



What else is special about December? AARDA Annual Appeal time, of course!

May we invite you? Through this Annual Appeal, you are invited to give your support to the **50 Million** who are affected by autoimmune diseases. AARDA doesn't flood your mailbox with Annual Appeal messages (one letter plus this article; that's all), and you don't receive telephone solicitations. **You decide what AARDA and the autoimmune cause mean to you.** They you choose your level of giving--no reminders, okay? **Large or small, your contribution will be received with gratitude.**

How is your money used? See "An overview of AARDA Major accomplishments for the past year" in this newsletter. Much of it may be familiar to you since some projects are ongoing.

What is one aspect of particular importance? While all areas of the autoimmune picture are important--education, advocacy, awareness, research--perhaps most threatened by cutbacks nationwide is the area of research. Read comments from Betty Diamond, M.D., Chair, AARDA Scientific Advisory Board.

Why join the fight against autoimmune disease? Read "A message from Kellie Martin..."--and then shine your own light!

How do you contribute? You may access AARDA's Web site (www.aarda.org) to donate on our secure page, call the AARDA office (586-776-3900) to donate via credit card (Visa, MasterCard, or American Express), or mail your donation (check or credit card information) to the AARDA office. Be sure to indicate "Annual Appeal."

While this is the season for giving, it's also the season for celebrating. For all of us in AARDA, we celebrate the gains that have been made in autoimmune diagnoses and treatments, the friends that we have gathered along the way, and the light emanating from research laboratories around the world.

For the **50 Million** whom we serve, we THANK YOU for your generosity and friendship--past, present, and future. ■

A message from Kellie Martin...

In the world of make believe, i.e., movies and television, I have been a little sister, a country school teacher, a detective, and a medical intern, among many roles. Nothing, however, compares in importance with the volunteer role I have held with AARDA for the past 16 years as its National Spokesperson.

Why does one become a spokesperson for a nonprofit organization?

For me, it was a major way to bring some good out of tragedy. At the age of 19, my beautiful older sister Heather passed away from lupus that had remained undiagnosed despite our attempts to find a physician who could understand the meaning of her many symptoms. Finally, too late, we found that physician.

AARDA is the traditional "beacon of hope" for the 50 million Americans suffering from autoimmune diseases. As National Spokesperson, I am determined to shine that beacon on Congress, advocating for research dollars for the National Institutes of Health. I carry the beacon when I speak at physician symposia, take part in media interviews, make public appearances on behalf of AARDA, advocate for a variety of research efforts, and sponsor my own AARDA fund raisers. For Heather, for all undiagnosed--and diagnosed--autoimmune disease patients, for my own little Margaret "Maggie" Heather who has been born into a family with autoimmune diseases, I will continue to speak out.

Do you know someone with an autoimmune disease? Do YOU have an autoimmune disease? I invite you to join me in the fight against this category of disease that appears as 100+ known autoimmune diseases. Together, through our financial contributions and our individual awareness efforts, we can promote collaborative research to find improved treatments and a cure for all autoimmune diseases.

If you already are a beacon of hope, thank you. If not, please shine your light in this fight against autoimmune disease. Every glimmer brightens a life somewhere. THANK YOU.

Kellie Martin

AARDA National Spokesperson and Dedicated Volunteer



A commentary from AARDA Scientific Advisory Board Chair Betty Diamond, M.D.

Each year, our understanding of autoimmune disease grows and new therapeutics are introduced. In the meantime, AARDA continues to be at the forefront of promising new insights into autoimmunity. For example, in 2014, AARDA cosponsored a workshop on the topic of the microbiome. There are exciting data suggesting that the predilection for autoimmune disease in women may result from gender-specific differences in gut

microbiome and intestinal immune activation. The role of specific gut bacteria in potentiating numerous autoimmune diseases offers exciting therapeutic opportunities.

This year, 2015, AARDA sponsored two important scientific meetings. The first addressed the role of eosinophils in



Article continued on page 10

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American Autoimmune Related Diseases Association, Inc.
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22100 Gratiot Avenue, East Detroit, MI 48021-2227
Phone 586-776-3900; Fax 586-776-3903;
E-mail: aarda@aarda.org; Web: www.aarda.org

~ Editor ~

Eula M. Hoover, Executive Assistant

~ Editorial Reviewers ~

Virginia T. Ladd, AARDA President/Executive Director

Patricia C. Barber, Assistant Director

~ Contributors ~

Deb Patrick, Special Events/Walk Coordinator

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~ Distribution Coordinator ~

Cathleen Cruchon, Accounting/Database

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



Do you remember when we were young children and the countdown to December and its joys took forever? Well, surprise! January to December 2015

passed in a flash--and here we are.

No regrets; it's been a great year for AARDA. We have many friends to thank for the gains that we have seen. Very likely, you, in your own way, are part of those gains. See "Overview of Major Accomplishments" for details.

Yes, no cure for autoimmune diseases has emerged; but certainly we have welcomed the introduction of new therapeutics and improved understanding in the health care community of the needs, physical and emotional, of autoimmune patients. "Autoimmune disease" has become a familiar term--almost unacknowledged when AARDA was established in December 1991. Through education and awareness, family members and friends who touch the lives of autoimmune patients have learned support techniques not only for the patients but also for themselves as loved ones. Through public awareness, life-saving knowledge has been brought to formerly unaware individuals touched by autoimmune disease.

