INFOCUS

Autoimmune Diseases Association

American Autoimmune Related Diseases Association, Inc.

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

Vol. 22 No. 2, June 2014

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

As we were working on copy for our Annual Report FY 2013, a quote from Archbishop Desmond Tutu, of South Africa, seemed appropriate: "Do your little bit of good where you are; it's those little bits of good put together that overwhelm the world." We agreed that some of our gains are "little bits" and some, not so little; but in acknowledging our own "bits," we recognized that, through the years, a number of friends have been helping to put the bits together.

An exciting example of friends working together was the highly significant news briefing at the National Press Club presented by AARDA and members of the National Coalition of Autoimmune Groups (NCAPG), on March 18. This was one of the activities of Autoimmune Diseases Awareness Month celebrated each March. The purpose of the news briefing was to announce findings from a series of surveys of autoimmune disease patients and a preliminary study of physicians. We also unveiled plans to create a new, first-of-its-kind national autoimmune disease registry. I would like to share with you some facts presented to members of the press.

What is happening with autoimmune diseases in the age of the Affordable Care Act (ACA)? To find some answers to this question, the NCAPG conducted a Web-based survey with the goal of collecting data and getting a sense of how implementation of the ACA is affecting autoimmune disease patients. The survey used information collected by 357 respondents, all of whom had one or more autoimmune diseases and who were directly affected by ACA.

• 66 percent have been able to continue seeing their specialists; 45 percent have concerns about continued accessibility to specialists under the ACA.

• 42 percent say their premiums have increased; 58 percent, no increase.

• 34 percent cite increased deductibles; 40 percent, the same; 8 percent, decreased.

• 36 percent believe the services they receive have decreased; 33 percent, the same; 23 percent, increased.

Stephanie P. Hales, Associate, with legal firm Sidley Austin LLP, said, "Appreciating how early it is in the ACA's implementation, this survey provides some very preliminary data on the experiences of patients with autoimmune diseases. This initial information reflects that the ACA has helped many people so far but that continued improvements are needed to ensure that the ACA is implemented in a way that meets the needs of patients with serious and chronic conditions--including autoimmune diseases." She added, "It is clear that more must be done to ensure that patients with autoimmune diseases have meaningful access to affordable coverage."

I said, "At AARDA, we hear from autoimmune disease patients every day who have had to find new plans that basically don't meet their health care needs. These are still early days for the Affordable Care Act. When it is fully implemented and employers are required to change the plans they offer their employees, the NCAPG does plan to do a follow-up survey of autoimmune disease patients to learn whether or not they still have access to the specialists and medicines they so desperately need."

What are some of the difficulties in obtaining an autoimmune disease diagnosis? **Dr. Stanley M. Finger**, Vice Chair of AARDA's Board of Directors, said that since 1996, AARDA has conducted benchmark research to track the number of years it takes and the number of doctors a patient sees from the onset of symptoms to proper diagnosis. According to the latest analysis, patients report it takes more than three-and-a-half years and nearly five doctors to receive a correct autoimmune disease diagnosis.

Dr. Finger commented, "While the numbers are down from the first survey which found it took five years and six doctors to get a diagnosis, that is still unacceptable. The reality is that this results in patients' suffering needlessly and often sustaining more severe, irreversible organ damage." He said that as an autoimmune patient himself and as a member of a family having autoimmune diseases, he understands the dangers of this situation.

Adding to the worry has been the risk of being labeled a chronic complainer by one's physician. Survey results in 1996 showed that 64 percent of patients were labeled "chronic complainers." In 2013, the percentage dropped to 51 percent--still too high, a very real roadblock to receiving timely diagnosis and treatment. In a survey of five diseases (Sjögren's, rheumatoid arthritis, MS, lupus, and Crohn's), it was found that average total time for diagnosis was 3.5 years, ranging from 2.7 years for rheumatoid arthritis to 4.3 years for Sjögren's syndrome.

Also very likely causing patients to back off from pursuing diagnosis was being told that their disease was imagined or that they were overly concerned, ranging from 44 percent for rheumatoid arthritis to 59 percent for Sjögren's syndrome, for an average of 51 percent.

Dr. Finger added that these survey results led AARDA to conduct a preliminary study of 130 family physicians in the fall of 2013. That study found the following:

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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 A. Barber, AARDA Patient Educator

~ Editor ~
Eula M. Hoover, Executive Assistant

~ Contributor ~
Sharon L. Harris, Project Manager

~ Distribution Coordinator ~
Cathleen Cruchon, Accounting/Database

President/Executive Director's message continued

• 64 percent of family physicians stated that they are "uncomfortable" or "stressed" when diagnosing autoimmune disease in patients.

• 73 percent do not believe that they received adequate training in diagnosing and treating autoimmune diseases.

• 57 percent reported that they had only one or two lectures on autoimmune disease in medical school.

"Based on the doctors' responses," Dr. Finger said, "AARDA has launched a full-scale study of family physicians, both medical and osteopathic, to further explore these issues and develop targeted education programs to bolster physician awareness of and comfort levels in diagnosing and treating autoimmune diseases."

The full-scale study is currently in the field and will be released later in 2014.

What possibility lies ahead for a National Autoimmune Disease Registry?

Aaron Abend, AARDA Informatics Director, announced that a National Autoimmune Disease Registry will be compiled utilizing information contributed by NCAPG members. It will be the first-of-its-kind database that will eventually include every patient suffering from an autoimmune disease. Modeled on a similar registry for cancer patients (www.seer.gov), the National Autoimmune Disease Registry will provide researchers much needed information:

• Statistics on the burden of autoimmune diseases on public health.

• Statistics on multiple-disease sufferers.

• Central resource for recruitment of patients for clinical trials.

