



AARDA AT 25

Since 1991, AARDA has significantly moved the needle in all aspects of the autoimmune disease agenda, from patient care and research to education and advocacy.

70 – public forums sponsored/supported in 28 U.S. states and five other countries

Tens of Millions

autoimmune disease patients and their families around the globe AARDA has provided information, resources and referrals through the 800 numbers, web site, email, mail, patient educator and in person at events

155 – research/scientific/clinical meetings and conferences sponsored/supported in 23 U.S. states and 20 other countries

\$5 Million

awarded in research grants, fellowships and medical school scholarships

125

– research grants and fellowships at prestigious research institutions and/or in partnership with various National Institutes of Health institutes and offices that have furthered the collective understanding of autoimmunity and autoimmune diseases

17 years

that Emmy-nominated actress Kellie Martin has served as AARDA's celebrity spokesperson, generously giving her time and voice to autoimmune education and awareness

1

– National Coalition of Autoimmune Patient Groups (NCAPG), a coalition of 38 single autoimmune disease patient organizations, created and facilitated by AARDA to advocate on behalf of the millions of U.S. autoimmune disease patients research and health care related legislative issues

3 major legislative achievements

including

- Establishment of the Autoimmune Disease Coordinating Committee at the National Institutes of Health (NIH)
- Increase in NIH budget for autoimmune diseases by \$30 million
- Passage of the Children's Health Act of 2000 with inclusion of major autoimmune language resulting in the NIH Office of the Director developing a national autoimmune research strategic plan with outside input from scientific and patient groups

6

– annual National Autoimmune Disease Awareness Month celebrations, a designation sought and achieved by AARDA in 2010

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



Since this issue of *InFocus* is quite full, my message will be short. However, it's always a pleasure to have this means of staying in touch with all of you who mean so much to us at AARDA and to the 50 Million who need us.

◆ The great news is that, thanks to our loyal supporters, we have surpassed last year's Annual Appeal total. Our total to date for this year is \$55,774.16, compared to \$53,664 for the past year. We see your contributions as both financial support and encouragement--and we love the notes and comments which frequently accompany those contributions.

◆ More really great news is that our "acorns to mighty oaks" campaign for our National Autoimmune Diagnostic and Triage Center is growing. From \$26,682.92 as reported in the September 2015 newsletter, the amount has inched up to \$28,282.92. In the meantime, the autoimmune center pilot study headed by **Dr. Abid Khan**, of MidMichigan Health, is getting positive reviews (see article in this newsletter). Remember--we welcome all contributions, large or small. If you have a couple billion dollars ready to contribute, that would be great; but whatever your budget allows will join others to swell that acorn--and you will take your place in this great project.

◆ You who have been with us over the years know the importance of **advocacy** and **awareness** to life-saving early diagnosis and treatment. For that reason, each March we put special effort toward an entire month of concentrating on Autoimmune Awareness. Special thanks go not only to our many volunteers and other individuals but also to public relations firm **Carway Communications**, in New York, for their generous support in our March Autoimmune Awareness Month and, indeed, from our beginning 25 years ago.

◆ And, just a note--a special "Happy 25th" celebration will take place at our Derby Luncheon, scheduled for Saturday, May 7, in east suburban Detroit (Harrison Twp.). We will be honoring long-time mentor **Noel R. Rose, M.D., Ph.D.**, Chairman Emeritus of AARDA's Scientific Advisory Board and Immediate Past Director of the Johns Hopkins Center for Autoimmune Research, who now is affiliated with the Department of Pathology at Brigham and Women's Hospital and Harvard Medical School, Boston. We hope that many AARDA friends will join us in honoring **this very special autoimmune pioneer and AARDA friend**.

Happy Anniversary,
 AARDA! We're 25 years
 strong!

With gratefulness,
Virginia



The AARDA Store is now open!

You can now find AARDA branded water bottles, mugs, blankets, pillows, T-shirts, tote bags, scarves--even pet items and more--on our new online store.

Just go to the AARDA Website at www.aarda.org or one of our Facebook pages (www.facebook.com/Autoimmunity; or www.facebook.com/autoimmunewalk) to find high-quality items for yourself or for gifts.

So many of you asked for these items that we just had to make it happen! ■



AARDA Kicks Off Its 25th Anniversary with #25FOR25 CAMPAIGN

Actresses Kellie Martin and Haley Ramm Lead Campaign on Behalf of Families with #Autoimmune Disease during National Autoimmune Disease Awareness Month

Happy 25th Anniversary!

For National Autoimmune Disease Awareness Month, AARDA is kicking off its official yearlong 25th anniversary celebration with the #25for25 campaign.

#25for25 invites individuals and organizations the world over to recognize AARDA's achievements on behalf of people with autoimmune disease and support its work going forward by donating \$25 to the organization.