The beginning was exciting--climbing breath-challenging stairs to a donated one-room office, collecting canister donations at K-Mart, typing education brochures on vintage computers, recruiting dedicated

Board members and volunteers, convincing world-renowned researchers that AARDA was a respected organization worthy of their support, and bravely announcing AARDA's existence to health care professionals across the country.

Here we are--on the doorstep to 25 years! With the help of many, many supporters--individual, corporate, foundational--AARDA is known locally, nationally, and internationally. We are still thanking friends who have made and are making this possible. What do the Girl Scouts sing? "Make new friends but keep the old; one is silver but the other is gold." Whether you, our friends, are silver or gold, AARDA couldn't exist without you!

Leaving 2015, we are making our AARDA Annual Appeal, as you noted on the front page. Last year, we realized gifts totaling \$54,200. Can we top that? If every individual reading this newsletter makes a contribution--large or small--we'll do it. The 50 Million are depending on us. The "to do" list is waiting. Already some Annual Appeal donations are arriving. You have time to join the giving if you haven't already contributed. We're eager (and hopeful) to see the total for 2015. We'll let you know in a future newsletter.

With thankfulness, from all of us here at AARDA, I send you greetings for a blessed, glorious December. And may blessings follow you throughout the New Year.

With appreciation,
Virginia



Will you be invited?



The invitation list is being gathered for AARDA's Annual Fund Raiser, the Derby Luncheon and Auction, scheduled for Saturday, May 7, 2016, at MacRay Harbor, in Harrison Township, Michigan. Dr. Partha Nandi, Chief Health Editor, WXYZ-TV, and host of the Emmy Award-winning medical lifestyle show "Ask Dr. Nandi" returns as emcee. Once more popular AARDA volunteers and Honorary Chairs Chuck (WDIV-TV) and Susan Gaidica will lend their support.

If you think that you may not be on the invitation list, contact AARDA Special Events Coordinator Deb Patrick (dpatrik@aarda.org; or 586-776-3900). ■

What happened in FY 2015?

We present an "Overview of Major Accomplishments"

Research

- Continued research support for the following:
 - O'Leary-Wilson Autoimmune Disease Fellowship, basic autoimmune research, Johns Hopkins University, Baltimore, MD
 - Autoimmune liver research, Johns Hopkins University, Baltimore, MD
 - Role of the innate immune system in lupus, The Feinstein Institute for Medical Research, Manhasset, NY
 - Pilot study, Autoimmune Diagnostic and Triage Center, MidMichigan Physicians Group, University of Michigan, Midland, MI
- Provided grant to research associate, Johns Hopkins University
- Provided grant to medical student (SLE research) in the Feinstein Institute for Medical Research
- Provided grant for "Young Investigator," Massachusetts General Hospital, Boston, MA
- Sponsored five Johns Hopkins University students in the summer Diversity Student Internship Program
- Introduced campaign to fund a National Autoimmune Diagnostic and Triage Center
- Contributed to date \$4,762,310 to research

Education (Patient, Public, Scientific)

- Sponsored, cosponsored, or supported the following:
 - Scientific round table, "Eosinophils, Type II Immunity and Autoimmune Disease," Washington, DC
 - Scientific colloquium, "Neuropsychiatric Manifestations of Autoimmune Disease," Washington, DC
 - "Pregnancy and Lactation in Women with Autoimmune Disease: Sharing Knowledge Across Disciplines," San Diego, CA
 - "The State of Autoimmune Disease: A National Summit," Washington, DC
 - 17th Annual Autoimmunity Day, Center for Autoimmune Disease Research, Johns Hopkins University
 - AARDA public forums, "What Every American Needs to Know About Autoimmune Disease," Tampa, FL; West Bloomfield, MI

- "How to Dance in the Rain," Conference for the Autoimmune Community, Scleroderma Foundation Michigan Chapter and others, Grand Rapids, MI
- American College of Rheumatology Annual Meeting (AARDA staffed display booth), San Francisco, CA
- Continued to distribute Autoimmunity Curriculum for Elementary and Middle School Teachers, at no charge to teachers
- Completed research study, "Autoimmune Disease and Fatigue: Patients Speak"
- Provided representation at Congressional Briefing on "Inflammatory Eye Diseases, Focus on Uveitis," sponsored by National Alliance for Eye and Vision Research
- Continued as a source of autoimmune disease information on WebMD
- Continued to offer "My Autoimmune Story" video on AARDA YouTube channel
- Maintained social networking sites (Facebook page, 88,582 "likes," Twitter account, 2,497 followers)
- Published quarterly lay-friendly newsletter *InFocus*
- Made available informational brochure and PowerPoint presentation of AARDA's "Risk/Benefit" study
- Maintained 24-hour toll-free request line
- Provided referrals and non-medical information during office hours via the Patient Educator
- Provided free educational brochures and newsletters to numerous health-centered meetings and events (CA, VA, MI, NY, GA, DC, IL, AZ, NC, IN, AR, NJ)
- Maintained Local Contact list with support groups as available

