

AARDA Board news...FY 2017 brings changes

Going into the new fiscal year, changes were made in AARDA Board of Directors membership as elections were held at the September Board meeting. Now, we say “thank you for a job well done” to those leaving Board service and “welcome” to the newcomers.

Completing successful terms of office were Althea Cices, Linda Pesonen, and Lawrence Tobias. All have served in overall decision-making as well as in specific areas. **Althea Cices** has been particularly helpful in fund raising, especially the Autoimmune Walks, as well as in gracious Board representation at various significant events. **Linda Pesonen**, with her strong background in business management plus expertise in utilization of the Web in organization growth, has provided leadership to the Ad Hoc Web Strategy Committee and was a member of the planning committee for an AARDA annual fund raiser. **Lawrence Tobias** has shared his business acumen and writing skills in Board projects and has represented AARDA at various educational events. With deep appreciation, AARDA Board members thanked these outgoing members for their years of service to AARDA.

By unanimous vote, the Board elected new Board members, re-elected Board members whose terms had expired but who chose to serve again, and re-elected a former Board member. Also, some Board members chose to change Board assignments.

Staying in their Board positions for one more year were **Dr. Herbert G. Ford** and **Dr. Stanley M. Finger**, while **Virginia Ladd** continued her ongoing position.

Board members serve three-year terms; officers, two-year terms.

Nona Bear, a nationally known advocate of health care reform and champion of

seniors' issues, was elected as Board Secretary after having completed six years of AARDA Board membership. Nona has been especially effective as a member of AARDA's Advocacy Committee. In her six years of Board membership, she has provided a wealth of valuable information and guidance. Nona maintains a private practice as a consultant to publications, industry, and nonprofits on matters of health care and outreach to specialized audiences.

Michelle Ouellet, having served as Board Secretary for 11 years, has moved over to Board membership. A Federal government employee and a lawyer by profession, Michelle has contributed her legal knowledge to AARDA for 16-plus years and also has been active in Board work not only as secretary but also as a participant and advisor in fundraising. She was a co-founder of the AARDA Mid-Atlantic Affiliate and currently serves as a Local Contact in the Mid-Atlantic area.



John Kaiser, CPA, current AARDA Treasurer, was re-elected to another term in that position. John is a Partner in RSM US LLP, a global audit, tax, and consulting firm. Besides keeping close watch on AARDA's finances, John has been very active in fund raising. His AARDA golf outings in the Chicago area have been highly successful in both profit and autoimmune awareness.



Richard M. Hodge now enters his second term of Board membership. Over his past years of service to AARDA, Rich has been very effective as an AARDA Advocacy Committee member

Some thoughts about the Annual Appeal



It's "thank you" time again! While AARDA is known for its extreme care in the use of donor dollars--and its gratitude for dedicated volunteers and many in-kind contributors who help to stretch the donor dollars--your end-of-year generosity assures that AARDA's mission will continue. Please read "Overview of Major Accomplishments" in this newsletter.

AARDA has now earned Charity Navigator's second consecutive 4-star rating--its highest possible rating achieved by only 24 percent of charities it evaluates. The 4-star rating indicates that AARDA "executes its mission in a financially efficient way." According to Charity Navigator, AARDA exceeds industry standards and outperforms most charities in its area of work. This designation "sets AARDA apart from its peers and demonstrates to the public its trustworthiness."

Virginia Ladd wrote in her "View from the Top" in AARDA's Annual Report 2015: "Just as there is 'no such thing as a free lunch,' there are no such things as free research, education, patient services, and awareness or the administration to facilitate them. The 50 Million Americans, and others, are depending on us."

You won't receive telephone calls at dinner time from AARDA solicitors or find your mailboxes stuffed with AARDA solicitations. You are receiving instead this request that you consider the value of AARDA's accomplishments toward the autoimmune cause and give what you feel is possible for you. It all adds up!

You may give online at www.aarda.org by using your credit card (Visa, MasterCard, American Express) on our secure Web site; by calling (586-776-3900); or by sending a note to the AARDA office with your credit card information (Visa, MasterCard, American Express) or with your check. You may use the

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President/Executive Director's message

— Virginia T. Ladd

Dear AARDA Friends,

What a great time of year to reach into our hearts for the hope, love, and good will that we know is there. Yes, it's been a contentious and thought-provoking time, whatever your persuasion; but it's also been a time for clarifying what truly matters in our lives, our country, and the world. How grateful we can be for this Season of Celebration for all of us!

In this year, we had the pleasure of awarding the first-ever AARDA Champion Award to long-time AARDA friend and mentor **Noel R. Rose, M.D., Ph.D.** His many hours of wise counsel and dedicated service to AARDA have been crucial in the organization's growth and stature in the medical community; and as patients know, he has been a tremendous teacher and counselor.

Throughout 2016, AARDA has celebrated opportunities to sponsor and/or support significant educational meetings, both patient and scientific. We have achieved increased awareness for autoimmune disease through both national and grassroots-inspired local awareness. AARDA representatives have spoken out on behalf of autoimmune diseases and the persons--50 Million Americans--afflicted by them. They have challenged some ideas, e.g., "Non-Medical Switching." You can glimpse some of these in "Overview of Major Accomplishments" in this newsletter.

Honors, too, have come to AARDA. In May, AARDA received U.S. Congress acknowledgement through a proclamation printed in the *Congressional Record* and presented in the House of Representatives by Congresswoman **Debbie Dingell**. AARDA also received national recognition through my being awarded the 2016 Research and Hope Award for "Excellence in Advocacy and Activism" by the Pharmaceutical Research Manufacturers of America (PhRMA). What



a great description of what all of us in AARDA are doing!

