



December brings AARDA's Annual Appeal. You are invited!



THANK YOU, THANK YOU, THANK YOU...If you volunteered for AARDA in 2014, if you donated valuable in-kind items and services, if you helped to spread the autoimmune word in your community and among friends and professionals, if you sent a note of appreciation, or if you contributed to the \$38,767 for last year's annual appeal... THANK YOU. With your support, AARDA has flourished. We hope that you, too, benefited in some way (and felt good about helping).

❖ **Now we invite you to step forward for AARDA's Annual Appeal, to contribute whatever you can to meet--or surpass--last year's total.** Demands for our services are increasing; costs are rising; projects for advocacy, awareness, education, both patient and professional, are needing support; and autoimmune diagnosis and treatment centers are awaiting funds for implementation. Also, very high on the "want" list are funding dollars for autoimmune researchers.

❖ **How can you contribute to AARDA's Annual Appeal?** You may send a check or money order to the AARDA office: 22100 Gratiot Avenue, Eastpointe, MI 48021; or contribute via credit card (Visa, MasterCard, American Express) by calling the AARDA office (586-776-3900) or going to our secure Web site (www.aarda.org).

Article continued on page 10

What happened in 2014? Let's see the "Overview of Major Accomplishments"

Research

- Continued research support for the following:
 - O'Leary-Wilson Autoimmune Disease Fellowship, basic autoimmune research, Johns Hopkins University
 - Autoimmune liver research, Johns Hopkins University
 - "Role of Sex Hormones in Regulation of Interferon Genes in Autoimmunity (SLE)," University of California, Los Angeles, CA
 - Pilot study, Autoimmune Diagnostic and Triage Center, MidMichigan Physicians Group, University of Michigan, Midland, MI

Education - Patient, Public, Scientific

- Sponsored, cosponsored, or supported the following:
 - "The Microbiome and Autoimmune Disease," Leesburg, VA
 - 9th International Congress on Autoimmunity, Nice, France
 - 16th Annual Autoimmunity Day, Center for Autoimmune Disease Research, Johns Hopkins University
 - Federation of Clinical Immunology Societies Annual Meeting "FOCiS 2014"
 - AARDA public forums, "What Every American Needs to Know About Autoimmune Disease," Atlanta, GA; Los Angeles, CA; Boston, MA; Seattle, WA; Midland, MI
 - "How to Dance in the Rain," Conference for the Autoimmune Community, Scleroderma Foundation Michigan Chapter and others, Grand Rapids, MI
 - American College of Rheumatology Annual Meeting (AARDA staffed display

booth), Boston, MA

- 3rd USA Science & Engineering Festival, Washington, DC
- Interdisciplinary Autoimmune Summit, Las Vegas, NV
- Launched Autoimmunity Curriculum for Elementary and Middle School Teachers
- Continued as a source of autoimmune disease information on WebMD
- Continued to offer "My Autoimmune Story" video on AARDA YouTube channel
- Maintained social networking sites (Facebook page, Twitter account)
- Published quarterly lay-friendly newsletter *InFocus*
- Made available informational brochure and PowerPoint presentation of AARDA's "Risk/Benefit" study
- Maintained 24-hour toll-free request line
- Provided referrals and non-medical information during office hours via the Patient Educator
- Provided free educational brochures and newsletters to numerous health-centered meetings and events
- Maintained Local Contact list with support groups as available

Advocacy and Awareness

- Continued facilitation of the National Coalition of Autoimmune Patient Groups (NCAPG)
- Co-sponsored with the NCAPG a news briefing at the National Press Club, Washington, DC
- Unveiled plans to create a new, first-of-its-kind National Autoimmune Disease Registry

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InFocus, a quarterly newsletter of the
American Autoimmune Related Diseases Association, Inc.
(DBA Autoimmune Diseases Association)

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

~ Editorial Reviewers ~

Virginia T. Ladd, AARDA President/Executive Director
Patricia C. Barber, Assistant Director

~ Editor ~

Eula M. Hoover, Executive Assistant

~ Contributor ~

Sharon L. Harris, Project Manager

~ Distribution Coordinator ~

Cathleen Cruchon, Accounting/Database

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



Snow blanket-
ing a large part of the
country, the Arctic
blast descending
as far as Florida,
retailers jockeying
for first place among
shoppers--and here
I come, sending

greetings to you, AARDA friends and
members, at the beginning of this season of
holidays.

Following up my announcement in the
September *InFocus*, I am pleased (and
relieved) to report that AARDA's expansion
to a second office, this one in Washington DC,
is proving not only possible but also effective.
Flights between Detroit and DC provide for
surprisingly uninterrupted work time, and the
Washington presence is allowing for a variety
of contacts and very valuable meetings where
AARDA's representation strengthens the
autoimmune voice.

In the meantime, things are humming
along in the Detroit (Eastpointe) office with
capable, dedicated staff. Perhaps some of you
have been in touch via phone, letter, Facebook,
or Twitter. Life is good!

Ushering in the holiday season is
AARDA's Annual Appeal--no phone calls to
interrupt your dinner, no stuffed mailboxes,
simply one urgent request for support. Would
you believe that we already are receiving
Annual Appeal donations, even before we ask?
What loyal supporters AARDA has!

