the autoimmune message. As we all know, awareness leads to education which leads to diagnoses and, in many cases, life-saving treatments.

Speaking of awareness, I want to say THANK YOU to our “grassroots” fundraising organizers and volunteers who not only are raising funds to support the fight against autoimmune diseases but also are spreading life-saving awareness in their own local communities. See the grassroots article in this newsletter concerning some of these projects. Results are amazing!

To all of you reading this newsletter: I thank you for your interest in AARDA and, for many of you, your active support. We are doing this together.

With gratitude,

Virginia

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President/Executive Director’s message

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#Autoimmune Heroes (continued)

Mrs. Zuckerman says, “AARDA was the only place that we could find for autoimmune liver disease. The doctors whom we contacted directly were not interested. We are honored to be recognized by AARDA for our persistence in gaining awareness of autoimmune hepatitis and soliciting funds for research.”

AARDA’s June Autoimmune Hero, simply one BIG Hero, is the Johns Hopkins University Center for Autoimmune Disease Research at the Bloomberg School of Public Health. Specifically, AARDA honors the Johns Hopkins Center for Autoimmune Disease Research for its nearly two decades of work:

- Promoting individual and collaborative research on the initiation and development of autoimmunity and the pathogenesis of the autoimmune diseases
- Fostering the sharing of specialized instruments and technologies, as well as precious samples from autoimmune disease patients
- Implementing a postdoctoral training program, providing an opportunity for young investigators to engage in fundamental or applied research on autoimmunity at an early formative stage of their careers
- Hosting regular seminars, workshops and colloquia focused on current research, beginning with the first-ever Johns Hopkins Autoimmunity Day, in June 1999, bringing together distinguished international experts exploring the frontiers of autoimmune disease research
- Partnering with AARDA to host international colloquia on interspecialty and interdisciplinary topics that cut across the broad field of autoimmune disease
- Enhancing education about the autoimmune diseases among medical students, graduate students, residents, and postdoctoral fellows, while encouraging the inclusion of, and greater attention to, the autoimmune diseases in the medical curriculum
- Recruiting and supporting junior faculty interested in autoimmunity aimed at sparking fresh insights into the pathogenesis of autoimmune disease, seeking novel treatments, and developing strategies to prevent these diseases among those at risk
- Serving as a clearinghouse for reliable information about autoimmune disease to the wider professional and lay public

Virginia Ladd, Founder and Executive Director of AARDA (@AARDAtweets), said, “AARDA has enjoyed a wonderful, collaborative relationship for many, many years with Johns Hopkins University, starting with Dr. Noel Rose and the very first Autoimmunity Day at Johns Hopkins in 1999. This led to our founding of the Center for Autoimmune Disease Research, aimed at increasing the research focus on autoimmune disease and introducing the pursuit of this area of study to talented young researchers, all in the hopes of benefiting the 50 million Americans who suffer from these diseases and their families.

“We thank Johns Hopkins University for being a driving force, and we look forward to many more years of partnership to identify the root cause of autoimmunity, understand the etiology of these 100-plus diseases, lay the groundwork for new treatments, and hopefully one day discover a cure for all autoimmune diseases.”

AARDA’s July Autoimmune Heroes include two very well known individuals and an outstanding national committee.

United States Vice President Joseph R. Biden, Jr., and retired U.S. Congressman Henry A. Waxman (D-CA) are honored for stepping forward for autoimmune diseases in specific ways:

- Showing strong leadership in spearheading the Children’s Health Act of 2000 legislation that resulted in the creation of a permanent Autoimmune Disease Coordinating Committee within the Director’s Office of the National Institutes of Health
- Exhibiting commitment to autoimmune disease and understanding how critical it was at that time for autoimmunity to be recognized as a major disease category and one that demanded significant research attention.

The National Institutes of Health’s Autoimmune Disease Coordinating Committee and all its members for

- Dedicating 16+ years of leadership on autoimmune disease research, with special thanks to the National Institute of Allergy and Infectious Diseases for chairing the Committee and facilitating coordination amongst all NIH Institutes, federal agencies, professional societies, and patient and advocacy groups with an interest in autoimmune disease
- Preparing and later updating the first-ever autoimmune disease research plan, charting a course for future research to determine causes of the diseases (epidemiology), addressing the frequency and national history of the diseases, including by gender and race (epidemiology), developing and evaluating new treatments, and providing educational programming for both health care professionals and the public

“The creation of the NIH Autoimmune Disease Coordinating Committee in 2000 marked a significant turning point in the recognition of autoimmunity as both a major disease category and a sorely underfunded research area,” said Virginia Ladd, AARDA Founder and Executive Director (@AARDAtweets). “All these years, AARDA has enjoyed a close, productive working relationship with the Autoimmune Disease Coordinating Committee and looks forward to many more.

