INFOCUS

American Autoimmune Related Diseases Association, Inc.

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

Vol. 27, No. 4, December 2019

AARDA's Annual Appeal: Your Opportunity to Make a Difference!

December is Annual Appeal season, a time when members and friends are asked to donate funds in support of our frontline work on behalf of some 50 million Americans affected by autoimmune diseases.

AARDA's Annual Appeal is earnest and urgent, mirroring real and pressing challenges and opportunities facing the autoimmune community. Your support makes it possible for AARDA to carry out its vital mission on behalf of people living with autoimmune diseases and those whose lives they touch--they all are counting on us!

Annual Appeal contributions last year enabled AARDA to accomplish an amazing array of important work, including the following achievements that your support made possible:

♦ The **Let My Doctors Decide** initiative piloted in Michigan became a nationwide campaign. In an effort to advocate for patients and physicians in the "step therapy" or "fail first" interventions of insurance companies, we joined with like-minded patient groups alongside medical and other health profession organizations to bring awareness and education on a national scale. The initiative equips patients themselves to be alert to the system's pitfalls and to partner with their physicians to obtain the medicines they know are best for them.

♦ The **Autoimmune Research Network (ARNet)**, a "patient powered database to further autoimmune disease research," expanded its outreach as patients provided helpful information to researchers (www.aarda.org/ARNet). Since the launch of ARNet in February 2017 to November 2019, we have registered 5,192 individuals. From October 1, 2018, to October 1, 2019, we saw 1,813 registered.

♦ The **Spanish translation** of 21 AARDA brochures is providing a much-needed bridge to awareness and education for the Spanish-speaking autoimmune sufferers and their families.

♦ **Research support** was given to the Allegheny Health Network Autoimmunity Institute, Brigham and Women's Hospital, Johns Hopkins University, Massachusetts General Hospital, and others.

♦ AARDA's **Young Investigators** program provided funds for autoimmune disease research being carried out by five young medical students at leading institutions.

♦ Annual **Autoimmunity Day** at Johns Hopkins University, originated by AARDA, received funding.

♦ The **Diversity Summer Internship Program support** at Johns Hopkins University was renewed.

♦ **Autoimmune advocacy** was brought to Capitol Hill, including a March briefing for legislators and congressional staff on the "Growing Epidemic of Autoimmune Disease," and a written response to the U.S. Department of Health and Human Services on proposed "Patients Over Paperwork" guidelines issued this past summer.

♦ **Educational programs** were expanded, including the presentation of three highly successful webinars and three public forums as well as three outstanding scientific colloquia resulting in the publication of acclaimed articles in peer-reviewed journals.

♦ **Inquirers' requests** were met through telephone calls, emails, social media, and printed information. From October 1, 2018, to October 1, 2019, approximately 1,850 inquirers were processed and added to the database (new, not already in the system; 20-30 called for additional information).

♦ **Services and Program Activities** included Washington DC and the following

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We are increasing paperless communications to our subscribers and stakeholders to respond to requests, to share more information, and to reduce costs. *InFocus* subscribers now have a choice of paper or paperless.

Which option do you prefer for your *InFocus* subscription? The *E-InFocus* is available now to current and future subscribers via email for the same subscription membership contribution of $34 USD (International $44 USD) that is paid by postal subscribers.

If you would like to receive an electronic newsletter in place of our mailed quarterly newsletter, please contact the AARDA office at 586-776-3900 or email at aarda@aarda.org. Otherwise, your same delivery method will continue. ■

InFocus, *a quarterly newsletter of the Amercian Autoimmune Related Diseases Association, Inc. (DBA Autoimmune Diseases Association)*
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President/CEO's message - Randall L. Rutta

Dear AARDA Friends and Supporters:

After only a few months at the helm, I am deeply moved by AARDA's positive impact on behalf of people living with autoimmune diseases and their families. Together, as a community, we are making a big and important difference through research, public awareness, patient education, and advocacy that break down persistent barriers to achieving health and well-being. I am awed and energized by...

---the passion of patients to secure a diagnosis and proactively improve their health which was clear to me in Pittsburgh, in late September, where more than 200 people living with autoimmune disease gathered to learn, share, and engage with peers and experts. This Summit was co-sponsored by AARDA and the Autoimmunity Institute at the Allegheny Health Network. World-class speakers, including physicians, allied health professionals, and patient advocates, addressed key topics and facilitated valuable discussion to those in the room and beyond.

...the commitment of researchers from highly regarded institutions across the U.S. who participated in a ground breaking scientific colloquium planned and facilitated by AARDA's Scientific Advisory Board Chairman Emeritus Dr. Noel R. Rose. They spent a mid-October week-end exploring their research and that of their colleagues to advance understanding of the impact of metabolic defects on autoimmunity. The seeds of important discovery surely were planted that day.