One of the real challenges that we faced this year was trying to compile a list of 25 **#AutoimmuneHeroes** to celebrate our 25th Anniversary. We failed; it grew! Even with the enlarged list, we know that there are many others. Some "heroes" are obvious; others are moving unsung in the background; and all are crucial to the AARDA mission. How do we highlight every worthy person? Perhaps you, our readers, are enjoying having a glimpse into the Autoimmune Heroes stories on our Web site and in this newsletter.

One of our unsung Autoimmune Heroes is a donor who recently was inspired by our "Acorn" fund to support my stated dream of having a National Autoimmune Diagnostic and Treatment Center. She writes that she is giving this (more than her Social Security Disability) "Because I BELIEVE in Virginia's vision and if not for my own autoimmune benefit then for my family's next generation."

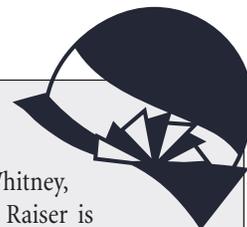
We truly are grateful for all Autoimmune Heroes, whoever and wherever you are.

Now we are rounding out the year with our Annual Appeal. Whatever you can give, large or small, is significant and much appreciated. The 2015 Appeal brought \$55,774.16. Can we top that?

To all of you reading this, and to your dear ones, we at AARDA send you best wishes for peace, joy, and prosperity in all areas of your lives. Thank you for all you do, in your own special way, toward AARDA's mission and for autoimmune patients everywhere.

With gratefulness,

Virginia



Heads up, Downton Abbey fans!

AARDA is bringing its own version of Downton Abbey to The Whitney, Detroit's most elegant venue, when the 17th Annual AARDA Fund Raiser is presented on Saturday, May 20, 2017. Guests are encouraged to dress the part for an enjoyable, lovely afternoon as AARDA revives its tradition of a gracious tea, including entertainment and a silent auction at this beautiful 1894 mansion. Limited seating. Valet parking available.

To assure a spot on the guest list, email dpatrick@aarda.org; or call the AARDA office at 586-776-3900. ■



AARDA Board *(continued from page 1)*

and has represented AARDA at home and abroad. With his over 35 years of experience in government, industry, and nonprofit associations as a healthcare administrator, health policy analyst, consultant, patient advocate, and government affairs director, Rich is utilizing his considerable knowledge for advancing the AARDA mission.



Returning to the Board after the required hiatus is **Robert M. Phillips, Ph.D.**, a licensed psychologist who first joined the Board of Directors in 2009. He is a charter member of AARDA's Scientific Advisory Board and is founder and director of the Center for Coping, in Hicksville (Long Island), New York. Dr. Phillips ("Dr. Coping") is a prolific writer, having authored more than 30 books and many articles on coping with physical ailments and on various psychological topics. He is a frequent speaker at AARDA's public forums. In his return to the AARDA Board, Dr. Phillips intends to continue his focus on autoimmune education, advocacy, and support.

Newly elected Board Members are the following:



Michael J. Linn is Chief Operating Officer and Chief Compliance Officer of Varadero Capital, L.P., in New York. He and his family are strong team supporters of the Los Angeles Autoimmune Walks, and he and his wife Rosalie have been active volunteers with the Tri-State Autoimmune Walk, in Manhattan. Mike organized the Ferrari South Bay, California, awareness event for AARDA and the Relapsing Polychondritis Awareness & Support Foundation. He and Rosalie joined new Board member Scott Selby and his wife Jackie to facilitate the beautifully presented AARDA 25th Anniversary dinner, held at Bouley Botanical, in Manhattan. Mike has made a personal commitment to support AARDA's critical mission.

Scott Edward Selby, Head of Business Development at Varadero Capital, L.P., develops new partnerships and cultivates existing partnerships with pensions, retirement systems, endowments, hospitals, and family offices across North America, Europe, and Asia. With those contacts, Scott feels that he can leverage his network appropriately to generate awareness and support for AARDA globally. Scott has been active with AARDA through his help with the Los Angeles Autoimmune Walk in addition to his work on AARDA's 25th Anniversary dinner with his wife Jaclyn, who chaired the host committee along with fellow Board member Mike Linn.



New Board member **Lilly Stairs**, in patient advocacy relations at JPA Health Communications, works with life sciences companies to build and develop their patient advocacy initiatives. Writing on her Board application, Lilly stated, "It is a dream of mine to serve on AARDA's board and I believe that my talents, perspective and expertise would be an asset to the organization." Even before joining the Board, Lilly proved to be an asset to AARDA and autoimmune patients: blogging, raising over \$11,599 for AARDA, supervising the creation of an awareness video, founding and leading the "50 Cents for 50 Million" campaign, visiting children and teens battling autoimmune diseases, and on and on!