“We also are forever grateful to Vice President Biden and Congressman Waxman for working so diligently to get the legislation introduced and passed.” She added, “This particular moment in autoimmune disease history was truly a game-changer for the 50 million Americans with autoimmune disease and their families in terms of better diagnostic tools and treatments--and one day, hopefully, ultimately, prevention.”
A day of celebration...
AARDA’s Annual Derby Luncheon

For the 16th year of AARDA’s Annual Fund Raiser, a tradition that started with the first “Victorian Tea at The Whitney” and evolved into this year’s 4th Derby Day Luncheon and Silent Auction, long-time and committed supporters of AARDA gathered on May 7 for a day of celebration.

Against a spectacular view of Michigan’s Lake St. Clair, in the Greater Detroit area, speakers and guests offered a toast to AARDA on its 25th Anniversary. A major event of the day was the honoring of Noel R. Rose, M.D., Ph.D., the first recipient of the AARDA Champion Award. Dr. Rose, founding director of the Center for Autoimmune Disease Research, Bloomberg School of Public Health, Johns Hopkins University, is now a member of the pathology department at Brigham and Women’s Hospital, Harvard Medical School, in Boston. Currently Chairman Emeritus of AARDA’s Scientific Advisory Board, Dr. Rose, from AARDA’s earliest days, has been instrumental in advancing the mission, growth, longevity, and standing of the Association.

Emcee for the day was Partha Nandi, M.D., Chief Health Editor at WXYZ ABC Detroit and creator and host of the internationally syndicated medical lifestyle television show “Ask Dr. Nandi.” This was Dr. Nandi’s second year as volunteer emcee for the Derby Luncheon.

Susan and Chuck Gaidica, currently of WDIV Channel 4, Detroit, headed the Derby Honorary Committee which included Congresswoman Debbie Dingell, Jane Ilitch, and AARDA National Spokesperson Kellie Martin.

We in AARDA gratefully acknowledge the generous contributions of Event Underwriter Pfizer, Inc., and dozens of in-kind donors who contributed to the silent auction and raffle—most notably Caesars Windsor, Detroit Tigers Community Affairs, DoubleTree Suites by Hilton, Meijer #63, and our good friends Autoimmune Heroes Kellie Martin and Chuck Gaidica.

We give a special “thank you” to the Event Committee volunteers for our Derby Day: Marilyn Assiff, Donna DiSante, Ruth Kibler, Carolyn Ugval, and Mary Beaupre Yavor. Also, we couldn’t have carried the day without our corps of loyal volunteers, most of whom have been with us for the full 16 years: Katie Kibler Coyne, Kerri Dettmer, Sharon Dettmer, and Lisa Evans.

With photos provided by photographer Brittany Crutcher, we are pleased to share a glimpse of the day with you, our readers. And may we suggest that in 2017 you join us for the real deal—whatever the theme and whatever the place. Come alone or come with friends. It’s always a welcoming, gracious afternoon.
AARDA’s tiny acorn promises great results

Ralph Waldo Emerson said, “The creation of a thousand forests is in one acorn.” AARDA friends believe that the creation of hope for many of the 50 Million American autoimmune disease patients will be found in a National Autoimmune Diagnostic and Treatment Center coming from our own AARDA acorn. AARDA’s fund for such a center is growing through individual donations, adding to the substantial contribution from Virginia Ladd (who never gives up on a good idea). Although a major philanthropist is needed to put the project over the top, the steady contributions from AARDA friends are keeping hope alive.

If you see a reason for the creation of a National Autoimmune Diagnostic and Treatment Center, please help to give our little acorn the boost it needs.

Welcome to AARDA’s newest SAB member

On behalf of the Board of Directors and all of us at AARDA, we are pleased to welcome Patrizio Caturegli, M.D., to AARDA’s Scientific Advisory Board.