As many of you know, while AARDA
receives some support from corporations and
foundations, the bulk of the support comes
from individual contributions. They arrive in
varying amounts, from small to substantial,
each one gratefully accepted. Last year's total
was \$38,767, surpassing the previous year's
total by \$5,000. Can we do even better this
year? In advance, on behalf of AARDA and the
50 Million Americans we represent, I thank
you for making AARDA's gains possible.

This year AARDA garnered over one
million dollars in in-kind pro bono service. A
special "thank you" goes to the Sidley Austin
law firm and member Aaron Abend for their
in-kind contributions worth over \$200,000.
A huge note of thanks goes to all of our in-
kind donors who graciously donate their
professional services or their goods.

The AARDA Board of Directors is
concentrating efforts on carrying out our
Strategic Plan, and I am pleased to report that
we are pretty much on target. Funding is a big
issue, of course; but the Board members are
addressing that issue as well. As you can see
on the Board list, we are fortunate to have a
wide range of talents represented.

I also want to pay tribute to our
Scientific Advisory Board members. They,
too, represent a wide range of backgrounds
and countries both inside and outside of the
United States (see list on page 11). What a
wealth of credentials and experience! I have
never encountered a "no, sorry" when I have
approached any of the advisors for assistance
with reviewing grants, speaking, or providing
other information. I especially want to thank
SAB Chair Dr. Betty Diamond and SAB Chair
Emeritus Dr. Noel Rose for their leadership.

This is also a good opportunity to
give a special "thank you" for our National
Spokesperson Kellie Martin who, as an
outstanding volunteer, manages to represent
AARDA whenever and wherever possible
despite her busy work/parenting schedule.

No successful organization ever depends
on one small group "at the top." AARDA is
very fortunate to have a loyal base of members
and other supporters. Truly this is a season of
thankfulness!

My message in this issue is short. While
I'm tempted to "tell all," I'll let the newsletter
speak for AARDA and much of its happenings.
I'll simply send **best wishes to you and your
loved ones for many blessings** from all of us
here at the AARDA office as we embrace the
joys (and stresses?) of this glorious season.
Enjoy!

With appreciation,
Virginia



Keep up with AARDA!

Sign up for our ENews on the front page of
our Web site (www.aarda.org).

Help with awareness!

Like us on Facebook
(www.facebook.com/autoimmunity)



"Overview of Major Accomplishments" continued

- Conducted a Web-based survey to collect data on how the Affordable Care Act is affecting autoimmune disease patients
- Provided interviews and information for news media
- Resumed work on development of AARDA's "Advocacy Tool Kit" with designated grant

Fund Raising

- Continued to encourage and provide support for "grassroots fund raising," including the online Grassroots Newsletter
- Expanded the Autoimmune Disease Awareness Walks schedule and provided support for establishment of Virtual Walks

(raised \$70,000)

- Sponsored the AARDA Annual Fund Raiser in the Greater Detroit area (\$54,877 profit)

Administration

- Opened satellite office in Washington DC with presence of AARDA Executive Director as scheduled
- Appointed an Assistant Director to oversee AARDA's national office (Michigan) in conjunction with Executive Director
- Maintained the following ratings:
 - Better Business Bureau Wise Giving Alliance Charity
 - Best in America Certified by Independent Charities of America

--Charity Navigator Three Star Charity

- Maintained membership and active participation in the International Alliance of Patients' Organizations (IAPO)
- Continued to meet all Standards of National Health Council and maintain long-time membership
- Continued standing in the Combined Federal Campaign (CFC)
- Remained recognized Member Organization of Health & Medical Research Charities of America
- Held combined management and fundraising costs at 7.3 percent of total expenses (compared with 25 percent acceptable for nonprofit organizations) ■

Exchange plans fail autoimmune patients

--The following is an editorial written by AARDA President/Executive Director Virginia T. Ladd for the Detroit News, in August 2014, and picked up by wire services.

The latest wrangle over the Affordable Care Act raises the prospect that millions will find themselves unable to afford health insurance. Just as vexing, though, is the quality of coverage insurers are currently offering.

Even with generous federal subsidies, many available plans make paying for medication to treat cancer, HIV/AIDS, autoimmune diseases, bipolar disorder, and other serious conditions totally unaffordable. If the Affordable Care Act doesn't help the most vulnerable Americans pay for treatment, who is it helping?

A report by the research group Milliman found that 46 percent of all enrollees with a Silver plan--the most popular level of coverage--have a single, combined deductible for medical and pharmacy benefits. As a result, it's not uncommon for those who are covered to pay more than \$2,000 out of pocket before they get any prescription drug coverage. And for the Bronze level plans, the deductibles average more than \$4,000.

Compounding this problem is the high cost-sharing involved in most plans. Typically, insurance plans have four or five cost-sharing tiers. The lowest tier might have a small co-pay of \$15 for prescription drugs, while the highest tier might require patients to pay 40 percent or more of the actual cost of the medication.

For serious conditions, such cost-sharing can run patients hundreds of dollars per month or more.

A new report by Avalere health analyzed cost-sharing in Affordable Care Act plans for all brand name and generic drugs within 19 different classes of prescription drugs used to treat specific illnesses. The results are troubling, to put it mildly.

A shocking number of vital drug treatments are in the top cost-sharing tier for enrollees. In seven of the classes, one in five Silver

plans require coinsurance of 40 percent for all covered medications.