To AARDA members and other friends, let's have a tip of the hat to the AARDA Board of Directors. It's quite a team! ■

What's been happening in FY 2016? We present an "Overview of Major Accomplishments"

Research

- Continued research support for the following:
 - O'Leary-Wilson Autoimmune Disease Fellowship, basic autoimmune research, Johns Hopkins University, Baltimore, MD
 - Autoimmune liver research, Johns Hopkins University, Baltimore, MD
 - Role of the innate immune system in lupus, The Feinstein Institute for Medical Research, Manhasset, NY
- Sponsored five Johns Hopkins University students in the summer Diversity Student Internship Program
- Continued campaign to fund a National Autoimmune Diagnostic and Triage Center
- Contributed to date \$4,827,310 to research
- Continued to develop the Autoimmune Registry Network (ARNet)
- Continued to approve "Young Investigators" grants

Education (Patient, Public, Scientific)

- Sponsored, cosponsored, or supported the following:
 - AARDA public forum, "What Every American Needs to Know About Autoimmune Disease," Tallahassee, FL
 - "How to Dance in the Rain," Conference for the Autoimmune Community, Scleroderma Foundation Michigan Chapter and others, Okemos, MI
 - American College of Rheumatology Annual Meeting (AARDA staffed display booth), Washington, DC
 - Scientific Meeting, Novel Cellular Pathways in Autoimmunity, Washington, DC
 - Federation of Clinical Immunology Societies (FOCIS) Annual Meeting, Boston, MA
- Welcomed new member to Scientific Advisory Board, Patrizio Caturegli, M.D., Incoming Director, Johns Hopkins University Center for Autoimmune Disease Research, Baltimore, MD
- Began support for organizer/facilitator of AARDA scientific meetings, Noel R. Rose, M.D., Ph. D., Pathology Dept., Brigham and Women's Hospital and Harvard Medical School, Boston, MA
- Continued to distribute Autoimmunity Curriculum for Elementary and Middle School Teachers, at no charge to teachers
- Continued as a source of autoimmune disease information on WebMD
- Maintained social networking sites
- Published quarterly lay-friendly newsletter *InFocus*
- Continued to make available AARDA patient-friendly "Risk/Benefit" brochure
- Continued to provide AARDA's "Three-Second Benefit Factor" study for physicians
- Maintained 24-hour toll-free request line
- Provided referrals and non-medical information during office hours
- Provided free educational brochures and newsletters to numerous health-centered meetings and events (CA, VA, MI, NY, GA, DC, IL, AZ, NC, IN, AR, NJ, CO)
- Maintained Local Contact list with support groups as available

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#AutoimmuneHeroes - Do you know them?

In this issue of *InFocus*, we continue our 25th Anniversary celebration by expanding our listing of AARDA's Autoimmune Heroes, many of whom have been with the organization from its earliest years. Here we present some outstanding members of the Board of Directors and AARDA's Advisory Board.



A familiar name in AARDA is Board Vice Chairman **Stanley M. Finger, Ph.D.**, who was appointed to the Board of Directors in 1995 and then elected Chairman of the Board in 2000 where he served for 13 years.

Why did Dr. Finger join AARDA? Originally he joined because he, his wife, and their two daughters have autoimmune diseases. Then, Dr. Finger says, AARDA became a real cause for him beyond his own family. Curious, he proposed a literature study of the number of people in the U.S. having an autoimmune disease. That study resulted in a publication by Noel R. Rose, M.D., Ph.D, with his team at Johns Hopkins University which revealed that at least 8.5 million people in the U.S. were afflicted with at least one autoimmune disease. This was a shock to the National Institutes of Health (NIH) which was estimating one million Americans with an autoimmune disease. Subsequent NIH studies spurred pharmaceutical companies to develop biological treatments that showed dramatic improvement over earlier drugs and now are helping to minimize the impact of autoimmune disease on patients and their families.

Of particular note is Dr. Finger's major role in the development and ongoing advocacy work of the National Coalition of Autoimmune Patient Groups (NCAPG), representing 39 national disease-specific patient organizations. He also was instrumental in assisting in the development of the National Institutes of Health's (NIH) Autoimmune Diseases Research Plan through serving as a Representative Member of the NIH Autoimmune Diseases Coordinating Committee and Chair of the Committee's Training, Education, and Information Dissemination Working Group.

Dr. Finger says, "I applaud the dedicated AARDA team that has been key to driving these major advances in the recognition and treatment of autoimmune diseases."



One of the earliest AARDA leaders was **Robert Meyer, CPA**, a founding member of AARDA's Board of Directors. Upon being elected to the Board, Bob realized the tremendous impact the organization was having on people's lives, even in its earliest days. Bob quickly became involved in the business aspects of the organization. For nearly 20 years, he provided accounting services to AARDA, from setting up AARDA's initial accounting system to serving as AARDA Treasurer for 19 years. His careful monitoring and counsel allowed AARDA to grow on stable financial footing.

In addition to his time as Treasurer, Bob served one term as Chairman of the Board. Now having left Board involvement but still maintaining an ongoing interest and involvement in AARDA's mission, he serves AARDA as a Board Advisor.

Bob Meyer says, "The dedication of the board, the employees, and the volunteers has been an awe-inspiring experience for me."



Who has not had the pleasure of meeting former AARDA Board member **Rita Baron-Faust**, serving from December 1998 to 2004? Generously volunteering her time to speak at dozens of AARDA public forums and other meetings all over the U.S.

for more than a decade, Rita has helped patients to understand their autoimmune diseases and to have productive conversations with their doctors, family members, and friends.

An award-winning medical journalist and author, Rita credits Virginia Ladd, AARDA's founding President, with inspiring her to co-author with Jill P. Buyon, M.D., *The Autoimmune Connection*, "Essential Information for Women on Diagnosis, Treatment, and Getting on with Your Life," and making it possible for her to bring empowering information to autoimmune patients at AARDA's public forums. As a writer, Rita explains that she often doesn't know where her words land; but at AARDA forums, she can see and feel their impact on patients. She calls it an incredible gift.

