

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. 1, March 2019

March is ADAM ~ Autoimmune Disease Awareness Month



President/Executive Director's Message - Virginia Ladd

Dear AARDA Friends,

How exciting to have a whole month to bring special attention to autoimmune disease! AARDA staff and others have planned educational and awareness activities for each of those 31 days in March. Look for ADAM, Autoimmune Disease Awareness Month, exposure in

national, local, and social network sources.

You can take part in ADAM by sharing autoimmune disease awareness and education. Even one person reached may be a life saved. As one person has written: "The more people are informed, they then take their education out into the world and word continues to spread."

- ◆ Write a Letter to the Editor in your local newspaper.
- ◆ Contact AARDA for brochures to share with doctors' offices, libraries, or friends.
- ◆ Share an *InFocus*, maybe a past issue, with an autoimmune patient or interested other.
- ◆ Contact your representative to urge increased funding for autoimmune disease research.
- ◆ Commit to talking about autoimmune disease as a category of disease, not just a single disease.
- ◆ Take the ARNet survey to help researchers gain insight into autoimmune disease (www.aarda.org/arnet).
- ◆ Make a donation to AARDA to help support and continue our work.
- ◆ Paint your nails! Our Oklahoma Local Contact has a clever idea. She paints her nails to show the many autoimmune diseases afflicting her family, a different color for each autoimmune disease. When she is questioned about the variety of colors, she explains about the diseases represented--autoimmune education and awareness with a bit of fun.

Also highlighting ADAM is another congressional briefing, "The Hidden Epidemic of Autoimmune Disease," which we are bringing to Capitol Hill on Thursday, March 21. Upon request, AARDA provides a travel grant of \$1,000 to all member organizations of the National

Coalition of Autoimmune Groups (NCAPG) with budgets under \$1 million to allow their representatives to attend this briefing.

Autoimmune advocacy affecting physicians and their patients continues. One of the most complicated but meaningful is the "Let MI Doctors Decide," addressing the issues surrounding step therapy, in which the doctor's orders may be sidestepped in favor of the insurance company's choice of medication. While this campaign has started in Michigan, it soon may be ready to reach into other states. We will keep you informed. To read stories from doctors and patients who have navigated the step therapy process, submit your own story, or learn more about working through step therapy, log onto www.letMIDoctorsDecide.org.

Our three webinars held in 2018 ("The Doctor-Patient Relationship," "Self-Advocacy & Clinical Trials," and "Q and A with Dr. Rose") received great feedback--enough for us to continue this program. More are scheduled to be held throughout the year. Viewers can see our previous webinars at www.youtube.com/AARDATube.

So much done--and so much still to do! This letter gives you a smattering of what's been going on, but look for news on the following pages. We hope that you enjoy this issue of *InFocus* celebrating ADAM 2019.

Know that YOU are the reason for AARDA. All of us at AARDA are grateful for your interest, support, and friendship.

With appreciation,
Virginia



The Autoimmune Research Network

ARNet

Patient powered
database to
further
autoimmune
disease research



- Help find new drugs and treatments, through clinical trial opportunities
- Help develop tests to get faster diagnoses.
- Help researchers learn why autoimmune diseases cluster.



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22100 Gratiot Avenue, Eastpointe, MI 48021-2227
Phone 586-776-3900; Fax 586-776-3903;
E-mail: aarda@aarda.org; Web: www.aarda.org

~ Editor ~

Eula M. Hoover, Executive Assistant

~ Editorial Reviewers ~

Virginia T. Ladd, AARDA President/Executive Director

Katie Simons, Project Manager

~ Contributors ~

Deb Patrick, Special Events and National Walk Coordinator

Katie Simons, Project Manager

Sandra Cobb – Resource Development and

Community Outreach Manager

~ Distribution Coordinators ~

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Aricka Tuttle, Database Assistant, Patient Educator

and Support Specialist

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AARDA's Annual Spring Event turns 19

Not simply a local event but a major fund raiser and awareness event to support AARDA's mission as a whole, AARDA's Annual Spring Benefit began 19 years ago as a Victorian Tea. Since that time, the event has enjoyed many themes--a Derby luncheon; a "Return to Downton" fantasy; a variety of historical and current fashion shows; and perhaps the most mission-focused theme of all, the 2018 "Bound by a Common Thread" lunch with fashions at the grand Masonic Temple, in Detroit.

This year, on Saturday, May 11, AARDA will continue its theme of "Bound by a Common Thread" with lunch and a "Fast Fashion" show, at the Detroit Athletic Club (DAC) in downtown Detroit. The fashion show features the work of students in the Wayne State University Fashion Design & Merchandising program. Returning as emcee will be WDIV, Channel 4, Style Editor Jon Jordan, a Detroit style icon.