Advocacy and Awareness

- Continued facilitation of the 38-member National Coalition of Autoimmune Patient Groups (NCAPG)
- Provided representative at United Nations World Health Organization meeting on biologic and biosimilar drugs, Geneva, Switzerland
- Provided representative to Advocacy Day sponsored by the Partnership to Fight Chronic Disease
- Cosponsored with the NCAPG a news

briefing ("The State of Autoimmune Disease") at the National Press Club, Washington, DC

- Continued development and information gathering for a first-of-its-kind National Autoimmune Disease Registry
- Cosponsored Capitol Hill Congressional Briefing ("Step Therapy and Related Patient Concerns"), Washington, DC
- Compiled data collected from a Web-based survey on how the Affordable Care Act is affecting autoimmune disease patients
- Provided interviews and information for news media; had major advertisements in national publications

Fundraising

- Continued to encourage and provide support for "grassroots fundraising," including the online Grassroots Newsletter
- Expanded the Autoimmune Disease Awareness Walks schedule and provided support for Virtual Walks
- Sponsored the AARDA Annual Fund Raiser in the Greater Detroit area (\$59,817 profit)

Administration

- Maintained the following ratings:
 - Better Business Bureau Wise Giving Alliance Charity
 - Best in America Certified by Independent Charities of America
 - Charity Navigator Three Star Charity
- Maintained membership and active participation in the International Alliance of Patients' Organizations (IAPO)
- Continued to meet all Standards of the National Health Council and maintain long-time membership
- Continued standing in the Combined Federal Campaign (CFC)
- Remained recognized Member Organization of Health & Medical Research Charities of America
- Held combined management and fundraising costs at 7 percent of total expenses (compared with 25 percent acceptable for nonprofit organizations) ■

AARDA continues sponsorship of JHU diversity interns

Once more AARDA research monies helped to provide scholarships for undergraduate students in the Diversity Summer Internship Program of the Johns Hopkins University Bloomberg School of Public Health. This year marks the 20th anniversary of this program which provides grants to students interested in careers in science and public health. This includes students from underrepresented minority groups and economically disadvantaged backgrounds. The students work under the direct mentoring of established Johns Hopkins researchers.

Through the suggestion of Noel R. Rose, M.D., Ph.D., Chairman Emeritus of AARDA's Scientific Advisory Board and former Director, Johns Hopkins University Center for Autoimmune Disease Research, five students received AARDA grants enabling them to participate in JHU's Diversity Summer Internship Program 2015.

◆ **Mankaah Acho** - Mankaah, of the University of Maryland College Park, studied "Effects of Interleukin-22 on Cardiac Fibroblasts." Cardiac fibroblasts are one of the resident cells found in the heart. Mankaah's study shows that interleukin-22 and interleukin-17 (IL-17A) results suggest that IL-22 may play an important role in preventing fibrosis in dilated cardiomyopathy (DCMi).

◆ **Felix Contreras-Castro** - Felix, an undergraduate at Amherst college, proceeded with the fact that membranous nephropathy (MN) is an important cause of nephrotic syndrome in adults. While idiopathic MN is a disease limited to the kidney, secondary MN may be secondary to a wide variety of underlying conditions. His study was titled "Evaluation of anti-Phospholipase A2 Receptor (PLA2R) Enzyme Immunoassay in Individuals with Idiopathic Membranous Nephropathy (IMN)."

◆ **Alejandra Garcia** - Alejandra, from the University of Maryland Baltimore County, was interested in a possible cause of the rapid increase in obesity which has pushed up levels of diabetes as well. The glucose homeostasis factor, added to the effect that *Helicobacter* species had on glucose homeostasis factor in Syndecan-1 deficient



Young researchers, JHU Diversity Summer Internship Program 2015
L to r: Alejandra Garcia, Chelsee Sauni, Mankaah Acho, Brandon Mallory, Felix Contreras-Castro

mice, was studied. Alejandra's study results are described in her paper "Glucose Homeostasis Depends on Microenvironment and Syndecan-1 Deficiency."

◆ **Brandon Mallory** - Brandon, a student at the University of Texas at Dallas, chose to study "Genetic Mechanisms of Drug-Induced Hepatotoxicity." He states, "Drug-induced hepatotoxicity can be induced by many widely used medications, and is a leading cause of liver failure." Brandon suggests that the results of his study "may lead to more discussion on how to best prevent occurrences of drug-induced liver injury..."

◆ **Chelsee Sauni** - Chelsee, from Coppin State College, Baltimore, Maryland, shared an interest in obesity with fellow intern Alejandra Garcia. Chelsee points out that since behavioral intervention has been unsuccessful in combating obesity and type II diabetes, alternative modes of regulation need to be found. Her study addressed "The Role of Syndecan-1 Expression in Glucose Metabolism."

It is hoped that by introducing these young medical students to AARDA and supporting them in their research projects, we have set into motion their future involvement in autoimmune disease research. Past and present researchers have been and are vital to improved outcomes for autoimmune diagnostic and treatment efforts, and we are grateful that many current researchers are mentoring the "new crop." We in AARDA are pleased to be able to provide tangible support, thanks to generous contributions from loyal individual, foundation, and corporate friends. ■

Childhood cancer survivors need long-term consideration

What are the long-term quality of life and health challenges faced by childhood cancer survivors? What is the connection to autoimmune disorders? As recently reported in *Annals of the Rheumatic Diseases*, researchers in Denmark sought answers to these questions.

