INFOCUS

American
Autoimmune
Related Diseases Association, Inc.

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

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What medication? Who decides? AARDA survey seeks viewpoints

Non-medical switching, step therapy, and the doctor-patient relationship--all of these topics have been causes of concern for AARDA in working with members and other friends. A recently completed AARDA survey of 500 randomly chosen Michigan residents shows that many respondents have similar concerns; and most Michigan residents think their doctors--not their health insurance companies--should decide what medications they should take.

Virginia Ladd, AARDA President and Executive Director, says, "About a year ago, we started really getting an increase in the number of calls [about] pre-authorization--step therapy was a big one; and even where patients were just being switched [to a different medication] without even the doctor having any say in the decision.

"To me, it is a matter of principle that the doctor-patient relationship is being eroded significantly by such insurance practices. Doctors have many years of education and training in order to be licensed to practice medicine. It is a major concern when someone without such training and licensing can override a doctor's decision regarding the best treatment for his/her patient."

The first drugs of choice for many autoimmune diseases, such as the corticosteroids, are less expensive than the newer options but often don't work for the most serious cases.

Biologics, a new class of medications, have brought hope to many people with autoimmune disorders. However, they can cost tens of thousands of dollars annually, and insurers often require patients to try less expensive drugs first, a process referred to as step therapy, while ignoring the fact that biologics reduce inflammation that can lead to debilitating symptoms or damage to vital organs if their administration is delayed. For the patient who changes insurers, the delay may be greatly increased as the step process is repeated multiple times.

Dominick Pallone, Executive Director of the Michigan Association of Health Plans (MAHP), explains that the insurers "use policies such as step therapy or prior authorization as ways to help provide their members with access to high quality healthcare while trying to contain costs." He says, "MAHP appreciates the opportunity that this survey presents to have a dialogue about the true concerns of the American public--unsustainably high drug prices, and [their] impact on the affordability of health care."

However, as patients--especially autoimmune patients--know, delaying use of the most effective drug not only can result in serious damage to the patient's body but also may even increase the cost of his or her care, to both the insurer and the patient.

Virginia Ladd says, "When autoimmune disease...starts to involve the major organs or joints, that is when the new biologics, which fortunately came on line about 12 years ago, made a significant difference for those patients--even a life-saving difference.

"When you have inflammation that's prolonged or becomes chronic, it can cause scar tissue," Virginia explains. "Scar tissue in the kidneys cannot be reversed. You end up with severe kidney disease and often a transplant. In the case of multiple sclerosis, you have scar tissue affecting the nervous system. You end up back in a wheel chair, and then you become disabled."

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Gerald "Jerry" Ladd

June 9, 1939 - September 14, 2017

A dear AARDA family member, Jerry Ladd, left us this past September 14 after an extended illness. A supporter of AARDA from its very beginning, he was a hands-on volunteer and part-time staff member, termed Director of Operations but taking on many responsibilities as needed.

Jerry was a compassionate listener and counselor to many young people whose lives were enriched by his interest in them and to patients and their family members who called AARDA for both autoimmune facts and encouragement. He also shared that knowledge and understanding as a speaker at AARDA public meetings. He believed deeply in AARDA's mission. Even shortly before his passing, Jerry was making sure that certain AARDA details were covered. Those who knew Jerry well will understand!

Jerry and Virginia shared 55 years of marriage--a partnership not only of love for each other but also love and dedication to family and many philanthropic endeavors, from local to

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President/Executive Director's Message

— Virginia T. Ladd

Dear AARDA Friends,

This time of year marks an ending, a transition, a beginning, and reasons for rejoicing. If we stop long enough to take in the fullness of the season, it seems almost overwhelming in its beauty and promise. My hope for you is that you can find your own special moments.

I will share with you, my AARDA friends, that I have now experienced my own personal ending and transition. As you read in this newsletter, in September my husband Jerry succumbed to a terminal illness. While I move through this ending and the transition, I know that I share such a time with many others. I have the good fortune of loving support for this new time in my life, and I am thankful to all of you and the living mission of AARDA.

In the meantime, life in AARDA keeps moving along--26 years and counting! While "the cure" has eluded us, we know that the autoimmune star is shining brightly with improved diagnostic techniques, compassionate care, exciting research bringing new medicines, and growing knowledge of the value of integrative and complementary medical care to enhance the total health care picture.

Out of the past and into the future is the never-ending fight for research dollars. Thanks to generous donors--individuals and foundations--we have been able to continue to contribute to autoimmune research at major institutions: Johns Hopkins, National Institutes of Health, Feinstein Institute for Medical Research, University of California, Massachusetts General Hospital, and Harvard University to name a few.

In the areas of diagnosis and treatment, we have seen our modest financial grant to a pilot program at MidMichigan Health grow to a significant number of autoimmune patients coming for diagnosis and follow-up.

We also have seen the establishment of our own fund to encourage the founding of a National Diagnostic and Treatment Center. Affectionately called our "Acorn's Promise," the fund has grown with a number of personal contributions--but we still are looking for that major philanthropist who will bring the Center into reality.

Since this is the time for our Annual Appeal, the once-a-year invitation to all of our friends, I urge you to lend your support--whatever is possible for you--to the autoimmune cause. Requests for autoimmune information are increasing daily, researchers are desperate for autoimmune research grants, and we at AARDA are working to make the dollars match the demands.