Additionally, Avalere reports over 60 percent of Silver plans also placed treatments for certain types of cancer in the highest cost-sharing tier. More than 60 percent of Silver plans put all medicines for treating autoimmune diseases such as multiple sclerosis, rheumatoid arthritis, and Crohn's disease in the top tier.

The cost associated with non-adherence to prescription drug regimens is particularly problematic with regard to autoimmune disease. In many cases, these conditions can be managed quite effectively with drugs.

Autoimmune diseases are responsible for \$100 billion in direct medical costs annually, and much of that cost is because patients have trouble staying on top of their treatments and end up in hospitals.

By making autoimmune drugs unaffordable, these insurance plans could make other health care costs explode. What's more, 75 percent of those suffering from autoimmune diseases are women.

The top priority of the Affordable Care Act is right there in its name: affordability.

Instead, it is putting basic health care out of reach for many of the sickest and most vulnerable Americans. ■

--Post editorial note: The exchanges are now open for the new year's enrollment, and the government Website has improved in transparency as it has added a section on the drugs covered and their cost to the enrollee, enabling the enrollee to select the plan that offers the best coverage of the drugs they need. If the enrollee is on a very expensive drug, such as a biologic, the best choice may be the Platinum plan.

It's a wrap!

The 2014 AARDA Autoimmune Walks ended the year with \$78,276 raised. What a tremendous boost toward AARDA's mission! Those dollars represent a lot of walking, loads of dedication, and much heart-warming camaraderie. Walks were held in Chicago, New York, Washington DC, St. Louis, and Marietta, GA.

Can we count on those walking shoes for 2015? Plans are being made, and dates and locations will be announced as soon as possible. Contact Sharon Harris if you see possibilities for a walk in your area (sharris@aarda.org; or 586-776-3900).

Also, don't forget the Virtual Walks. Here is an opportunity for nonwalkers and scattered family members and friends to join the fun. Want to "walk" but don't want to collect your own team? Executive Director Virginia Ladd is always looking for

Autoimmune Walk

LINKING TOGETHER FOR A CURE

friends to join her team. Simply go to www.autoimmunewalk.org, type in "Virginia Ladd," and donate any amount.

AARDA's Autoimmune Walks are not only major fund raisers but also outstanding awareness opportunities--and awareness is the first step toward diagnosis and treatment.

To all the walkers, volunteers, donors, and enthusiastic supporters, we send our deep APPRECIATION. Now...we'll look for you in 2015! ■



Retiring Board member honored

Howard E. Hagon, longtime member of AARDA's Board of Directors, ended his most recent Board term in September with the announcement that he would not run again. With regret, the Board accepted Howard's decision with the following: RESOLVED: That the AARDA Board of Directors hereby acknowledges Howard E. Hagon's support, dedication, and commitment to the organization, with much admiration and respect. Furthermore, it is RESOLVED that Howard E. Hagon be recognized formally as a founding member of the American Autoimmune Related Diseases Association.

Howard's support of AARDA began even as the organization was in the process of being formed. With his strong business background and a strong personal commitment to combating autoimmune disease, Howard was readily available for advice and guidance. Although AARDA was chartered in 1991, it was



1997 before he was available to accept a Board nomination.

From his first term on the AARDA Board to his retirement, Howard has actively participated in Board business. Throughout that time, he served on various Board committees. In the bylaw-required periods between Board terms, he served as Board Advisor.

Having retired from the business that he founded, Contour Fabricators, in Flint, Michigan, and Ellenton, Florida, and now from formal AARDA Board business, Howard already has settled in to enjoying, with his wife Faye, life in Michigan and Florida. Our only complaint with Howard is that he loves to flaunt the lovely weather in Florida while AARDA staff is slogging through the snows of Michigan. Oh, Howard, we wish you and Faye all the best anyway! ■



**Autoimmune
Diseases
Association**

American Autoimmune
Related Diseases Association, Inc.

Subscribe today

If you are not currently a member of AARDA and you want to receive InFocus, subscribe today.

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4 issues/year

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A new season of public forums coming up

Will you find an AARDA Autoimmune Public Forum near you on the 2015 schedule? Locations and speakers soon will be announced. Stay informed by liking AARDA's Facebook page. Also, this newsletter plus local mailings will alert you to the public forum schedule.

The 2014 "What Every American Needs to Know About Autoimmune Disease" public forums were awesome and informative. AARDA speakers communicated with

autoimmune patients, families and friends, and health professionals at meetings in Atlanta, Los Angeles, Boston, Seattle, and Midland, Michigan.

Some topics presented were "Women and Autoimmune Disease," "Being Your Own Best Advocate," "Coping with Autoimmune Disease," "New Observations in Autoimmune Disease Research," "Coping: Patient to Patient," and "What Is Autoimmunity?" In addition, specific disease topics included

"Nephrology and Autoimmune Disease," "Rheumatoid Arthritis: What You Need to Know," "Autoimmune Diseases of the Eye," "Vitamin D and the Immune System," and "What Your Dentist Wants to Know About Your Autoimmune Disease," to name a few.

If you are not on AARDA's regular mailing list but are receiving this newsletter as a courtesy mailing, you might want to consider an AARDA membership--just to keep in touch. ■



Fancy hats, horses--hey, it's Derby Day

AARDA's signature annual fund raiser comes to the Greater Detroit area again with its Derby Luncheon and Silent Auction theme. This year the event, scheduled for Saturday, May 2, moves to the Iroquois Club, on Woodward Avenue, in Bloomfield Hills.