Rita says, "AARDA's advocacy has made a huge difference in the lives of thousands of people with autoimmune diseases, and for me to play even a small part in that is one of the greatest satisfactions in my life."



AARDA recognizes **T. Stephen Balch, M.D., FACP**, who served the organization as a mentor and participant even before his election to the Board of Directors in 2003, where he served until 2010. He says, "I believe that American Autoimmune Related Diseases Association and Virginia Ladd were crucial factors in the [public] education and [development of] treatment of these diseases."

With a passion for patient education, Dr. Balch made contributions not only through Board work but also through his willingness to speak regularly at AARDA forums as a clinician specializing in autoimmune diseases. He contributed to the AARDA newsletter, including "How do you help your doctor reach the right diagnosis?"

He developed a Statement of Values that was adopted by the Board in 2009. His "Defining the Indicators for Autoimmune Diseases" stated that "certain indicators can 'pave the way' for a vast number of autoimmune diseases." He wrote, "Such precursors act as clues as to what may lie ahead for the patient." This guide has proved helpful to AARDA's patient educator and others in assisting patients to find diagnosis.

A graduate of Northwestern University and Columbia College of Physicians and Surgeons, Dr. Balch served with the U.S. Public Health Services, National Institutes of Health (NIH), and later became affiliated with Emory University School of Medicine. It was after having completed his internship at Emory that he established a private practice and very quickly became interested in autoimmune disease. As he said, "I have been following patients with autoimmune diseases since 1980."



Autoimmune Hero **Michelle Ouellet** has filled many AARDA shoes since co-founding AARDA's Mid-Atlantic Affiliate in 1996. Her AARDA Board of Directors involvement began with being elected to the Board in 2004. She completed 11 years as Board Secretary in September 2016 and then was elected to Board membership at that time.

As a lawyer, Michelle has provided legal oversight as needed. She has organized and participated in AARDA fundraising events and has served as an instrumental member of AARDA's Ad Hoc Advocacy Committee, lending a strong voice for autoimmune disease and AARDA on Capitol Hill.

Michelle learned about AARDA when her daughter was diagnosed with autoimmune uveitis at age 7. She was driven to learn everything she could about autoimmunity. The more she learned, Michelle discovered that hers was an autoimmune family, with three generations of women having been stricken by different diseases--rheumatoid arthritis, pulmonary fibrosis, and uveitis.

Michelle says, "I know AARDA's work will help one day to prevent other little girls from suffering the fate of my grandmother, mother, and daughter. This is why I have been a steadfast supporter of AARDA, almost from the beginning. After all, we are supposed to leave this world a better place, right? AARDA is one amazing little organization that has, in fact, done so. I am proud to have been a part of this amazing group of people."



With 18 years of service as a Board Advisor and one term as a member of AARDA's Board of Directors, **Edward K. Christian** has been a big supporter of AARDA's mission since literally its beginning. Being part of a family with multiple autoimmune problems --ankylosing spondylitis, rheumatoid arthritis, and Raynaud's phenomenon--Ed has felt that it is imperative to understand and work to channel and direct funding of research in both immunity and autoimmunity. Therefore, he has been actively involved with AARDA.

As Chairman, President, and Chief Executive Officer of Saga Communications, he has been able to provide significant autoimmune awareness through donating voice and airtime on his more than 60 radio stations around the country. From Maine to South Dakota, AARDA's message has been heard through multiple public service campaigns over the years. By supporting AARDA, Ed and his Saga Communications employees have been able to provide hope, understanding, and information for a broad number of autoimmune situations.

Ed says, "There are so many organizations and precious little time and funds...but only one takes a top level view of autoimmunity, and it is AARDA."



Meeting Virginia Ladd many years ago when seeking help for a dear family member, **Howard E. Hagon**, now a Board Advisor, began to express his gratitude by generously sharing his business acumen as founder and owner of a company developing, manufacturing, and distributing health care appliances. He quickly became an unofficial advisor to fledgling AARDA. The "unofficial" became "official" when he was elected to AARDA Board of Directors membership in 1997.

Howard continued to supplement Board work by serving on multiple committees until retiring from Board involvement in 2014. At that time, the Board members recognized him by unanimous vote as a Founding Board member.

Through Howard's initial experience with AARDA, he says that he learned early the value of the encouragement and guidance offered through the assistance of knowledgeable volunteers united in a life-saving cause.

Howard says, "I would like to thank Virginia Ladd and all the Board members past and present for their dedication to AARDA and for all they have accomplished in recognizing the autoimmune diseases. It has been my pleasure to serve on the Board."



As a relatively new Board Advisor, serving since 2014, **Stephanie P. Hales** very quickly has made a tremendous difference in AARDA's ability to weigh in with governmental regulators and congressional offices on advocacy issues affecting autoimmune

patients. In addition, she provides direction and advice for AARDA's Ad Hoc Advocacy Committee.

An individual with autoimmune disease herself and coming from an autoimmune family, Stephanie has built her legal practice, and her life, on her passion for ensuring that access to health care and well-being, regardless of one's circumstances, is a reality and not a dream. She feels that her work with AARDA has been an honor and a privilege in helping to increase awareness, advance research, pursue advocacy, and "do all that we can to improve the lives of the millions of people affected by autoimmune disease."

Stephanie states, "I am grateful to be even just a small part of the tremendous progress that AARDA has achieved in its first 25 years--and the continued progress that is underway and on the horizon. And I am overjoyed and deeply humbled to be seen as a hero in the eyes of those who are heroes to me."