A highlight of the event will be the presentation of AARDA's Champion Award to race car driver Kyle Marcelli, winner of the 2016 Chevrolet Detroit Belle Isle Grand Prix and a brand ambassador for AARDA. Kyle will be honored for driving autoimmune awareness to new heights last year as he crossed the finish line with the AARDA logo on his car--a winner!

Bound by a Common Thread at the DAC also will include a V.I.P. reception with our honoree, a silent auction, and Photo Booth fun. Our goals are to ♦ raise program funding, ♦ highlight the common thread of autoimmunity that binds all autoimmune patients together, and ♦ underscore the need for improved patient care, including earlier diagnoses and more effective treatments than are currently available.

Joining AARDA staff on the event planning committee are very talented volunteers Donna DiSante, Ebony Dooley, Erica Copeland, Tracy Holloway, and Carrie Ryckman.

For a silent auction preview or to purchase tickets, visit aardabbct2.eventbrite.com. Early Bird Tickets (reduced rate) are available through March 31. Ticket prices rise after that date.



PHOTO BY LAURIE TENNENT

Jon Jordan



Pouring from an empty cup

Carey Nelson Handley, Special Needs Advisor and mother of a daughter with special needs, comes to an understanding of her own needs in the midst of her busy life.

Several years ago when I was in counseling for depression, my therapist asked when was the last time that I went away with the girls for the weekend. My very clever response was to look at her blankly and say, "Uh...never. It's never crossed my mind." She returned the blank look and, speaking with disbelief, told me that it was about time I did exactly that.

Later that night, as I was contemplating why it had never crossed my mind, I came to the conclusion that I was so busy taking care of everyone else that I hadn't stopped to think of doing anything for myself. While my daughter was in a school 25 miles from home, each trip, to and from, twice each day, required a half hour through heavy traffic. Upon returning home each morning, I would begin my day of networking and doing my graphic design work for my home-based business before heading back to school. Then there were therapies and doctors and then back home to make dinner and take care of the dogs. I realized that I had just assumed that I always had to be there.

It was a surprise when my husband told me to go visit a friend a few hours away for the weekend. He never had told me I had to be around all the time. After all, he was, and is, perfectly capable of taking care of things at home. He's not one of those dads who think they're babysitting when they watch

their own children. I guess I just thought that the world as we knew it would end if I wasn't there to make sure things ran smoothly.

A few weekends later, I packed a bag and drove to see my friend who, knowing I love taking pictures, planned the weekend around my hobby. I had a great time and vowed to do it again soon. Until I didn't.

Years went by, and I fell back into the same routine of taking care of everyone except myself. Something always had to be done, and it seemed like too much trouble to try to arrange a weekend away.

Recently, a networking group that I belong to participated in a psychological profile. As I outlined my day, it became obvious that I once again had forgotten that thing called "free time." It was firmly suggested that I get away for at least a few hours over the weekend to take some pictures since that's what I said I enjoy doing. I even was provided with an address in the country where I could go to take photos of animals, a particular interest of mine.

The next time I saw the group leader, I handed her several pictures that I had taken that weekend. She asked how it felt, and I told her it seemed rather strange. As I sat with my camera, I had to will myself to relax. I felt that I should be doing something (because I always am). I had to force myself not to look



at my phone. I capped the day off by seeing a movie with my mother, which I hadn't done in quite a while. I came back calmer and a bit more recharged.

This weekend reminded me that I can't be any good to others if I'm not willing to be good to myself. No one told me I couldn't. No one except me. Whether I will make this a habit or a practice, I can't say. But I can promise to try--to learn to say "no" to taking on too much and "yes" to taking care of myself so that I can be better for everyone else.

There's an old saying: You can't pour from an empty cup. I just have to remind myself that the cup is refillable. ■

--Source: Excerpted from "On Time for Myself," Carey Nelson Handley, (www.eParent.com/author/designwall/)

ADAM - It's been 12 years!

ADAM is in full swing. For most of us, Autoimmune Disease Awareness Month (ADAM) is every month. It's part of us. But March is the one month each year when we concentrate on telling the world--or our part of it--what "autoimmune" means to the 50 million Americans and many more autoimmune disease-affected individuals around the world.

Having been founded in Detroit, the American Autoimmune Related Diseases Association was confused, in its early days, with being an automobile organization, as well as an AIDS organization, and even an airline. For that reason, Autoimmune Disease Awareness Month--our month--was established in 2007, first in May and then switched to March for increased media opportunities.

In its first month-long ADAM celebration, AARDA undertook a series of events planned to call on Americans to learn about autoimmune diseases that were not well known or well understood by the medical and research communities and the general public at large.