Mr. Abend said, "The creation of the National Autoimmune Disease Registry will go a long way toward helping transform the image of autoimmune disease from a large number of related and mostly rare diseases to something similar to cancer--a single disease category with a variety of sometimes common, sometimes rare manifestations."

From AARDA's experience, I pointed out that a very important study on the costs of autoimmune diseases being conducted for us at Johns Hopkins had to be abandoned after three months of research for lack of data. The majority of autoimmune diseases have never been the subject of epidemiology studies. That is one reason that the NIH continues to use the 23.5 million figure for autoimmune diseases in the United States as opposed to AARDA's 50 million figure; the NIH was able to obtain epidemiology studies for only 24 of the 100+ known autoimmune diseases. Such lack of statistics makes this National Autoimmune Disease Registry a tremendously important undertaking. With the combined efforts of the 33 member groups of the NCAPG, plus the expertise of Aaron Abend, we can accomplish this much needed, long awaited registry.

What is the National Coalition of Autoimmune Patient Groups (NCAPG)? The National Coalition of Autoimmune Patient Groups, spearheaded by AARDA, is a coalition of 33 national autoimmune disease organizations representing people with autoimmune diseases throughout the United States and the world. Together, all of us work together to educate the public, medical professionals, and the patients themselves on the individual autoimmune diseases represented by each group as well as the common thread of autoimmunity which connects them all. In 2001, NCAPG member groups spearheaded advocacy efforts which were successful in having legislation passed that required the National Institutes of Health (NIH) to develop a National Autoimmune Disease Research Plan.

Our thanks go to those NCAPG groups who, along with AARDA, underwrote the cost of the news briefing: **American Behçet's Disease Association, Crohn's and Colitis Foundation, Dysautonomia International, Graves' Disease & Thyroid Foundation, Sjögren's Syndrome Foundation, and The Myositis Association**.

There you have one of Archbishop Desmond Tutu's "little bits." It's not so little, is it?

Best wishes to all of you,
Virginia

Why AARDA membership?

- ~ You receive a subscription to our quarterly newsletter, *InFocus.*
- ~ You receive notifications of any AARDA-sponsored meetings in your area.
- ~ You make a tax deductible contribution to a worthwhile cause (AARDA is a 501(c)(3) organization).
- ~ You contribute to a membership count which is significant in our applying for grants and other support.

Yes! Every member counts!
Are you an AARDA member?

It's here! Innovative autoimmunity curriculum for elementary and middle school teachers is launched by AARDA! And it's free!

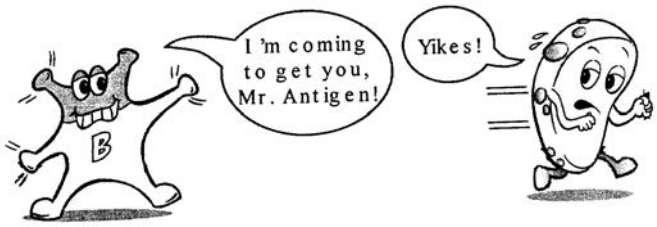
Working with life sciences curriculum experts from The Education Center, LLC, AARDA has developed the first-of-its-kind autoimmune disease curriculum for teachers of grades three through eight. This curriculum utilizes grade-appropriate teaching materials that align with the Common Core Standards.

Knowing that autoimmune awareness and education comprise first steps in leading to timely diagnosis and saved lives, AARDA leaders long have envisioned reaching out to children who would be the "message carriers" for their own and family education concerning autoimmune diseases. AARDA President and Executive Director Virginia Ladd says, "With this curriculum, The Education Center is helping us do precisely that--and doing it in a way that is informative, engaging and age appropriate while meeting the highest education standards."
She asks, "What better way can we help all Americans to truly understand autoimmunity and autoimmune diseases than to begin educating them at the earliest possible age?"

Since it is estimated that 50 million Americans are affected in some way with one or more of the 100+ known autoimmune diseases and since these diseases affect predominately women in their childbearing years, this study of autoimmune diseases and their impact on families becomes very personal in the lives of teachers, students, family members, and friends.

The curriculum is designed to educate not only students and their families but also the teachers themselves, a group of individuals particularly at risk of developing autoimmune diseases. Researchers believe that the school environment may contain more triggers for autoimmune diseases than other work environments. An early study by the U. S. National Institute of Occupational Safety and Health (NIOSH) showed that there was an association between the occupation "teaching, except post-secondary" and a number of possible autoimmune diseases, including diseases of connective tissue; diseases of musculoskeletal system, multiple sclerosis and other demyelinating diseases; rheumatic fever and heart disease; and rheumatoid arthritis and other inflammatory polyarthropathies. They also found excess mortality in most of these categories in white females whose place of employment was listed as "elementary and secondary schools." Among black females, teaching was listed as an occupation associated with elevated mortality from diffuse connective tissue diseases. Among white males, teaching was associated with excess mortality from multiple sclerosis. What better place to start this autoimmune disease education?

The course begins with **Autoimmunity and Autoimmune Diseases: What Teachers Should Know**. Questions are posed: "What is autoimmunity?" "What is an autoimmune disease?" "What are some autoimmune diseases your students may know?" With lay-friendly graphics, definitions, explanations, and study questions, the teacher is led through the course to a clear understanding of what can be presented to the students at the appropriate grade level.



Clearly presented comprehensive curriculum materials include teacher guides, information on how the immune system works, and how an unhealthy, malfunctioning immune system prompts the autoimmune response. Included are student research and report projects and activities. Also included is a parent send-home component. All projects call for easily obtainable materials, e.g., coat hangers(!), construction paper, markers.