Our longtime celebrity spokesperson, Emmy-nominated actress Kellie Martin, along with our newest celebrity ambassador, Haley Ramm, star of ABC Family's *Chasing Life* and recent guest star on the CW series *The Originals*, have teamed up to lead the #25for25 campaign.

Autoimmune disease has touched the lives of both actresses and AARDA has been there to help them.

Kellie's 19-year old sister, Heather, passed away suddenly and unexpectedly in 1998 from an undiagnosed case of lupus, while Haley's mother, Barbara, struggles daily with multiple autoimmune diseases, including relapsing polychondritis.

"For 25 years, AARDA has worked tirelessly, acting as the voice of autoimmune disease patients, advocating for their needs, health and well-being, often in the face of misunderstanding physicians, family, friends and co-workers. Please join me in the #25for25 campaign to say thank you to AARDA and support its important work going forward into the next quarter century," said Kellie (@kelliemartin).

"This year the American Autoimmune Related Diseases Association celebrates 25 years of helping people with autoimmune diseases and their families – just like mine,"



said Haley (@halesbells). "For AARDA, that means 25 years of making a real difference in people's lives....fighting for patient's rights.... raising money for research... educating the world about autoimmune diseases....and insisting on better treatments and diagnostic tools for patients. Let's thank them for their amazing work."

Despite our humble beginnings in one room in Detroit, AARDA always had a big vision to be the singular voice for the more than 50 million Americans who suffer from the 100-plus known autoimmune diseases.

When we started, most people thought autoimmune disease was AIDS. Today, while there is improved understanding, AARDA will not rest until autoimmunity is included in all medical school curricula, the public understands the debilitating

nature of these chronic diseases, including the profound fatigue virtually all AD patients deal with, and most important, all patients can get a correct diagnosis in a timely manner and full access to the medicines that can save their lives.

Stay tuned to AARDA's web site (www.aarda.org), social media channels (Facebook, Twitter, YouTube) and *InFocus* for the next 12 months about other special 25th anniversary events and programming.

Please spread the #25for25 campaign message on social media with family, friends and colleagues and don't forget to make your donation today.

Rest assured, here at AARDA, we are busy mapping out our next 25 years of service for you. ■

Join the celebration!

On Saturday, May 7, AARDA will celebrate its 25th Anniversary during its Annual Derby Luncheon & Auction at MacRay Harbor Resort on Michigan's beautiful Lake St. Clair. The event will feature **Dr. Partha Nandi**, chief health editor at WXYZ-TV Detroit as our emcee; the unique energetic styling of entertainer/violinist **Rodney Lamar Page**, former official DJ of the Detroit Pistons; a silent auction of memorable Mother's Day and Silver Anniversary items; and a tip of the Derby to AARDA's 25th anniversary.

A very special offering will be a presentation of the AARDA Champion Award to **Noel R. Rose, M.D., Ph.D.** Often referred to as "The Father of Autoimmunity," Dr. Rose is Chairman Emeritus of AARDA's Scientific Advisory Board; former Director of the Center for Autoimmune Disease Research, at Johns Hopkins University Bloomberg School of Public Health; Professor of Molecular Microbiology and Immunology at Johns Hopkins; and co-editor of the classic textbook *"The Autoimmune Diseases"* (now in its fifth edition). He currently is affiliated with Brigham and Women's Hospital and Harvard Medical School. Dr. Rose is a member of the Wayne State University Academy of Scholars.

AARDA's Derby Luncheon is an opportunity to broaden awareness in the Metro Detroit area and beyond--while enjoying this once-a-year opportunity to shop, share, and dine with friends in a fabulous setting. For tickets or more information, visit <http://aarda-derby-luncheon.eventbrite.com>, e-mail dpatrick@aarda.org, or call (586-776-3900). ■



What I've Learned: Noel Rose Pathologist and father of immunology

Dear Readers: A very special person in the life of AARDA is Noel R. Rose, M.D., Ph.D., a charter member and Chairman Emeritus of the American Autoimmune Related Diseases Association (AARDA) Scientific Advisory Board, frequent presenter at AARDA's scientific symposia and public forums, and caring mentor.

A former professor of molecular microbiology and immunology, Johns Hopkins University Bloomberg School of Public Health and of pathology at the JHU School of Medicine, Dr. Rose is well known for his pioneering studies on autoimmune thyroiditis conducted in the 1950s that ushered in the modern era of research on autoimmune disease. He was the first director of the Johns Hopkins Center for Autoimmune Disease Research, and in 2009 he received the Polish Academy of

Sciences' Nicolaus Copernicus Medal, the Academy's highest honor. Dr. Rose now is affiliated with Brigham and Women's Hospital, Harvard Medical School, in the department of pathology.

Dr. Rose will be AARDA's honored guest at its Silver Anniversary Celebration, scheduled for May 7, at MacRay Harbor, Harrison, Twp. Michigan.