...the enthusiasm of hundreds of doctors, patients, nurses, and other healthcare professionals who experienced--firsthand--the frustrations associated with step therapy and "fail first" protocols in an interactive escape room exhibit. While at the American College of Rheumatology Annual Conference in November, they navigated our maze of obstacles, stories, and facts about the challenge of step therapy facing physicians and patients. They emerged and took action--endorsing our principles, signing our petition, and joining us to change government policies and harmful insurance company practices.

...the focus of more than a dozen leaders of member organizations of the AARDA-founded and facilitated National Coalition of Autoimmune Patient Groups (NCAPG) who came together in Washington DC in October to discuss policy issues of importance to people living with autoimmune disease. Experts interpreted pending healthcare reform legislation in Congress and called out opportunities at federal agencies to ensure that autoimmune patients' interests are known and taken seriously.

You and all of AARDA's champions deserve to celebrate our progress over 28 years in advancing autoimmune community priorities. Through our Annual Appeal, I invite you to invest further in our mission and the machinery required to keep us moving forward. There remains much for us to do to understand the underlying causes of autoimmunity, shorten the time to diagnosis, raise awareness, help patients, and increase access to life-saving treatment and care.

All of us in the AARDA family are grateful to those who contribute to our financial strength and ability to make a positive difference together. Your friendship, funds, and loyalty drive our passion, our work, and our collective impact. Thank you!

With sincere appreciation,

Randy Rutta

Is this on your calendar?
AARDA's 20th Annual Spring Fund Raiser *"Bound by a Common Thread"*
Saturday, May 9, 2020
Skyline Club - 2000 Town Center, Southfield, Michigan 48075

AARDA Founder Virginia Ladd honored at luncheon

Lifetime Achievement Award Presented to Virginia T. Ladd

In recognition of her extraordinary vision, leadership, and advocacy for autoimmune disease patients throughout the world; for being the champion of research; the voice of hope; and the untiring standard bearer for awareness.

That is the tribute engraved on the Lifetime Achievement Award given to AARDA Founder and Immediate Past President and Executive Director Virginia T. Ladd at a special lunch in her honor at the offices of Sidley Austin, in Washington, D.C., on October 23, 2019.

Sponsored by the American Autoimmune Related Diseases Association (AARDA), the lunch was attended by members of the National Coalition of Autoimmune Patient Groups (NCAPG), founded and facilitated from its inception by Mrs. Ladd; institutional and corporate leaders representing organizations supportive of AARDA's mission; and AARDA Board members and advisors.

In accepting the award, Mrs. Ladd spoke of the beginning years of her work on behalf of autoimmune patients like herself and the advancements she has seen. She expressed her appreciation to the many individuals, including those present at the lunch, who had been participants in the struggle to have autoimmune disease receive recognition and support.

Having made her decision to step down from her 30-year leadership position at AARDA, Virginia Ladd remains on the staff of AARDA as Advisor to the President and as an AARDA representative and speaker at various conferences, meetings, and educational events as requested by AARDA President and CEO Randall Rutta and the Board of Directors. ■

Left to right: AARDA representatives President/CEO Randall Rutta, Board Advisor David Bammert, Board Treasurer Richard Hodge, Advisor to the President Virginia Ladd, Board Advisor Stephanie Hales, Board Member Lilly Stairs, Board Secretary Nona Bear

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states: California, Connecticut, Florida, Georgia, Illinois, Kansas, Kentucky, Maryland, Massachusetts, Michigan, Mississippi, Nevada, New Jersey, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, South Carolina, West Virginia, Washington, and Wisconsin.

♦ **Community outreach** brought educational support to churches, schools, and local organizations in several states.

♦ AARDA's **Autoimmune Walks** program stretched from New York to California, bringing needed research dollars--and camaraderie. There were 775 registered walkers plus a number of non-walking friends, media representatives, and exhibitors. Virtual Walk participants added to the success.

♦ **Collaboration**, an important aspect of AARDA's mission, was advanced as information and projects were shared with members of the National Coalition of Autoimmune Patient Groups (NCAPG), the Autoimmune Partners Council (patients, corporations, institutions), and outstanding researchers.

Be part of the growth of AARDA's mission. Please consider how you can help continue--and expand--these selected activities in the coming year. "Earnest" and "urgent" describe AARDA's needs expressed in our 2019 Annual Appeal. Great strides have been made in the past year; much remains to be done.

Were you were part of supporting these listed accomplishments (and more)? We THANK YOU. Will you be part of our autoimmune movement for the coming year? WELCOME. Your contribution--at any level--will make a positive difference in the year ahead. ■

Why consider chocolate?

Susan Parsley, certified health coach and blogger, writes, "Chocolate is a superfood that has strengthened the body and soul for many different cultures throughout the world."

Chocolate's health benefits are significant. The U.S. Department of Agriculture and the *Journal of American Chemical Society* say that dark chocolate contains 13,120 units on the ORAC (Oxygen Radical Absorbance Capacity) scale per 100 grams. Chocolate contains many different nutrients, including magnesium, iron, copper, phosphorous, potassium, fiber, zinc, manganese, selenium, and fatty acids.