Autoimmune disease was, and still is, a story that needs to be told. Very effective have been the efforts of AARDA as an organization plus our AARDA members and friends "in the field" who have told their stories among their own friends and local media. To everyone in AARDA: Let's be our own "people blitz" for ADAM 2019, Autoimmune Disease Awareness Month. Let's save lives. ■



Newly Diagnosed? Now what? 153 Strategies to Help You Take Action and Cope After Your Medical Diagnosis

Prolific writer and internationally renowned psychologist Robert H. Phillips, Ph.D., also known

as “Dr. Coping,” calls on his experience and knowledge gained over 40 years to write this book for newly diagnosed patients and those significant others who want to support them. It is a book of hope, wise counsel, and down-to-earth strategies.

Dr. Phillips suggests that three initial goals prepare one for dealing with the diagnosis: (1) try to do what you can about the illness itself, (2) try to cope with any of the ways it is affecting your life, and (3) take charge and live a happier life, *despite* the diagnosis.

Chapter 1 starts with “I need to get ready to help myself.” The setting up of a “Coping” book, using a looseleaf notebook, is explained. This also can be set up using your computer, tablet, or mobile device--whatever works for you. This book can be strictly factual--list of doctors, appointments, medications--or very personal, almost like a journal to record your feelings and experiences.

Subsequent chapters deal with “I need to understand,” “I need to accept,” “I need to get back on my feet,” “I need to participate in my treatment,” “I need to work with my treatment team,” “I need to strengthen my inner self,” “I need to work on my physical well-being,” “I need to benefit from support,” and “I need to move on.” Within each chapter are a number of strategies used to facilitate the “I need...” of each chapter.

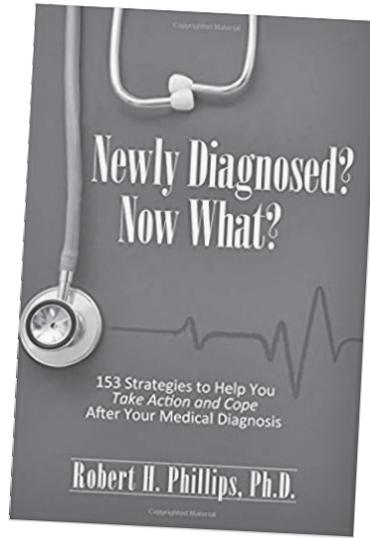
Dr. Phillips wraps up with “What’s Next? Keep moving forward, regardless...” He writes: “Always remember to have hope, and try to maintain a positive attitude. New advances are being made in the field of medicine almost every day. Remember that statistics are just numbers and there are always success stories. Why can’t you be one of them?”

Dr. Phillips says, “Remember that you are not defined by your illness. Don’t let yourself feel that way. Focus on the whole person that you are.”

The book includes suggestions for help that is available to the reader from Dr. Phillips’ Center for Coping.

Newly Diagnosed? Now What? is like having a friend accompany you as you step into your new experience. You will read the book, take notes, and skim through again and again. As the author says, “The good news is that you’re now equipped with dozens and dozens of strategies to help you move forward with your diagnosis.”

--*Newly Diagnosed? Now What?* Published by Coping Press, www.copingpress.com, February 2018, 187 pp., softcover ■



Grassroots fund raisers serve AARDA’s mission

Grassroots events organizers and project leaders continue to raise funds and autoimmune awareness on behalf of AARDA and those we serve. With creativity and dedication, a variety of events raised \$6,821.85 over a period of four months. Here is a sampling...

- **Truffles** - University of Florida student Sarah Bowlby, a member of Kappa Kappa Gamma sorority, decided that truffles were treats that were budget-friendly, compactly stored, and easily transported around campus. At one of her KKG meetings, she spoke about the impact of her journey with an autoimmune disease, the impact of autoimmune diseases, and the lack of public awareness. Her sorority sisters pitched in to help, and they made over 300 truffles, including gluten-free. They raised \$500 in one week! Sarah writes, “With the increase in research and awareness, I believe the future of autoimmune illnesses is very bright!”

- **Achelois Palette eyeshadow** - JaLeeda Floyd and Kalon Kosmetics LLC are dedicating their eyeshadow to autoimmune awareness, and 20 percent of sales go to AARDA.

- **RC Fitnez Studio, Stone Mountain, GA** - Renee Burwell and Stephanie Edwards-Crawl raised \$455 for AARDA through a fitness event.

- **Autoimmuni-Tea** - Karla Mazariegos, Donna Mazzola, and their creative company raised \$340 in a fundraiser for AARDA

- **Boston Marathon** - This effort by Ryan Lubben has brought \$800 to AARDA.

- **Cara Lian LeBedda** - Friends of Cara raised \$50 as a tribute to her.

- **Virtual Walk** - Alex Payne, a senior at E.S. Laney High School, raised \$1,200 for AARDA through a Virtual Walk in Wilmington, NC. Alex’s mom has an autoimmune disease.

- **Facebook Fund Raisers** - These raised \$82,708 during the 2018 calendar year.