Through the following interview with Dr. Rose by a writer for the Johns Hopkins University Gazette, we share some behind-the-scenes views of this dear friend and internationally known researcher.



In ninth grade I knew exactly what I wanted to be. My school had the common exercise of writing a paper on what our future career might be. I wrote an essay called "The Small Game Hunter." The paper portrayed me as a microbiologist in a small New England town like Stamford, Connecticut, where I was born.

My interest in microbiology certainly stemmed from my seventh grade science teacher. He owned a monocular microscope that he brought into class. The students took turns looking through it to see bacteria and other microbes. I was thrilled to learn that there was a whole world that I didn't even know existed.

The other great influence was my father. He was a physician engaged in a very busy practice. He would see patients in his office or at the hospital during the day and then would come home, have dinner, and go out again to see four or five patients in their homes.

When World War II came along, even though he was over age, my father volunteered and went into the Army as a medical officer. When he returned to the United States, he had to start from the beginning and chose to build his practice as a specialist in heart disease. One of the things that my father became very interested in was rheumatic fever, which we now know to be an autoimmune disease caused by a strep infection. My father started a program to treat young people with this disease. The only treatment then was absolute bed rest. Many were athletes who would not get out of bed even to go to the bathroom. My father made a great effort to support a facility to take care of these young people and received funding from the local Lions Club. He called it Camp Lionheart.

A great influence on me was seeing what impact my father could have. I admired him greatly. My father was the wisest man I ever encountered. Although I never felt any desire to become a clinician like him, I wanted to make an impact through basic research. However, I wanted to spend more time with my children than my father ever could. He carried a terrible burden through working as much as he did.

When I graduated from Stamford High School, I was granted a working scholarship to Yale. It meant that I had to work 20 hours a week, but I was lucky to go to such a fine university. I worked my tail off and finished in three years. I guess that I just wanted to get on with my life. I graduated from Yale in the Class of 1948, the same class as President George H. W. Bush.

I went on to the University of Pennsylvania where I received my Ph.D. in three years, working night and day. There I met my wife, who is the single most important person in my life. She was a nursing student at the time. We married two days after we both graduated.

In order to earn my M.D., I took a job as an assistant instructor at the University of Buffalo School of Medicine. That position was about as low on the faculty ladder as one could get, but it did give me a chance to complete my medical courses. I thought that I would earn my M.D. just as quickly as I had achieved my other degrees, but I had a bit of "bad luck"--I made a major discovery; and suddenly I had a research laboratory, a technician, graduate students, and grants. So it took me a long time, about ten years.

My boss at Buffalo, Ernst Witebsky, was an extraordinary person. He was a refugee who came from Germany in the early 1930s. His interest was in immunology. He started

me working on topics that he had long been interested in, organ-specific antigens. He was studying the immunologically active molecules that are unique in certain cells and tissues. Dr. Witebsky thought they might, and rightfully so, be important in the unique physiology of the cell and important in cancer. His main fame came from his work on human blood groups because he was the first to isolate the blood group A and B substances. They were important in making transfusion safe during World War II.

Professor Witebsky suggested that I work on the thyroid gland because he had some experience in Germany suggesting that it had a very powerful organ-specific antigen. The substance specific for the thyroid is a protein called thyroglobulin. It could be denatured very easily, and Witebsky wanted me to prepare thyroglobulin in a natural state. At that time, it was assumed by everybody that an animal could not respond immunologically to one of its own proteins.

I prepared thyroglobulin from rabbit thyroid and tested it by injecting it into another rabbit. I assumed that if I prepared it well and it had not denatured, the animal would fail to respond. This looked like the pivotal test. The first results were devastating--the animal produced antibody specific for thyroglobulin. Is it actually possible that an animal can respond to its own antigen? Maybe something happened to the rabbit's thyroid gland. Under the microscope, the thyroid was severely inflamed.

Since Witebsky was so conscious of the difference between different humans in his work on blood groups, he insisted that the next step was to inject rabbit thyroglobulin into

the very same rabbit. I performed a partial thyroidectomy. I took one lobe of the gland and prepared the thyroglobulin by my usual method. Because it was not easy to get much thyroglobulin, I had to use a powerful adjuvant to induce immunity. We finally realized that we essentially had induced an autoimmune disease experimentally. That changed the world.

Suddenly some of the leading immunologists came visiting to see our work. People began to say that if we can induce thyroiditis by autoimmunization, maybe we can produce other diseases the same way. The toothpaste was out of the tube.

When I began, autoimmune disease was a field that was nonexistent. People thought it was a crazy idea. As we, and others, began to publish more articles, the world began to change. Autoimmune diseases started popping up all over the place.

Witebsky was a wonderful mentor and a gifted lecturer. In addition to rigorous research, I learned a great deal of teaching from him. I also was part of a small group of faculty at Buffalo who spent time investigating and evaluating the medical curriculum and working with the School of Education in improving teaching skills. I think that I went on to become a very good teacher. The main lesson I learned is that teachers are there to serve the students, not to demonstrate their own accomplishments.