To receive the nutritional benefits of chocolate, we need chocolate, not chocolate candy, although for the health-conscious on a budget, many chocolate candy bars are available that are processed with better nutritional additives than the frequently seen sugar and artificial ingredients. The best nutritional source is raw cocoa.

The words "cacao" and "cocoa" often are used synonymously, but cacao is a tree which produces football-sized pods called "cacao pods." Within these pods is a creamy white substance, the seed of the theobroma or cacao tree. Cocoa beans are the source of cocoa powder. Chocolate bars, cacao nibs (ground up cocoa beans), desserts, teas, and everything else "chocolate" begins with these delectable, yet bitter, seeds.

Chocolate originated in Mesoamerica. During the time of the Olmec, Mayan, and Aztec empires, cocoa beans were valued so highly that they were used as currency. Cocoa was also a frothed drink made from crushed beans and flavored with spices.

After the Aztec was conquered by Cortez and the population was diminished by smallpox, missionary nuns came to the new world and began the transformation of chocolate into a sweet delicacy by adding sugar to reduce its bitterness.

In England, the first chocolate house opened in 1657. This men's social club served chocolate as a refreshing drink with health benefits. Gradually more sugar, milk, vanilla, and other ingredients were added. These additives and the practice of over-roasting beans removed many health benefits of cacao. Thus, in the 1800s, chocolate became synonymous with candy rather than the superfood it is.

Manufacturing cocoa beans into chocolate candy involves, among other steps, roasting which brings out the flavor of the cocoa bean and removes the natural bitterness at the expense of many of the over 4,500 antioxidants and polyphenols which cocoa beans contain. Raw cacao is minimally processed, thus retaining most of its nutrients.

There are three classifications of cacao: forestero, criollo, and trinitario. Forestero is almost commonly grown and produced. It is disease-resistant and represents 85 percent of the world's chocolate production. Because of the low quality and extreme bitterness of forestero, chocolatiers tend to over-roast the beans and add excessive amounts of vanilla and sugar to make it palatable.

General guidelines for a bar to be considered chocolate require five ingredients or less with a 70 percent cacao minimum. The remaining ingredients can be cocoa butter, sugar, vanilla, and/or soy lecithin. The preferred chocolate bar has only two ingredients, cacao and sugar.

Parsley advises that chocolate bars should be savored like fine wines. Place a small piece in your mouth. Chew a few times and then let it melt on your tongue. Experience the flavor tones--fruity? floral? smoky? Since a small piece usually satisfies a craving, genuine chocolate bars, while more expensive than commonly available bars, are really economical. ■

--Source: Excerpted and adapted from "Chocolate: What's in a Word?" Susan Parsley, BME, CHC, AADP, blogger, Riordan Clinic, Wichita, Kansas, posted October 16, 2018

Let My Doctors Decide exhibit debuts at ACR conference

Escape the System: Stop the Madness of Step Therapy. Visitors to the 2019 Annual Conference of the American College of Rheumatology experienced the debut of this exhibit hosted by AARDA and sponsored by the Let My Doctors Decide (LMDD) national initiative which is driven by an advisory task force comprised of national patient advocacy and provider groups, including AARDA.

The "Escape the System: Stop the Madness of Step Therapy" exhibit provides a walk-through experience to understanding the current "fail first" system which requires a patient to try, and fail on, medicines preferred by the insurer before the insurer will cover the cost of the drug that the patient's physician has prescribed. The exhibit is designed to be adaptable for use at meetings of various sizes.

Visit the LMDD website for a view of the closing/thank-you video featuring AARDA President/CEO Randall Rutta and AARDA Board member Lilly Stairs (https://t.co/pEvwev7hCD). ■

Fatigue--What is it? Why is it?

Profound and debilitating fatigue is the most common complaint reported among individuals with autoimmune disease, with almost 98 percent in one study reporting that they suffer from fatigue. Even in the general population, it is estimated that 7-45 percent exhibit persistent fatigue.

Fatigue is a multifaceted and broadly defined condition. This makes understanding the cause of its manifestations especially difficult in conditions with diverse pathology, including autoimmune disease. Fatigue is defined by debilitating periods of exhaustion that interfere with normal activities, even such simple tasks as climbing stairs or crossing the room. The type of fatigue experienced in autoimmune disease is variable. These differences are likely related to the particular tissues/organs, cell types, brain areas, and molecular and physiological mechanisms affected by the condition.

While the exact mechanisms of fatigue are not well understood, physiological processes known to play a role in fatigue include oxygen/nutrient supply, metabolism, mood, motivation, and daytime sleepiness--which are affected by inflammation. Additionally, an important contributing element to fatigue is the central nervous system, a region impacted either directly or indirectly in many autoimmune disorders.