Heading the planning are AARDA Board member Linda Pesonen and volunteer event planner Krista Wiseman who will be coordinating with our veteran fundraising team. Silent Auction Chair Carolyn Ugval says that she is ready!

Thanks to major underwriters and sponsors, plus guests who loved the Silent Auction and raffle, the 2014 Derby Luncheon realized a profit of \$54,877--a healthy contribution toward AARDA's mission.

Are you on the Derby list? If you have any doubt, you may call the AARDA office (586-776-3900) to receive an invitation. ■



An updated resource book for lupus...

Authors Robert G. Lahita, M.D., Ph.D., and Robert H. Phillips, Ph.D., are announcing the publication of their latest book, *Lupus Q & A, Everything You Need to Know, 3rd Edition*. Described as "An informative and compassionate perspective on coping with lupus," the book starts with an overview of lupus and follows with diagnosing lupus and its treatment, medications, and impact on the patient and others. "Triggers of Lupus Flares" is a helpful list in the Appendix.

The section on pregnancy is particularly sensitive and informative. What is a high risk pregnancy? What are the chances of the baby's developing lupus? How can a woman with lupus ensure a safe pregnancy?

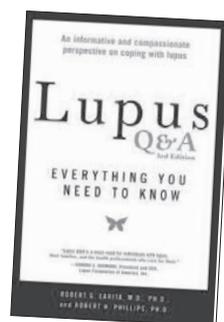
Lupus Q & A offers practical advice on seeking insurance and social security benefits, problems faced by many patients.

Chronic illness patients frequently are concerned with sex life in connection with their illness, and the authors offer helpful suggestions.

The sometimes sensitive doctor-patient relationship receives thoughtful consideration.

Authors Lahita and Phillips give encouraging words when they state, "Individuals living with lupus are becoming their own best advocates as they become more knowledgeable about the disease. It is hoped that this book will provide a lot of the information that will help in that regard."

Readers will find this a valuable resource to be kept close at hand for both knowledge and reassurance. This will be a well thumbed book. --*Lupus A & A, Everything You Need to Know, 3rd Edition*, Robert G. Lahita, M.D., Ph.D., and Robert H. Phillips, Ph.D., Avery, the Penguin Group, softcover 291 pp. ■



Volunteers dedicate time and talent for AARDA

Have wheels, will travel--Volunteer Lisa Brunckhorst, of Oxford, Ohio, is coordinating four riders for a 2015 team for RaceAcrossAmerica, a bicycle race that raises over \$2 million each year for charities internationally. Lisa and her team would like to race for autoimmune disorders, and AARDA specifically. Most teams raise money for charities in addition to competing.

Lisa says that she will know within the next three months whether her team is a solid go and would then start taking donations in February 2015. Under the racer's profile is a link to that racer's charity

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Obesity from a sweet view-- or maybe not so sweet

What is the relationship of sugar to obesity? Ron Hunninghake, M.D., Chief Medical Director of the Riordan Clinic, Wichita, Kansas, offers a look at that relationship.

Thousands of years ago our ancestors needed that sugar. They learned that a sweet taste meant "safe" while a bitter taste meant "poison," and sweet foods growing just prior to the winter season gave them opportunity for stocking up on a key survival substance. By eating fructose rich fruits, they gained fat rapidly before the lean winter months, a time of poor hunting and near starvation.

However, the winter fat storage that our ancestors made thousands of years ago is not wise for us, even though our genetic radar gives sweet foods the "green go-ahead light." Our genetic programming still thinks that high sugar consumption has those same survival advantages--but in our world, sugar isn't limited to one short period a year. Food cues are available everywhere, day and night, throughout many parts of the world--food ads, food sales, fast food stores, convenience shops, vending machines, processed foods/drinks, etc. How much sugar are we consuming? Think about this: 4g of sugar equals 1 teaspoon.

Recently medical experts in obesity are beginning to use a new term: "the obesogenic environment." Humans suffering from obesity-related diseases--including autoimmune diseases--now outnumber humans suffering from poverty-related starvation.

Obese people typically are blamed for their condition. Even many trained doctors believe that obesity is due to excessive calorie intake in conjunction with inadequate exercise. Dr. Hunninghake states, "Fortunately science is finally revealing the common denominator to all obesity. It's literally the elephant in the living room. Societally, we've refused to look the demon in the eye."

Sugar causes physical, personal, and societal pain on many levels. Dr. Hunninghake warns, "Because these consequences develop slowly; because the true cause is fundamentally a lifestyle choice (for example, one can severely moderate sugar intake by choosing healthier foods first); because of blaming the overweight individual's character instead of pursuing the correction of the hormonal imbalances that result from insulin resistance; because the many levels of suffering and pain are not addressed, the culprit--sugar--gets away with murder."