I don't much like distance education because you're seated in a dark room and asked to give a lecture but do not see the students. I never follow my outline, but I vary it according to the signals I receive from the audience. It doesn't matter if you are talking with 10 or 100 people, you are getting signals if they are receiving the information. If you learn to sense that, you can become a good teacher.

I was granted an opportunity at Wayne

State University, in Detroit. The school had received a large amount of money to build a medical school building with a new department of immunology and microbiology. I was able to hire new faculty, and I had a great time bringing people together from various institutions. Our department became one of the top ten departments of its kind in the nation. When I hired faculty, I was most interested in their potential and less interested in their specific areas of research.

I received a call from a guy named Abe Lillienfeld, a great name at Johns Hopkins. He was a dynamic teacher and major faculty member in the School of Public Health. Previously, he had been on the faculty of the University of Buffalo where I was one of his students. He was chairman of the search committee for a department at Hopkins called Pathobiology. Lillienfeld told me that I might be interested. I didn't really know much about public health, but I decided to meet with him. When I came to understand what public health really is, I thought that it was something I would love to do. I'd have the opportunity to have impact, as we say, on millions at a time. That's how I came to Hopkins.

My first major discovery, of course, was on thyroid autoimmunity, and we continued to work on that problem. The next major discovery was the genetic basis of autoimmune disease. We showed for the first time that something called the major histocompatibility complex contains the main genes determining the risk of all autoimmune disease. That is true in humans and animals and virtually every autoimmune disease we have looked at. I spent the decades of the 1970s at Wayne State looking into the genetic basis of autoimmunity. At Johns Hopkins, I've taken up the study of other things that impact autoimmunity, a major one being infection.

I have been funded by the National Institutes of Health from the first moment that I made the big discovery in autoimmunity to the present time. There are a very few people who have had 60 straight years of NIH support. I even received a Nobel nomination out of it.

We have four children, all married, and ten grandchildren. They are my pride and joy, all doing wonderful and interesting things. Ours is a very close family. We're very proud of this, and it is mostly due to my wife.

Music has been a passion of mine, although I personally have no talent. All the boys and girls where I grew up in Stamford went to Mrs. Leonard for their piano lessons. My brother went, and he turned out to be very good. So off I went at age 7, going every week. I was just awful. At the end of one year, all the boys and girls participated in a recital, and the parents would come to applaud; but the first year, Mrs. Leonard didn't put me on. The second year, I also didn't appear in the final recital. My mother was concerned. The third year, maybe my mother said something to Mrs. Leonard. She handed me a triangle.

In school, I took part in track, but the only sport I stayed with has been tennis. My interest started in the old days when "Fox Movietone News" was shown between the double features in all the movie houses. They showed King Gustaf V, of Sweden, on his birthday playing tennis at the age of 80, then age 85, and then 90. I thought that is the sport for me. You can't play football or baseball when you're 90.

All in all, I think I'm pretty well known around the world for the research I've done. I'm sometimes called the father of autoimmune disease. I keep saying that I'm really the son of autoimmune disease.

--Source: "What I've Learned: Noel Rose," Greg Rienzi, *Johns Hopkins University Gazette*, July-August 2014, reprinted with permission

Rheumatology scholarship offered

AbbVie has launched the AbbVie Rheumatology Scholarship, designed to provide financial support for exceptional students in higher education living with rheumatologic diseases.

- ◆ Available to students seeking an undergraduate or graduate degree from an accredited US university/college or trade school who plan to enroll for the 2016-2017 school year.
- ◆ Applicants judged based on academic excellence, community involvement, written response to essay question, and ability to serve as positive role model for rheumatology community.
- ◆ Applications available on www.rheumscholarship.com (to be submitted by April 4, 2016).

Each of 15 AbbVie scholars will be selected to receive \$15,000 for use during the 2016-2017 academic year.

Grassroots fundraising for AARDA...all sizes and ages join the cause



◆ A little Hollywood; a lot of heart

Canadian Nicolas Collins has been doing great things for autoimmune disease research. He has hosted two bake sales, organized an Autoimmune Walk, donated proceeds from a birthday party, and sold lemonade for AARDA. Oh, did we mention that Nicolas is 10 years old?

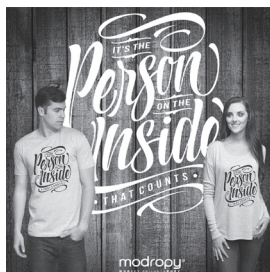
Along with his family, Nicolas flew to California to deliver the money that he had raised to “Chasing Life” star and AARDA spokeswoman Haley Ramm. It turns out that Haley was instrumental in helping Nicolas with a bullying problem that he had in school. He turned his gratitude into dollars for AARDA! Since Haley’s mother

Barbara has an autoimmune disease, raising money for AARDA for autoimmune disease research was Nicolas’s way of saying “thank you.” Way to go, Nicolas! The 50 Million with autoimmune disease admire your thoughtfulness and spunk.