Growing evidence indicates that neuroinflammation is a primary factor contributing to fatigue. Since inflammation plays a large part in inducing fatigue, it is plausible that inflammatory pathways and the subsequent physiological alterations are treatable targets for fatigue in patients with autoimmune disease. Evidence in autoimmune and related disease conditions such as neurosarcoidosis, which is associated with increased lung inflammation, sleep disturbances, and fatigue, exhibit reduced fatigue from anti-inflammatory treatment.

Several non-inflammatory factors are known to affect fatigue, including impairments in hydration status, pain, interactions from pharmaceuticals, muscle/exercise, hypothyroidism, radiation therapy, lung function, and cardiac characteristics such as blood pressure, heart rate, cardiac output, and stroke volume. Inflammatory mediators are reported to affect different aspects that contribute to fatigue, including motivation, sleepiness, cognition, anxiety, depression, and stress.

Cognitive (learning) fatigue involves declines in alertness, orientation, and mental performance on cognitive tasks. It is associated with feelings of exhaustion that follow sustained cognitive demands. Individuals with autoimmune diseases such as multiple sclerosis often experience cognitive deficits and increased perceived cognitive fatigue associated with impaired cortical brain activity.

Autoimmune diseases, including inflammatory bowel disease, multiple sclerosis, and rheumatoid arthritis, have a high coexistence with anxiety, depression and pain, which can serve to induce fatigue.

The perception of effort and motivation can modify fatigue and are affected in autoimmune disease. Animal studies indicate that effort expenditure is influenced by inflammation. In general, inflammation increases averseness toward negative stimuli and positive stimuli.

Metabolism, a physiological process known to play a role in fatigue, as previously mentioned, involves the conversion of fuel sources to energy-related molecules. Alterations in metabolism have been implicated in sleep regulation and fatigue. It also is tied to glycogen (animal starch) metabolism, glycogen synthesis, and energy enzymes and their derivatives, which could potentially alter fatigue. Alterations in metabolism also are implicated in the development of autoimmune disease.

Sleepiness, a factor in fatigue, occurs with chronic insomnia which also is associated with an increased incidence of developing an autoimmune disease. Findings in animal model of systemic lupus erythematosus suggest that sleep deprivation could be involved in the cause of the disease. Clinical diagnosis of chronic fatigue syndrome/myalgic encephalomyelitis is also partially based upon non-restorative sleep, suggesting relationships between poor sleep and fatigue. It is reported that up to 50 percent of individuals with insomnia also indicate enhanced pain, which could contribute to fatigue.

What are the future directions for study? First, a detailed description of particular types of fatigue needs to be established in the clinic. Second, standardized questionnaires and diagnostic tests that can indicate more precisely the determinants observed from fatigue are needed. Also, understanding the neurocircuitry of fatigue and its relationship between inflammation and autoimmune diseases is needed.

More information on interactions between circadian timing and sleep/wake state or sleep loss, alterations in neuronal activity, and normal daily functioning that affect fatigue is required.

The relationship of gender to fatigue in autoimmune disease should be a topic for future research. Several autoimmune diseases are associated with disproportionately greater incidence and disease severity in particular genders, and little information is known regarding the relationship of fatigue with these gender differences.

Recent research reveals a relationship between types of fatigue and certain brain areas, cell types, and phenotypes that mediate the symptoms observed. Immunomodulatory agents and drugs targeting inflammatory pathways could serve to treat fatigue occurring in autoimmune and related diseases. Understanding the mechanisms behind fatigue not only will aid individuals with autoimmune diseases but also could benefit transplant recipients, cancer patients, and infectious disease patients who experience debilitating fatigue. ■

--Source: Excerpted and adapted from "Fatigue, Sleep and Autoimmune Related Disorders," report by Doctors Mark R. Zielinski, David M. Systrom, and Noel R. Rose, May 21, 2019, from an American Autoimmune Related Diseases Association (AARDA)-sponsored symposium; submitted to "Autoimmune and Autoinflammatory Disorders," a section of Frontiers in Immunology, published August 6, 2019

Immune-related events, autoimmune disease, and cancer therapy

Cancer is like an infection that can't be cleared. Mutations can be recognized; but the tumor defends itself using local immune suppression, just like some viruses, e.g., hepatitis C, varicella, human papilloma virus. With help, the immune system can attack cancer cells. The use of immunotherapy can aid this defense, and it has transformed cancer care. However, altering immune regulation is not without consequences.

Called "immune-related events," the consequences of immunotherapy can be inflammatory side effects in any organ--joints, skin, gut--plus fatigue. These side effects can limit treatment opportunities and often require immune suppression.

It is important to recognize that immune-related adverse events are not just "side effects." They can provide a window into the body of immune regulation and offer potential insight into "spontaneous" autoimmune disease, and researchers can learn things that animal models can't teach them. This insight is an opportunity to look for new treatments.