Obesity is associated with a lengthy array of abnormalities, e.g., sugar levels, many of which can be measured through laboratory testing. In the meantime, perhaps we may want to face the elephant in the room. ■

--Source: Adapted from "Sugar, Obesity, and Pain," Ron Hunninghake, M.D., *Health Hunters Newsletter*, Riordan Clinic, Wichita, Kansas, June 2014

Another mark against obesity: autoimmune disease

The World Health Organization indicates that approximately 35 percent of the global community is overweight or obese; yet, generally speaking, no one sets out to be obese. Likely it sneaks up as overweight (body mass index, BMI, greater than 25) and then progresses to obese (BMI greater than 30). Gradually various complaints arise--joint pain, fatigue, inflammation, sleep apnea, high blood pressure, depression, etc. Now, out of a research laboratory at Tel Aviv University, Tel Hashomer, Israel, comes another health problem.

In a study published recently in *Autoimmunity Reviews*, Professor Yehuda Shoenfeld, the Laura Schwarz-Kipp Chair for Research of Autoimmune Diseases at Tel Aviv University's Sackler Faculty of Medicine and Scientific Advisory Board member, American Autoimmune Related Diseases Association, reported that the study pointed to the major role that obesity plays in triggering and prolonging autoimmune diseases. Study results showed that obesity leads to a breakdown of the body's protective self-tolerance, creating the optimal environment for autoimmune disease in which the immune system attacks its own body rather than only predatory invaders.

Prof. Shoenfeld stated that more than ten autoimmune diseases are known to be associated with increased weight. In addition to their own research, the Tel Aviv University team conducted a systematic review of 329 studies from around the world on the relationship between obesity, adipokines, and immune-related conditions like rheumatoid arthritis, multiple sclerosis, type 1 diabetes, psoriasis, inflammatory bowel disease, psoriatic arthritis, and Hashimoto's thyroiditis. Adipokines are compounds secreted by fat tissue and involved in numerous physiological functions, including the immune response.

"According to our study and the clinical and experimental data reviewed, the involvement of adipokines in the pathogenesis of these autoimmune diseases is clear," said Prof. Shoenfeld.

Another detriment to good health was shown in a study conducted by Prof. Shoenfeld on mouse populations with multiple sclerosis given a Mediterranean diet rich in unsaturated fats. It was shown that vitamin D deficiency also was a result of obesity. Once corrected, paralysis and kidney deterioration associated with the deficiency were alleviated. Prof. Shoenfeld commented, "When vitamin D is secreted in fat tissue, it is not released into the body which needs vitamin D to function properly." He added, "Since vitamin D supplements are very cheap and have no side effects, they are an ideal compound that should be prescribed to anyone at risk of a compromised immune system."

Prof. Shoenfeld believes that his team's research can be a basis for specific therapies to treat autoimmune syndrome. He suggests, "If a patient is at risk, he or she should be told to do everything in his or her power to maintain a healthy weight." ■

--Source: Adapted from "Obesity plays major role in triggering autoimmune disease," Tel Aviv University, via *medicalxpress*, November 10, 2014

Newly published book offers view of autoimmune disease from an historical, yet new, perspective

Normally a biography is an account of a person's life. However, in *Intolerant Bodies*, authors Warwick Anderson and Ian R. Mackay have chosen to present their newly published book as one that "unfolds as a biography of a relatively new concept of pathogenesis, one that was accepted only in the 1950s." This concept is described in Anderson and Mackay's well researched, highly readable history of autoimmune disease, a category of at least 100 related diseases, many life-threatening, that still, for the most part, hide the "cause" and "cure" answers.

Authors Anderson and Mackay point out that early researchers resisted facing the fact that the body could attack itself. They found the idea of the betrayal of the immune system "curiously disturbing and repellent." The failure of the body to recognize itself, its capacity to treat itself as foreign, was both "sinister and bizarre." Indeed, the authors say, "As a pathological process, autoimmunity is still emerging, still to gain broad cultural acceptance. Only recently has autoimmunity begun to find its voice in public."

Looking back to the 19th century, fever was the cardinal disorder--mysterious, patient-centered, frequently treated by blood-letting. It was only toward the end of the 19th century that clinical features of fevers would cause physicians to begin to take an ontological view, to look for the disease, not just the strange things happening to the person. What was the possibility of invading germs? The authors state, "In our time, autoimmunity has acted as a cognitive substitute for nineteenth-century notions of essential fevers, offering yet another way of talking about abnormalities or exaggerations of bodily function."

In Chapter Two, the authors trace "Immunological Thought Styles." What did it really mean for a body to be immune to a disease? By the late 19th century, immunity was acquiring precise and scientific meanings. Also, studies were showing the significance between "toxic doses" and "sensitizing doses" in the treatment of illnesses which resulted in a reaction newly called "anaphylaxis."

In the early 20th century, in 1906, the

term "allergy" was coined. And in 1911, Polish biochemist Casimir Funk isolated the active ingredient of brown rice, which he called "vitamine," that prevented beriberi. He claimed that "many other constitutional disorders resulted from nutritional deficiencies or imbalances causing abnormal metabolism."

In 1903, the connection between a bacterial infection of the throat and rheumatic fever was established; and researchers attempted to discover a bacterial cause of rheumatoid arthritis. However, by the 1930s, bacteriologic skepticism began to prevail.

It is intriguing to see how the authors trace and tie together the scattered research efforts. They describe researchers working in different parts of the world to put together bits and pieces of the immunity and autoimmunity puzzles while seeing their progress hampered in many cases by politics, rivalries, anti-semitism, and the lack of research monies. In one case, a report of post-Communist connections of a researcher caused the cancellation of his passport and the withdrawal of his Public Health Service grants. This necessitated his having to kill off the only monkey colony in the world then being devoted to the problem of multiple sclerosis.