The course proceeds to teach **Your Immune System; What You Need to Know**, adapted for the various grade levels. Specific projects are designed for the teacher to use in the teaching process. One project, for grades 3 and 4, is an autoimmune disease mobile. One carries the heading "Here's the Scoop on Celiac Disease"--an excellent learning and take-home tool.

Grades 5 and 6 students research a disease of their choice. Each student does research on the disease and prepares notes for conducting an interview between an expert on the chosen autoimmune disease and the host of the "Linking with the Experts" television show. The student plays the part of the expert, and his/her partner plays the role of the show's host. The student has prepared a poster to illustrate aspects of the disease being discussed.

Students in grades 7 and 8 delve into deeper study of the diseases. Working with the topic "Tuning into autoimmune disease," they devise their own Medical News Network with its Medical Links Channel. Dividing into groups, each group creates and presents a booklet, "Program Proposals for The Medical Links Channel." As a group, they decide on the order in which their shows should be featured. They must be prepared to convince network executives to air their shows.

Teachers who already are overburdened with demands on their time, from family obligations to the stress--and joys!--of the teaching job itself, will be relieved to know that all the steps and materials are laid out for them. The curriculum materials are available for download for all interested teachers nationwide. To download the curriculum, teachers can go to **themailbox.com/immunesystem** until September 30, 2014. After that date, it will be available on AARDA's Web site, **www.aarda.org**.

The development cost of this autoimmune education curriculum was underwritten by grants from Genentech and the Bayer Foundation. ■

Quote to ponder and enjoy...

Don't stumble over things that are already behind you.

Lynda Wallace, Life and Career Coach, via Taste for Life, April 2014

Guillain-Barré: A case for coordinated research

Summary of an article written by John M. Ostheimer, Ph.D., a recent victim of Guillain-Barré syndrome

August 24, 2013, marked one year since I had collapsed with a poorly understood ailment known as Guillain-Barré syndrome. One moment, I was showering and the next moment I was lying on the floor, shouting for help. My life was to change radically from that moment.

I was taken to the Emergency Room of a local hospital. The next morning, my wife was told that I might have Guillain-Barré syndrome (GBS) and that the doctors also wanted to test for West Nile virus as the trigger for the GBS. I had both an MRI and a spinal tap that afternoon.

In the neurology ward, a neurologist seemed confident in his diagnosis of GBS. That day, I began to have trouble with respiration. Since the paralysis was creeping from my legs to my upper body, I was transferred to the ICU for closer monitoring. My children began to arrive; I recognized them and was able to raise my arms slightly.

A more accurate name for GBS is "acute inflammatory demyelinating polyneuropathy" (AIDP). Translating this more medically term into English, AIDP is an illness with a sudden onset, in which the nervous system becomes inflamed, causing damage to the nerves' outer coating called myelin. Many nerves are attacked, as described by Joel S. Steinberg and Carol Lee Koski, authors of the GBS/AIDP Foundation's pamphlet "Guillain-Barré Syndrome, CIDP and Variants: An Overview for the Layperson." But even this technically complete name fails to encompass the *peripheral nerve involvement* of the syndrome, rather than the central nervous system. GBS is rare enough that I shall use this common name, rather than AIDP.

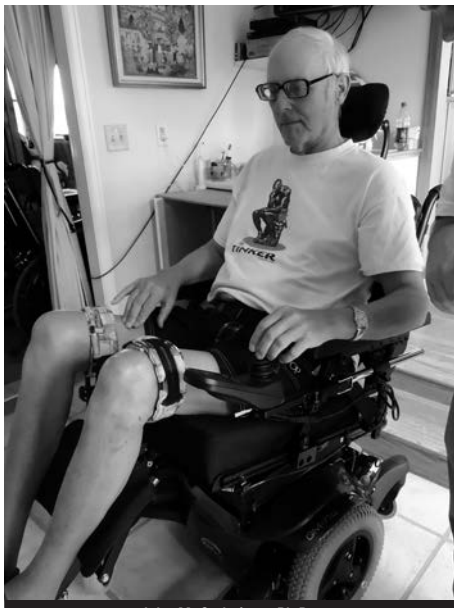
To put GBS in historical perspective, I have learned that I am lucky to be alive. As recently as 1980, when such treatments as plasma exchange (PE), or plasmapheresis, and intravenous immunoglobulin (IVIG) began to be applied, a common outcome of GBS was death. Medical experience has now established that either IVIG or PE will reverse the progression of life-threatening complications of GBS. They both are treatments for cleansing the blood of autoantibodies that are causing the damage. In my case, both treatments were applied. I did not respond to IVIG; and after a few days, I began a course of seven plasma exchanges. PE did seem to reverse or, at least, stop the course of the disease. Neither of these treatments is really a cure; they do not produce remyelination.

Lack of progress in research - In spite of many years that have passed since GBS was identified in 1916, medical research has *not* progressed to the key stage of understanding which medicines or therapies will remyelinate the victims' nerves. The medical community readily admits this situation, according to the aforementioned authors Steinberg and Koski who point out: "Just why the immune system acts out of control in some people but not others is not fully understood."

Why is this the case? To make an informed guess, I would argue that, in spite of the fact that there are thousands of victims of GBS around the world, this syndrome is far from a household word. There are so many more victims of multiple sclerosis (MS); amyotrophic lateral sclerosis, or Lou Gehrig's disease (ALS); idiopathic Parkinsonism, or Parkinson's disease; Alzheimer's disease, etc. The statistical gap might be overcome by a few cases of famous individuals who have had GBS; but to my knowledge, there haven't been any notable cases. Recent research, however, as revealed in "What was the cause of Franklin Delano Roosevelt's paralytic illness?" by Armond S. Goldman, et al., suggests that President Roosevelt had GBS, not poliomyelitis.