Careful immune regulation is essential to the gut. Through it flow dietary antigens, commensal (nonparasitic relationship) bacteria, pathogenic microorganisms, and toxins. Altering immune regulation leads to a wide spectrum of gut toxicities--constitutional, dermatological, gastrointestinal, musculoskeletal, endocrine, and pulmonary. The effects of those illnesses can be seen while other immune-mediated diseases of the gut are not seen, e.g., food allergies that cause anaphylaxis (like peanut allergies) and eosinophilic esophagitis (an allergic disease of swallowing).

Solving the problem of immune toxicities will be important for expanding the reach of immunotherapy. Maybe these toxicities are the key to unlocking autoimmunity. The similarities and differences from spontaneous disease teach us something about all people with autoimmunity. This could give researchers an opportunity to learn more about "causes" and to develop new treatments that target the first steps, rather than the consequences. ■

--Source: Adapted from "Cancer Immune Therapy and Auto-Inflammation in the Gut," a presentation by Michael Dougan, M.D., Ph.D., AARDA Autoimmune Summit Meeting, Washington DC, March 21, 2018

What's one advantage of being 70½ or older?

Being at least 70½ and subject to mandatory withdrawals (RMDs) from your IRA could give you a good last-minute opportunity to give to your favorite charity which we hope, of course, will be AARDA.

Remember...federal legislation provides that mandatory RMD withdrawals may be donated to charity with no taxes owed by the donor or the charity (qualified charitable distribution, QCD).

Be aware that certain rules apply to making this charitable contribution, and it is important to weigh all the factors before you decide the best route for your situation. Your tax adviser can help you determine the best course of action for you.

Contribution deadline is December 31. The charity's tax ID number (EIN) is needed (AARDA is 38-3027574). ■

Can the body be protected in autoimmune fight?

For decades medical researchers have known that an effective way to control autoimmune disease is to suppress the immune system, but such a treatment can cripple the body's ability to fight off ordinary infections. This can lead to serious conditions or even death. The ideal would be to fight the autoimmune disease while protecting the body. In July 2019, a group of researchers from the University of Utah reported progress toward this ideal.

Using mice models with MS (autoimmune multiple sclerosis)-like disease, investigators saw a significant reduction in symptoms after knocking out a transcription factor called Oct1. More importantly, the mice preserved most of their ability to clear viral infections. Oct1, a protein shared among mice and humans, is found, among other places, in the T-cells, a type of white blood cell that often resides in the lymph nodes. Previous studies of Oct1 have shown that it is essential for forming immune memory of pathogens but isn't necessary for fighting them off.

"Our expectation was that a model of MS would go hand-in-hand with poor defense against viruses; however, that was not the case," said Dean Tantin, Ph.D., a geneticist in the Department of Pathology, University of Utah Health, and coauthor of the report along with Thomas Lane, Ph.D., also of the University of Utah Health.

The key step was evaluating whether the immune systems in mice without Oct1 were compromised. The researchers found that immune responses were normal, although slowed; and all mice cleared the infection.

Dr. Tantin said that the results suggest that Oct1 and the immune functions involving it could be potential targets for human drugs designed to "suppress autoimmune diseases like MS." Such drugs could leave the immune system capable of fighting infection while decreasing inflammation in the brain and spine.

Unfortunately, it likely will be a long time before the results of this study lead to the development of new drugs; but Dr. Tantin believes that transcription factors offer researchers unique advantages in developing therapies. ■

--Source: "Study in Mice Suggest Possible Treatment Approach of Multiple Sclerosis in Humans," University of Utah Health, July 2, 2019, via Newswise

New finding shows autoimmune link in Parkinson's

A recent study found that in mice, infections trigger an autoimmune reaction that leads to Parkinson's in animals with specific genetic mutations. In mice with $PINK_1$ and PRKN genetic mutations, even mild infections led to Parkinson's.

Researchers are now working to replicate the finding in people. ■

--Source: Research Briefs, Krishna Knabe and Maggie Kuhl, "New Finding Links Genetics and the Immune System," The Fox Focus on Parkinson's. Fall/Winter 2019

Out of sight. Out of Mind? Not according to the "Ostomy Guy"

Austin Powers (the "Ostomy Guy," not the actor), author of "The Ostomy Guy Story: Memoirs of a Bagman," podcaster, and Crohn's and colitis sufferer, writes of his experiences with a chronic illness.

I was diagnosed with fistulizing Crohn's and colitis when I was 10 years old, in 1992. It all started because of a fistula opening near my rectum. At that time, there were no answers as to how to handle physically something like this, let alone emotionally, and there still are too few answers. Children of all ages are getting diagnosed with chronic diseases--and left with many questions. The important questions have too many answers, while the most important ones have no answers. Both leave the afflicted person feeling paralyzed.