Thanks to careful management and the involvement of many volunteers and in-kind services, we keep our management expenses well below the limit for nonprofit organizations--at 7.7 percent of our expenditures in 2016. The 50 Million are depending on us.

To all of you, during this glorious season of celebration, I send my best wishes for joy, good health, and many blessings in the year ahead.

With appreciation,
Virginia

we are 50 million

In memory of Rita

We mourn the loss of a dear AARDA friend, Rita Wilson. From the very beginning of AARDA, Rita gave her support to both the organization and to other autoimmune sufferers, especially through her Downriver Detroit Support Group. She was one of AARDA's earliest local contacts, offering a lending ear to autoimmune patients and others. Rita will be missed by loving family members and all of us who had the pleasure of knowing her, a beautiful, caring person.

When does ANNUAL really mean ANNUAL?

If you're a longtime AARDA member or other friend....

...you know that **Annual Appeal** truly means once each year-- no stuffed mailboxes, no phone messages, no clever "gifts" to prompt your giving. You probably will receive an "appeal" letter, plus this newsletter message. How's that for no-fuss Holiday Cheer?

On a serious note, this Annual Appeal is a very, very important lifeline to AARDA's programming throughout the year. As a nonprofit organization, AARDA exists through the generosity of the individuals, foundations, and corporations who believe in AARDA's mission.

And what is AARDA's mission? AARDA's efforts are aimed at...

- bringing a national focus to autoimmunity as a category of disease,
- alleviating the suffering and the socioeconomic impact of autoimmunity,
- initiating, fostering, and facilitating collaboration in the areas of education, public awareness, research, and patient services in an effective, ethical, and efficient manner,
- promoting collaborative research efforts in order to find improved treatments and a cure for all autoimmune diseases.

AARDA is the only national organization dedicated to addressing the problem of autoimmunity, the major cause of chronic illness.

How does AARDA use donors' contributions? See "What's been happening in 2017?" in this newsletter for an overall view of research, education, advocacy, and patient services. It's been a busy, productive year.

How do donors know that AARDA is an organization worthy of trust? AARDA has maintained the following ratings:

--*Charity Navigator Four Star Charity*

--*Better Business Bureau Wise Giving Alliance Charity*

--*Best in America Certified by Independent Charities of America*

In addition, AARDA is a GuideStar Platinum Participant, continues to meet the Standards of Excellence Certification Program for Voluntary Health Agencies of the National Health Council, continues standing in the Combined Federal Campaign (CFC), and remains a recognized Member of the Organization of Health & Medical Research Charities of America.

How does AARDA compare on a nationwide scale? Thanks to a broad network of volunteers and in-kind donors (national and international), combined management and fundraising expenses have averaged 8 percent of total expenses over past years (compared with 25 percent acceptable for nonprofit organizations).

We invite you to continue your generosity or step forward as a newcomer in support of the 50 Million Americans plus many others who are affected by autoimmune disease.

THANK YOU for caring.

Fall brings payroll deduction time for your favorite charity

CFC (Combined Federal Campaign) is the payroll deduction plan for charity that's used by all Federal workers. Every Federal employee selects from a large list his/her favorite charity. If you are (or if you know) a Federal worker, we hope that you'll choose, or ask the worker to choose, the Autoimmune Diseases Association at pledge time this fall. **Please note: Our CFC number is 10548.**

State employee campaigns are payroll deduction campaigns for charities just like the CFC campaign except that they're for state employees. We are currently in the plans of **CT**, **CA**, **FL**, **IL**, **MD**, **MI**, **MO**, NY, **PA**, **TX**, **VA**, **WA**, and **WI**. If you know any state employees in these states, please ask them to consider the Autoimmune Diseases Association.

Other workplace campaigns (including United Way) are too numerous and varying to give many specifics, but many do offer employees the opportunity to donate to specific charities through payroll deduction. Many plans even allow you to add a charity that is not in the campaign booklet.

The write-in system is a good and convenient way to donate, but it's also a good idea to be sure that your company allows write-in charities. If it doesn't, you'll be doing us a big favor by suggesting that next year the company includes us in its campaign booklet!

In any case, it's always important with write-ins to give our address along with our name. Giving our Employer Identification Number (E.I.N.) 38-3027574 would further enable your company to recognize our legitimacy.

These payroll deduction campaigns are very important to AARDA. As a far-reaching charitable organization that does a lot with a little, AARDA programs truly are helping to make a difference in the lives and futures of millions of Americans with autoimmune diseases.

Is AARDA a reputable charity? Our association still maintains the coveted Charity Navigator 4-Star Rating (its highest); is rated "Best in America" by Independent Charities of America; has received GuideStar Platinum Participant status, and is recognized as a Better Business Bureau (BBB) Accredited Charity.

Please do your part in helping to ensure the continuance of AARDA's work by donating to the Autoimmune Diseases Association --or by suggesting AARDA to any Federal government, state government, or private workplace employee whom you know.

For autoimmune disease patients everywhere--
Many thanks!