Do you have a possible fundraising idea? How about a jeans day at your workplace? Bowling can be fun. Do you want to explore possibilities? Just about anywhere will do--school, workplace, community center, worship center. To explore a grassroots idea, email dpatrik@aarda.org. The possibilities are endless. ■

Quote to ponder & enjoy...

History is a vast early warning system.

~ Norman Cousins

Women are people, too!

Many times when visiting doctors' offices, women feel that they are not being taken seriously. A recent article in Prevention Magazine calls attention to that problem. We offer some information from that article.

In Ancient Greece, it was believed that a woman's uterus could wander throughout her body, causing symptoms wherever it landed. Thus was born the diagnosis of "hysteria," derived from *hystera*, the Greek word for uterus, to apply to problems plaguing women.

Hysteria as a medical diagnosis appeared in medical texts for centuries, the definition evolving over time eventually to describe psychological issues in women. Doctors diagnosed hysteria through the early 20th century. It was dropped by the American Psychiatric Association as an official diagnosis in 1980.

Research suggests women are more likely than men to be on the receiving end of medical mistakes, and the conditions can be life-threatening. Compared to men, women are 50 percent more likely to receive the wrong diagnosis following a heart attack, according to a study from the University of Leeds, in the UK; and 33 percent are more likely to be misdiagnosed following a stroke, according to research published in *Diagnosis*.

Why do these mistakes occur? Some doctors have ingrained prejudice against women; but also women are under-represented in medical research. "There's a growing awareness of the importance of including adequate numbers of women in clinical studies," says Reshma Jaggi, M.D., director of the Center for Bioethics and Social Sciences in Medicine, at the University of Michigan. She says that "there's a deeply rooted concept that the 70kg white male is 'normal' and that women are deviations from that model."

Dr. Jaggi observes, "There are important biologic differences between men and women that may lead to differences in, say, how drugs are metabolized." She says, "Generalizing from studies conducted largely or exclusively in men to make treatment recommendations for women can be inappropriate and downright dangerous."



The three times women are most likely to be misdiagnosed are when experiencing a heart attack or heart attack symptoms, when an autoimmune disease exists, and when a sex-specific condition develops, e.g., endometriosis or polycystic ovary syndrome (PCOS), since they have symptoms that may overlap with other issues.

Delayed diagnosis of gynecological cancers also is common since they often mimic other conditions.

How to avoid becoming another victim of misdiagnosis? Don't be a passive patient, get a second opinion, bring up everything that's bothering you.

Barbara Goff, M.D., chair of obstetrics and gynecology at the University of Washington in Seattle, says, "Women often attribute symptoms to getting older or going through menopause, but it's important to mention anything that deviates from your normal."

"Lots of women are told to see a psychiatrist in the early stages of their illness," says Betty Diamond, M.D., head of the Center for Autoimmune and Musculoskeletal Diseases, Feinstein Center for Medical Research, Manhasset, New York, and chair of the Scientific Advisory Board of the American Autoimmune Related Diseases Association (AARDA).

Dr. Diamond advises, "Do your own research, then discuss your findings with your doctor. And don't leave the office until your questions are answered." ■

--Source: *Excerpted and adapted from "The Horrifying Reasons Why Women Are Constantly Let Down by Their Doctors," Kiera Carter, Prevention Magazine, January 31, 2019*

AARDA Community Outreach brings autoimmune education

In support of Autoimmune Disease Awareness Month (ADAM), AARDA is sponsoring or supporting the following outreach activities:

San Jose, California - AARDA is providing literature for San Jose's First Annual Walk for Rare Diseases at Martin Murphy Middle School, March 2, 9:00 a.m. to 12:00 noon.

Clinton Township, Michigan - AARDA is presenting a "Lunch & Learn" at Clinton Township Senior Adult Life Center, in Clinton Township, on March 12, at 12:30 p.m.

Won't you join us and help spread the word about ADAM and autoimmune disease? How can you help?

- Let us know about a company or faith organization in your community where we may send educational literature.
- Is there an organization that might be willing to Adopt-a-Day in March and make a donation in support of ADAM? AARDA also will provide educational literature to the organization. Donate online at www.aarda.org/ADAM.

Other outreach activities: May 12 to May 18, 2019, is National Women's Health Week. AARDA is looking to connect with women's groups to share educational materials regarding autoimmune disease during National Women's Health Week. To assist in this outreach in your local or state area, please contact AARDA Resource Development and Community Outreach Manager Sandra Cobb at scobb@aarda.org.

Savvy methods to wellness worth observing

Most individuals agree that good nutrition is important. As we were growing up, we heard versions of “it’s good for you,” usually when we refused to eat our vegetables. Now, as adults, we are perhaps a little more receptive to that advice. In fact, nutritionists and others are advising that a proper diet—including those vegetables and “savvy methods to wellness” can be of utmost importance to the care and treatment of autoimmune disease.