With degrees in literature (“La Querce” College, Florence, Italy) and medicine (University of Pisa Medical School, Pisa, Italy), a Board certified residency in endocrinology (University of Pisa Medical School), and a Johns Hopkins University School of Medicine fellowship in immunology, plus many publications to his credit, Dr. Caturegli promises to be an outstanding member of our Scientific Advisory Board.

You’re stressed? So what’s happening?

From scientists at the University of Pittsburgh comes new information of what can happen in a stressful situation. Let’s say that you are struggling with a problem. As you self-talk about it, anxiety develops. Then it’s decision time—and you make the wrong decision. What happened?

The scientists, in their research, have determined that anxiety disengages a region of the brain called the prefrontal cortex which is vital for flexible decision-making. Lead researcher Bita Moghaddam, Ph.D., commented, “Anxiety disengages brain cells in a highly specialized manner.”

Based on trials made with anxious rats, the researchers made two observations: first, anxiety has a negative effect on decision-making when conflicting distractors are present; and second, bad decisions made during a time of anxiety involve a numbing of neurons in the prefrontal cortex. Thus, it’s more than just a feeling of stress that affects decision-making; it’s an actual physical change.

What are some anxiety reducers? It’s not “one size fits all.” Gentle exercise can be very effective for some individuals. Quiet, rhythmic breathing can be very calming. Some look to a soothing drink of herbal tea—or yoga might be your thing.

Some foods and drinks trigger anxiety—caffeinated drinks, highly sugared foods, loads of carbohydrates (not always comforting), drinks and foods containing aspartame, just as some examples.

On the other hand, in “Feeling Frazzled? Certain Foods Can Help Reduce Anxiety,” experts at Massachusetts General Hospital suggest trying, for example, cashews, spinach, and oysters (all high in zinc); turkey, eggs, fish (for tryptophan); broccoli, beans and asparagus (for folate); and yogurt, bananas, and nuts (for magnesium).

No more bad decision-making now that we know why—right?


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Non-Medical Switching: Insurers Playing Doctor

Being a knowledgeable healthcare consumer in today's world can be challenging, frustrating, reassuring, complicated, satisfying, alarming, interesting, overwhelming, important. In what category, or categories, might the following information fit?

What is non-medical switching?

Non-medical switching, as compared to the very common generic switching, is an increasingly popular practice used by insurance companies to switch a patient from a current medication to a different medication even though it has not been approved by the patient's doctor. In both cases, the switch is done to substitute a medication that is less expensive than the one originally prescribed; but the generic switch cannot be made if the doctor has indicated that the prescription must be filled as written. That protection does not exist with the non-medical switching.

Non-medical switching differs also in a very important way from generic switching in that the generic medication has the same active ingredient as the brand name medication while the non-medical switching medication, although having been approved for the same condition as the brand name medication, does not have the same active ingredient. This switch is made for the purpose of saving money without having to notify the physician.

For an explanation of how non-medical switching works, go to http://www.aarda.org/non-medical-switching/.

How do insurance companies practice non-medical switching?

Insurers encourage non-medical switching in the following ways:

- Limiting or completely restricting access to the medication originally prescribed by the doctor
- Increasing out-of-pocket costs and/or switching the medication’s tier to encourage the patient to select a less expensive medication
- Offering pharmacists and health care providers financial incentives to switch the patient to a different drug preferred by the insurance company

How does non-medical switching impact the autoimmune disease patient?

It would seem, according to views of some medical professionals and healthcare consumers themselves, that insurance companies are trying to play doctor. This practice of non-medical switching has the potential to lead to serious medical consequences for the autoimmune patient who often endures a long and painful struggle in search of an effective treatment. One study showed that it is not unusual for an autoimmune disease patient to need to try more than one medication before finding the one that works, and sometimes that search covers almost three years.

Even more concerning, when autoimmune patients in one study were switched for non-medical reasons from a medication that was keeping them stable, a number of respondents said that their condition worsened or they experienced side effects.

Switching a patient’s therapy for non-medical reasons can have a devastating impact, triggering an autoimmune disease flare and burdening the patient with pain, frustration, and financial consequences.

Is it safe to be switched from a biologic to a biosimilar?

Non-medical switching raises an important question about biologics and biosimilars, a class of treatment widely prescribed to autoimmune patients. While the decision should be decided ultimately by the patient’s doctor, AARDA believes that no patient should be switched from a biologic to a biosimilar unless it has been deemed interchangeable by the FDA.