A second reason is that these other diseases are more terrible (if that's possible) or they are more socially "compelling" and, therefore, more capable of commanding major research funding because they victimize children.

Third, research on GBS and allied conditions has not even reached the level of accurate taxonomic specificity. Meghan O'Rourke, a New York teacher, carried out research on her own situation before concluding: "Today researchers believe that they have discovered eighty to a hundred autoimmune disorders...we don't know in every case whether autoimmune dysfunction



John M. Ostheimer, Ph.D.

is the cause of the disease, rather than, say, a consequence." Her article drew the following letter, written by Philip Porat and published in *The New Yorker*, that argued: "Our health-care system is reactive in nature and biased toward immediate or terminal illnesses characterized by discrete symptoms. Long-term diseases under the autoimmunity umbrella are often treated on a trial-and-error basis and plagued by a lag of diagnosis...."

Insurance-driven odyssey - After I became stable, and breathing, elimination, and other vital functions seemed under control, I began the usual insurance-driven tour of appropriate medical establishments. My odyssey began at our local hospital; but after 17 days, I was sent to a long-term acute care hospital. After another 23 days at L-TAC, I went to a rehabilitation facility; and after four months there, I came home. Insurance has covered an additional six months of therapy care at home, plus an added three months as an outpatient at a rehab center.

I have no right to complain about the amount or quality of nursing, therapy, or facilities I have been privileged to experience. Nevertheless, I am distressed about the lack of fit between my illness and the therapies I've received. My therapists have always gone "all out" to do what they can for me. On the basis of my experience, I believe that the patients must communicate clearly their therapeutic goals. This is my fourth go-round with basically the same regimen of therapies. At least, this time I started out by stating that my major goal is to regain the ability to walk. Unfortunately

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Guillain-Barré syndrome continued from page 4

when the therapists tried to get me walking, all discovered that I lack control over the required leg and core muscles. We immediately went back to the slide-board.

What have I learned from this? Besides being the most beautiful of human souls, therapists must also be among the most patient: they are reduced to helping the body to prepare for that blessed day when remyelination has gone far enough for one's body to genuinely respond.

I am now 19 months into this experience, and I still can do little physically. I have a very expensive motorized wheelchair, and we have bought a six-year-old mobility van. I am now able to "get around" better. My most important contribution at this stage of my life may be to raise awareness of autoimmune disease. This ailment has put an end to the outdoors things I love to do.

Conclusions for further research - Generally, my conclusion is that medical research should pull back from the study of individual syndromes like GBS. There is only so much research funding. If it is spread around literally dozens of specific illnesses, the science of medicine will take that much longer to "get to the bottom" of any of them. Bake sales might make victims of GBS and their families feel good, but the scientific effort will require real funding.

The work of the three scientists who won the 2013 Nobel Prize in Physiology or Medicine is a case in point. It is striking to me that the work of Drs. Stockman, Schekman, and Sudhof, on communication among cells, covering the past three decades, began when cellular communication was "...virgin scientific territory. Researchers had not identified a single protein in the neurotransmission process." This was reported in a *New York Times* article, "3 Win Joint Nobel Prize in Medicine," by Lawrence K. Altman.

The Nobel Prize winners worked on cellular communication for 30 years before finding a breakthrough. The solution to GBS and other autoimmune diseases may well lie in this cell communication. I only can hope that it doesn't take another three decades to find the answer.

Note: For complete list of references used in this article, contact Newsletter Editor, aarda@aarda.org, or 586-776-3900. ■

Every horse a winner!

Well, they were plastic horses--and while AARDA's 14th Annual Fund Raiser, the Derby Luncheon, may not have had live horses and jockeys with colorful silks, it was a winner. No bets were laid; but bidding was spirited in the Silent Auction, and raffle ticket buyers had high hopes of winning desired items. Will there be a Derby next year? That's to be determined. We do know that these major fund raisers are not only fun but also profitable for AARDA.

We are grateful for the group of volunteers, including AARDA staff, mostly 14-year veterans of these events, who planned and facilitated the Derby Luncheon; for the many local businesses that donated an array of items for the auction; and for the outstanding staff at The Henry Hotel, in Dearborn, Michigan.

We are grateful for our emcee, Chuck Gaidica, WDIV-TV Channel 4 Director of Meteorology, and the entire Gaidica family who support us at the annual event and behind the scenes.

Also, we are very grateful to Pfizer, Inc., underwriter of the event; Genentech, gold sponsor; and Detroit-based NECABA Management Group, Inc., silver sponsor. They assured the financial success of this venture.

We are grateful for the Honorary Committee, headed by Mr. and Mrs. Chuck Gaidica, Honorary Chairs, of Northville, Michigan. The committee was comprised of prominent philanthropists who annually support this special event: Michigan residents Sandra and James H. Vandenberghe and Mary Ann Van Elslander, of Grosse Pointe Shores; Gail and Lois Warden, of Grosse Pointe; Mr. and Mrs. Gordon H. Willett, of Grosse Pointe Farms; Ed and Judy Christian, of Grosse Pointe Farms and Longboat Key, Florida; and The Rev. Dr. and Mrs. Herbert G. Ford, of Oak Park. Also, California residents Mr. and Mrs. G. Howard Willett III, of Danville, were Honorary Committee members.

This year's event raised $61,131 in support of AARDA's mission. Now...what's for next year? ■

AARDA pops up in social conscience

Alexandra Martinez

Students in Northridge (CA) Academy High School had a group social conscience project, where they were to choose a problem that existed in the world that they wanted to help solve. The purpose of the project was to show students the power they have to make a real difference in the world through their intention, action, and mastery of language and communication. Student Alexandra Martinez chose AARDA because she had lost family members to an autoimmune disease.