Soon after World War II, clinical investigators in North America and Europe uncovered the autoimmune origins of systemic lupus and rheumatoid arthritis. In the 1950s, autoimmunity became widely available as a conception of disease causation; and various blood disorders and chronic inflammations of thyroid, liver, gut, and kidney secured autoimmune explanation. Names now familiar to autoimmune disease patients and the medical community were being brought to light as young, enthusiastic researchers made discoveries in the autoimmune field. Among those were autoimmune pioneers Ian Mackay and Noel R. Rose.

Studying thyroglobulin in rabbits, Rose reported, "We were forced to conclude that we had actually produced an autoimmune response, and even more exciting, an autoimmune disease."

In the next decade, the 1960s, investigators were delving into the biochemical analysis

of causative mechanisms, seeking the molecular basis of immunological agency.

Another exciting step forward was made when, trying to devise a new procedure for detecting hepatitis virus, young researcher Ian Mackay suggested to D. Carleton Gajdusek, with whom he was working, that they use as controls the serum from patients suffering from other liver diseases, including chronic active hepatitis. They had, in effect, identified chronic active hepatitis as an autoimmune disease.

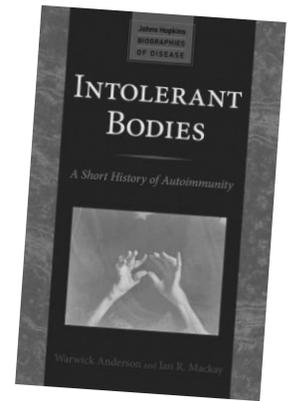
The authors include a number of cases of patients whom they encountered through the years, including not only the descriptions of the illnesses but also the very personal effects on the patients themselves. They point out, "In chronic illness--and autoimmune disease epitomizes this--one can be left with the feeling of a foreclosed future and a lost past, the person left behind."

Medical anthropologist Arthur Kleinman is quoted as writing, "Acting like a sponge, illness soaks up personal and social significance from the world of the sick person."

In "Acknowledgements," the authors state: "Not a page of this book was written without thought of patients we have seen with autoimmune diseases." The authors end with the hope "that those with autoimmune diseases will appreciate our efforts."

Intolerant Bodies does hold true to the definition that "biography" implies a coherent identity and a narrative, a discernible movement through time. The reader will journey in company with the authors on their fascinating tour of autoimmune history, facts, and observations. And what a journey indeed! ■

--*Intolerant Bodies, A Short History of Autoimmunity, Warwick Anderson and Ian R. Mackay, Johns Hopkins University Press, paperback 264 pages, November 2014*





Researchers pinpoint risks for autoimmune diseases

A team of scientists from the University of California San Francisco (UCSF), the Broad Institute of the Massachusetts Institute of Technology and Harvard, and Yale School of Medicine have developed a new mathematical tool to probe more deeply existing DNA databases. Utilizing this tool, they discovered how certain DNA variations, when inherited, are likely to contribute to disease. The discovery may lead to advanced diagnostic knowledge and ultimately to improved treatment for the scores of autoimmune diseases that mysteriously cause the immune system to harm tissues within their own bodies.

In this new study, researchers found that the presence of specific genetic variants in different autoimmune diseases can alter patterns of activity of genes in particular ways that affect functions of the immune system. The researchers point out that this was true despite the fact that the genetic variants are not within genes.

Corresponding author for the study Alexander Marson, M.D., Ph.D., UCSF Sandler Faculty Fellow, said, "Once again, research is revealing new meaning in the world of DNA once thought of as junk--short, seemingly random DNA sequences that in fact serve meaningful roles in human physiology."

By mapping enhancers, functional bits of DNA, in specialized cells and by tracking down patterns of altered gene activation that resulted from the presence of variants found in genome-wide association studies, the researchers identified patterns of activity within the genome and cell types associated with autoimmune diseases. Many autoimmune diseases were associated with immune cells known as T helpers. Dr. Marson and his team suggest that genetic variation may be tuning the response of these key immune cells to stimuli within their surroundings to increase the risk of autoimmunity.

In the case of the multiple sclerosis (MS),

an autoimmune neurologic disease, the team's findings strongly link the cause to the immune system. "This is highly consistent with the new MS treatments that work on the immune system, suggesting that we finally have a good handle as to the underlying causes of MS," stated co-senior author of the study Dr. Bradley Bernstein, senior associate member of Broad Institute and professor of pathology at Massachusetts General Hospital. ■

--Sources: Excerpted from "In Autoimmune Diseases Affecting Millions, Researchers Pinpoint Genetic Risks, Cellular Culprits," Jeffrey Norris, University of California San Francisco News Center, October 29, 2014; "Molecular Map reveals genetic origins of 21 autoimmune diseases," domain-b.com, November 1, 2014; "Genetic and epigenetic fine mapping of causal autoimmune disease variants," Kyle Kai-How Farh, Alexander Marson, et al., *Nature* (2014), published online October 29, 2014

What's happening with juvenile (type 1) diabetes?

Pediatric type 1 diabetes increased by 30 percent over a recent eight-year period, according to a study reported in the May 5, 2014, Medscape Medical News. Why the increase?