Consider the case of one autoimmune disease, multiple sclerosis and its related fatigue. Terry Wahls, M.D, clinical professor of medicine, nutritional epidemiology at the University of Iowa, says that research suggests that fatigue in the multiple sclerosis (MS) patient is a reflection of brain inflammation. Thus, removing foods that drive up the inflammatory cytokines (inflammation molecules) may be very helpful.

She says that, for example, people who are genetically vulnerable to having a severe immune response to gluten or casein may find a marked improvement in energy after adopting a meticulously gluten-free and casein-free diet.

Dr. Wahls teaches clinicians about using therapeutic diet and lifestyle to treat autoimmune disease, and she believes that doctors could be helping their patients by setting a proper course of action. “We rely on the food we eat to have the building blocks to make the proteins that are necessary for cellular structures.” She says, “We also rely on the foods to speak to our genes and our microbes to create the cellular environment—which leads to a health-promoting environment or disease-promoting environment.”

Dr. Wahls explains that diet quality impacts gene expression and one’s microbiome (gut), both of which have a huge impact on risk of developing autoimmune problems. Leaky gut, for instance, is an early step that leads to leaking of the incompletely digested food proteins into the blood stream.

“Eating very little fiber starves the health-promoting bacteria that live in the bowels, which speak to our immune cells and create a pro-inflammatory environment or an anti-inflammatory environment,” Dr. Wahls says. “Furthermore, the bacteria breakdown the foods and help digest food, make vitamins, and help to absorb our food so that we utilize the food we consume.”

Dr. Anne Zauderer, of the Riordan Clinic, in Wichita, Kansas, writes: “Our bodies’ first line of defense is the cells that line our



digestive tract. These cells, called epithelial cells, provide a strong barrier against anything crossing into the bloodstream that our body doesn’t want there. Proteins cement these cells together; this is like building an impenetrable wall.”

Dr. Zauderer points out that our immune system makes up another one of our body’s defenses against outside invaders, and we wouldn’t last a day without our immune system. She says that approximately 80 percent of our immune system surrounds the gut. She advises, “It just makes sense to put the greatest number of guards around one of the most vulnerable areas in the body.” Dr. Zauderer comments that “the gut plays a significant role in the development and management of autoimmune conditions.”

Dr. Zauderer says, “The key with the immune system is BALANCE.” She adds, “The good news is there are many ways you can help promote balance and support for the immune system.” Among those ways are probiotics, digestive enzymes, vitamin D, and others.

Also in line with a savvy method to wellness, Dr. Wahls recommends a sound exercise program. ■

--Sources: Excerpted from “A Wellness Approach to MS-Related Fatigue,” Keith Loria, Autoimmune Diseases, Health Management, Medical Health Executive Articles, January 4, 2019; “How Your Gut Affects Your Immune System...And Makes You Sick,” Dr. Anne Zauderer, Health Hunters Newsletter, Vol. 28, No. 8, Riordan Clinic, Wichita, Kansas



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AARDA Autoimmune Walks and Public Forums scheduled



What makes a great AARDA Walk? No matter where or when a Walk may be, it's the people who make it great. Women and men of all ages, teens, and toddlers show up, bringing with them a wonderful energy, optimism, goodwill, and hope.

Walking is part of the event, but participants hear from speakers, such as AARDA Board member and autoimmune patient and advocate Lilly Stairs who spoke at the November 2018 Los Angeles area walk. Lilly, Head of Patient Advocacy for Clara Health, spoke about the power of being your own best advocate. Participants at the LA walk enjoyed the beautiful voice of songstress Lori Jenaire, also an autoimmune patient. Singer-songwriter Dayna Caddell, who has been an autoimmune advocate since 2012, shared her autoimmune story.

Dayna Caddell will be the Walk Ambassador for the **5th Los Angeles Area Autoimmune Walk** on Sunday, November 3, 2019, at Lake Balboa Park, Van Nuys, California.

Other scheduled 2019 Autoimmune Walks and Public Forums, with details to be announced, are the following:

Metro Detroit Walkabout and Public Forum - Saturday, August 24, 10:00 a.m., VisTaTech Center, Schoolcraft College, Livonia, Michigan

New York Walk - Sunday, September 15, Hudson River Park, Pier 45 (Time to be announced)

Virtual Walk - Any day, Anytime, Anywhere, your choice

To register for an Autoimmune Walk or receive more information, you may visit www.AutoimmuneWalk.org. Like us on Facebook at [www/Facebook.com/AutoimmuneWalk](https://www.facebook.com/AutoimmuneWalk) or tweet us @ [AutoimmuneWalk](https://twitter.com/AutoimmuneWalk). Also, you may call (855-239-2557) or email (walk@aarda.org) with questions or suggestions. ■



With Special Thoughts...