Analyzing data collected from more than 20,000 adults in Denmark, Iceland, and Sweden who had been diagnosed with cancer before the age of 20 and survived for at least one year, investigators compared them to nearly 126,000 adults who had not experienced childhood cancer. Over an average follow-up of 15 to 19 years, it was found that 3.6 percent of childhood cancer survivors had been treated in a hospital at least once for an autoimmune disease. According to Dr. Ann Sallfors Holmqvist, of pediatric oncology and

hematology, at Skane University Hospital in Lund, Sweden, and colleagues, this rate is 40 percent higher than among adults who had not had childhood cancer.

The findings showed that diabetes and Addison's disease, a condition in which the adrenal gland doesn't work properly, accounted for nearly half of the excess cases of autoimmune diseases among childhood cancer survivors. Autoimmune diseases involving the thyroid gland also were more prevalent in this group. However, the greatest risk of developing an autoimmune disorder was seen among adult survivors of childhood leukemia, Hodgkin's lymphoma, kidney cancer, and central nervous system disorders--a risk up to 60 percent higher than those who had not had childhood cancer.

The increased risk for autoimmune

disorders peaked during the first five years after cancer diagnosis although the risk persisted for up to 30 years for most conditions and up to 50 years for some conditions.

Is the increased risk of autoimmune disorders the result of cancer? Or is it the altering of the immune system through chemotherapy and radiation treatments? The association seen in the study does not prove a cause-and-effect relationship; and as the researchers pointed out in their report, "Cure is no longer a sufficient goal in childhood cancer care." Attention must be paid to the future health challenges faced by these survivors. ■

--Source: "Childhood Cancer Tied to Raised Risk for Other Ills in Adult Life," Robert Preidt, *HealthDay*, via *Medline Plus*, November 2015

Let's consider good bacteria, friends of immunity

Most people know that their digestive tracts are home to what are commonly referred to as “the friendly bacteria.” The actual number is over 100,000,000,000,000 (100 trillion) bacteria and other symbiotic microbes. Counting the gut, the bacteria in anatomical cavities, such as our sinuses, and then the large numbers on our skin, these microbes outnumber human cells by a factor of 10 to 1!

Even more striking is that the microbial genes of this “human microbiome” (as renamed by the National Institutes of Health), outnumber human genes by a factor of 100 to 1. Since all life is carried out by genetic information, this amazing statistic begs the question, Are we more bacterial than human?

The biomass of bacteria and other microbial species actually outweighs the human liver. As previously unsuspected functions of the human microbiome are being discovered, scientists are now speaking of it as the “forgotten organ” within the body. Some examples--just the tip of the iceberg--of important microbiome functions in regulating and maintaining human health include control of unwanted pathogens in the gut, regulation of immune function, synthesis of vitamin K and biotin, enhanced mineral bioavailability, synthesis of many neurotransmitters, and detoxification and inflammation regulation.

The probiotics, i.e., friendly bacteria, have become household names as we learn about supplementing diets and overcoming the negative effects of antibiotics with capsules, pills, liquids, and a variety of yogurts. The first yogurts and kefir probably occurred in milk-filled goat stomach bags draped over the backs of camels in the hot deserts of North Africa. Temperatures reaching 110°F were ideal for lactic acid-producing bacteria found in the stomach linings to go to work. Since this early period in human history, many races have fermented dairy to improve “shelf life” and enjoy the many diverse tastes.

In the early 1900s, Nobel laureate Elie Metchnikoff, a Russian zoologist, reported on the enhanced health effects and improved longevity of those consuming fermented milk products. Because these bacteria were found to be “for us” instead of “against us,” the terminology of “probiotic” was introduced by Lilly and Stillwell in 1965.

Probiotics promote healthy bacteria in the gut as opposed to antibiotics, pharmaceutical agents that generally kill both pathogenic and friendly bacteria. Typical symptoms that may be improved by the regular consumption of probiotics include vaginitis, diarrhea, indigestion, flatulence, “brain fog,” lactose intolerance, and bloating.

Probiotics also promise better immune function--but how can bacteria in the gut help our immunity? Enter the Mighty Macrophage.

The defensive linebacker of the cellular immune system is the macrophage. These “Pacman” cells not only gobble up invading viruses and bacteria but also generally direct the other elements and various cell types in a synchronized immune defense.

There are two branches of the immune system in which the macrophage functions: the innate (non-specific immune defense) and the adaptive (specific immune defense mechanisms). Macrophages are themselves signal-directed. The signal that activates macrophages, and subsequently the whole immune response, is a glycoprotein, a molecule made up of a sugar and a protein, called “Gc protein-derived Macrophage Activating Factor.” The abbreviation for this long name is GcMAF. The important precursor to GcMAF is “Gc,” a big protein with 458 amino acids containing three domains.

The first domain of Gc binds vitamin D. For this reason, Gc sometimes is called “vitamin D binding protein” although vitamin D is not required for activation of Gc. There is a small sugar attached on the threonine amino acid at position 420 of Gc, i.e., 420 is “glycosylated.” When injury, inflammation, or any immune challenge is detected in the body, the sugar at position 420 is deglycosylated by enzymes produced by B- and T-lymphocytes. The result is the conversion of Gc into GcMAF, one of the most powerful activators of the entire immune system discovered to date.