Having shown his commitment to AARDA since its founding, Chairman of the Board the **Rev. Herbert G. Ford, D.Min.**, is credited with assuring donated office space for AARDA in its start-up years and providing sage financial advice that has allowed AARDA to save and direct funds for much needed awareness and research programs. He also has been a diligent fund raiser for many years.

Dr. Ford initially was elected to Board membership in 1999, served several terms, and then was elected Chairman in 2013. He says that he intends to continue working with AARDA to raise awareness and funds for those struggling with autoimmune disease. Dr. Ford and his wife have a personal interest since their daughter has an autoimmune disease, multiple sclerosis.

"I am dedicated to AARDA because of its unrelenting work not only to increase awareness of autoimmune disease but also to improve the effectiveness of diagnosis and research on new treatments," Dr. Ford explains. "I really love the work that AARDA does to promote awareness of autoimmune disease and to encourage young scientists to pursue research careers in the field."

The National Coalition of Autoimmune Patient Groups (NCAPG) takes its place among AARDA's #AutoimmuneHeroes. Comprised of 39 national autoimmune disease-specific groups, the NCAPG has far exceeded the earliest expectations of its founder and present facilitator Virginia Ladd, AARDA President/Executive Director. This is due, she indicates, to the committed and collaborative spirit of the member organizations.

"By understanding there is strength in numbers and speaking out on the issues with a unified voice, the NCAPG members have made a tremendous impact on increasing autoimmune education, awareness, research, and patient safety."

With gratitude we recognize the following NCAPG members, true Autoimmune Heroes:

- American Autoimmune Related Diseases Association
- American Behçet's Disease Association
- Autoimmune Hepatitis Association
- American Liver Foundation
- American Vitiligo Research Foundation
- APS Foundation of America
- Arthritis Foundation
- Autoimmune Encephalitis Alliance
- Beyond Celiac

————— *Article continued on page 10*

JHU Diversity Summer Interns receive AARDA support

Once more we were pleased to provide support for five undergraduate students in the Diversity Summer Internship Program (DSIP) at Johns Hopkins University Bloomberg School of Public Health. This program, established in 1995, provides a graduate level, independent research experience in biomedical and/or public health research to undergraduate students under the direct mentoring of established Johns Hopkins researchers. The group includes students from under-represented minority groups and economically disadvantaged backgrounds.

AARDA's support of this program is intended to encourage young students to embrace research opportunities that may reap advances in autoimmune disease knowledge and treatments.

The closing activity of the 10-week program was the Annual Poster Session Presentation. The following presentations were made by "our" interns:

◆ **Christina Blonski-Cupo**, of Caldwell University (New Jersey), presented "Evaluation of Mycobacterium smegmatis as an invitro Model for Viable But Non-Culturable (VBNC) Bacteria."

◆ **Pamela Marte Perez**, of Caldwell (New Jersey) University, chose "Evaluation of Cytokines in Autoimmune Retinopathy."



Haroldo Rodriguez Chevez, Jelonia Rumph, Pamela Marte Perez, Christina Blonski-Cupo, Gabriel Smith

◆ **Haroldo Rodriguez Chevez**, of Florida International University, presented "Identification of Novel Pituitary Autoantigens in a Patient with Idiopathic Central Diabetes Insipidus."

◆ **Jelonia Rumph**, from Florida Memorial College, studied "Cardiac Fibroblasts Functionality Under the Influence of Th2 Cytokines."

◆ **Gabriel Smith**, of University of Maryland College Park, presented "Pituitary Autoantibodies Targeting Immunodeficiency."

AARDA may choose to support some of these students in the future as a new opportunity begins this year for eligible DSIP alumni to receive a scholarship upon matriculating into a qualified graduate program in the Bloomberg School of Public Health. ■

Appeal (continued from page 1)
form on page 11 of this newsletter.

As Dr. Herbert Ford, Chair of AARDA's Board of Directors, said in his Annual Report message, "On behalf of the 50 Million whom we serve, I thank you for any support you have given--or will give." **Yes, you are thanked.**

NCAPG members welcome new group

The membership of the National Coalition of Autoimmune Patient Groups (NCAPG) has now grown to 39 with the welcoming of the Autoimmune Encephalitis Alliance (AE Alliance), based in Durham, North Carolina. The group was launched in December 2012 to help catalyze this future: to change how patients with autoimmune encephalitis are diagnosed and treated, to support families coping with the disease, and to promote new scientific and clinical research that will lead in time to a cure.

The members of the AE Alliance strive to create a community of patients, families, and caregivers so that no one faces autoimmune encephalitis alone.

The *New York Times* best-selling book *Brain on Fire: My Month of Madness* chronicles the experience of author Susannah Cahalan who was diagnosed with anti-NMDA-receptor autoimmune encephalitis in 2009. Susannah is on the Board of Directors of the AE Alliance.

The National Coalition of Autoimmune Patient Groups (NCAPG), founded and facilitated by AARDA, is finding an increasingly strong voice nationally in gaining recognition and support for the 50 million autoimmune disease patients in the United States--and even in other countries. ■

Family pets have autoimmune disease, too

Autoimmune disease in canines was brought to national attention when First Dog Millie, residing in the White House with President George H.W. and Barbara Bush, was announced as having lupus. The term "autoimmune disease" is now making its rounds among dog breeders and exhibitors in the veterinary community. Among those groups, the most obvious implications have to do with devastating financial losses concerning breeding or the actual death of the dog, not to minimize the emotional attachment that the owner may feel.