What medication continued from page 1

The release of the AARDA survey coincides with AARDA's launch of a statewide consumer education initiative and Website, called "Let MI Doctors Decide," to help patients obtain coverage for medications their doctors prescribe. The Website, which is open to the public, includes a sample appeal letter, a log for tracking treatment, and tips for dealing with doctors and health insurance companies. Also included are stories from patients and doctors about managing autoimmune disease.

Laura Simpson, AARDA Assistant Director, says, "We're explaining in simple terms what step therapy is and how to help patients better navigate the appeals process." She adds, "We also have some recommended questions to ask the doctor. A lot of patients feel intimidated, or they don't want to bother their doctor, so it helps with the doctor-patient relationship."

A sampling of survey results shows the concern expressed by respondents.

♦ Who should choose the most appropriate medications for the ailing person? The survey found that 95 percent of respondents agree in principle that doctors should have the final say on patient treatment (98 percent with autoimmune patients).

♦ What about step therapy, where insurers require patients to try less expensive medications before they agree to pay for higher-priced options prescribed by their doctors? Respondents didn't like the idea of bypassing the doctors' orders (69 percent had an "unfavorable" impression of the practice, and 57 percent said their impression was "very unfavorable").

♦ Should doctors be allowed to overrule insurers on step therapy if they expect the treatment to be ineffective (89 percent support this overrule; 78 percent strongly favor the idea).

♦ Step therapy decisions should be required to be based on guidelines developed by doctors (90 percent favor; 76 percent strongly favor the proposal).

♦ Insurance companies should be required to cover all prescriptions written by a patient's doctor (84 percent favor; 72 percent strongly favor the proposal)

♦ Insurance companies should be required to speed up the appeal process (82 percent favor; 68 percent strongly favor).

According to Virginia Ladd, while AARDA hasn't proposed any legislation, it is clear that survey respondents supported by wide margins several measures aimed to give doctors more say over a patient's treatment. This concern continues to be an AARDA patient advocacy area.

For more information, access **www.letmidoctorsdecide.org**. Call AARDA (586-776-3900) for a free copy of the patient guide. ■

--Source: Adapted from "Let doctors decide patient's medications," Karen Bouffard, The Detroit News, October 3, 2017

Keep up with AARDA!

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Autoimmune disease as a category?

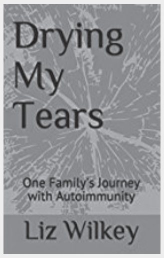
Autoimmune disease as a category, like heart disease and cancer, for example, is being recognized at last, largely thanks to the efforts of the American Autoimmune Related Diseases Association (AARDA). The need for such a category and the efforts of AARDA have now been recognized by members of the European Parliament who recently turned to AARDA for information.

In response to an invitation from the European Parliament for an AARDA representative to address this issue, AARDA Scientific Advisory Board member Jean-François Bach, M.D., D.Sc., was asked by AARDA President/Executive Director Virginia Ladd to represent AARDA in this presentation. Dr. Bach is *Secrétaire perpétuel, Academie des Sciences*, in Paris, France.

By bringing recognition to autoimmune disease as a category, not simply 100+ separate "diseases," researchers can be encouraged to consider the autoimmunity picture as a whole, physicians may see the autoimmune family connections, and diagnostic and treatment options will be enhanced.

This interest on the part of the European Parliament is an exciting development, and we in AARDA are pleased to share our experience with our friends across the Atlantic. ■

A book worth considering...



We know that autoimmune disease tends to cluster in people and families, but how do you handle all of that when it is your family that seems to be so unfairly impacted? For Liz Wilkey, author of *Drying My Tears, One Family's Journey with Autoimmunity*, laughter seems to be the best medicine. At the very least, a good sense of humor has maneuvered her family through their autoimmune disease journey.

Heartwarming and down to earth, Liz recounts her tale as again and again a new autoimmune disease diagnosis is added to the list. Starting with her daughters and eventually herself, Liz describes how these diseases transformed her home and family. From watching the progression of diseases happen to those she loved to dealing with it herself, Liz tells how her daughters have fought their conditions from very young ages to adulthood as she has navigated her own illness as a parent, wife, and professional, all the while adapting to the new circumstances while still handling the normal demands and delights that life brings.

The struggles of Liz, her three daughters, and her husband are all too familiar for any person or family impacted by autoimmune diseases. However, Liz brings a healthy dose of humor and humility as she describes how her family has continued to grow and thrive despite the challenges and pain of lupus, Guillain-Barré, Hashimoto's thyroiditis, spondylarthrosis, and Sjögren's syndrome.

Liz offers up her own experiences and ways that she and her family have lived and coped with autoimmune diseases. She affirms the value of the practical, loving support of her husband; and Liz says of the many physicians in her life, "I have found that the best doctors are the ones who work collaboratively with their patients." ■

--Drying My Tears, One Family's Journey with Autoimmunity, Liz Wilkey, Amazon Kindle Direct Publishing, 2017, 257 pp. Available exclusively on Amazon: $4.99, ebook; $7.99, paperback.

What's been happening in FY 2017? We present an "Overview of Major Accomplishments"....