Interestingly, the same enzymes used by the immune system to transform Gc into GcMAF appear to occur during fermentation of milk. Perhaps Metchnikoff’s observation of “favorable health effects” in those consuming fermented milk products was, in actuality, the first documentation of enhanced GcMAF formation in the body from a natural food source.

With modern research demonstrating the remarkably diverse ways that the human biome influences overall human health, from chronic mood disorders, psychiatric illness, heart disease, diabetes, obesity, and the whole gamut of modern degenerative and inflammatory illness, suddenly these complex illnesses become viable targets for a breakthrough in a food technology that would revolutionize sickness care around the world.

It is important to remember that beneficial bacteria do not always stay in our gut. We need to replenish them often, perhaps by utilizing probiotic supplements or by eating fermented and cultured foods on a regular basis. This may allow us to maintain a well-balanced gastrointestinal ecosystem. Current research suggests that these microbes are only “transient residents” within our intestines and may stay in our body for up to 12 days.

A famous naturopath truism states: “Death begins in the gut.” As the digestive system goes, so goes the patient’s health. And digestive health is highly influenced by the health of the living organisms that occupy it. So, take good care of your gut bacteria. Science is showing that they’re as much as you are. ■

--Source: Excerpted from “All About Fermented Foods,” Ola Buhr, M.D., and “The Super Probiotic,” Ron Humminghake, M.D., Chief Medical Officer, Riordan Clinic, Wichita, Kansas, *Health Hunters Newsletter*, September 2015

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, East Detroit, 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 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.

Holidays: stressful? manageable? enjoyable?

In the following message, we share advice gleaned from articles written in past issues by the late Audrey Kron, M.A., CGP, medical psychotherapist, licensed marriage counselor, author, and columnist ("Ask Audrey"); and of Robert H. Phillips, Ph.D., practicing psychologist, founder and director of the Long Island, NY, Center for Coping, author, speaker, and member of AARDA's Scientific Advisory Board.

Holidays frequently can be the proverbial "mixed blessing" for anyone; but for individuals with chronic illness, they can cause more than the usual concerns. In "Holidays--Meeting the Challenge," Audrey Kron, herself a chronic illness patient, writes: "Realize that things don't have to be perfect. Everything doesn't have to resemble *Better Homes and Gardens*."

Audrey comments that a person who isn't feeling well may worry that the illness could ruin the holidays for family and friends. She says, "Often we lose sight of the fact that the most important aspect of the holidays is celebrating with loved ones." Sometimes friends, or even chance acquaintances, are the "loved ones" who share the day.

Audrey advises using (or maybe learning, of necessity) time management techniques, such as prioritizing, delegating, and, most importantly, saying "no" when necessary. For some reason, the worse (or more depressed) we feel, the more likely we are to refuse help or not ask for it. Stop! Let friends or family members feel the joy of giving of themselves.

What about food that plays such an important part of the holidays? Simplify meal preparation. Order in, use frozen food, welcome dishes offered by others. Are there one or two foods that are must-haves on your traditional menu? Who among your family or friends would be pleased to show off their talents? Remember--it's not what you eat that is important; it's celebrating together.

"Pinpoint your stress" and "divide and conquer" are two suggestions of Dr. Robert H. Phillips. He suggests determining exactly what is stressful for you. Is it specifically related to the holidays (buying gifts, attending dreaded family get-togethers, etc.)? Or is it more that the stress of living with autoimmune disease just seems to be exacerbated by the joy that others seem to be experiencing during holiday time?

When you have pinpointed the specific things that are bothering you, divide the items into two categories--things you can do something about, and things you can't. In the "can do" category, jot down specific steps to do or change. Dr. Phillips advises making your steps as small as possible since being able to check them off as you accomplish them can be a terrific motivator to continue efforts. Maybe you'll want to discuss this with some successful "action-oriented" people in your life.

What about the "can't do" things? Which ones are truly important? Audrey Kron advises, "Make sure that your expectations are realistic. Remember that everything is 'time limited.'" She adds, "Modify plans to suit your requirements." If you can make changes or ask for help, make it a "can do." If not, feel the power of crossing things off your list



and charging ahead with what's possible and joyful.

What if you are invited to someone else's home? Not feeling well can add special anxiety for one who wants to avoid creating problems as a guest. Audrey advises that you communicate ahead of time. Let your hostess and host know if you are on a special diet, but focus more on what you can eat than what you can't. Let them know if you have special requirements, such as time for adequate rest. Audrey says, "The most important items to pack are a sense of humor and a pleasant disposition..." She suggests that you "go expecting to enjoy yourself."

But what if you are going to be on your own? As Dr. Phillips suggests, "Schedule time for things you enjoy. This is not a luxury; it's a necessity." Find someone whose situation is worse than yours. Make a phone call to a shut-in (it will make you feel better as well). Do not leave having company to chance. Make plans to be with someone--either in person or via telephone or perhaps Skype. Take control; you decide how you want to celebrate.

Both Audrey Kron and Dr. Phillips caution that if you're still having trouble dealing with stress on your own, consider seeking the help of a mental health professional. Audrey advises that, if possible, you try to find someone who has some understanding of the special needs of the physically ill patient.

Dr. Phillips says, "Believe it or not, there are as many people who are stressed out by the holidays as there are who enjoy them!" But he advises, "Holiday time need not be unpleasant. Given the stress in our world and the stress of living with autoimmune disease, it makes sense to do what you can to enjoy this time of year as much as possible."