Alex and the other students each prepared a ten-minute multimedia presentation designed to persuade a panel to fund the charity they thought best helped solve the problem. Because of her professionalism, creativity, and courage, and the rhetorical power of her presentation, Alex raised $175 for AARDA. This was the highest award given to any presenter.

We in AARDA thank Alexandra Martinez for not only raising funds but also spreading autoimmune education and awareness. Through awareness comes opportunity for diagnosis which leads to an increased chance of timely treatment before irreversible damage occurs. Alex, you are a life saver! ■

Misdiagnosed bipolar: one child's struggle

What a nightmare! One day a happy child; the next, frantic and out of control--diagnosed psychotic, bipolar--ending up in psych wards, group homes, and isolation rooms. But the story has a happy ending. Read on....

The sadness began when Tessa was six years old. Now, at sixteen, she is ready to help others. What happened during those ten years?

As reported in an article in the *San Jose Mercury News*, the normally happy Tessa was acting as frantic as a caged animal, darting out of the family car into traffic, hiding in bushes, and then refusing to talk. She was diagnosed with bipolar disorder, prescribed psychiatric drugs that didn't work, and institutionalized in various facilities.

Finally, almost impossibly, the family found a pair of Stanford University doctors--Drs. Kiki Chang, a child psychiatrist, and Jennifer Frankovich, a pediatric rheumatologist--who said that Tessa probably wasn't bipolar at all. She very likely was suffering from a tragically misdiagnosed condition that mimics mental illness but is only just starting to be understood by the medical community.

After a careful assessment, Dr. Chang said, "This is not bipolar. This is an autoimmune disease...." Tessa likely had an infection or other trigger that had caused her immune system to attack her brain mistakenly. He then made Tessa an appointment with Dr. Frankovich who was working with him to help diagnose and treat cases of pediatric acute-onset neuropsychiatric syndrome (PANS), a brain disorder that affects children and teens and is often misdiagnosed as bipolar disorder. A subset of the disease, pediatric autoimmune neuropsychiatric disorder associated with strep (PANDAS) can be cured by a common antibiotic if caught early enough.

When Dr. Frankovich began treating Tessa with the same autoimmune and anti-inflammatory therapies she used on her lupus patients, whose immune systems become hyperactive and attack their healthy tissue, Tessa started getting better.

"Nothing worked for ten months in the psych wards," Dr. Frankovich said, "but after three days of an infusion of steroids, it was a pretty dramatic improvement that was sustained." Back home, Tessa could write and draw again, her obsessive compulsive disorder (OCD) symptoms calmed, and finally she spoke after several months of silence.

Then, when the doctor tried to wean her from steroids, she started hearing voices. Getting permission for more aggressive treatment, the doctor started Tessa on a three-day treatment of plasmapheresis that would run Tessa's blood through a machine to clean out toxic antibodies, followed by a powerful immune-suppressing drug called Rituximab. Although this treatment had its dangers, it was Tessa's last hope.

Gradually Tessa improved. As her mother says, "Watching Tessa come out of this was like watching a child come out of a coma."

Now Tessa, an outgoing jokester, attends special education high school classes, plays softball, enjoys Girl Scouts, and attends a hip-hop class each week. She still gets mild cases of OCD, but they're manageable. She had another flare this past December, but more immunosuppressants brought her about 80 to 90 percent back.

At a recent meeting in Burlingame, California, attended by 200 parents of children with PANS and sponsored by the PANDAS Network, a parent support group, Dr. Frankovich said, "This is not a psychiatric problem. It's a medical problem." Parents from 16 states and four countries, including China and Scotland, made the trip to the conference. PANDAS Network is a member of the National Coalition of Autoimmune Patient Groups. ■

--Sources: "Tessa's Ordeal," Julia Prodis Sulek, San Jose Mercury News, April 20, 2014; and "Parents provide disease support," Julia Prodis Sulek, jsulek@mercurynews.com

Autoimmune Walk

LINKING TOGETHER FOR A CURE

Virtual or real? Let's walk!

Past Autoimmune Walks have been so successful that they are continuing in 2014. "Linking together for a cure" has brought local autoimmune awareness, education, and research monies to advance AARDA's mission. Walks in 2013 brought $78,500 to AARDA--and would you believe that the first year of Virtual Walks (where no one really walks!) realized a total of $20,000. Either wear your shoes or leave them in the closet, but PLEASE DO PARTICIPATE.

As Kellie Martin, AARDA's National Spokesperson and Autoimmune Walk Ambassador says, "Together we will step closer to a cure!"

Here's the current schedule for 2014: Saturday, June 21, 3rd Annual DC Metro Walk, McLean, VA; Saturday, June 19, 2nd Annual Georgia Walk, Marietta, GA; Saturday, July 26, Chicago Area Walk, Tinley Park, IL; Sunday, September 7, 3rd Annual Tristate Autoimmune Walk, Manhattan, NY; and Saturday, September 27, 2nd Annual Missouri Walk, St. Louis, MO.

Dates will be announced later for walks in Kentucky, Michigan, Florida, Ohio, and Connecticut.

Your Virtual Walk can be held at any time--your choice.

For help in setting up your walk or to ask questions, contact Christy at the AARDA office: 586-776-3900 or autoimmunewalk@aarda.org. ■

New evidence of autoimmunity in POTS

Exciting news of studies connecting an autoimmune condition and POTS, postural tachycardia syndrome, has been reported recently. With its abnormal rapidity of heart action, POTS can be a minor annoyance for some patients but can lead to significant life changes and limitations in normal life for others. POTS occurs frequently, but not exclusively, in younger females; and it is occasionally preceded by or associated with a viral-like illness.