Research

- Continued support for autoimmune disease research at Johns Hopkins University through Barbara Gómez Estate
- Provided grants to five researchers in the "Young Investigators" program: University of California, Feinstein institute for Medical Research, Johns Hopkins University, and (with Relapsing Polychondritis Awareness and Research Foundation) National Institutes of Health (NIH), Critical Care Medicine Department
- Continued to collect funds for a National Autoimmune Diagnostic and Triage Center
- Launched the Autoimmune Registry Network (ARNet)

Education (Patient, Public, Scientific)

- Sponsored, cosponsored, or supported the following:
  –"How to Dance in the Rain," Conference for the Autoimmune Community, Scleroderma Foundation Michigan Chapter and others, Okemos, MI
  –American College of Rheumatology Annual Meeting (AARDA staffed display booth), San Diego, CA
  –Federation of Clinical Immunology Societies (FOCiS) Annual Meeting, Chicago, IL
  –18th Annual Autoimmunity Day, Johns Hopkins University, Baltimore, MD
  –Colloquium, Cancer Immunotherapy and Autoimmune Disease, Washington, DC
  –Symposium, Infection As a Trigger for Autoimmune Diseases, Washington, DC
- Presented Autoimmune Summit, "Autoimmunity: Yesterday, Today, and Tomorrow," Washington, DC
- Continued support for organizer/facilitator of AARDA scientific meetings, Noel R. Rose, M.D., Ph. D., Pathology Dept., Brigham and Women's Hospital and Harvard Medical School, Boston, MA
- Continued to distribute Autoimmunity Curriculum for Elementary and Middle School Teachers, at no charge to teachers
- Continued as a source of autoimmune disease information on WebMD
- Maintained social networking sites
- Published quarterly lay-friendly newsletter *InFocus*
- Continued to make available AARDA patient-friendly "Risk/Benefit" brochure
- Continued to provide AARDA's "Three-Second Benefit Factor" study for physicians
- Maintained 24-hour toll-free request line
- Provided referrals and non-medical information during office hours
- Provided free educational brochures and newsletters to numerous health-centered meetings and events (TN, OK, MI, CT, MD, KY, IL, MA, CA, SC, IN, FL, TX, NC, NJ, AL, CO)
- Maintained Local Contact list with support groups as available
- Provided groundwork for Step Therapy and Awareness program

Advocacy and Awareness

- By invitation, provided a speaker at the European Parliament of the European Union, Brussels, on establishing autoimmune disease as a disease category
- Sponsored ads on behalf of autoimmune patients concerning Prescription Drug User Fee Act (PDUFA), Fastercures legislation, and autoimmune disease patients to have access to specialists
- Continued AARDA 25th Anniversary Campaign and highlighted #AutoimmuneHeroes
- Expanded membership in the Autoimmune Partners Council
- Continued facilitation of the 36-member National Coalition of Autoimmune Patient Groups (NCAPG)
- Provided interviews and information for news media; had major advertisements and articles (or acknowledgement) in local and national publications

Fundraising

- Continued to encourage and provide support for "grassroots fundraising," including the digital *Grassroots Newsletter*
- Continued to expand the Autoimmune Disease Awareness Walks schedule (New York, Virginia, Michigan, California, Kentucky, Georgia) and provide support for Virtual Walks
- Sponsored the AARDA Annual Fund Raiser in the Greater Detroit area (an AARDA national event)

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.

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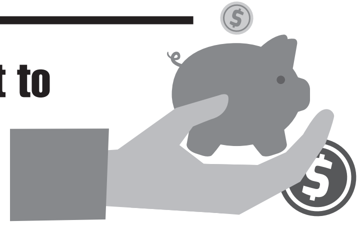
To our readers: Autoimmune diseases are conditions in which the body's own immune system can (among other things) cause damage to the skin, joints, and internal organs. Although most autoimmune diseases are not yet preventable or curable, most can be controlled to varying degrees. It is because of the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

Are you at least 70½ and subject to mandatory withdrawals from your IRA? This may be for you!



Yes, it's true. Federal legislation provides that mandatory IRA withdrawals may be donated to charity with no taxes owed by the donor or the charity (qualified charitable distribution, QCD).

IRA owners age 70½ or older may donate up to $100,000 from their traditional IRA directly to a qualified charity (AARDA is qualified) and have it count toward their minimum required distribution (MRD). The break comes from not having to pay tax on the donated amount. The donor can donate all or a portion of the MRD. Contribution deadline is December 31.

The charity's tax ID number (EIN) is needed (AARDA is 38-3027574). ■

Premature ovarian failure and autoimmunity

The following information is provided by Judy Luborsky, Ph.D., Biology Department, Woods Hole Oceanographic Institution, Woods Hole, Massachusetts. Dr. Luborsky has studied the relationship of autoimmunity and ovarian failure extensively and has several patents for specific autoantigens associated with autoantibodies in premature ovarian failure.

Premature ovarian failure (POF) affects an estimated 0.5-3 percent of women. POF, also termed premature menopause or premature ovarian insufficiency (POI), was defined traditionally as menopause before age 40. There is evidence for sub-types of POF/POI based on different spontaneous and induced causes, such as autoimmune, environmental toxin exposure, chemotherapy, genetic alterations, and others. The impact of a diagnosis of POF/POI can be profound, with multiple physical and psychological consequences.