An autoimmune disease, type 1 diabetes occurs when the immune system mistakes the insulin-making islet cells of the pancreas for enemies and destroys them. When two-thirds of these cells are destroyed, the body no longer produces a sufficient amount of insulin.

A study from an Israel Prize laureate, Prof. Zvi Laron, suggests that a virus could be triggering the autoimmune disease before birth. In a recent paper, Prof. Laron, Professor Emeritus of Pediatric Endocrinology at Tel Aviv University's Sackler Faculty of Medicine and Director of the Endocrinology and Diabetes Research Unit at Schneider Children's Medical Center of Israel, presented evidence that a viral infection during pregnancy may spark the development of type 1 diabetes in the mother's genetically susceptible fetus.

Prof. Laron and collaborators from Israel (including the Hadassah Medical Organization), the University of Washington, and Sweden's Lund University, tested 107 healthy expectant mothers for islet cell autoantibodies, a sign of diabetes that appears years before initial symptoms appear. They also tested for anti-rotavirus and anti-CoxB3 antibodies.

The results pointed to evidence that viral infections contracted during pregnancy caused damage to the pancreas of the mother and/

or the baby. They saw specific antibodies, including those affecting the pancreatic cells, producing insulin. In addition, the cord blood antibody concentrations that exceeded those of the corresponding maternal sample, or antibody-positive cord blood samples with antibody-negative maternal samples, implied an in-utero immune response by the baby.

Time of year appeared significant, too, as during viral epidemics of the winter months, 10 percent of the healthy pregnant women who had no family background of autoimmune diseases tested positive for damaging antibodies.

Prof. Laron suggests that, since there is no cure for this diabetes at this time, true intervention would be important medically, psychologically, and financially. He says, "If our hypothesis can be verified, then preventive vaccine before conception would be useful in stopping the increasing incidence of type 1 diabetes and other autoimmune diseases."

Dr. Laron and his international collaborators currently are raising funds to expand their research to include nearly 1,000 women and their newborns. ■

--Source: "Viral infection may trigger childhood diabetes in utero," American Friends of the Tel Aviv University, *ScienceDaily*, October 3, 2014

Vitamin D study reveals new link with autoimmune disease

Chinese researcher Guofang Chen, M.D., a resident at Jiangsu Province Hospital, reported the findings of her team's research on the connection of vitamin D levels and autoimmune disease at the most recent annual meeting of the American Thyroid Association.

The team conducted a cross-sectional study of 66 patients with autoimmune thyroid disease plus 52 healthy controls to determine vitamin D status as well as affecting factors of the disease. All participants were measured for 25-hydroxyvitamin D, calcium, parathyroid hormone (PTH), triiodothyronine (TS), thyroxine (T4), thyroid stimulating hormone (TSH), thyroid peroxidase autoantibody (TPOAb), and thyroglobulin antibody (TgAb).

Test results showed that significantly lower 25-hydroxyvitamin D levels were present in autoimmune thyroid disease patients (81.7 percent) compared with controls (71.1 percent). Also, autoimmune thyroid disease patients had significantly higher levels of parathyroid hormone and calcium compared with controls. No associations were found among levels of 25-hydroxyvitamin D, PTH, and T4.

Dr. Chen said that vitamin D insufficiency is very high in China, especially for autoimmune disease thyroid patients. She points out, "Clinicians should pay special attention to these patients, and when possible give them vitamin D supplements to make up for the insufficiency." ■

--Source: "Autoimmune thyroid disease occurrence linked to vitamin D insufficiency," *Endocrine today*, October 30, 2014

Medications and supplements--maybe not a happy mix

It is estimated that 34 percent of the respondents in a national health and examination study indicated that they were taking some kind of dietary supplement along with a prescription medication. Certainly dietary supplements are widely used. These include vitamins, minerals, and other less familiar substances, such as herbals, botanicals, amino acids, and enzymes. Is there any danger in mixing medications and dietary supplements?

Robert Mozersky, a medical officer at the Food and Drug Administration (FDA), says, "Some dietary supplements may increase the effect of your medication, and other dietary supplements may decrease it." He cautions that certain dietary supplements can change absorption, metabolism, or excretion of a medication; and, therefore, combining dietary supplements and medications could have dangerous and even life-threatening effects.

Dr. Mozersky suggests that, for example, drugs for HIV/AIDS, heart disease, depression, treatments for organ transplants, and birth control are less effective when taken with St. John's Wort, an herbal supplement. Warfarin (a prescription blood thinner), ginkgo biloba (an herbal supplement), aspirin, and vitamin E each can thin the blood. Taking any of these products together may increase the potential for internal bleeding or stroke.

Also, in preparing for surgery, one should be aware that some dietary supplements can interact in a harmful way with medication that must be taken before, after, or during that surgery.

Dr. Mozersky advises that before taking any dietary supplement or medication, either over-the-counter or prescription, the patient should discuss it with his or her health care professional. He shares the following tips:

- Every time you visit a health care professional's office, bring a list of all the dietary supplements and medications you are currently taking. Include the dosages and how many times a day you take them. Some people find it easiest to throw all their dietary supplements and medications in a bag to bring to the medical visit.
- If you're thinking of adding a dietary supplement to your daily routine, call your health care professional first to let him or her know what other supplements and medications you're taking.
- Also tell your health care professional if your health status has changed, particularly if you are pregnant or breastfeeding, or if you have had any recent illnesses or surgery.