From the University of Oklahoma and Vanderbilt University comes word that researchers conducting a study called "Autoimmune Basis for Postural Tachycardia Syndrome" have produced data supporting the idea that production of autoantibodies, circulating proteins that normally fight such infections, have interacted with critical sites on specialized cell membrane proteins which alter their normal cell function. These autoantibodies interfere with the system which controls the ability of blood vessels to constrict, an action that is needed to prevent a drop in blood pressure as a person stands.

In POTS patients, this inadequate response to standing leads to a generalized increase of activity in the body's sympathetic nerve system which frequently normalizes the blood pressure. However, this increased nerve activity increases the heart rate, a prominent symptom in POTS.

The researchers also discovered a second group of autoantibodies in some POTS patients which directly increase the heart rate. The combination of these two autoantibodies appears to cause the abnormal heart rate response observed in all POTS patients that the researchers have tested to date for these autoantibodies.

The presence of these autoantibodies may explain why beta blockers aren't always effective in treating the tachycardia seen in POTS since beta blockers fail to block completely autoantibody activity on their protein receptor. Also, they fail to alter the partial blockade of autoantibodies on the arteriole blood vessels that initiate the erect posture problem.

The researchers hope eventually to develop treatments to block these autoantibodies without blocking the target receptor proteins at the cell surface at the same time. This approach may prove useful in several other diseases which are caused by similar autoantibodies. ■

--Source: Excerpted from "New evidence of autoimmunity in POTS!" The Dysautonomia Dispatch, the blog of Dysautonomia International, February 25, 2014

Upcoming Education Events for 2014

Sponsored, cosponsored, or supported by AARDA

June 20-22 - Interdisciplinary Autoimmune Summit, North American Center for Continuing Medical Education (NACCME) - The Mirage Hotel, Las Vegas, NV

July 20 - AARDA Public forum, "What Every American Needs to Know About Autoimmune Disease" (Partnering with Emory University) - Atlanta, GA

June 25-28 - FOCiS 2014, Annual Meeting, Federation of Clinical Immunology Societies - Chicago, IL

November 14-16 - 2014 American College of Rheumatology Annual Meeting (AARDA dislay booth) - Boston, MA

Grassroots Fund Raisers-- *Cheers!*

❁ She did it again! Mary S. DeBruycker, of Loudoun County Public Schools, in Ashburn, Virginia, organized another "Wear Jeans to Work Friday." Result? This special day, held on March 21, brought a $720 donation to AARDA. THANK YOU.

❁ In the planning...the annual Pittsburgh benefit organized by Dominica Piscitelli Pavlik and friends in memory of Cara Lian Lebeda. This is a fun-filled evening that honors a dear young woman and serves a great cause. ■

Aldara and Zyclara: Possible side effects

Patients with autoimmune disorders may want to be sure that their physicians know of this health problem before accepting a prescription for Aldara or Zyclara (generic name imiquimod topical). It may also be a problem for a person with a weak immune system, graft-versus-host disease, recent bone marrow transplant, or cord blood transplant.

What is imiquimod topical? It is an immune response modifier used to treat actinic keratosis (a condition on the face and scalp caused by too much sun exposure), superficial basal cell carcinoma, genital warts that appear on the outside of the body, and some other purposes. ■

Local Contacts wear many hats

AARDA's Local Contacts provide a variety of volunteer services, from simply being available as autoimmune contacts within their own locales to sponsoring support groups. Much depends on how much time the Local Contact has available and what interest is being shown in his/her area. Setting up a support group is not usually a one-person venture. One of the Michigan Local Contacts has been having a good attendance at her monthly autoimmune disease support group, billed as an "Autoimmune Awareness Peer Group Meeting." The east suburban Detroit area support group features each month a talk by a health professional (researcher, rheumatologist, dietitian, etc.). For the list of Local Contacts, see the back page of this newsletter. ■

New discovery may aid therapy in gluten intolerance

Researchers at McMaster University, in Hamilton, Ontario, have discovered a key molecule that could lead to new therapies for people with gluten intolerance. This includes those with such illnesses as celiac disease, irritable bowel syndrome, and some other common gastrointestinal disorders as well as other diseases that are now seen as reacting favorably to gluten-free diets ("non-celiac gluten sensitivity"). Thus, the research has implications even beyond celiac disease, an autoimmune disease affecting approximately one out of one hundred Americans.

Dietary gluten is found in all forms of wheat (spelt, triticale, kamut, durum, semolina, einkorn, faro), rye, barley, and sometimes oats. When people who are genetically predisposed to gluten sensitivity ingest gluten in any form, an immune response is triggered that can lead to destruction of the intestinal lining, abdominal pain, changes in bowel habits, malnutrition, and many other symptoms that include anemia and neurological problems.

The digestive enzymes of gluten-intolerant individuals cannot digest the gluten, and left-over peptides from digestion induce inflammation. This inflammation is further amplified by an enzyme called tissue transglutaminase 2. And here enters elafin, the newly discovered molecule.

Researchers in the Farncombe Family Digestive Health Research Institute, at McMaster, have discovered that elafin, which is present in the intestines of healthy individuals, is significantly decreased in patients with celiac disease. The researchers found that elafin, by interacting with the transglutaminase 2 enzyme, decreased the enzymatic reaction that increases the toxicity of peptides derived from gluten. In mice, it has been found that the administration of the elafin molecule protects the intestinal lining of the upper gut that is damaged by gluten.

The possibility of elafin administration or replacement as a new adjuvant therapy to the gluten-free diet could add flexibility to a restrictive lifelong diet. This would increase patients' quality of life and potentially accelerate the healing of celiac lesions.