Premature Ovarian Failure: POF/POI has the same features as natural menopause, such as, no menstrual cycles and elevated follicle stimulating hormone (FSH) and luteinizing hormone (LH). FSH and LH are secreted from the pituitary gland, a small organ at the base of the brain; and their levels are controlled by circulating ovarian hormones. However, POI is not identical to menopause--as discovered by some women with POF/POI who have resumed ovarian function and become pregnant, indicating that their ovarian function was not ended permanently.

In normal ovarian function, the ovaries produce eggs and sex hormones, such as estrogen, during the reproductive years under the control of FSH and LH. Egg and estrogen production ends at menopause, which typically occurs around age 50 (plus/minus 2-5 years).

A gradual peri-menopausal transition precedes menopause, whether it occurs prematurely or at the expected age. It is characterized by irregular menstrual cycles, missed ovulations, and sub-fertility. A woman is considered to have reached menopause after 12 months without a menstrual period.

Progress in diagnosis and understanding of POF/POI has occurred although the causes remain to be determined. As estrogen production by the ovary declines, FSH rises. Elevated FSH measured in a clinical laboratory test is a hallmark of menopause and premature menopause. The diagnosis is made by measuring the FSH in blood as an indicator of reduced ovarian function. Additional measurement of blood levels of ovarian anti-Mullerian hormone (AMH), a product of ovarian follicle cells, may be used to indicate the approximate size of the remaining follicle pool. If FSH is above normal and serum AMH is low, this may indicate POF/POI.

Autoimmune Premature Ovarian Failure: Autoantibodies against the ovary occur in 30-50 percent of patients with POF/POI, suggesting that a significant proportion of women have an autoimmune disorder directed against their ovaries. This autoimmune disorder has been documented in numerous research studies and is supported by the demonstration of anti-ovarian antibodies (AOA), the presence of lymphocytic oophoritis (inflammation of the ovary detected in biopsies), and clustering with other autoimmune disorders, such as Addison's disease or autoimmune polyendocrine syndrome.

Addison's disease is an autoimmune reaction to adrenal gland cells, and autoimmune polyendocrine syndrome is a cluster that involves Addison's disease, thyroiditis, and often diabetes type I. The autoantibodies in Addison's disease react with cell components also found in ovarian cells, which may account for the association of POF/POI to associate with Addison's or autoimmune polyendocrine syndrome.

Research studies by multiple groups show that anti-ovarian antibodies (AOA) may interact with different parts of the ovary, such as, with cells in follicles and with eggs. Antibodies may also react with hormones such as FSH.

When we began developing a test, the tissue site of antibody binding was not known. Therefore, in our early studies, we used whole ovary tissue extracts as the antigen mixture to "capture" and detect AOA in an immunoassay test. Ovarian tissue AOA were associated with premature menopause and unexplained infertility and not control subjects (for example, clinical controls with normal fertility and menstrual cycles). AOA also predicted a poorer response to hormone stimulation to induce ovulation and a lower chance of attaining a pregnancy by Assisted Reproduction Technologies.

We went on to identify specific proteins from the tissue extract mixture that accounted for the AOA. To date, there is no evidence that these autoantibodies affect ovarian function directly. Rather, AOA signals that there is inflammation and possible tissue damage.

Currently, AOA tests have not been developed for commercial use, but some clinical laboratories perform AOA tests. The test types differ in different laboratories. The immunoassay plate (ELISA) technology is more easily standardized than the older immunofluorescence histology test.

What is the treatment for POF/POI? Unfortunately there is no standard treatment for this disorder, particularly that of autoimmune origin. A recent clinical trial of POF/POI ("Steroid Therapy in Autoimmune Premature Ovarian Failure") was completed, but results have not been posted yet (see ClinicalTrials.gov). For the present, the most common treatment is hormone replacement therapy to replace estrogen.

A large support organization for women with POF/POI is the Daisy Network, a registered charity in the UK which has members all over the world (https://www.daisynetwork.org.uk/). The Website has information and discussion forums.

Another possible contact is RESOLVE, the National Infertility Association, a patient-supported organization that provides information for women concerned about fertility (http://www.resolve.org). ■

~ 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.

Board Advisor, Iceland, and autoimmunity...what's the connection?

When Edward K. Christian, AARDA Board Advisor and former AARDA Board member, was featured as one of the #AutoimmuneHeroes for AARDA's 25th Anniversary celebration, *InFocus* readers weren't treated to another side of this dynamic personality. Yes, he is a successful business man, owner of Saga Communications, with more than 60 radio stations from Maine to South Dakota (many of them running AARDA PSAs from time to time); but the other perhaps little known side of Ed is that he is Iceland's Honorary Consul, representing Michigan, Ohio, and Indiana. Who knew that AARDA has some contact with Iceland! And why Edward Christian?

Ed says, "Because of the pure genetic pool in Iceland, I can trace my ancestry back to the first settler." His grandparents immigrated to Canada in the 1880s, and his father eventually settled in Metro Detroit. For 25 years, Ed has been Iceland's Honorary Consul; and his son Eric, the current Vice Consul, will eventually take his spot.

That "pure genetic pool" has other implications as well. The island's relative isolation has resulted in a population of approximately 332,000 people that is almost entirely descended from a single family tree--hence, Ed Christian's success in tracing his ancestry. Data about the population's genealogy has been extensively recorded since 740 A.D. and sits in an accessible database called Islendingabók, or Book of Icelanders. Now comes word that this information from the little country of Iceland is providing insights into disease and paving the way for large-scale genomic studies.