How can the healthcare consumer or advocate help?

Let your legislative representative know that you don't want your insurance company “playing doctor.” Remember to share the following key points when communicating reasons that non-medical switching can be a dangerous practice:

- **Share your patient story.** How long did it take you to find a medication that works? How would your life be impacted if suddenly you were taken off your medication and switched to a different one?
- **Share the unintended cost.** Non-medical switching by insurance companies is not only a dangerous practice but also a costly one. Patients who are switched from a medication that was keeping their symptoms

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Grassroots fund raisers keep growing!

What gratitude we in AARDA feel for the tremendous energy, talent, and dedication shown by AARDA friends in fundraising and awareness activities! We are sure that lives are being saved by dollars and awareness raised by these widespread events. Let’s hear it for all those “in the field”! WE THANK YOU.

- Compassionate students at Deer Path Middle School East, in Illinois, didn’t let cloudy skies deter them in honoring school staff and faculty who suffer from autoimmune diseases. They made AARDA their charity of choice for their Annual Color Run. The result? They raised $4,091.50 for autoimmune disease research. Hey, who gave the 50 cents? Rock on!

- The “Virginia Team” keeps moving along. The team members not only raised $3,379 for AARDA through their “Baskets and Bingo,” as reported in the June InFocus, but also held a successful raffle of a beautiful signed and framed P. Buckley Moss AARDA print, “Linking Together for a Cure”—resulting in $1,076 more for AARDA! The Virginia Team, led by AARDA Board Secretary Michelle Ouellet and enthusiastic volunteers Pat Jones, Leigh-Anne Sheppard, and Nancy Sheppard, gives credit to “lots of help from family members, friends, and the community.”

- The Thimble Pleasures Quilt Guild, of Massachusetts comprise a real get-up-and-go bunch of quilters who don’t confine their talents to needles and thread. Through their “Good Foods To Go” fundraising campaign, they raised $2,287.50 to support women’s health by bringing awareness regarding autoimmune diseases and to support good, healthful food choices for all. During their biannual quilt show, they sold hundreds of beautifully handcrafted lunch and casserole carriers. They also handed out hundreds of AARDA information brochures to their members and guests. Way to go, Chair Kathryn Sperino and Guild members!

- Tribute to Cara Lian Lebedda - This annual tribute to Cara is held by her many friends in the Pittsburgh area who keep alive her memory through a joyous---

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Article continued on page 7
AARDA shoes making tracks again! Here’s news....

Autoimmune Walks 2016 open in Cleveland

Initiating the AARDA “Linking Together for a Cure” Autoimmune Walks 2016 season were the more than 100 people who came to Cleveland MetroParks, South Chagrin Reservation, on Sunday, May 22. On a beautiful spring day, friends and families linked together with autoimmune diseases in various ways shared their personal journeys while talking and walking together—all in support of AARDA’s mission.

Our thanks go to the Cleveland Women’s Journal for their sponsorship of this event and to the following in-kind donors who helped make the Walk a great experience: Café Avauna, Davis Bakery & Delicatessen, Giant Eagle Market District, Giant Eagle Legacy Village, Miles Farmers Market, Pamela’s Products, Pepsi, Solon Massage Therapy, Trader Joe’s, and Whole Foods Market. Thanks, also, to the many generous donors to the Walk raffle.

We are grateful to AARDA staff to lay the groundwork for this Walk. The outcome was so successful that it’s on the calendar again for 2017! See you there!

Virtual Walkers prompted to join the effort

Unable to participate in the AARDA Tri-State Walk in September, New Yorker Vanessa Caine decided to hold a Virtual Walk in the Bronx, in July. She was determined to do her part to bring attention to autoimmune disease because, like so many in her own situation, her road to the diagnoses of Hashimoto’s thyroiditis and Sjögren’s disease had been long and arduous.

“It was an uphill battle to get the correct diagnoses,” she explains, “and then to find a doctor who could help. Looking back, I had been suffering for many years but didn’t connect the dots.” Vanessa and her team, Vanessa’s Warriors, have raised $2,035 thus far for the cause. This is support that will help others connect the dots.

Wanted: Virtual Walk Leaders

You, too, could be a Virtual Walk leader like Vanessa. Please contact Deb Patrick at 855-239-2557 for help in getting started.