◆ Kappa Kappa Gamma has talent!

Each year the Epsilon Xi Chapter of Kappa Kappa Gamma sorority at the California State University Northridge hosts “KKGlee” in the fall semester. Katie Day, KKG philanthropy chair, says, “This event is special to us because we decide where we want the proceeds to go, and this year we have chosen AARDA because five of our sisters struggle with an autoimmune disease.”

The November 2015 talent show featured performances by members of several fraternities and sororities on the Northridge campus. What a great opportunity to spread the AARDA word while raising funds!



◆ Modern Philanthropy features AARDA

For the second year in a row, AARDA has teamed with Modern Philanthropy (Modropy) in raising funds for AARDA. Modropy designs tee shirts and sweatshirts with autoimmune disease patients in mind and sells the items for a week. With a portion of the proceeds going to AARDA, \$288 was the most recent contribution for AARDA’s mission.



Do YOU have the root of a great idea for an AARDA fund raiser? Maybe it’s a Dress Down Day, a Pop-Up Dinner in the Park, a Hot Dog Dinner House Party, a birthday party with AARDA contributions in lieu of gifts--whatever catches your imagination. These events, large or small, always are opportunities for funds, awareness, and education. Contact Sharon at AARDA (sharris@aarda.org; 586-776-3900) to discuss your idea. ■

Linking Together Again

Last year, AARDA exceeded its goal of raising \$125,000 through “Linking Together” in Autoimmune Awareness Walks across the country by raising nearly \$150,000. This year, we have set our goal higher and will be investing more time and resources in more cities because we have learned that “Linking Together for a Cure” always counts – in our advocacy for patients and families; in our delivery of patient services; and in our support of critical research. We invite you to save the Walk schedules below and join us if you can for an Autoimmune Awareness Walk near you!

Autoimmune Walk

LINKING TOGETHER FOR A CURE

Sunday, May 22

Cleveland Autoimmune Walk,
Cleveland Metroparks,
South Chagrin Reservation

Saturday, June 25

5th Annual DC Metro,
McLean Central Park, McLean, VA

Saturday, September 17

Atlanta Autoimmune Walk,
Piedmont Park

Sunday, September 18

Tri-State Autoimmune Walk,
Hudson River Park, Pier 84, Manhattan

Saturday, October 8

Metro Detroit Autoimmune Walk,
Belle Isle Park

Register Today: www.autoimmunewalk.org

Get Updates: www.facebook.com/AutoimmuneWalk

AutoimmuneWalk

E-mail: walk@aarda.org

Call: (855) 239-2557

Yes, you can! It's here--The NEW Virtual Walk

While our real-time Walks across the country gained in participants and in dollars raised last year, our Virtual Walk drew far less support. That’s why we have revamped it for 2016.

The new and improved AARDA Virtual Autoimmune Walk has gone global! Now walkers in any country and on any day

can participate. Online registration allows individuals and teams to participate whether they’re walking a mountain trail, claiming a treadmill at the gym, or simply taking a walk around the block.

Virtual Walk Team Captains will receive a Virtual Walk Kit that includes a T-shirt, Walk bibs for their team members,

registration forms for off-line registrants, and “Linking Together for a Cure” wristbands for their team members.

To find more information on this Walk, to register, or to create an online fundraising page, please e-mail walk@aarda.org; or visit www.autoimmunewalk.org and click on the Virtual Walk link. ■

Planned Giving: What? Why?

Planned Giving is win-win gifting. It benefits both the giver and the receiver. Let's consider some of the possibilities.

Bequests - You leave money to your favorite charity through your will or trust. Your heir(s) will pay no estate tax on the amount bequested since your estate receives a charitable deduction for the full amount given.

Gifts of Life Insurance - A life insurance policy that is no longer needed could provide a year-end tax deduction if donated to a charity. You can make a chosen charity the whole or partial beneficiary of your insurance plan. Contact your insurance agent for details.

Gifts of Stock - By donating your appreciated stock rather than the cash you receive from the sale, you avoid the capital gains tax that occurs from your sale of those shares. Also, you receive a charitable income tax deduction based on the fair market value of the donated stock.

Charitable Remainder Trust - The trust is a tax-exempt trust that enables you to make a gift into the trust using appreciated assets. It pays income to the beneficiaries you designate--to you or to you and others whom you designate in the trust document. The income stream can be structured in the form of an annuity or as a percentage of the value of the trust, revalued annually. Because this is a tax-exempt trust, the trustee can see the appreciated assets given to the trust without incurring capital gains tax. Thus, the entire proceeds from that sale, reduced only by costs incurred to complete the sale, are available for reinvestment by the trustee to generate your stream of income.