Recent information from researchers Kári Stefánsson, M.D., Daniela Fanners Gudbjartsson, Ph.D., and their research team at deCode genetics has announced findings based on the whole genome sequence information of 2,636 Icelanders and the genotypic information of 104,220 other Icelanders. In population genomics, this is called the founder effect, in which the lack of diversity limits the number of genomic variants (differences between people) and allows usually rare variants to become common enough in the population to be more easily noticed and studied.

And who also would imagine that an Icelandic native, studying in the United States and working at the National Institutes of Health (NIH), in Bethesda, Maryland, would decide to specialize in autoimmune diseases and end up taking his knowledge back to his home country? That was the trail followed by Dr. Björn R Lúdviksson, Professor and Head of the Department of Immunology at the University Hospital in Reykjavik, Iceland.

The Department of Immunology, established in 1981, is the central service and research laboratory for rheumatologic, allergic, and immunologic disease in Iceland. The department offers a clinical treatment center for individuals suffering from autoimmunity, allergy, asthma, immune deficiency, and other immunologic diseases.

According to Dr. Lúdviksson, approximately 800 to 900 patients are treated for autoimmune conditions at their center. He says, "I have a very mixed bag of patients. Many patients don't have a known diagnosis, and maybe half of my patients have a primary immune deficiency along with vascular problems."

Honorary Consul Ed Christian, with a family history of multiple autoimmune problems (ankylosing spondylitis, rheumatoid arthritis, and Raynaud's phenomenon), should feel in good hands while spending time in Iceland. Understanding the prevalence and impact of all autoimmune disease in Iceland is a key part of Dr. Lúdviksson's research. He was instrumental in developing a Web-based application currently in use at the hospital to provide greater statistical analysis for doctors and researchers on the patients being treated for autoimmune-based diseases.

Autoimmune patients in Iceland can feel isolated. One patient says, "The problem is that we don't have a way to meet each other because the doctors can't share that private information." However, she and other patients have found the Internet to be a bridge to at least communicate with others. A vasculitis patient herself, she also keeps in touch with the Vasculitis Foundation, a Missouri-based member group of the National Coalition of Autoimmune Patient Groups which was founded and is facilitated by AARDA.

Of Iceland, Ed Christian says, "The stark beauty is just overwhelming. You can lose your soul in some of the back areas; you have this feeling of awe and wonder." Encouraging visits to Iceland, Honorary Consul Christian says, "We have volcanoes, running glaciers, great lakes, and waterfalls and in the winter, the northern lights."

Ed might add also that autoimmune patients have assurance that if medical need for an autoimmune flare arises while visiting Iceland, knowledgeable care likely is available with Dr. Lúdviksson and staff--certainly an added feature of Iceland! ■

--Source: Adapted from "On air with Icelandic consul," Joyce Wiswell, Grosse Pointe Magazine, Pointe Media Incorporated, September-October 2017; and "Treating Patients with Vasculitis in Iceland: A Profile of Dr. Björn R Lúdviksson," Ed Becker, and "Iceland Study Provides Insights into Disease, Paves Way for Large-scale Genomic Studies," Yekaterina Vaydylevich, Vasculitis Foundation Newsletter, September/October 2017

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Keychain food allergy lab--true!

What if you could sit at your restaurant table and determine whether you will be allergic to your preferred menu item? Researchers at Harvard Medical School have developed a $40 device that fits on a key chain and can accurately test for allergens, like gluten or nuts, in a restaurant meal in less than 10 minutes. The project was funded by the National Institute of Biomedical Imaging and Bioengineering.

The system, called integrated exogenous antigen testing (*i*EAT), is a device consisting of three components. A small plastic test tube is used to dissolve a small sample of the food being tested and to add magnetic beads that capture the food allergen of interest, such as gluten. A bit of that solution is then dropped onto electrode strips on a small module that is then inserted into the electronic key chain reader. The reader has a small display that indicates whether the allergen is present and, if so, in what concentration. Testing showed that measurements of the concentration of the allergen is extremely accurate. For example, extensive testing of the *i*EAT revealed that the system could detect levels of gluten that were 200 times lower than the Federal standards.

Hakho Lee, co-senior leader of the project, said, "We are receiving calls from people asking if we can adapt *i*EAT to test for other substances such as MSG or even pesticides." He said, "The good news is that we definitely can adapt the device to test for just about any allergen or substance."

The research team has granted a license to a local start-up company to make *i*EAT commercially available. The company plans to merge the three components into a single module to make it even easier and more convenient to use.

The inventors point out that another use of the system would be to trace the source of food contamination with bacteria, such as E. Coli or Salmonella to a specific food processing site by testing DNA in the samples to identify personally and contain an outbreak more quickly. ■

--Source: "Food Allergy Lab Fits on Your Keychain," National Institute of Biomedical Imaging and Bioengineering, October 25, 2017, via Newswise

You've probably never heard of my disease

While this article is written by a Sjögren's syndrome patient, Vicki Baldwin, much of her experiences and insights can be appreciated by those who struggle with other autoimmune diseases as well--and by many who want to support their loved ones. We thank Vicki and the Sjögren's Syndrome Foundation for sharing.