First, it's hard. The spectrum of inflammatory bowel disease (IBD) is so broad that each one of us seems to land on a different spot. With many different experiences, identifying where we fit and what paths we're most likely to travel flusters our minds and weakens our will to fight. That's the foundation of the chronic illness struggle. Every day you will have to fight, via your diet and lifestyle, just to give your body a level playing ground to defend itself against an illness.

Second, you have a chronic illness. EVERYONE will expect you to get over it as if you have a mild cold. The rule so far is that there is no cure for Crohn's and colitis. Since the day of my diagnosis, I've been approached by over a hundred people with a juice, powder, supplement, super food, diet, or you name it that would be the solution to my problem. In every pitch, someone with Crohn's was cured, which hooked me into buying. The disease evolved each time. Symptoms eventually returned in the same or sometimes new and different ways. It's this way with many medications, too.

Whether we like it or not, we have this illness and we have some responsibility to it. Constantly getting let down by drugs or treatments no longer working is almost harder than just living with the disease.

Third, you will feel totally alone until you share your story and realize there are others out there like you. In all areas of life, this illness presents itself. I realized very early that even with boys, conversation about bowels is funny only under certain circumstances. Otherwise, it's mostly TMI, too much information. I secluded myself and hid everything. Out of sight, out of mind.

However, always acting like someone I wasn't eventually caught up with me. Mine was in the form of depression and anxiety. I say all the time, "Your head is like a bad neighborhood; you should never go through it alone." I had to start talking to someone professionally to help me dig up everything I had suppressed all those years. I wish I had opened up much sooner with someone about the mental side of living with a major illness.

Fourth, your suffering is not in vain. I might act tough about pain with the guys, but I don't prefer or enjoy pain. However, I have found incredible value in embracing and allowing myself to be formed by the suffering in my life. The difficulties drew out perseverance and optimism toward life that helped me overcome hard times. The forever, chronic nature of this illness and its restrictions forced temperance out of me, which resulted in compassionate empathy toward others who suffer. The loneliness sent me on a spiritual journey that I wouldn't have gone on otherwise

I wrote my story to shine a bright light into the dark world that is living with Crohn's and colitis and an ostomy bag. This is a map for those living with a chronic illness, to find their way to peace of mind in their daily journey. Chronic illness is a lot like a daily giant multivitamin--just get a big glass of water and swallow it or you'll choke. Get it down and let it digest.

To all my readers, go back to your lives and live more intentionally and love more selflessly. Life's not perfect, but it's manageable. That's what we all should be searching for as we seek a cure. ■

--Source: Excerpted and adapted from "Living (and Thriving!) with Crohn's and Colitis: The Ostomy Guy," Austin Powers, Health Hunters Newsletter, Riordan Clinic, Wichita, KS, October 2019 (The Ostomy Guy Story, Memoirs of a Bagman, soft cover, 95 pp., available on Amazon)

Personalized treatment for Sjögren's may be possible

A new study conducted by scientists at Newcastle University, UK, has shed light on Sjögren's syndrome, a debilitating autoimmune disease affecting 1.2 percent of the population. The Sjögren's Syndrome Foundation estimates that two to four million people, 90 percent of them women, may be affected. The scientists believe that their findings have key implications for drug development, particularly in clinical trial design and informing molecular targets. For the first time, the Newcastle scientists have found at least four versions of primary Sjögren's syndrome.

"One of the key barriers to research has been that the clinical presentations of patients with the condition differs markedly from patient to patient," said Newcastle University Professor Fai Ng, who led the European study. "Knowledge of these subtypes will now help us to develop more personalized management plans for those with the condition, which in turn will help to improve people's quality of life."

Professor Fai Ng commented, "A vital lesson we've learned is the importance of a team science approach. We didn't rely on clustering metrics alone but took into consideration clinical experience and common sense."

Further research will focus on the biology of each Sjögren subtype--to test the stability and long-term outcome of each subtype and to validate the different responses to treatment of each.

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Autoimmunity Center of Excellence established

With a $4.5 million grant from the National Institutes of Health (NIH) National Institute of Allergy and Infectious Diseases (NIAID), a new Autoimmunity Center of Excellence has been established at the University of Pennsylvania. This center is the fifth of its kind in the United States.

Penn professors Dr. Amit Bar-Or, Dr. Luning Prak, and Dr. Aimee Payne were awarded the grant to establish the clinical center which will bring together professors of dermatology, neurology, and pathology to study the role of B cells in autoimmune diseases.

Dr. Payne will lead a clinical trial testing a new immunotherapy technique called DSG3-CAART on pemphigus vulgaris, an autoimmune disease that causes blistering of the skin and mucus membranes. She says that the grant will enable her to use human participants in studies, unlike her previous research in the area.

Dr. Bar-Or will lead a clinical trial which focuses on Ocrelizumab, a medication that effectively treats multiple sclerosis (MS) but can leave patients at risk for infection. Some patients experience remission of MS despite discontinuing their use of Ocrelizumab, and Bar-Or's research will explore the potential of using the medication for limited periods of time and creating a system for more tailored patient treatment. He says, "This will let us be one step closer towards the concept of precision medicine."