You receive a charitable income tax deduction for the portion of the trust that will pass to charity when the trust terminates. You must pay income tax on the income you receive from the trust. If either you and/or your spouse is the sole or joint beneficiary of the trust, no estate tax will be incurred at either of your deaths. However, this is limited to the property in the charitable remainder trust.

Following the death of the last surviving income beneficiary, the remaining assets will begin to fund the programs and services of your designated charity.

Charitable Lead Trust - Your designated charity is the income beneficiary of this trust; and the assets of the trust, when it terminates, revert to you or to any other person or persons you designate. Your Charitable Lead Trust immediately benefits the programs of your designated charity. Your trust can be structured to provide you with immediate income tax benefits, immediate gift tax benefits, estate tax benefits when you die, or relief from all of them.

Gifts of Real Estate with a Retained Life Estate - A couple or individual can gift a personal residence to their chosen charity and retain the right to live in the home for the rest of their lives or until they decide to move voluntarily. The donor may receive a charitable income tax deduction for the gift, based upon the donor's life expectancy and the value of the property.

For further information on Planned Giving, contact the AARDA office (586-776-3900) or your tax advisor. ■

Rosacea: what connection to autoimmune disease?

Rosacea, a chronic disease of the skin of the face, normally occurs in middle-aged and older persons, cause unknown. It is characterized by varying degrees of inflammatory spots and excessive proliferation of normal cells of the soft tissues of the nose. In adults, it occurs three times as often in females as in males.

Rosacea shares genetic risks with some autoimmune diseases. A recent genomewide association study identified 90 genetic regions associated with type 1 diabetes, celiac disease, multiple sclerosis, and rheumatoid arthritis. A total of 6,759 patients with rosacea were identified and matched with 33,795 control subjects on age, sex, and calendar time.

After adjustment for smoking and socioeconomic status, patients with rosacea had significantly increased odds ratios for celiac disease, multiple sclerosis, and rheumatoid arthritis. The association was mainly observed in women. The conclusion was that rosacea is associated with type 1 diabetes, celiac disease, multiple sclerosis, and rheumatoid arthritis, respectively, in women, whereas the association in men reached statistical significance only for rheumatoid arthritis. ■

--Source: Excerpted from "Clustering of autoimmune diseases in patients with rosacea," Alexander Egeberg, M.D., et al., *Journal of the American Academy of Dermatology*, 2015, published by Elsevier Inc., and *Taber's Cyclopedic Medical Dictionary*, Edition 17

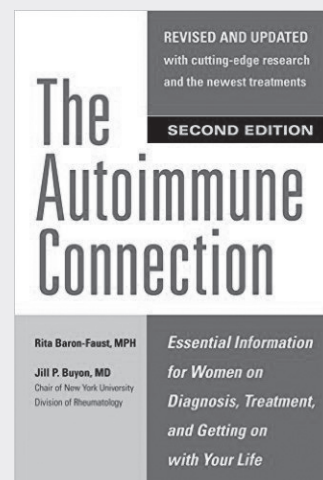
The Autoimmune Connection: Announcing second edition

Authors Rita Baron-Faust, M.P.H., and Jill P. Buyon, M.D., are presenting the second edition of their very factual, very readable book *The Autoimmune Connection: Essential Information for Women on Diagnosis, Treatment, and Getting on with Your Life*. In their book, the authors explain the links between autoimmune diseases and offer up-to-date information on diagnosis, treatments, and risks for women with one or more autoimmune diseases.

New in this second edition of *The Autoimmune Connection* are major breakthroughs in the treatment of rheumatoid

arthritis, thyroid disease, diabetes, celiac, and multiple sclerosis; and potential environmental triggers for autoimmunity. Also new is updated information on current drugs on the market and recently discovered side effects and long-term complications connected to existing drug therapies. In addition, healthcare law reform provisions and key changes to Medicare and Medicaid are described.

The book, a paperback, will be available after March 18 on Amazon (\$17.43, plus shipping and handling) and through AARDA (\$25, includes shipping and handling).





Researchers take a new look at pain

Pains may come and pains may go, but what happens when pain becomes chronic pain, i.e., pain that lasts six months or more? Although chronic pain is one of the most common causes of disability worldwide and enormous efforts are being made to find new therapeutic strategies, effective treatments remain elusive. A recently reported study being conducted by researchers at McGill University, Canada, suggests that their findings could open new avenues to diagnosing and treating chronic pain in humans.

The researchers report that chronic pain may reprogram the way genes work in the immune system. As stated by Moshe Szyf, professor in the Faculty of Medicine at McGill,

"We found that chronic pain changes the way DNA is marked not only in the brain but also in T cells, a type of white blood cell essential for immunity." He added, "Our findings highlight the devastating impact of chronic pain on other important parts of the body such as the immune system."