Although the FDA has oversight of the dietary supplement industry, it is the supplement manufacturers and distributors that are responsible for making sure their products are safe before they're marketed. Manufacturers are required to produce dietary supplements that meet minimum quality standards, do not contain contaminants or impurities, and are accurately labeled. ■

--Source: "Mixing Medications and Dietary Supplements Can Endanger Your Health," FDA's *Consumer Updates* page, October 27, 2014

Upcoming Education Events for 2015

Sponsored, cosponsored, or supported by AARDA

February 6-7 - "Pregnancy & Lactation in Women with Autoimmune Diseases: Sharing Knowledge Across Disciplines" - Courtyard Marriott at Liberty Station, San Diego, CA - Information: cme.ucsd.edu/plwad

TBA - Scientific colloquium - "Eosinophils and Autoimmune Disease," Washington, DC

TBA - Scientific colloquium - "Mental Illness Involvement in Autoimmune Disease"

TBA - AARDA Public Forums - "What Every American Needs to Know About Autoimmune Disease" ■

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Contributions in this category are too numerous to mention, but we would like to say "thank you" again for the many donations that have been made. Each one is noted with appreciation.

Annual Appeal continued from page 1

In advance, and on behalf of the 50 Million needing our services, we say THANK YOU.

❖ **What's in the planning for 2015?** Two scientific colloquia are in the planning stages: "Eosinophils and Autoimmune Disease" and "Mental Illness Involvement in Autoimmune Disease." Another congressional briefing, planned with the National Coalition of Autoimmune Patient Groups (NCAPG), will continue our outreach of autoimmune awareness and education on a national level; and Autoimmune Disease Awareness Month, in March, will highlight new awareness opportunities--and reach out for AARDA member involvement in a "Call for Action."

We will continue our educational outreach to grade school level classes on the immune system and autoimmunity, and physician education projects are expanding.

The AARDA Public Forum programs and schedules are being completed. Members and others on our mailing list will be alerted to locations and dates.

❖ **Where did the 2014 money go?** For a quick overview, see "Major Accomplishments for 2014." Both ongoing and newly completed activities for 2014 are listed. ■

Volunteers continued from page 5

so that supporters can give directly to the charity. Team sponsorship monies are handled separately.

Lisa says, "We are primarily a self-funded team but will approach a local hospital health care corporation for promotional jerseys." Starting in June 2015, the team, "Oxford Autoimmune," will travel from Oceanside, CA, to Annapolis, MD. Watch AARDA's Web site (www.aarda.org) for updates.

Campaign to be launched in Boston - Volunteer Lilly Stairs is organizing a fundraising and awareness campaign in Boston for next spring. Anyone wanting to be involved may call the AARDA office (586-776-3900) for contact information. ■

With Special Thoughts...

Tributes

Lora Kling - In her honor for Ice Bucket Challenge - Mary Canniff
Chelsea Goldstein - In her honor on her trip to Mayo - Kerri Lindberg

Joyce Bollenbacher - In honor of her birthday - Heather Frulla
Rebecca Chouteau - In her honor - Marlene Jimmerson
Lynzie Munsell - In her honor for the glorious summer vacation trip - Ward Pimley

Deborah Newton - In her honor for Ice Bucket Challenge - Babe Free

Alice Rodner - In honor of her birthday - Phyllis Freeman
Ann Wagner - In her honor - Patty & Thomas Kuehn
Child Hall - In honor of - Sue Sanders
Melissa Soderholm - In her honor - Donna & Mike Thiellen

Memorials

Mary Gayle Schwarz - Lew & Judy Bradbury, Janice Mills, Gregg Williams

Susie Greene - Catherine Cummins

Massoud Nooralian - Kibart, Inc., Richard & Marilyn Nelson

Susan Wuerzner - David & Billie Bowen

Boris Antolos - Dane & Brankica Grgas, Marine Clerks Association Local 63 ILWU

Grandpa Howard - Logan & Ginny Shaw

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Lillie Ann Daniels Crowe - Barry & Patti Nelson

Patrick Hunt - Ginny & Don Oldakowski, Joyce Oldakowski, Monica Oldakowski

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Charles Frazier - Miltpw: Susie, Julie, Cassi, Eynav, Amy, Suzanne, Carolynne

Claudia Daileader Ruland - Eric & Tara Belfi

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Ben Polk - Mr. & Mrs. James Faletti, Phyllis Ruscella & St. Pete Beach Library Staff

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

American Autoimmune Related Diseases Association

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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 necessarily reflect the views of the American Autoimmune Related Diseases Association or its Scientific Advisory Board.

If you belong to a Service Organization or Fraternal (or other) group which provides financial contributions to charitable organizations, please ask them to consider the AARDA as a potential recipient. Your thoughtfulness could provide a vital link in helping our efforts to promote autoimmune research, education and awareness. (The AARDA is a fully accredited IRS 501 (c) (3) tax exempt organization.)

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- ~ You contribute to a membership count which is significant in our applying for grants and other support.

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Local Contacts, International

Israel	Sarah Krein.....972-54-810-1245
Italy	Christine Gammon.....085-9353560 (<i>Support Group</i>)

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