I'm outdoorsy, but I rarely go hiking anymore. I love live music, but I've had to skip many concerts. I enjoy my job, but I often find myself struggling to stay awake. I enjoy time with friends, but I frequently find myself needing to cancel plans.

I'm not lazy. I'm not an introvert. I'm not a pessimist. I have Sjögren's.

Chances are you've never heard of Sjögren's; and if you have heard of it, you probably don't understand it.

Sjögren's is an autoimmune disease affecting more than 4 million Americans--90 percent of whom are women. Sjögren's causes the body to attack moisture-producing glands--most commonly the eyes and mouth--and presents symptoms of fatigue and joint pain. It also can cause dysfunction of other organs, affect the kidneys, gastrointestinal system, blood vessels, lungs, liver, pancreas, and nervous system.

I've been living with a Sjögren's diagnosis for nearly seven years, but I've had it much longer. When I first saw my health care provider about my original symptoms--dry eyes and severe fatigue--they were brushed off. The dry eyes were attributed to Lasik surgery I had, and the fatigue was thought to be thyroid related. After having a thyroidectomy--surgery to remove my entire thyroid gland--my fatigue became worse. It took four long years to receive my Sjögren's diagnosis.

Once I received my diagnosis, I was relieved; but I also knew that life would not go back to being normal--ever. Yes, I received treatment, which helped, but fatigue and pain are a constant. I deal with them daily.

I didn't just watch my life slip away, though. I made adjustments. I live a wonderful life, despite Sjögren's, by:

- ♦ Working from home, which allows me to rest as needed.
- ♦ Educating people about the disease. I carry pamphlets with me wherever I go. If Sjögren's comes up, I hand out a pamphlet. This includes educating health care professionals, many of whom aren't fully aware of this disease!
- ♦ Carefully planning my schedule. If I plan to go to a concert on a Friday, I know I will need the entire weekend to recover and rest.
- ♦ Having a therapy dog. Being at home alone can become isolating, so having a companion helps. I also bring my dog to visit people in nursing homes, which gets me out of the house and brings joy to others.
- ♦ Joining and creating support groups. I'm not alone, and it helps to know there are other people living with Sjögren's. I've formed very close friendships with several people from Facebook pages that provide support to people living with Sjögren's, and I even created a local support group in my town. ■

--Source: "You've Probably Never Heard of My Disease," Vicki Baldwin, The Moisture Seekers, Sjögren's Syndrome Foundation, www.sjogrens.org, Summer 2017

Walkers keep walking!

Camaraderie abounds at AARDA's Autoimmune Walks. Some people walk, some stroll (a number pushing strollers), and some simply sit and enjoy chatting as they watch the activity. All ages take part in their own chosen ways. Who says fund raising can't be fun?

Ending the 2017 Autoimmune Walk schedule were Walks held in September and November, from New York to California and some in between.

◆ **New York City** (September 10) - Enjoying the sunny afternoon, 125 people came out to raise awareness, honor and support family members and friends, and hear guest speaker Nika Beamon ("Misdiagnosed: The Search for Dr. House") tell her moving autoimmune story. Nika led the top Walk team, "Nika's No Excuses Walkers," raising $3,915 for autoimmune research; "Team PBCers," led by Althea Cices, came in second; and "Wegener's Warriors," led by Julie DiGregorio, held third place.

Special thanks go to pop duo Danielle & Jenniger for their inspiring performance; Nespresso; BungyPump; and Intercept, our Champion Sponsor. The New York Walk raised a total of $21,003.

◆ **DC Metro Walk**, Arlington, VA (September 16) - This drew about 75 people, including lots of families with junior walkers. The day included guest speaker Dr. Stephanie Seibert of MindBodyHealth (mindfulness and coping), a pre-Walk warm-up led by Courtney Kraus, and a silent auction. "We got this!" was the top team with $2,485 raised, led by Sera Yoho. Second place was the "Gebhardt Family" team, and the third place team was "Pearson Smith Realty." The DC Metro Walk raised $10,850. Special thanks go to Walk Coordinator Robin Gebhardt for leading the way.

◆ **Metro Detroit Walk**, Lake St. Clair Metropark, Harrison Twp., MI (September 30) - This Walk, which drew about 75 people, featured representatives and resources from several AARDA partners, including Adult Well-being Services, American Diabetes Association, Crohn's & Colitis Foundation, and Wrigley's Pharmacy, our Champion Sponsor (special thanks!). Participants enjoyed music played by DJ Shon, a raffle, and special children's activities. Guest speaker was Dr. Peter Watson, vice president for Care Management and Outcomes at Health Alliance Plan (HAP), part of the Henry Ford Health System. Top Team, raising $1,310, was "Charlotte's Angels," led by Charlotte Marshall-Lawson. The Walk raised $7,155.

◆ **Third Los Angeles Walk**, Culver City, CA (November 11) - The last Walk of the season, this 3rd Los Angeles Autoimmune Walk drew 200 participants for a day that included top-notch entertainment by Yowzza!, Mini golf, and singer-songwriter Cody DiGerolamo; great food by Chef Mike Aliotta and crew; a silent auction; and a red-carpet experience where walkers, including Charlie McDermott ("The Middle"); Miranda Cosgrove ("Despicable Me"); Grace Kaufman ("Man With a Plan"); Aisha Dee ("Chasing Life"); Madison McLaughlin ("Arrow"); and our Walk Ambassador Haley Ramm ("Seven in Heaven"), had their photos taken. LA Walk founder Barbara Ramm and AARDA Executive Director Virginia Ladd spoke to the crowd. The Top Team ($21,500), "For RP," was led by Carole Cooper. Special thanks go to Champion Sponsor Eli Lilly and Company.