The McGill team examined DNA from the brains and white blood cells of rats, using a method that mapped DNA marking by a chemical called a methyl group. Co-author of the study, Laura Stone, explained the importance of methyl marks in regulating how these genes function. This sort of chemical marking is part of the growing field of epigenetics which involves modifications that

turn genes "on" or "off," a process that effectively reprograms how they work.

Dr. Szyf observed, "We were surprised by the sheer number of genes that were marked by the chronic pain--hundreds to thousands of different genes were changed." He said, "We can now consider the implications that chronic pain might have on other systems in the body that we don't normally associate with pain." ■

--Source: "Chronic Pain Changes Our Immune Systems," McGill University, January 27, 2016, via Newswise

Autoimmune center pilot study reaping good results



In August 2014, the American Autoimmune Related Diseases Association (AARDA) engaged MidMichigan Health, a nonprofit health system affiliated with the University of Michigan Health System and headquartered in Midland, Michigan, to conduct a six-month study on patients referred or self-referred to its Autoimmune Disease Diagnostic Triage

Clinic for the purpose of gaining a correct diagnosis. The ultimate goal of the study is to validate this new model of triage and referral for autoimmune diseases and then replicate that model at other institutions nationwide.

This comprehensive autoimmune clinic, the first of its kind in the nation, is headed by internal medicine physician Abid Khan, M.D., who serves as medical director. The Midland clinic, unlike specialty clinics, such as a rheumatology center or a gastroenterology clinic, sees patients with a broad spectrum of autoimmune diseases across the specialties. Dr. Kahn and staff assist patients in getting to the right diagnosis and the best available treatment through comprehensive evaluations and coordination of care with specialists across the country.

Dr. Khan has been designated a Visiting Scholar in the department of Molecular Microbiology and Immunology at the Bloomberg School of Health at Johns Hopkins University. In his role as a Visiting Scholar, Dr. Khan is working with researchers and clinicians at Johns Hopkins University, the University of Michigan, and other institutions to optimize and roll out an innovative new model that he has developed for diagnosing and triaging autoimmune diseases. The new approach could greatly ease the future path for patients by providing quick

referral to the right specialists, a definitive diagnosis, and relief for their symptoms.

One of the clients reporting a positive experience at the Clinic, Pamela Krabill, of Farwell, Michigan, has had an array of health problems: severe joint and muscle pain, headaches, eye problems, pleurisy, a series of mini-heart attacks, a stroke, gestational diabetes, and more. Separate specialists treated her separate problems, but that wasn't working. She needed a coordinated approach to address an underlying problem, lupus, an autoimmune disease.

One of the first steps that Dr. Khan took with Pamela was to refer her to a rheumatologist to confirm her diagnosis of lupus. He also prepared a time line for her ongoing care, and he continues to see her regularly, assessing and explaining any new diagnosis and any other steps that may be beneficial. For example, as he monitored Pamela's treatment with one rheumatologist, he and Pamela agreed that the treatment that she was receiving was not aggressive enough. Since it was not producing the results she needed, he referred her to the specialized Lupus Clinic at University of Michigan Health System. They worked out a new treatment plan for her that brought her symptoms under better control. With focused support from the staff at the Midland clinic, Pamela is experiencing improved health and a more normal family life.

The Autoimmune Clinic at MidMichigan Health is currently welcoming patients who have been diagnosed with an autoimmune disease or who are experiencing common symptoms of autoimmunity and have not been diagnosed. To learn more about the Autoimmune Disease Diagnostic Triage Clinic at MidMichigan Health or read the rest of Pamela's story, visit www.midmichigan.org/autoimmune. ■

--Source: Adapted from "Autoimmune center offers new hope for diagnosing, treating autoimmune disease," *Record and Clarion*, Clare, Michigan, January 19, 2016

Looking to the past for clues to future prevention

Through a study begun under the leadership of Dr. Noel Rose, Immediate Past Director of the Johns Hopkins University (JHU) Center for Autoimmune Disease Research, researchers at JHU are using rheumatic fever, an autoimmune disease caused by infection that has been cured or nearly eliminated in the developed world, as a window into how autoimmune diseases potentially may be prevented.

Rheumatic fever is a disease whereby the genetics are triggered by a specific pathogenic organism, a bacterium known as the beta hemolytic streptococcus, the “strep” that causes common sore throats. In 1944, the bacterium first was treated successfully with antibiotics. This scenario offers a path for the prevention of other autoimmune diseases at relatively low cost.

Rather than tampering with genes to eradicate disease, which is risky and expensive, Dr. Rose believes that it is preferable to identify the organism causing the disease and to separate the patient from that organism, thereby preventing and, it is hoped, eradicating the disease. The challenge, however, is that unlike rheumatic fever, most autoimmune diseases do not exhibit a good one-to-one ratio of infection to disease.