Tributes

Rei Takver - In honor - Cambridge-Ellis School Administrative Team (Katie Clark)
Nancy Harding - In her honor for the holidays - Dick & Pam McSeveney
Mary Michael Maggio - In her honor for the holidays - Paul, Janet & Elizabeth Caldarelli
Nancy Linn & Neil Langberg - In their honor for the New Year - Roz & Pete Fanello
Julie Kozumplik - In her honor for her birthday - Frances & Mike Kozumplik
Patrick Wells - In his honor for the holidays - Christopher Dubey
Narda Johnson - In her honor for Christmas - Elizabeth & Delton Boardman
Judy Brack - In her honor for Christmas - Elizabeth & Delton Boardman
Mary Fran Niemeyer - In her honor for Christmas - John Cretzmeyer
Beth A. Yumlu - In her honor - Zada K. Yumlu
Kelli Graham - In her honor for Christmas - Lance Perkins
Kevin & Lori Martin - In their honor for Christmas - Maureen Burgess
Jim and Becky Witt - In their honor for Christmas - Frederick Witt & Family
Ali, Jay, Keith and Laura Howard - In their honor - Leigh Moore & Shawne Shiflett
Marina Yonan - In her honor for Christmas - Rebecca Yonan
Leah Wilkey - In her honor for her birthday - Keith Milligan
Parks & Kelly Kessler - In their honor for Christmas - Konstantin Yemelyanov
Ma & Pa Maloney - In their honor for Christmas - Michael Maloney
Mara Sims - In her honor for her continued perseverance and bravery - Norine Sims
Christine Johnson - In her honor for Christmas - Christine Tunstall
Carly Farrell & Patrice Farrell - In their honor for the holidays - James Farrell HS General Contractors
John M. DeVito - In his honor for his birthday - Lillian & John M. DeVito, Jr.
Orly Benezra - In her honor for her birthday - Rifka Claypool

Memorials

Elizabeth Lynn Allard - Terry and Tracy Smith, Anonymous
Michel Armstrong - Joan & Pete Schessler
Margaret Awbery - David R. Awbery
Ralph Bammert, Jr. - Virginia Ladd
Dr. Marvin Bellin - Judith C. Bellin
Dorothy Brew-Miller - Carol L. Miller
William H. Davitt - Christine Hostetter
Mary Dixon-Callicott - Virginia Noland
Rosemary Dybowski - Mike & Kristen Burnett & Family
Helen Frost - Donald Frost
Steve Gardner - Your School Psych Family (Alison Gross)
Chris Gilbert - Karen Nauss
Judith R. Harris - Harris/Wilkinson Family Fund, Leonard Zimmerman
Cheryl Howell - Pamela Howell
Jonathan Josephs - Laura & Lawrence Josephs
Carol Ann Kaufman - Nancy Wrensch
Sloane Maria Mills - Pam Bethke-Cooper, Emily Cepak & Ann Ammon
Rosanne Moscato - Nancy Cangelose
Anita O. Nicolaides - Cleo Miliareisis
Lillian H. Peppercorn - Nigel, Lynn, Kelly & Chris Groves; Howard & June Deemer; Mark Sandi, Kent & Evan Groves; Tim & Lisa Miller
Susan A. Pickrell - Terry Pickrell
Treva Michele Pratt - Julie Baker & Family, Gary Barlet, Janice Grant & Family, Sherr Puchacz, Jimmy & Patsy Grissom
Thomas J. Quinn - Jane Quinn, Gerald & Kathleen Walsh, Maura & Kelly Quinn, William (Papa) Therrien, Sheila Hochlander
Judy Rantschler - Virginia "Ginny" Ramey
Linda L. Robinson - Ann & Gordon Willett
Diana Landau Sasson - Arrows Youth Hockey, Wanda Weaver, Maryanne Wittenberg, Keith Lavan, Natalie Bonvicin, Paulette & Doug Cywar, Laurie Berke-Weiss, Helene Rothstein, James & Dawn Crocicchia, Michael Dallos, Leonard & Helena Mazur, Paul Howe, Gruber-Jakubovitz Family
Corinne Scalzott - Leslie & Charlene Scalzott
Abinaya "Abi" Shanmugaraj - The Kabbage Team (Kabbage Inc.)
Lisa B. Sherlock - William Sherlock
Mary Simkin - Earl & Tina Williams
Roselyn R. Weil - Marcie Weil
Meghan K. Williams - George & Joyce Dworsky
Dawn L. Zierzow - Mary Ann Zabik; Beverly & Rodney Stone Sr., Deborah Maccalous, Patricia & Roger Newbury, Carolyn Ford, Charles & Patricia Rossi



How does the body restrain autoimmune and oncological diseases?