The canine autoimmune factor was highlighted in the AARDA family when First Dog Tucker Barber, afflicted with diabetes, headed Team Tucker in the October Detroit Area AARDA Autoimmune Walk. His team brought \$1,896 to AARDA. Now, sadly, we announce that Tucker lost his fight with diabetes in November--but not before adding his support to the autoimmune cause.

As understanding of autoimmune disease broadens and as physicians--and veterinarians--increase the screening for this category of disease, AARDA's mission may eventually be realized. In the meantime, pet owners might do well to learn the possible signs of autoimmune disease. It's not just for human beings! ■

--Source: Excerpt from "Autoimmune Diseases, Immune system failures are a serious threat to your dog's health," Kathleen R. Hutton, DVM, *Dog Owner's Guide*, Canis Major Publications



Annual Report FY 2015 available

If you would like a copy of the AARDA Annual Report 2015, go to www.aarda.org. For those who do not have access to the Web, you may call the AARDA office (586-776-3900) and request that a copy be printed for you.

Fall Autoimmune Walks reach new audiences

Five AARDA Autoimmune Walks were held from September through November 2016--two of them inaugural events in Atlanta and Detroit. They engaged autoimmune patients and their families who never before had participated in an AARDA event or any event bringing autoimmune patients together to network with, support, and inform one another.

◆ In **Atlanta**, several Walk participants now are working to form a support group. Others have volunteered to help grow the Walks in their area and are looking forward to the 2017 Atlanta Walk. Special thanks go to coordinator Vanessa Hamler and the top team, Tomboy2Diva, led by team captain Cerica Collins.

◆ In **Detroit**, 137 people registered online or in person for the Walk on scenic Belle Isle, on the Detroit River, with a view of our friendly neighbor Windsor, Ontario, Canada. While most participants were Metro Detroiters, a number came the distances from Grand Rapids, Saginaw, and Monroe, Michigan. Our thanks go to Absopure, Kroger, and Better Made Snack Foods for their generous donations in support of the Walk. Special note is made of Team Tucker which honored a little dog with an autoimmune disease, diabetes. Congratulations go to the top team, Party People, led by Shannon Marold.

◆ The **DC Metro Walk** and the **Tri-State (New York) Walk** both marked an important milestone--year five of presenting an Autoimmune Walk.

--The DC Walk drew 125 people to Bluemont Park, in Arlington, Virginia, thanks to Robin Gebhardt. AARDA thanks Giant Good for its support, Arlington County, and all the auction donors. Special thanks go to the top DC team, Bear Foot Walkers.

--The Tri-State Walk, held at Hudson River Park's Clinton Cove, was sponsored by Intercept Pharmaceuticals. We thank singers



Danielle and Jennifer who donated their talents and joined the Walk. Both have Hashimoto's thyroiditis and facilitate an online support group called "Damn the Butterfly." Special thanks go to the top team, the PBCers.



◆ The **2nd Los Angeles Walk** drew nearly 300 people to Culver City Park on November 5. Led by Walk Ambassador Haley Ramm ("Notorious," ABC), her mom Barbara, and their family members and friends, the Walk was a great day. It included live bands, a silent auction and raffle, autoimmune stories and education, and lots of networking. AARDA is especially grateful to the Ramms' crew of exceptional volunteers. Special thanks go to the top team, Relapsing Polychondritis (RP).

◆ Students at Washington University in St. Louis held their fourth **Missouri Autoimmune Walk** on the Brookings Quadrangle, on September 17, after a week-long series of education and awareness events featuring speakers Emily Filmore, author of *The Marvelous Transformation: Living Well with Autoimmune Disease*, and Tiffany Westrich-Robertson, CEO of the International Foundation for Autoimmune Arthritis. Special thanks go to Walk Coordinator Courtney Vishy and the top team, The Autobots.

Plans for upcoming Autoimmune Walks are being completed and will be announced soon. What great opportunities for awareness, networking, education, fundraising--and, oh, yes, lots of fun! Want information? Go to www.AutoimmuneWalk.org. ■

A doctor looks at Hashimoto's thyroiditis and diet

What is Hashimoto's thyroiditis? This autoimmune disease develops when the body's immune system mistakenly attacks the thyroid, a small, butterfly-shaped gland at the front of the neck. Hormones produced by the thyroid, triiodothyronine (T3) and thyroxine (T4), maintain the rate at which the body uses fats and carbohydrates, help control body temperature, influence the heart rate, and help regulate the production of proteins.

Will a specific diet help? Certainly a healthy lifestyle that includes eating well, getting plenty of sleep, exercising regularly, and limiting stress can benefit the immune system and could contribute to an improvement in one's immune health. However, there is no evidence that following one diet in particular is an effective treatment for Hashimoto's thyroiditis or other autoimmune disorders.

What can the Hashimoto's patient do? The most effective way to control symptoms is to take a hormone replacement. Typically this means a daily use of a synthetic thyroid hormone called levothyroxine that is taken orally. It is identical to thyroxine, the natural version of one of the hormones made by the thyroid gland. This medication restores the hormone levels to normal and eliminates hypothyroid symptoms.