Is an AARDA Autoimmune Walk in your future—walk leader? volunteer? sponsor? donor?

You may register for any of the following upcoming events at AutoimmuneWalk.org:

DC Metro Autoimmune Walk
Saturday, September 10
Bluemont Park, Arlington VA
Coordinator: Robin Gebhardt

4th Annual Missouri Autoimmune Walk
Saturday, September 17
Washington University, St. Louis MO
Coordinator: Courtney Vishy

5th Annual Tri-State Walk (NY, NJ, CT)
Saturday, September 18
Hudson River Park’s Clinton Cove, Manhattan NY
Performing Live: Pop Duo Danielle & Jennifer

Atlanta Autoimmune Walk
Saturday, September 24
Piedmont Park, Atlanta GA
Coordinator: Vanessa Hamler

Metro Detroit Autoimmune Walk
Saturday, October 8
Walk Ambassador: Dr. Partha Nandi, Chief Health Editor, WXYZ
Belle Isle Park, Detroit MI
Contact: dpatrick@aarda.org

2nd Annual Los Angeles Walk
Saturday, November 5
Walk Ambassador: Haley Ramm
Culver City Park
Coordinator: Barbara Ramm

Is HPV vaccine safe for autoimmune patients?

To vaccinate or not to vaccinate is frequently a subject for debate, but a recent study involving girls and women diagnosed with at least one autoimmune disease showed that vaccination against human papilloma virus (HPV) did not increase the risk of developing another autoimmune disease. In fact, being vaccinated was shown to be associated with a slightly reduced risk compared with not being vaccinated.

The study included 70,265 girls and women between 10 and 30 years of age in Sweden, in 2006 to 2010, who had been diagnosed with an autoimmune disease. It is hoped that the results of this recently reported study will be of help in decision-making, on the part of both physicians and their patients, for those contemplating the safety of HPV vaccinations for women and girls with autoimmune diseases. Dr. Lisen Arnheim-Dahlstrom, senior author of the Journal of Internal Medicine study, noted that individuals with autoimmune disease are vulnerable to vaccine-preventable diseases.

“Non-Medical continued from page 6...under control are likely to end up in the Emergency Room and endure countless doctor appointments to try to manage a disease flare caused by the switch. We at AARDA see this as an important patient issue, especially for autoimmune disease patients. You may want to be aware of “Non-Medical Switching” for yourself and/or family members. Frequently “the patients themselves” are very effective in assisting with their own health care.
Rare disorder may have role in preventing type 1 diabetes

In an international study led by researchers at King’s College London, samples were taken from 81 individuals with a rare autoimmune disorder, autoimmune polyendocrine syndrome type 1 (APECED), who have defects in the autoimmune regulator gene. Defects in this gene mean that it no longer can fulfill its role as a regulator that helps purge the body of autoreactive immune cells, called T cells, that can react against the body’s own proteins, mistaking them for a foreign invader.

“APECED is a rare and poorly understood autoimmune disease,” said Professor Adrian Hayday, senior author of the study, from the Department of Immunobiology at King’s College London and Group Leader at the Francis Crick Institute. “The defect in the autoimmune regulator gene should put APECED patients at severe risk of developing myriad autoimmune diseases, including type 1 diabetes, multiple sclerosis, lupus and rheumatoid arthritis in which an immune system that has not been purged of autoreactive cells attacks vital organs.

“Yet it’s very unusual—possibly unprecedented—for APECED patients to develop multiple sclerosis or lupus, and most do not develop type 1 diabetes,” Professor Hayday further commented. “So why don’t they get these diseases?”

To discover whether APECED patients’ autoantibodies could have therapeutic potential, the research team tested them in a mouse model of psoriasis, an autoimmune condition that causes red, itchy, scaly skin. The researchers found that injecting the mice with autoantibodies from the APECED patients could inhibit the development of psoriatic pathology.

The researchers also noted that only 10 to 20 percent of people with APECED develop diabetes. The patients without diabetes produced autoantibodies that completely impaired the activity of a subtype of interferon known as interferon-alpha, which is produced by the immune cells and may cause inflammation. By contrast, such potent antibodies were not produced by patients with diabetes.