Scientists at the Memorial Sloan Kettering Cancer Center and the Higher School of Economics, the Institute of Bioorganic Chemistry of the Russian Academy of Sciences created a genetic model that helps to understand how the body restrains autoimmune and oncological diseases.

The immune systems of humans and animals enable them to resist infectious diseases by recognizing and destroying pathogens, such as viruses, bacteria, fungi, protozoa, and multicellular parasites. The T lymphocyte, or “helper lymphocyte,” is a special type of immune cell that identifies pathogens and helps other immune cells destroy both the pathogens and the cells they infect.

The helper lymphocytes also contain a specialized lineage, called a T-regulatory, or “Treg,” that instead of helping to fight infection, actually inhibits the response of normal lymphocytes. Mutations that interfere with the development and proper functioning of Treg cells lead to disastrous consequences for the body. Mice and humans without Treg cells develop fatal autoimmune diseases caused by T-helper cells’ uncontrolled attack on the body’s own cells.

The researchers studied the properties of the Foxp3 protein that is responsible for the development and proper functioning of Treg cells. They found that removing the

Foxp3 protein gene from the genomic DNA prevent development of Treg cells. This leads to the death of the organism.

It also is known that numerous autoimmune diseases are associated with abnormal Foxp3 synthesis and Treg cell quantities. The Foxp3 protein does not work alone, but, rather, as part of a complex of proteins that help it regulate the work of genes necessary for the proper function of Treg cells. That set of proteins includes Foxp1, which has been the subject of much less research.

The authors of this study, under the guidance of scientist Aleksander Rudensky, created a genetic model to explain exactly how the Foxp1 protein affects Foxp3. They began the process by removing part of the Foxp1 gene in Treg from laboratory mice.

A comparison of the “normal” cells with the cells in which Foxp1 had been removed revealed that Foxp3 is much worse at binding DNA in the absence of Foxp1. That is, the genes of the proteins crucial for the proper functioning of Treg cells do not work correctly without Foxp1. Thus, if Foxp3 is essential for Treg, then Foxp1 also holds great importance because its removal negatively affects Foxp3.

According to the researchers, achieving an understanding of the structure of the complex of proteins that includes Foxp3 and

Foxp1 is the key to creating drugs that can selectively affect Treg cells.

“The results significantly broaden our knowledge of the molecular mechanisms regulating immunological tolerance that can be used for treating cancer and autoimmune diseases,” notes Yury Rubtsov, a co-author of the study, who is associate professor of the Higher School of Economics faculty of Biology and Biotechnologies and senior researcher at the Institute of Bioorganic chemistry of the Russian Academy of Sciences.

Rubtsov adds, “Cancerous tumours attract Treg cells to defend themselves against the body’s immune system. The more Treg cells present in the tumour, the worse the patients’ prognosis. Thus, if we could control the quantity and activity of Treg cells by, for example, decreasing them in the case of a tumour or, on the contrary, increasing them in the case of autoimmune disease, we could create safe medicines for treating heretofore incurable illnesses.”

--Source: Adapted from “Researchers identify possible role of Foxp1 protein in control of autoimmune diseases,” National Research University Higher School of Economics, via EurekaAlert! Science News, February 25, 2019

New diagnosis and early intervention of lupus studied

A University of Oklahoma researcher, Dr. Si Wu, and collaborators from the Oklahoma Medical Research Foundation and Indiana University are developing new strategies leading to diagnosis and early intervention of lupus, an autoimmune disease that may affect up to 1.5 million Americans. Dr. Wu is an assistant professor, Department of Chemistry and Biochemistry, Oklahoma University College of Arts and Sciences.

Dr. Wu says, “We are providing the first snapshot of autoantibody development in lupus patients by developing a novel detection method using a top-down mass spectrometry approach for identifying disease-specific autoantibodies quickly.” She adds, “This may lead to novel biomarkers and a foundation for new strategies for the early detection of lupus. To our knowledge, we are the first to apply this approach to understanding how autoantibodies become pathogenic.”

Dr. Ken Smith, Oklahoma Medical Research Foundation investigator, is purifying antibodies from samples of over 50

patients from Oklahoma and surrounding states for this research. In collaboration with rheumatologists Dr. Judith James and Dr. Eliza Chakravarty, these longitudinal samples will come from well-characterized lupus patients collected over several decades, allowing for evaluation of the disease over time.

Dr. Xiaowen Liu, associate professor in the School of Informatics and Computing, Indiana University-Purdue University Indianapolis, will work with Dr. Wu on the development of the needed software tools.