Is hormone replacement a cure? No, while it can control the symptoms of Hashimoto's thyroiditis, treatment is usually lifelong and may need to be adjusted from time to time. It is advisable that, if symptoms persist despite evidence of adequate hormone replacement therapy, this should be explored with one's health care provider as some problem other than Hashimoto's thyroiditis may exist. ■

--Source: "Hashimoto's thyroiditis--will diet alone help?" Victor Bernet, M.D., *Endocrinology, Mayo Clinic, Jacksonville, FL, November 13, 2016*

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"The New Normal"



Birgit Daniels, Mrs. Colorado International 2017, has made Autoimmune Awareness her platform during her year-long reign;

and she plans to hold monthly awareness and fundraising events in The Centennial State. She is the mother of three children and stepmom to two. She also works as Project Manager at Hill Commercial which specializes in ground-up builds.

Sometime ago, Birgit began experiencing a great deal of pain and swelling in her hands, shoulders, knees, ankles, and feet on the job, making it "literally unbearable to work." While the pain and swelling would come and go, Birgit kept working--and even got married.

Later, she received a diagnosis of rheumatoid arthritis. Her response: "Great! Now fix it."

However, as Birgit says, "I learned that there is no fixing it. It was very irritating. Medications were administered to alleviate the swelling and inflammation. In time, symptoms have gotten better but the chronic fatigue now takes its toll.

"Living with the new normal of give and take that this disease offers, I desperately try to have a decent sense of humor about this." Birgit adds, "I am here to not only advocate for research funding, but I am also here to be a motivator to those who need it. Trust me when I tell you I have lived and still live the bad days, but there are good days; and looking at me, you'd never know the difference."

Birgit comments, "I live by an old SeeBee motto: "The difficult we do at once; the impossible takes a bit longer." ■

AARDA's tiny acorn continues to inspire

Yes, there is a tree in there; and what hope it gives! Slowly the fund is growing. It may even inspire a major donor to make the National Autoimmune Diagnostic and Treatment Center a reality.

As one donor wrote (see President/Executive Director's message), "...I believe in your vision, your acorn promise. There is a huge gaping hole in the understanding, diagnosing, educating, and treating autoimmune diseases for all those whose lives it touches as well as a huge lack of learned specialists who see outside the box.

"I truly wish I was rich so I could give more and help this tree grow and grow. Thank you for all you do to help all of us suffering with autoimmune diseases in every aspect of our lives towards a better tomorrow."

The little acorn is waiting. Can you give it a boost? Little but mighty! ■



Grassroots special note

The donor amount listed in the September newsletter for the Deer Path Middle School East (Lake Forest, IL) Color Run was incomplete. The amount was \$4,643.69, not the \$4,019.50 originally indicated. Good job! We thank you for supporting AARDA.

AARDA Accomplishments *(continued from page 3)*

Advocacy and Awareness

- Began AARDA 25th Anniversary Campaign
- Held highly successful 25th Anniversary Gala, Bouley Botanical, New York, NY
- Expanded membership in the Autoimmune Partnership Council
- Continued facilitation of the 39-member National Coalition of Autoimmune Patient Groups (NCAPG)
- Received national recognition through the awarding to AARDA President/Executive Virginia Ladd the 2016 Research and Hope Award for "Excellence in Advocacy and Activism" by the Pharmaceutical Research Manufacturers of America (PhRMA).
- Continued development and information gathering for a first-of-its-kind National Autoimmune Disease Registry
- Cosponsored Capitol Hill Congressional Briefing ("Step Therapy and Related Patient Concerns"), Washington, DC
- Compiled data collected from a Web-based survey on how the Affordable Care Act is affecting autoimmune disease patients
- Provided interviews and information for news media; had major advertisements and articles (or acknowledgement) in national publications, including *Delta Sky* magazine, "Super Bowl 50" edition of *USA Today Sports*, *Modern Women*, *Crain's Detroit Business*, and autoimmune disease insert in *USA Today*

Fundraising

- Continued to encourage and provide support for "grassroots fundraising," including the digital *Grassroots Newsletter*
- Continued to expand the Autoimmune Disease Awareness Walks schedule (Cleveland, Ohio; McLean, VA; Atlanta, GA; Manhattan, NY; Detroit, MI; Los Angeles, CA; St. Louis, MO) and provide support for Virtual Walks
- Sponsored the AARDA Annual Fund Raiser in the Greater Detroit area

Administration

- Maintained the following ratings:
 - Charity Navigator Four Star Charity
 - Better Business Bureau Wise Giving Alliance Charity
 - Best in America Certified by Independent Charities of America
- Maintained membership and active participation in the International Alliance of Patients' Organizations (IAPO)
- Continued to meet the Standards of Excellence Certification Program for Voluntary Health Agencies of the National Health Council and maintain long-time membership
- Continued standing in the Combined Federal Campaign (CFC)
- Remained recognized Member Organization of Health & Medical Research Charities of America
- Held combined management and fundraising costs at 10 percent of total expenses (compared with 25 percent acceptable for nonprofit organizations)



Immune system and brain cells--what connection?

Over the past two decades, researchers have recognized that the entire immune system is very much a part of a functional central nervous system, having vital roles in cognition, injury repair, neurodegenerative disease, and sensory systems. Only until recently, the central nervous system was thought to be blocked off from the peripheral immune system. Now researchers know that diverse immune cells, possibly by the millions, circulate in the cerebral spinal fluid and live in the brain's outer membranes even in healthy individuals.