Following a gluten-free diet is very difficult because gluten is used not only in foods but in cosmetics and pharmaceuticals as a common, low-cost filler. ■

--Source: Adapted from "Research Finding Could Lead to New Therapies for Patients with Gluten Intolerance," McMaster University and American Journal of Gastroenterology, March 31, 2014, via Newswise

Scientists study genome analysis to improve drug screening

A recent research discovery presents a completely new approach to autoimmune disease therapies. This is according to Dr. Alexander Marson, a leading T cell expert and member of the University of California in San Francisco (UCSF) Diabetes Center. This new study from UCSF and Harvard Genome suggests that the effective identification of drugs for autoimmune disease may be increased by using genome analysis in standard drug screening.

Using the combination of drug screening and cutting edge techniques for genome analysis, the researchers identified three small molecules that improved symptoms in a mouse model of multiple sclerosis. The three potential drug candidates, selected from a large library of screened chemicals, knocked down the response of Th17 cells, immune cells that are implicated in many autoimmune diseases because they attack normal cells. The three drug candidates chosen for the study targeted an essential molecule within these Th17 immune cells.

Dr. Marson reported, "We examined what makes Th17 cells--which play a crucial role in multiple autoimmune disease--distinct from other closely related T cells within the immune system." He continued, "Then we investigated several small molecules that inhibit the development and function of these cells. When the Th17 cells were hit by these molecules, we saw less severe multiple sclerosis-like symptoms in the mice."

The research team found that a transcription factor named ROR gamma t played a unique role in the development of Th17 cells while inhibiting development of other immune cells. Inhibition of the transcription factor offered a possible strategy to fight autoimmune diseases.

Dr. Marson said that drug makers could use the large data sets generated from such experiments to develop drugs that target transcription factors. This would help drug developers gain an improved understanding of drug mechanism of action to see gene activities that trigger side effects.

These study findings appeared online in the journal Immunity. ■

--Source: "Genome Analysis in Drug Screening Could Improve Fight Against Autoimmune Diseases," Estel Grace Musangkay, Bioresearch Online, May 6, 2014

Study of diabetes and youth reveals disturbing trend

What's happening with diabetes and young people? The prevalence of type 2 diabetes, once thought of as "adult onset," has increased in American tweens and teens by 35 percent over an eight-year period, from 2001 to 2009. Pediatric type 1 diabetes, an autoimmune disease, increased by 30 percent in the same amount of time. This is consistent with worldwide estimates, according to researchers.

The greatest change in type 2 diabetes is occurring in Hispanic young people, followed by African Americans and Causasians. No significant changes were observed among Asian Pacific Islanders or Native Americans. According to Dana Dabelea, M.D., Ph.D, from the Colorado School of Public Health, Aurora, the increasing rates of type 2 diabetes likely reflect the current obesity epidemic and also the long-term impact of higher gestational diabetes rates.

As to type 1 diabetes, historically it has been considered a disease that affects primarily Caucasian youth. However, the researchers saw significant increases not only among that group but also among minorities: African Americans, Hispanics, and Asian Pacific Islanders. No significant changes were shown in Native Americans.

Speculating on possible causes, Dr. Dabelea mentioned a lack of certain viral or bacterial triggers at an early age ("hygiene hypothesis"), changes in early diet that might negatively affect the developing gut microenvironment, and increased rates of obesity in the general population. She said that further studies are required to determine the causes of these increases in both type 1 and type 2 diabetes in children.

--Source: "Diabetes Rates Rocket in US Tweens and Teens," Yael Waknine, Medscape Medical News, May 5, 2014

The microbiome and lupus: what influence?

The complex study of the network of genetic, environmental, and hormonal factors thought to contribute to systemic lupus erythematosus (SLE) continues.

Karen H. Costenbader, M.D., MPH, associate professor of medicine, Harvard Medical School, and co-director of the Lupus Center, Brigham and Women's Hospital, Boston, Massachusetts, states, "We have thought for a long time that lupus and other autoimmune and inflammatory diseases like it are caused by both genetic and environmental factors and their interactions. Epigenetic modifications, influenced by the environment and controlling the expression of the genes, may explain how the environment acts via the genes to produce lupus." She says, "We still don't know very much about exactly which factors are involved or how those interactions and the coordination of gene expression across the genome work, though." Epigenetic refers to changes in gene expression resulting from changes in the structure of DNA that influence how available a gene is for transcription.

Several lines of research have converged on the bacteria in the gastrointestinal tract (the gut microbiota), that can be influenced by dietary and other factors to alter immune response, as well as on environmental factors which can trigger lupus flares in the genetically predisposed. These bacteria aid in digestion, influence the host immune system, and produce basic changes. Animal studies being conducted at Yale University have produced findings suggesting that the gut microbiota is not only involved in antiphospholipid syndrome (APS) but, surprisingly, in the pathogenesis of lupus.

For the first time, says Christopher J. Edwards, M.D., MBBS, FRCP, we can now suggest how this actually works. He says that recent research "really shines a light on a complex area." Dr. Edwards is consultant rheumatologist and associate director of the National Institute for Health Research Wellcome Trust Clinical Research Facility, in Southampton, UK.

Martin A. Kriegel, M.D., Ph.D, senior author of the study, and assistant professor

Article continued on page 10

Non-celiac gluten sensitivity: for real?

Celiac disease is an autoimmune condition in which eating gluten, a protein found in grains such as wheat, barley, rye, and sometimes oats, damages the lining of the intestines, resulting in digestive symptoms and potential complications. Increasing numbers of individuals are claiming to have "non-celiac gluten sensitivity." What does it matter if people are diagnosing themselves concerning gluten sensitivity?