Start that "can do" list. Make this your own happy, healthy, joy-filled holiday. ■

Quote to ponder, enjoy, and (perhaps) consider for harmonious family holiday gatherings...

There is a rule in sailing where the more maneuverable ship should give way to the less maneuverable craft. I think this is sometimes a good rule to follow in human relations as well.

--Dr. Joyce Brothers

Board honors outgoing members

At its September meeting, the AARDA Board of Directors honored two outgoing members. Both Julia Pandl and Dr. Robert Phillips had completed two 3-year terms on the AARDA Board, making them ineligible to serve succeeding terms at this time.



Julia Pandl, humorist and writer, is a resident of Bayside, Wisconsin. She has contributed her dedication to Board responsibilities with a spirit of openness and honesty, a willingness to lead, a commitment to fund raising, and a sense of humor. She has served on several Board committees. In addition, her Milwaukee-area fund raisers are noted for creativity and generous contributions to AARDA. Julia's book, *Memoirs of a Sunday Brunch*, her personal account of growing up in a large family with a restaurant tradition, is both funny and poignant. She is excited about continuing with the writing of another book.



Dr. Robert Phillips, of Long Island, New York, not only has served AARDA as a member of the Board of Directors but also is a charter member of AARDA's Scientific Advisory Board, a position in which he will continue to serve. Dr. Phillips, a licensed psychologist, is founder and director of the Center for Coping, in Hicksville (Long Island), New York. A prolific writer, he has authored more than 30 books and many articles on coping with physical ailments and other psychological topics. Dr. Phillips

has given generously of his time to AARDA, not only as a Board member and advisor but also as a speaker at autoimmune public forums and additional venues. He sees his role in AARDA as focusing on the liaison between medical, research, and organizational components of AARDA's activities and the consumer advocacy and coping needs--among others.

On behalf of all of us at AARDA, we say "thank you"--but not "farewell"--to Julia Pandl and Dr. Robert Phillips. ■

Linked together for a cure--AARDA walkers keep going!

◆ **Inaugural Los Angeles Walk** - The Inaugural Los Angeles Autoimmune Walk drew 300 walkers, 40 volunteers, and four bands to Culver City Park on Sunday, November 8. Walk Ambassador actress Haley Ramm (*Chasing Life*, ABC Family), her family, and many of their celebrated friends put on an amazing event that featured a Red Carpet and celebrity walkers; a silent auction; music by Tall Bones, Dee Dee and the Beagles, Richard Brancatisano, and Zack Zotos; and fun activities for children. The event raised more than \$87,700 for autoimmune awareness and research. Special thanks to our Presenting Sponsor, the Relapsing Polychondritis Awareness and Support Foundation, and to our Gold Sponsor David Zehnpfennig. Kudos to the Top Teams (Relapsing Polychondritis (RP), Team Rammians, Blue Angels, Melanie Shawn, and Dunder Mifflin Squad) and to the Top Individual



LA Walk Ambassador Haley Ramm (center) chats with fans on Walk Day

fundraisers (Nancy Linn, Haley Ramm, Patrice Reiss, Bleau Faz, and Shawna Wesley-Roza. A great big hug and many blessings to Barbara Ramm for all her help.



Savannah Morris (right) leading Louisa County Walk

◆ **Louisa Walk to Remember** - Savannah Morris, a student at the Louisa County High School in Virginia, turned her senior project into a grassroots "Walk to Remember" on Sunday, October 18. Savannah read an article about fellow Virginian Leigh-Anne Sheppard, an AARDA volunteer contending with autoimmune disease. Inspired by Leigh-Anne's story, Savannah contacted her and decided to organize a Walk to raise awareness in her community. With support from AARDA, Savannah gathered students, local business owners--even the high school band--to participate; and The Central Virginian to publish a story. The event drew more than 50 people and raised \$902.

◆ **4th Annual Tri-State Walk** - This year's Tri-State Walk saw more than 100 supporters at Hudson River Parks's Clinton Cove, in Manhattan, New York, on Sunday, September 20. Thanks to the incredible commitment and energy of the Walk Teams and our sponsors, the original goal of \$10,000 was exceeded by more than 200 percent, bringing the total raised to \$35,636. Special thanks go to the Top Teams--Taylor Tough, PBCers, Relapsing Polychondritis Awareness Team, Team Zebra, and United We Fight--and to the Top Individual fund raisers: Marty Pietanza, Althea Cices, DanaWyn Sherman, Elizabeth Ortiz, and Renee Marrero. We also deeply appreciate the generosity of our sponsors, CVS Health and Intercept Pharmaceuticals.

Cheers and thanks go to planners, participants, and everyone else who are making these tremendous contributions on behalf of the 50 Million people affected by autoimmune diseases. What terrific efforts!

Are there any other Linking Together for a Cure possibilities out there? You may contact Deb Patrick, AARDA Special Events/Walks Coordinator (dpatrick@aarda.org; or 586-776-3900).