As early as the 1980s, researchers knew that immune cells infiltrated the central nervous system after injury, but such immune activity was viewed as something to be thwarted, not encouraged. For many decades, doctors used corticosteroids, which suppress immune-cell activity, to treat brain injuries. However, Michal Schwartz, at the Weizmann Institute, in Rehovot, Israel, says that it didn't make sense to her that tissues as indispensable as the brain and spinal cord wouldn't take advantage of the immune system's ability to protect against pathogens, substances capable of producing disease, and to repair damaged tissues. In the mid-1990s, she began searching for a positive neurological role of the immune system.

Despite a "high degree of skepticism" from a number of researchers, Schwartz and others continued to uncover ways that the immune system promotes central nervous system repair after trauma. Further

discoveries took place, and views began to change on the clinical side after the 2004 Corticosteroid Randomization After Significant Head Injury (CRASH) study showed that corticosteroids didn't help brain injury patients recover but actually increased their disability and death.

In 2013, Schwartz and her colleagues demonstrated in mice that the lining of each of the brain's four chambers harbors memory T cells whose receptors bind proteins found in the central nervous system. These T cells, although specific for central nervous system proteins, don't cause autoimmune disease. Schwartz contends that they actually respond to local central nervous system damage.

In addition to repairing neural injury, immune cells appear to play a role in fighting neurodegenerative disease, such as Alzheimer's disease. Ongoing studies show promise for multiple sclerosis, amyotrophic lateral sclerosis (Lou Gehrig's disease), and others.

Serge Rivest, of Québec's Centre Hospitalier de l'Université, says that a fuller appreciation of the benefits in immunity in the central nervous system could open a lot more doors for potential treatments than simply looking for way to block inflammation "whole hog." He adds, "The field is really moving toward that direction." ■

--Source: Excerpted from "Immune System Maintains Brain Health," Amanda B. Keener, *The Scientist Magazine*, November 1, 2016

New studies highlight viral infections in Sjögren's disease

Two new studies by researchers at the NIH National Institute of Dental and Craniofacial Research (NIDCR) provide insight into the roles played by two viruses involved in Sjögren's disease syndrome, an autoimmune disease in which the immune system mistakenly attacks the glands that produce tears and saliva. One of the most common of the autoimmune disorders, it affects 1 to 4 million people in the U.S., most of them women older than 40.

One of the viruses studied was the Epstein-Barr (EBV) virus which has been linked to Sjögren's and other autoimmune diseases. While most individuals recover quickly from the virus, in some cases it causes infectious mononucleosis. Following infection, the virus persists in the dormant form.

"The prevailing view has been that tissue damage in Sjögren's arises from longstanding inflammation brought on by autoimmune attack, but there is little correlation between inflammation and salivary gland function in patients," says Dr. Ilias Alevizos, of the NIDCR Sjögren's Syndrome Clinic. He comments that the researchers' work suggests a novel disease

mechanism and new therapeutic strategies for combating the syndrome.

In the second study, evidence was uncovered of Hepatitis delta virus (HDV) in salivary glands of people with Sjögren's syndrome. While HDV is known to infect the liver, researcher Dr. Melodie L. Weller reported that she and her colleagues found low levels of replicating virus in the salivary glands of 50 percent of Sjögren's patients tested. Intrigued by HDV's unexpected presence in patients' salivary glands, the researchers proceeded to investigate a possible role for the virus in the disease.

The discovery of the presence of HDV in a substantial fraction of Sjögren's patients and the finding that HDV proteins can trigger signs of the disease suggest a causal relationship between the virus and the disease. Dr. Weller aims to investigate how patients acquire HDV and to delve into how the virus affects salivary gland function. That knowledge may have a major impact on treatment as well. ■

Source: Excerpted from "NIDCR Studies Provide Evidence for Long-Suspected Role of Viral Infections in Sjögren's Syndrome," October 2016

Omega-3 fatty acid and lupus studied at MSU

Researchers at Michigan State University found that when lupus was triggered by crystalline silica, a toxic mineral known as quartz that's linked to autoimmunity, an omega-3 fatty acid called DHA blocked activation of the disease. DHA, or docosahexaenoic acid, can stop the trigger of lupus and potentially other autoimmune diseases.

DHA, found in fatty, cold water fish, is produced by the algae that the fish eat and is stored in their bodies. It can be found in fish oil supplements as well.

Although the researchers still don't know exactly why the DHA is able to prevent the onset of lupus, study author and pulmonary pathologist Jack Harkema says that one theory is that DHA helps cells send an anti-inflammatory signal to the body so it doesn't overcompensate and trigger an autoimmune response.

Dr. James Pestka, a co-leader of the research, says, "What we do know is this study is a clear indication that eating DHA can prevent this one type of environmental triggering of lupus." ■

--Source: Excerpted from "Omega-3 Fatty Acid Stops Known Trigger of Lupus," Michigan State University, via Newswise, September 29, 2016

~ EDITOR'S NOTE ~

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

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Heros (continued from page 5)

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Does AARDA have more Autoimmune Heroes? Look for them in the next issue of *InFocus*, March 2017. ■

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To our readers: Autoimmune diseases are conditions in which the body's own immune system can (among other things) cause damage to the skin, joints, and internal organs. Although most autoimmune diseases are not yet preventable or curable, most can be controlled to varying degrees. It is because of the wide variance and severity that **the individualization of medical management** is so important. It is vital that persons diagnosed with (or suspected of having) an autoimmune disease consult with their physician or with the appropriate division at a major teaching hospital to assure proper evaluation, treatment, and interpretation of information contained in this newsletter. Opinions expressed in this newsletter do not necessarily reflect the views of the American Autoimmune Related Diseases Association or its Scientific Advisory Board.

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