“This study provides correlational evidence for active anti-interferon antibodies providing protection from type 1 diabetes, but more research is needed to prove causation in humans,” reported Professor Hayday. “These findings give a firm foundation for exploring the potentials of autoantibodies from APECED patients to ameliorate type 1 diabetes and other important autoimmune diseases that are rarely, if ever, present in APECED patients.”

--Source: “Antibodies in patients with rare disorder may have role preventing type 1 diabetes,” King’s College London, via Medical Xpress, July 14, 2016

Researchers study effect of antibiotics in diabetes

What is the connection between antibiotics and type 1 diabetes as well as other autoimmune diseases? Scientists at New York University (NYU) Langone Medical Center set out to find some answers.

In type 1 diabetes, the immune system mistakenly destroys the islet cells in the pancreas that produce insulin. Without insulin, patients cannot properly control their levels of blood sugar (glucose) which builds up to damage nerves and blood vessels. Some studies suggest that naturally occurring microbiomes teach newly formed immune systems to be less sensitive and, therefore, less capable of self-attack. Antibiotics, say the study authors, may interfere with this education.

The study results reported by the Langone Center researchers center on the microbiome, the bacterial species in guts that co-evolved with human beings to play roles in digestion, metabolism, and immunity. It is known that as children’s exposure to microbe-killing antibiotics has increased in recent years, the incidence of autoimmune diseases, such as type 1 diabetes, has more than doubled. The average American child currently receives 10 courses of antibiotics by age 10.

Utilizing non-obese diabetic (NOD) mice, which are known to be more susceptible to type 1 diabetes, the new study found that short pulses of antibiotics cause the mice to develop the disease more quickly and more often than mice not treated with antibiotics. The NOD mice are the best model of type 1 diabetes to date; and in the study, they were given doses of antibiotics like those received by most children to treat common infections. In doses equivalent to those used regularly in human children, antibiotics changed the mix of gut microbes in young mice to dramatically increase their risk for type 1 diabetes.

“Our study begins to clarify the mechanisms by which antibiotic-driven changes in gut microbiomes may increase risk for type 1 diabetes,” says study senior author Martin Blaser, M.D., The Muriel G. and George W. Singer Professor of Translational Medicine at NYU School of Medicine.

“This latest study result is compelling, linking the effects of use of antibiotics in mice to type 1 diabetes,” says Jessica Dunne, Director of Discovery Research, at the Juvenile Diabetes Research Foundation. “This is the first study of its kind suggesting that antibiotic use can alter the microbiota and have lasting effects on immunological and metabolic development, resulting in autoimmunity.” She adds, “We’re eager to see how these findings may impact the discovery of type 1 diabetes preventive treatments in the future and continued research in the area of vaccines.”

--Source: Excerpted from “Antibiotic Treatment Increased Risk for Type 1 Diabetes in Animal Study,” NYU Langone Medical Center, August 18, 2016, via Newswise
Are we too bacteria phobic?

With all the anti-bacterial soaps, sprays, ointments, etc., springing from laboratories and being used generously throughout much of the world, immune systems should be successfully functioning to the good of all concerned. However, over the past few decades, the healthcare community has observed an intriguing development: diseases related to the immune system, such as type 1 diabetes and other autoimmune diseases, as well as allergies, and other ailments, have taken hold in countries with thriving, modern economies--while hardly making a mark in the developing world. What's happening?

The best-supported theory, dubbed the hygiene hypothesis, has emerged to explain this troubling public health pattern. The theory is based on the premise that exposure to pathogens (specific causative agents of diseases, i.e., bacteria and viruses) early in life is actually beneficial to the education and development of the human immune system.

Researchers are uncovering evidence that not only supports the hygiene hypothesis but also points to interactions among bacterial species that may account, at least in part, for the spike in immune disorders seen in western societies. The researchers suggest that exposure to bacteria may play a pivotal role in the immune system; and by studying the human microbiome, researchers might be able to understand what that role is.

This study was conducted by researchers at Aalto University, Broad Institute, University of Helsinki, and other organizations across the globe. Their work involved evaluation of data collected from over 200 infants, birth to age three, from Finland, Estonia, and Russian Karelia.

Commenting on a difference in bacterial populations among babies from the three countries, co-first author of the Cell study, Doctoral candidate Tommi Vatanen said, “We can only speculate why this difference in bacterial populations exists; what we could show was what implications that difference in populations might have.”