The research team is providing the first quantitative top-down platform for characterizing these autoantibodies. After development, the top-down autoantibody characterization platform can be adapted easily to other autoimmune diseases. ■

--Source: “OU Researcher Developing New Approach for Early Intervention of Lupus,” Jana Smith, The University of Oklahoma, February 1, 2019

Discovery may improve treatment of rare autoimmune diseases

A team from Scripps Research has found a molecular cause of a group of rare autoimmune disorders, some so rare that only a few cases have been described in medical literature. These disorders include Singleton-Merten syndrome (SMS), Aicardi-Goutières syndrome, familial chilblain lupus, proteasome-associated autoinflammatory syndromes, and many others which involve improper stimulation of interferon, a key component of our frontline defense against pathogens.

Interferon earned its name because it literally interferes with the ability of viruses to make copies of themselves. The immune system relies on a gene call RIG-I, short for retinoic acid inducible gene-1, to signal for the release of interferon whenever certain viral markers are encountered.

RIG-I has to determine whether the markers are of foreign origin or are from its own body. The scientists demonstrated precisely how mistakes in a molecular proofreading system can lead to confusion and generate out-of-control interferon signaling, setting off development of autoimmune disease.

"This dysregulated molecular mechanism of RIG-I mediated RNA proofreading that we identified may help us understand and treat SMS and other autoimmune disorders," says Jie Zheng, PhD, a postdoctoral associate and the first author and co-corresponding author of the study. In SMS, patients develop serious bone, heart, muscle, and skin problems starting in early childhood, largely due

to chronic inflammation from an overactive immune system. The scientists' aim was to understand how two RIG-I mutations linked to SMS end up triggering autoimmunity.

Scientists have known that RIG-I has a particular segment that it keeps mostly covered and concealed. When RIG-I encounters and recognizes ribonucleic acid, or RNA, a close chemical cousin of DNA, this segment is supposed to briefly swing open and, thus, become available for binding to another protein called MAVS, an event that triggers the immune response. The researchers found that the two SMS-linked mutations, in subtly different ways, cause this key segment of RIG-I to become stuck open--making it much more likely to bind to MAVS and trigger an immune response.

The scientists now are using their data to attempt to find a way to target mutant RIG-I to target its inappropriate signaling to MAVS and thus alleviate the autoimmunity it causes.

Patrick Griffin, Ph.D, professor and co-chair of the Department of Molecular Medicine at Scripps Research's Florida campus, says that the new detailed understanding of RIG-I's dysfunction may not only provide insights into the origins of more common autoimmune disorders but also clarifies how RIG-I works normally to detect viruses, a discovery that may bring about development of new antiviral drugs. ■

--Source: *Excerpted from "Proofreading mistakes drive autoimmune disease involving key protein, scientists find," Scripps Research, Jupiter, Florida, December 18, 2018*

Purdue researchers announce new treatment options

A series of molecules that may provide more reliable relief with fewer side effects than some current treatments has been developed by Purdue University researchers. The new molecules overcome difficulties with current drugs in targeting the appropriate form of Janus kinase, which has four forms affecting cell signaling and gene expression. The new inhibitors, with a reduction in side effects shown in current therapies, may provide relief for people suffering from rheumatoid arthritis, psoriasis, myelofibrosis, and other autoimmune diseases.

"Our new molecules fit within the emerging field of therapeutically useful Janus kinase inhibitors that have attracted a lot of attention and excitement within the medicinal chemistry community and the general field of medicine," reports Dr. Mark Cushman, a distinguished professor of

medicinal chemistry, in Purdue's College of Pharmacy, and leader of the research team. He says, "Our compounds contribute a new structural chemotype that is expected to have pharmacological properties relative to the other known Janus kinase inhibitors."

Dr. Cushman, a member of the Purdue Center for Cancer Research, said the new molecules also show potential to allow for additional treatment options for people with autoimmune disease. Abnormalities of the immune system often lead to autoimmune disease or cancer.

Researchers filed a patent with the Purdue Office of Technology Commercialization, and the technology is available for licensing. ■

--Source: *Mark Cushman, "Purdue developing new treatment options for millions with autoimmune diseases," Chris Adam, Purdue University, December 8, 2018*

Yoga and RA study shows positive results

A recently published study shows that an eight-week intensive yoga practice significantly decreased the severity of physical and psychological symptoms in patients with active rheumatoid arthritis (RA). This was a mind-body intervention randomized trial to analyze the effects of practicing 120 minutes of yoga, five days a week for eight weeks.

Measurement improvements for patients in the test group suggest an immune regulatory role of yoga practice in the treatment of RA, stated lead investigator Rima Dada, M.D., Ph.D., All Institute of Medical Sciences, New Delhi, India. She said the research results provided evidence that yoga positively modifies the pathobiology of autoimmunity at cellular and molecular levels by targeting mind-body communications. ■

--Source: *"Yoga Regimen Reduces Severity of Rheumatoid Arthritis Symptoms..." Rima Dada, et al, Restorative Neurology and Neuroscience, IOS Press, Amsterdam NL, February 5, 2019*

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