Dr. Prak will lead a project using tissue samples from Penn's Human Pancreas Analysis Program to assess the protein-level mechanisms of type 1 diabetes. She says that the grant will enable Penn's Autoimmunity Center of Excellence to work with investigators across the country.

Dr. Payne says that the Center at Penn will establish a mentor program to help researchers pursue careers in autoimmunity, including the next generation of "physician-scientists," those who both perform research and see patients. ■

--Source: "Penn receives $4.5 million to create center on autoimmune disease research," Harshita Gupta, The Daily Pennsylvanian, University of Pennsylvania, June 19, 2019

Mammograms and women with disabilities

Having a screening mammogram regularly is an important way to maintain good health, but it's "easier said than done" for women with certain disabilities. In one study, it was shown that the percentage of U.S. adult women 50-74 years of age who received a mammogram over a two-year period was 75 percent without disabilities compared with 61 percent with disabilities. What are some screening tips that might be helpful?

Besides the usual suggestions--blouse open in front, bra easily removed, no deodorant or body powder--the woman with disabilities might ask the following questions when scheduling a mammogram:

- How do I prepare if I use a wheelchair or a scooter?
- Can the machine be adjusted so that I can remain seated?
- How long is the appointment, and can I have more time if I need it?

Let the scheduling staff, radiology technicians, or radiologist know if you can/cannot sit upright with or without assistance, lift and move your arms, transfer from your chair/scooter, undress/dress without assistance. If you have any disability-related concerns, discuss them with your primary care physician, women's health specialist, radiologist, physician's assistant, or other healthcare professional.

A number of states have developed programs to help women with disabilities obtain screening for breast cancer. The Association of Maternal and Child Health Programs is one source of information. Also, the Centers for Disease Control and Prevention (CDC) offers "Breast Cancer Screening: The Right to Know" (https://www.cdc.gov/ncbddd/disabilityandhealth/righttoknow/). ■

--Source: "Breast Cancer Screening for Women with Disabilities," eParent.com, October 17, 2019

Families rule! Fall walks draw many family teams

One of the best things about participating in an AARDA Autoimmune Walk is the warmth and energy that families bring. This year families were in evidence more than ever--in New York, Pennsylvania, and California--walking to support loved ones in their fight with autoimmune disease; to honor the memories of those who had been lost; and to raise research funding for a cure.

The top team of this year's New York Autoimmune Walk, **Walter's Warriors**, walked to honor the memory of Walter Krokowski who lost his battle with granulomatosis with polyangiitis (formerly Wegener's disease) at age 27. Led by Walter's sister Ashley Krokowski, Walter's Warriors were 23 members strong and raised $5,855 for autoimmune research.

Team **Got Spoons?**, led by Rosalyn Heleniak, became the top team of the inaugural Pittsburgh Autoimmune Walk. This team of 12, which included Rosalyn's beloved pets Bentley Cash Heleniak and Cooper Jack Heleniak, raised $3,315.

In Culver City, California, 22 members of the **Purple Flares** team, led by Jasmine Hackett, raised $1,445 to become the top team of the 5th Los Angeles Autoimmune Walk.

On the same day, just five hours from Culver City, a Virtual Walk was held in Lafayette, California. Team **Walk for Adley** raised $11,041 in memory of 10-year-old Adley Osborne who lost her battle with Evans syndrome last summer. The team of 230 members, most of them families with children, was led by Emma Coffey, a school psychologist in the Lafayette School District.

You, too, can help spread the word and share the warmth! Register your family for an AARDA Walk in 2020--or register for yourself. Contact Event Coordinator Deb Patrick at dpatrick@aarda.org or 586-776-3900 ext. 6. Sponsorships and auction donations are welcome. ■

Celiac research shows promising results

Still in clinical trials but holding promise for celiac disease patients is new technology showing that it is possible to induce immune tolerance to gluten in individuals with celiac disease. Presently no treatment is available specifically for celiac disease except the avoidance of gluten which is found in wheat, barley, rye, and oats unless certified gluten-free. The phase 2 clinical trial has been completed.

The technology developed in the laboratory of Stephen Miller, Ph.D., professor of microbiology and immunology at Northwestern University Feinberg School of Medicine, is a biodegradable nanoparticle containing gluten that teaches the immune system that the antigen (allergen) is safe. The nanoparticle acts like a Trojan horse, hiding the allergen in a friendly shell to convince the immune system not to attack it.

When the allergen-loaded nanoparticle is injected into the bloodstream, the immune system isn't concerned with it because it sees the particle as innocuous debris. Then the nanoparticle and its hidden cargo are consumed by a macrophage, essentially a vacuum cleaner cell that clears cellular debris and pathogens from the body. The immune system then shuts down its attack on the allergen, and the immune system is reset to normal.