Vatanen said, “We believe that E. coli, which lives in the infant gut in all three countries, might be one of the immune educating bacteria responsible for training the immune system early in life. But we found that if you mix Bacteroides [the most common bacteria in the colon, where they outnumber E. coli by at least 100 to 1], it can actually inhibit the immune-activating properties of E. coli; and we suspect this might have consequences on the development of the immune system.”

Results of another study, reported in Science, involved pregnant mice. The study showed that pregnant mice expose their unborn pups to maternal gut microbes, which can affect the development of the innate immune system after birth. The results challenge the notion that a pup’s own gut microbiome drives immune system development.

Andrew Macpherson, a gastroenterologist and researcher at University Hospital, in Bern, Switzerland, commented, “There is a tsunami of microbes that colonize the intestine starting at birth and there has to be a system that prepares for this onslaught.” He added, “It was previously assumed that development of the innate immune system was just through colonization after birth, but the reality is that the maternal microbiome has a powerful additive effect on the endogenous development of the pups.”


~ 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.
The 1st Annual SENTINELMUSIC LTD “Community for Autoimmunity,” another Pennsylvania fund raiser, featured an array of bands, including Dissension Rising, “directly from Dublin, Ireland!!!, for an evening of music, food, and drink organized by AARDA friend Brian Goldstein. This festive event, on behalf of AARDA’s mission, realized a net profit of $1,380. What a great awareness and fundraising project! Sorry we missed it!

◆ Senior Service Project, a two-week endeavor of Worthington (Ohio) Kilbourne High School student Ellie Darby, raised $130.18 for AARDA and achieved a great deal of awareness through a news segment produced by Ellie. Having an autoimmune disease herself and feeling a need for better awareness than she could raise in two short weeks, she suggests that we contact Worthington schools to stimulate interest in autoimmune awareness. Hmm...it’s a thought. In the meantime, we thank Ellie for her contribution to the fight against autoimmune disease and wish her well in her own health challenge.

Fund Raisers
50 Cents for 50 Million • Deer Path Middle School East Annual Color Run
Worthington Kilbourne High School Senior Service Project
Sentinel Music LTD Community for Autoimmunity
Annual Event in honor of Cara Lian Lebedda • Good Foods to Go

Payroll Deduction Programs ($50 or more) and Matching Gifts
AT & T • Allstate • IBM • KPMG’s Community Giving • Maryland Charity Campaign
Merck • Morgan Stanley • New York Life • Shell Oil Company
United Way of Greater Philadelphia & S. New Jersey

Friends (to $49) and Autoimmune Walk Donors (to $249)
Contributions in these categories are too numerous to print, but we would like to say “thank you” again for the many donations that have been made. These loyal friends are noted with appreciation.

Grassroots continued from page 6 —

community get-together. They raise money for research into idiopathic/thrombocytopenic purpura (TTP/ITP), the autoimmune disease that afflicted her. This year the net profit totaled $3,060, which adds handsomely to the research contributions earned over past years. A loving, living tribute!

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With Special Thoughts...

Tributes
Anna Burns - In her honor - Deer Path Middle School Dash
Billie Johnson - In honor of her birthday - Judy Udove
Nancy Linn - In her honor - Jean Sweeney
Josh & Anne Sportas - In honor of their anniversary - Marilyn & Sam Perkul
Elaine Waldeck & Steve Foley - In honor of their marriage - Bonnie & Tom Clark

Memorials
Braedon Matthew Barnett - Union City Elementary, Middle, & High Schools
Jan Beebe - Jovie Murtha
Brian Carpenter - Mike & Stephanie Cluff; Teresa & Manouch Sadeghin; Susan, Bob, & Nana Lassee; Pam Connolly; Shirley Brooks & George Hollenderswick; Mary Rouse; Donna Minner; Veronica Starkey; Sayres & Associates Corp.; Bettye Oswalt; Bladenburg’s 60th Reunion

Kumar Chinnaswamy - Shannon, Andrew, Martin, & Christina Gill; Dave & Pat Riley; Mike & Dale Landers; Jim & Julie Bucyzynski; Mark Linderman & Jennifer Geiger; The Cappucci Family; Kathy Stoltz; Marty & Jan Stoltz and Family; Lisa, Steve, Sam, & Sydney Neuman; Friends from Applewild School; Louis & Marty Kupermsmith; Suzanna & Lauren Staffieri; Northeastern Men’s Lacrosse Team