If one has possible problems with gluten, it would be wise to see a gastroenterologist for definitive tests before going gluten-free, according to Jessica R. Biesiekierski, of Monash University and Alfred Hospital, in Melbourne, Victoria, Australia. She says, "Testing for celiac disease becomes less accurate and can take longer if gluten is already removed from the diet." She says that people with trouble digesting gluten who are not tested for celiac disease may not get proper treatment, which could lead to health problems down the line.

Dr. Alessio Fasano, of Massachusetts General Hospital, agrees. He says that celiac disease and other possible causes of symptoms must be ruled out before a person is diagnosed with gluten sensitivity. Dr. Fasano also says that symptoms of non-celiac gluten sensitivity aren't limited to digestive issues. "We're talking about skin rash, headaches, foggy minds, joint (pain), anemia, and diarrhea--not just irritable bowel syndrome," he observes.

Biesiekierski comments, "There is a great deal of hype and misinformation surrounding gluten and wheat allergies and sensitivities. The group of so-called `non-celiac gluten sensitivity' remains undefined and largely ambiguous because of the minimal scientific evidence." ■

--Source: "Proper Tests," Reuters Health, via Medscape, Nutrition in Clinical Practice, online April 16, 2014

~EDITOR'S NOTE~

The information on these pages is provided without implied recommendation, solely as a service to those who may be interested. As with all research projects, interested parties should thoroughly question and have a complete understanding before considering participation.

Save the good T cells!

Researchers at the University of Kansas, in Lawrence, are working toward a potential breakthrough therapy for autoimmune diseases with an approach that targets only the dangerous "self-reactive" T cells that can harm the body while it leaves alone the vast majority of T cells that are vital to the human immune system. Most therapeutic approaches that target T cells do not distinguish between good and bad and just kill T cells, leaving the patient without proper defenses against infections and cancer, i.e., immunosuppressed.

Dr. Stephen Benedict, professor of molecular biology who co-authored the findings, says, "T cells are controlling cells of the immune response and are designed to attack cells infected with viruses, bacteria, fungi, parasites and cancer cells." He explains, "Self-reactive T cells are T cells that mistakenly can attack normal things in our bodies." He says that if self-reactive T cells enter the immune system, they could cause autoimmune diseases, such as, multiple sclerosis, rheumatoid arthritis, psoriasis, type 1 diabetes, and others.

Dr. Benedict adds that self-reactive T cells participate in emphysema and atherosclerosis as well. He points out that this is the same process that attacks and rejects organ transplants.

To target only the self-reactive T cells, Dr. Benedict and his colleagues interrupt the second of two signals T cells rely upon before attacking a cell in the human body. Mimicking the normal situation where a T cell receives the first signal that is specific to disease but does not receive the second signal that is the fail-safe signal, the approach hinders the T cells' attack.

In animal models, the researchers were able to preserve a large amount of pancreatic tissue, including beta cells, from being destroyed and to delay appearance of the aggressive symptoms of diabetes.

Dr. Benedict reports, "The major point of enthusiasm is that we may have inactivated the disease-specific T cells and left the major populations of T cells alone to continue to function."

The scientists plan to seek funding and eventually take the therapy through the clinical trials process for use in humans. ■

--Source: "Research points way to 'holy grail' therapy for autoimmune diseases," University of Kansas KU News Service, May 5, 2014

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Microbiome continued from page 9

of immunobiology and of medicine, Yale University School of Medicine, says, "Many details still remain to be determined, but the general finding that there is a connection between the microbiome [the total population of bacteria and other microorganisms that reside in the gut] and lupus is quite clear and suggests that novel therapeutic avenues could be developed in the future that are targeting not the host but one's microbiota." He explains, "Since lupus has classically been considered to be a disease independent from the microbiota, it does change our basic understanding of the pathogenesis."

Dr. Kriegel recommends that patients pay a little more attention to what effects various diets may have on their disease. He says, "The long-standing anecdotal patient reports of certain diets worsening or improving flares might be more real than we thought." He adds, "They should be studied more systematically, now that we know that almost any dietary component acts on the gut microbiota, [which] in turn has profound effects on the immune system."

Dr. Kriegel also comments on the current emphasis on the advantages of probiotics: "Probiotics could theoretically even worsen a disease state, since it is possible that physiologic immune responses against benign commensals [i.e., organisms that live in an intimate, nonparasitic relationship] could fuel autoimmune responses via cross-reactivity (as we hypothesize) or other mechanisms."

Dr. Edwards says, "It is early days, but there is very real hope and promise here for new therapies aimed at the heart of the gene-environment interaction." ■

--Source: Excerpted from "Lupus Studies Point to Gut Microbes, Epigenetic," from Lupus, special issue, 2014, via Medscape, May 13, 2014

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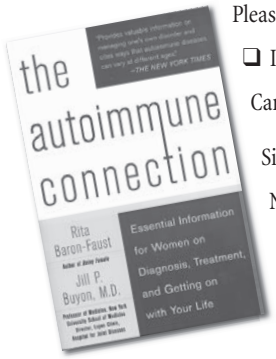

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Connecticut	Geri Viola Callahan	(203) 656-2866
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Nevada	Mercedes Barris	(702) 617-0072
New Jersey	Althea Cices	(845) 517-2491
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South Carolina	Stanley Finger	(843) 705-5580
	Charlie Wofford	(864) 271-2750
Texas	Mittie Lewis	(210) 653-6114 *(San Antonio area)*
	Jean Palmeri	(830) 885-7603 *(Support Group, San Antonio area)*
Virginia	Jennifer Aaron	(304) 229-0439 *(Shenandoah Valley area)*
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West Virginia	Jennifer Aaron	(304) 229-0439 *(Eastern Panhandle area)*
Washington DC area	Michelle Ouellet	(703) 893-1681 *(Mid-Atlantic Affiliate)*
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Local Contacts, International

Israel	Sarah Krein	972-54-810-1245
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