In the celiac disease trial, the nanoparticle was loaded with gliadin, the major component of dietary gluten. A week after treatment, the patients were fed gluten for 14 days. Without treatment, celiac patients eating gluten developed marked immune responses to gliadin and damage in their small intestine. Celiac patients treated with the COUR nanoparticle CNP-101 showed 90 percent less inflammation response than untreated patients. By stopping the inflammatory response, CNP-101 showed the ability to protect the intestines from gluten-related injury.

Dr. Ciaran Kelly, professor of medicine at Harvard Medical School and director of the Celiac Center at Beth Israel Deaconess Medical Center, commented, "Celiac disease is unlike many other autoimmune disorders because the offending antigen (environmental trigger) is well known--gluten in the diet. This makes celiac disease a perfect condition to address using this exciting nanoparticle induced immune tolerance approach."

Beyond celiac disease, the finding sets the stage for the technology to treat a host of other diseases and allergies including multiple sclerosis, type 1 diabetes, peanut allergy, asthma, and more. ■

--Source: Excerpted from "New treatment may reverse celiac disease," Maria Paul, Northwestern Now (//), Northwestern University, Evanston, Illinois, October 22, 2019

Human health and intestinal gases subject of study

Out of growing interest in the microbiome of the gut comes increasing awareness of the important role that the gases of the intestines play in digestive health. A study led by a research team at the University of New South Wales (UNSW) Sidney has examined all available literature on gastrointestinal gases, their interactions with the microbiome of the gut, their associated disorders, and the way that they can be measured and analyzed.

Lead author Professor Kourosh Kalantar-Zadeh, of the UNSW School of Chemical Engineering, says that the purpose of the study is to show how vital the gases of the gut are for human health. He points out that even Benjamin Franklin, 200 years ago, wrote to the Royal Academy of Brussels suggesting the possible development of a drug that might be "wholesome and not disagreeable, to be mix'd with our common Food or Sauces" to render the bodily gases "inoffensive."

While Franklin's challenge continues to elude modern pharmacology, a change of diet to avoid foods rich in sulphide such as broccoli, cauliflower, eggs, beef, and garlic, could be helpful.

Professor Kalantar-Zadeh says, "Interestingly, the gases in most abundance throughout the digestive system--nitrogen, carbon dioxide, hydrogen, and even methane--are odorless." By contrast, smelly sulphide gases exist in trace amounts in the colon. "The rest," says the Professor, "are mostly by-products of the microbiome--the colonies of bacteria living in our intestines--as they break down fats, carbohydrates, and proteins."

With the exception of nitrogen, the gases found in the intestine have been linked with various gut diseases, including malabsorption of food, irritable bowel syndrome (IBS), inflammatory bowel disease (IBD), and even colon cancer, especially when the gas profiles deviate from the norm.

The UNSW team, together with Monash University and startup company Almo Biosciences, is commercializing a tool to analyze the gastrointestinal gases within the body in the form of an ingestible capsule loaded with gas-sensing technology. The capsule can detect gaseous biomarkers as it passes through the gut, all the while transmitting the captured data wirelessly to the cloud for collection and analysis.

"In early trials, the capsule has accurately shown the onset of food-related fermentation in the gut, which would be immensely valuable for clinical studies of food digestion and normal gut function," states Professor Zalantar-Zadeh. He says that this non-invasive process ensures that the gases can be analyzed in their natural environment. ■

--Source: "Gutsy effort to produce a comprehensive study of intestinal gases," University of New South Wales, September 16, 2019, via Newswise

~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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Sjögren's article continued from page 7

According to authors Rita Baron-Faust and Jill P. Buyon, writing in *The Autoimmune Connection*, "Sjögren's syndrome is actually the second most common autoimmune rheumatic disease after rheumatoid arthritis." Generally thought of as "dry eye syndrome," it is much more than dry eyes or dry mouth. Sjögren's syndrome targets the moisture-producing glands and tissues, including mucous membranes in the nose, vagina, and lungs.

Besides the problem of dry eyes, there can be debilitating fatigue, aching joints, and "small fiber neuropathy" in forearms and legs, and other problems. Secondary Sjögren's syndrome frequently accompanies other autoimmune diseases. ■

--Sources: Excerpted and adapted from "New Study could lead to personalized treatment for debilitating autoimmune condition," Newcastle University, Reviewer Kate Anderson, B.Sc., October 29, 2019, via www.news-medical.net; and The Autoimmune Connection, Rita Baron-Faust, MPH, CHES, and Jill P. Buyon, M.D., McGraw-Hill Education, 2016

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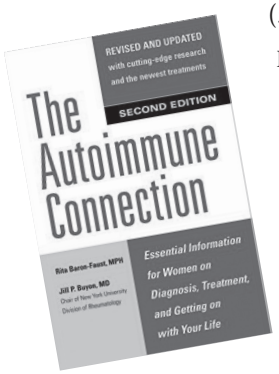

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