Rita Costanza - Tom & Heidi Hall, Sue Derkowski, Denise Moneyman & John Zawacky, Barbara & Bob Mooney, Stephen Kelly, Sandy Gianakakos & Elda Sonvico, Frank Cannistra, Albert & Lorraine Rizzo, Rahi & Lori Loder, Brian Kronick, Terry & Valerie Ritson, McElroy Family, Debbie & Bob Schramek, Molly & Vincent Emiliani, Jim Haynes, IGT-Texas

Marsha Davis - Carolann & John Riccardi, Bonnie & David Jacobson, Ronny Berlin, Cindy & Seth Kipinis, Ruth & Robbie Helicher

Gary Duncan - Jackie Malone
Sarah Dickinson Grant - Ann Keyser
Sharon Kaplan - Miriam & Don Schlier
Aundrea Lansdown-Powers - The Sellers Girls: Cathy Hayes, Jean Heil, Mary Johns, and Margie Rice
Carmine Longo, Sr. - Geraldine & Bill Fleming
Suzanne Madden - Gene & Karen Ogrodnik, Dr. & Mrs. Barry Lease, Jean Moore, Ronald & Betty Reita
Janie Needham - Shane Needham Family
Mary Neufeld - Candi & Evan Williams
Massood Nooralian - Terry Tehaan
Deborah Ann Pugh - Jie Ruan
Ralph Psick - Hal Psick
Bella Sery - The Juanteguy Family
Ellen Maas Sullivan - Lori Airhart

AARDA Memorial / Tribute Program
Write or call us for full details of this program. It can be handled by mail or by phone using Visa, MasterCard, or American Express.
Memorial and Tribute contributions bring great satisfaction to donors AND to the recipients (or their families).
They also help greatly in our ongoing fight against all autoimmune diseases.

American Autoimmune Related Diseases Association
22100 Gratiot Avenue, Eastpointe, MI 48021-2227
Phone: (586) 776-3900 • Web site: www.aarda.org

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 variety 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.
LET'S STAY IN TOUCH... AUTOIMMUNE DISEASES ASSOCIATION, American Autoimmune Related Diseases Association, Inc. needs your help in continuing its vital work. Join us and receive our quarterly newsletter InFocus to keep informed of our patient and physician education programs, research advancements, and excellent autoimmune disease-specific information. You can join online at www.aarda.org by using your credit card on our secure Web site... calling the AARDA office at 586-776-3900... or completing this form.

Please print

Name: ____________________________________________
Address: ____________________________________________
City: __________________ State: __________________ Zip: ________________
Phone: __________ E-mail: _____________________________

YES, I/we would like to join AARDA in its vital work and receive its quarterly newsletter - InFocus. Enclosed is the $34 membership/subscription donation. (international, $44 USD)*

YES, I/we would like to help further the fight against autoimmune diseases. Enclosed is an extra donation of $25; $50; $100; $300; Other $__________

YES, I/we would like to join AARDA's Honorary Leadership Circle to receive InFocus plus periodic research updates and an annual report. Enclosed is $500.

AARDA is a fully accredited IRS 501(c)(3) tax exempt organization.

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

MAIL TO: Address on reverse side
(Please be assured that AARDA does not sell, rent, or exchange its mailing list.)
Inside this issue

AARDA continues salute to #Autoimmune Heroes ........................................................... 1
President/Executive Director’s message ................. 2
Day of Celebration: Annual Derby Luncheon .... 4
Welcome to newest SAB member (Dr. Caturegli) ................................................... 5
You’re stressed? So what’s happening? ............... 5
AARDA’s tiny acorn promises great results ....... 5
Non-Medical Switching: Insurers Playing Doctors ....................................................... 6
Grassroots fundraisers keep growing .......... 6
AARDA shoes making tracks again! .............. 7
Is HPV vaccine safe for autoimmune patients? ... 7
Rare disorder (APECED) may prevent type 1 diabetes ...................................................... 8
Researchers study effect of antibiotics in diabetes............................................................. 8
Are we too bacteria phobic?......................... 9
Virginia Ladd receives Research and Hope Award ......................................................... 9
AARDA says “thank you” to .................................. 10
With special thoughts... Tributes and Memorials ................................................ 10
AARDA Scientific Advisory Board ................ 11

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