With that in mind, Dr. Rose’s team is looking at inflammatory heart disease or autoimmune myocarditis, the major cause of heart disease in people under 40. The team is tracing the progression of disease from infection to autoimmunity in order to obtain clues for earlier diagnosis, treatment, and

prevention. Using animal models, they can study the disease from the outset, rather than just at the end when patients are very sick. How is that being done?

The researchers infect mice with a virus that they believe is involved, Coxsackie virus. This produces viral myocarditis, an infectious disease which they then eradicate from the heart. But some mice go on to develop a second disease called autoimmune myocarditis.

The research team now is trying to dissect this process to see what the virus is doing to initiate the autoimmune process. The researchers have isolated a peptide called cardiac myosin that is responsible for the autoimmune disease. By injecting mice with this peptide, they then induce autoimmune myocarditis. If the mice go on to develop disease, the researchers have been able to identify in those mice biomarkers or cytokines, basically genetic traits.

Cytokines are the mediators of inflammation, and higher levels are an early sign that the mouse will go on to develop a potentially inflammatory autoimmune disease. However, the researchers believe that they can block those particular cytokines and prevent the disease. If, indeed, this is accomplished, it will be a major milestone in autoimmunity prevention. ■

--Source: “Infection to Prevention: From Rheumatic Fever to Autoimmune Myocarditis,” *Highlights from “The State of Autoimmune Disease: A National Summit,”* AARDA, October 2015

New study finds increased risk of autoimmune disorders

An online report in the March 16, 2015, journal *Arthritis & Rheumatology* states that in the 12 years following 9/11, researchers found 59 new cases of autoimmune conditions among more than 13,600 firefighters and other workers who were potentially at risk. Their odds of getting such a diagnosis rose 13 percent for each month they spent at the Twin Towers site, the findings showed. Workers who spent 10 months there had a threefold higher risk than those who were on-site for one month. ■

--Source: Amy Norton, *Healthday*, reported in *Highlights from “The State of Autoimmune Disease: A National Summit,”* AARDA, October 2015

Rare autoimmune disorder creates pregnancy problems

A relatively small study involving 60 pregnant women has presented a disturbing connection between a rare autoimmune disorder, neuromyelitis optica, and miscarriages. This inflammatory disease, often mistaken for multiple sclerosis, affects the nerves to the eyes and the spinal cord, and sometimes the brain.

In the study, conducted by researchers from the University of Oxford, in England, medical records of 60 pregnant women with neuromyelitis optica and a history of at least one previous pregnancy were studied. Forty women were analyzed for miscarriage and 57 women were analyzed for pre-eclampsia, a condition marked by high blood pressure and protein in the urine that can threaten the life of the mother and baby.

Eleven pregnancies in six of the women (13 percent) ended in miscarriage, a rate similar to that reported in the general population. However, six of the 14 pregnancies (43 percent) that had occurred after the disease started ended in miscarriage. Pregnancies conceived up to three years before disease onset were nearly 12 times as likely to end in miscarriage, regardless of the mother’s age or past history of miscarriage.

The researchers reported, “Women whose pregnancies ended in miscarriage after or up to one year before disease began also had more disease activity from nine months prior to conception to the end of pregnancy, compared to viable pregnancies.”

The rate of eclampsia among women with neuromyelitis optica was 11.5 percent compared with about 3 percent in the general population. The risk of pre-eclampsia was even higher among women with neuromyelitis optica who had other autoimmune disorders or had suffered a miscarriage in their most recent pregnancy.

Researcher Dr. Maria Isabel Leite, from the University of Oxford, said, “Women with neuromyelitis optica have a high risk of miscarriage, particularly in pregnancies occurring within the three years prior to, or after, when the disease starts.” She pointed out that unfortunately some of these women may not even know they are going to have the disease at the time of miscarriage. ■

--Source: “Rare Nervous System Disorder Can Put Pregnancy at Risk,” Robert Preidt, *National Institutes of Health*, November 18, 2015, via *MedlinePlus*

~ EDITOR’S NOTE ~

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Inside this issue

AARDA at 25	1
President/Executive Director's message.....	2
The AARDA Store is now open.....	2
AARDA kicks off its 25th Anniversary campaign ...	3
Join the celebration! (Derby).....	3
What I've Learned: Noel Rose	4
Rheumatology scholarship offered	5
Grassroots fundraising for AARDA.....	6
Yes, you can! The NEW Virtual Walk.....	6
Linking Together Again.....	6
Planned Giving: What? Why?	7
The Autoimmune Connection: Announcing second edition	7
Rosacea: What connection to autoimmune disease?	7
Researchers take a new look at pain.....	8
Autoimmune center pilot study reaping good results	8
Looking to the past for clues to future prevention...	9
Rare autoimmune disorder creates pregnancy problems	9
New study finds increased risk of autoimmune disorders	9
AARDA says "thank you" to.....	10
With special thoughts...Tributes and Memorials ...	10