**Autoimmune
Walk**
LINKING TOGETHER FOR A CURE



Team TaylorTough's Taylor Brown (r) and Gina Brown-Pietanza



Shingles virus poses threat for autoimmune disease patients

Preliminary results of a study exploring the connection between the shingles virus (herpes zoster) and autoimmune diseases have been reported by researchers from the Cleveland Clinic, in Ohio. According to Leonard H. Calabrese, D.O., and colleagues, patients with an autoimmune disease, such as rheumatoid arthritis, have a significantly elevated risk for having a stroke within a month of developing herpes zoster. They reported that the risk remained high throughout the first year after the shingles episode.

What is the incidence of shingles among autoimmune disease patients? While little is known about the risk for both zoster and stroke among patients with autoimmune

diseases, Dr. Calabrese and colleagues commented, "Among patients with immune-mediated diseases on certain biologics and immunomodulators, the rates [for herpes zoster] are extremely high in general." He said, "In general, we believe that patients in rheumatology practices have a 50 percent to 100 percent increased rate of herpes zoster."

What part might early diagnosis and treatment play in the prognosis for shingles patients? The researchers conducted a sensitivity analysis to see whether prompt diagnosis and treatment might mitigate the incidence of stroke. As compared with patients who had no antiviral therapy, patients having antivirals administered within seven days of diagnosis had a 16

percent lower risk of stroke.

Dr. Calabrese urged physicians to advocate for zoster vaccination. He said, "Our data also suggest that prompt antiviral therapy may actually reduce the rate of stroke following zoster, and thus prompt diagnosis and treatment are needed more than ever." He added, "These data are important as we now live in an era of increasing concern over herpes zoster." ■

--Source: "Stroke Spike Seen in Autoimmune Disorders After Shingles Attacks..." Nancy Walsh, *MedPage Today*, from abstract presented at the American College of Rheumatology conference, November 2015

Will newborn probiotic use lower the risk of type 1 diabetes?

The use of probiotics--good bacteria--is advocated by many health professionals and others. Now interesting study results have emerged on the introduction of probiotics to infants with a family history of type 1 diabetes.

Lead researcher Ulla Uusitalo, Ph.D., associate professor in the department of pediatric epidemiology, University of South Florida in Tampa, said, "Early probiotic exposure during the first 27 days is associated with a decreased risk of type 1 diabetes among those who have the highest genetic risk of type 1 diabetes." She said that while the researchers can't make a conclusion about causality, the association is so strong that these findings warrant further study.

The researchers found that probiotic use in the first 27 days is linked to reduced odds of type 1 diabetes by 60 percent for children with the highest risk of developing the disease--children with the genotype called DR3/4. Children without that genetic makeup didn't benefit from the early probiotics; and no one seemed to benefit from later probiotic use, according to the researchers.

George Weinstock, Ph.D., from the Jackson Laboratory for Genomic Medicine, in Farmington, Connecticut, said, "It was striking that the benefit was only seen when probiotics were administered in the first 27 days of life." He suggested that perhaps there is a window early in life when external microbes are entering the body and colonizing. During this period, it may be possible to intervene or direct the assembly of the microbiome with probiotics.

Dr. Weinstock observed, "It is also possible that autoimmune

effects begin during this early window and that is a critical period to interfere with the deleterious activation of the immune response."

Type 1 diabetes, an autoimmune disease, develops when the body's immune system mistakenly destroys the insulin-producing cells in the pancreas. This leaves people without enough insulin, a hormone that helps cells use sugar from foods as fuel, to meet the body's needs. What triggers type 1 diabetes? This is unclear. While a number of genes are suspect, experts believe that an environmental trigger also plays a role. The researchers suggest that a possible trigger is an imbalance in the bacteria in the gut, the microbiome, that may help fuel the autoimmune attack.

Researchers looked at an ongoing prospective study from six medical centers, three in the United States and three in Europe. The final study samples included nearly 7,500 children between 4 and 10 years old.

Should parents with a family history of type 1 diabetes start giving their babies probiotics? Dr. Uusitalo said that, while it is too early in the research to give any recommendations, parents whose baby is at higher risk might want to ask the baby's doctor about supplementing with probiotics early in the baby's life. She commented, "There are no reports that among healthy children there would be any adverse outcomes from probiotics." ■

--Source: "Newborn Probiotic Use Tied to Lower Risk of Type 1 Diabetes," *HealthDay News*, November 11, 2015

A major culprit of autoimmune disease discovered

Researchers at the University of Texas Southwestern Medical Center have announced that their recent findings building on two of their studies could lead someday to new therapies for autoimmune diseases. They discovered that activating an enzyme which sounds an alarm for the body's innate immune system causes two lethal autoimmune disease in mice, but inhibiting the same enzyme--known as cGAS--rescues them from the diseases.

Senior author Dr. Zhijian "James" Chen says, "These results suggest that inhibition of the enzyme cGAS may be an effective therapy for autoimmune diseases such as Aicardi-Goutieres Syndrome (AGS) and systemic lupus erythematosus (SLE), which are linked to the same inflammatory

pathway." He says that cGAS is likely amenable to inhibition by small-molecule drugs and that the recent determination of the high-resolution structures of cGAS should facilitate development of such inhibitors.