Thanks go from AARDA to each and every walker and every team for their amazing efforts this year. We gratefully acknowledge the support of all our silent auction, raffle, and in-kind donors whose gifts helped strengthen our endeavor.

Coming up...Oklahoma City Autoimmune Walk, Saturday, March 24, 2018, Wiley Post Park; and Metro Detroit Autoimmune Walk, Saturday, August 25, 2018, Millikin State Park, RiverWalk, Detroit

Always...Virtual Walk, any day, any time, your choice

- ◆ Register for an Autoimmune Walk: www.AutoimmuneWalk.org
- ◆ Like us on Facebook: www/Facebook.com/AutoimmuneWalk
- ◆ Tweet about us: @AutoimmuneWalk
- ◆ Email: walk@aarda.org (Questions or suggestions?)

New drug approved for multiple sclerosis

Multiple sclerosis patients now have a new treatment option in their fight against this chronic inflammatory progressive autoimmune disease of the central nervous system that disrupts communication between the brain and other parts of the body. The Federal Drug Administration (FDA) now has approved Ocrevus (ocrelizumab) to treat adult patients with relapsing forms of multiple sclerosis (MS) and primary progressive multiple sclerosis (PPMS). This is the first drug approved for PPMS in several decades.

Ocrevus, an intravenous infusion given by a health care professional, not only provides an approved therapy for those with relapsing MS but also provides for the first time an approved therapy for those with primary progressive MS. In studies comparing Ocrevus with another MS drug, Rebif (interferon beta-1a), the patients receiving Ocrevus had reduced relapse rates and reduced worsening of disability compared to Rebif.

For most people with MS, episodes of worsening function (relapses) are initially followed by recovery periods (remissions). However, primary progressive MS is characterized by steadily worsening function from the onset of symptoms, often without early relapses or remissions. Approximately 15 percent of patients with MS have primary progressive MS. Most people experience their first symptoms of MS between the ages of 20 and 40, and the disease occurs more frequently in women than men. ■

--Source: "FDA approves new drug to treat multiple sclerosis," FDA News Release, March 29, 2017

Grassroots Fund Raising Notes...

Imagination abounds as AARDA members and friends find ways to raise money for AARDA'a mission. The most recent two-month total shows $4,656.48, including Facebook donations. A plus of grassroots fundraising is local autoimmune awareness and education (see page 10 for listing).

Upcoming event - Scheduled for March Autoimmune Disease Awareness Month is a fundraising awareness project of Sedona Tap House, Mamaroneck, NY, where $1 per order, every Monday night during the month of March, will be donated to AARDA. They also will place AARDA literature inside their menus. Great idea! ■

AARDA says "thank you" to . . .

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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 received. These loyal friends are noted with appreciation.

Fund Raisers

Iota Elementary 4-H Club Fund Raiser $315.00
Glassbaby White Light Fund Fund Raiser $479.75
Facebook Fundraisers (to date) $3,326.23
Toll Gate Grammar School Spirit Donation $203.50
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Jerry Ladd continued from page 1

international. On the last day of his life, Jerry saw photos and heard the laughter of Ugandan children playing at the dedication of Jerryland, a gift from Jerry to the children at a school which receives support from the Ladds with other friends. A sign at the school states "Ladd Children's Center." This was a project dear to Jerry's heart, and he cherished memories of his visit there with the children.

Jerry's respect for the value of volunteers and their associations arose early in the Ladds' marriage when a lupus volunteer, via phone many states away, led them to a Detroit-area physician whose outside-the-box knowledge and concern saved Virginia's life.

Jerry is survived by his children and their spouses: John and Sandy, Shelly and Kenneth, Michael and Michelle, and Wayan Sukayada and Made; and grandchildren Allison, Jenna, Brendan, Bridget, Mika, and Kieka. He was known not only as "Dad" and "Grandad" but also lovingly as "Jokester," never missing a chance to bring surprises and laughter to family gatherings.

Jerry also is survived by one of his siblings, brother Verne, along with numerous nieces, nephews, and other extended family members, all of whom were very important to him.

How do we say "good-bye" to someone who remains with us in so many ways? Maybe we'll simply say, "Thank you for being you." ■

With Special Thoughts...

Tributes

Rachel Griggs - In her honor - Shannon & John Gray

Victoria Niblett - In honor of her birthday - Angela Hardiman

Mike & Carol Scott - In honor of their 50th Anniversary - Billie Prevoznik

Bonnie Sternback-Wilson - In her honor - Wheels Inc.

Memorials

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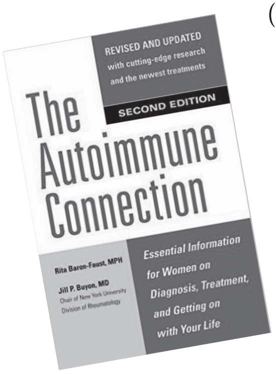

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