The researchers reported that they also studied mice genetically engineered to lack a DNA-digesting enzyme called DNase-II. When the resulting inability to degrade lysosomal DNA led to lethal autoimmunity, once again cGAS inhibition rescued the mice. ■

--Source: "Researchers identify an enzyme as a major culprit of autoimmune diseases," news release, University of Texas Southwestern Medical Center, October 27, 2015

Researchers explore effects of fats in autoimmune disease

German researchers recently have announced the results of their studies concerning the relationship between dietary fat and autoimmune disease. The research team compared in mice the effects of short-chain fatty acids, typically found in fiber-rich diets and solely metabolized by bacteria, with the effects of long-chain fatty acids, the most abundant component of western diets. They found that short-chain fatty acids promoted the development and propagation of regulatory T cells that kept the immune response in check, thus ameliorating the disease in animals. On the other hand, long-chain fatty acids promoted the development and release of proinflammatory T cells from the intestinal wall to other areas in the body, such as the brain.

Team leader Ralf Linker, of Friedrich-Alexander-University Erlangen-Nuremberg, says, "Most approved immunotherapies weaken or block proinflammatory components of the immune system, but by strengthening regulatory pathways, for example by using propionate as a supplement to established drugs, therapies could be further optimized." Propionate, a salt or ester of the fatty acid propionic acid, very often is used as a mold inhibitor in bread.

The researchers plan to use their new information to develop dietary add-on therapies to established immunotherapies in multiple sclerosis. ■

--Source: "Dietary fat impacts autoimmune flare-ups in mice," *Immunity*, Cell Press, October 20, 2015

New treatment for hypertension possible?

Concerning his experience with hypertension, Australian David Higginson declares that taking all the tablets are "a little bit of an inconvenience" and "a little bit of a nuisance." Millions of hypertension sufferers worldwide would agree, but what's to be done? Perhaps a new study lends some hope.

Researchers at Monash University, in Australia, now believe that hypertension is an autoimmune disease. This discovery, they say, could open up a whole new way of treating the condition. According to Associate Professor Grant Drummond, one of the researchers, the research findings could help revolutionize treatment "for the 15 to 20 percent of people with hypertension who are resistant to conventional drug therapies."

Dr. Drummond said that researchers found that stimulating the immune system in mice could cause hypertension, while reducing this response could restore their blood pressure to normal levels. He explained

that stimuli which cause hypertension actually trigger an increase in the activation of B cells and an excessive production of antibodies. He pointed out that these antibodies appear to get lodged within the walls of arteries. This action promotes an inflammatory response in those arteries, leading to the arteries becoming scarred and stiffened--one of the hallmarks and causes of hypertension.

"If we could ultimately identify the antigen that is the protein, or whatever it is in the blood vessel wall that's switching on these B cells," suggests Dr. Drummond, "there's potential in the future that we could actually immunise or tolerise the immune system in patients so they never go on to develop hypertension at all." ■

--Source: "High blood pressure: Hypertension could be autoimmune disease, study finds," Gloria Kalache, *The World Today*, September 9, 2015

~ 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.

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Contributions in this category 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.

Board Chair Betty Diamond continued from page 1

autoimmune disease, raising awareness of a novel player in disease. The second focused on neuropsychiatric manifestations of autoimmune disease, an area of increasing concern to patients. There is more and more evidence of neuropsychiatric impairments associated with autoimmunity and an increased frequency of neuropsychiatric problems in the children of women with autoimmune disease. This meeting dealt with our current understanding of these issues and approaches that need to be explored.

New therapeutics, some offering the hope of long-term drug-free remissions, continue to make their way into the clinical, thanks to effective research. Nevertheless, while opportunities are great, resources remain limited.

Increasing funding for research is a priority. Stable funding levels threaten the work force. Indeed, funding has actually decreased over the past several years when inflation is considered. Young scientists and young physician-scientists are discouraged from embarking on careers as independent, creative investigators, raising concerns about the future cadre of creative scientists.

AARDA plays a key role in raising awareness in Congress and in the public of the need for research funding. All AARDA supporters need to do likewise to maintain the excellence of the U.S. biomedical research enterprise. AARDA's Annual Appeal offers an excellent opportunity for joining hands in this autoimmune research effort. ■

--From Dr. Diamond's commentary in AARDA's Annual Report 2014

With Special Thoughts...

Tributes

Virginia Ladd - In her honor for founding AARDA and her pioneering role in establishing autoimmunity as a specialized field for research, education and treatment of patients - Ina Cohen

Virginia Ladd - In her honor - Gwen Knapp

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Michigan	Kimberly Radomski(586) 741-9918 (<i>Clinton Township area; Peer Group</i>)
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Inside this issue

What else is special...? Annual Appeal	1
A message from Kellie Martin.....	1
Commentary from Betty Diamond, M.D.....	1
President/Executive Director's message.....	2
Will you be invited? (Derby)	2
What happened in FY 2015?	3
AARDA continues sponsorship of JHU diversity interns	4
Childhood cancer survivors need long-term consideration	4
Let's consider good bacteria, friends of immunity	5
Holidays: stressful? manageable? enjoyable?..	6
Quote to ponder	6
Board honors outgoing members	7
Linked together for a cure: AARDA walkers ..	7
Shingles virus poses threat for AD patients ..	8
Will newborn probiotic use lower the risk of type 1 diabetes?.....	8
Major culprit of AD discovered	9
New treatment for hypertension possible?....	9
Researchers explore effects of fats in AD	9
AARDA says "thank you" to.....	10
With special thoughts...Tributes and Memorials	10