

# American Autoimmune

Related Diseases Association, Inc.



[www.aarda.org](http://www.aarda.org)



# ANNUAL REPORT 2019

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Please note, AARDA moved  
into our new headquarters in  
September 2020. Our previous  
mailing address was 22100  
Gratiot Ave, Eastpointe, MI 48021.

## OUR MISSION



# American Autoimmune

Related Diseases Association, Inc.

**The American Autoimmune Related Diseases Association (AARDA)** is dedicated to the eradication of autoimmune diseases and the alleviation of suffering and the socio-economic impact of autoimmunity through initiating, fostering, and facilitating collaboration in the areas of education, public awareness, research, and patient services in an effective, ethical, and efficient manner.



## MESSAGE FROM VIRGINIA LADD

September 2019 marked the end of our 2019 fiscal year, and I am making an exciting transition to a new role at AARDA and in life. I end my 28-year tenure as AARDA President/Executive Director to continue to serve as Founder, as Advisor to the President, and as the organization's lead in managing its science and medical research portfolio. In this part-time position, I will be active in autoimmune awareness, resource development, advocacy, education, and perhaps other areas—just enough to keep the autoimmune cause and AARDA in my life.

While I knew that I eventually would see a new person in the AARDA president and CEO role, I wondered who that person would be. As the AARDA government relations issues became increasingly more of a priority, the Board of Directors and I saw a well-informed and enthusiastic individual with the dedication and leadership qualities necessary to continue – and expand – AARDA's mission.

We welcome Randall ("Randy") Rutta as AARDA's next President and CEO.

I am pleased and, quite honestly, very relieved, to know that such a capable, experienced, knowledgeable, and personable individual as Randy is assuming the position that I held dear for nearly 3 decades. I hope that many of our members and friends will have the pleasure of meeting Randy and working with him and the outstanding AARDA staff.

Randy has a keen understanding of his new role and the organization itself through his advocacy and government relations work. It has proved to be a solid and strategic foundation for his transition to the AARDA leadership role.

During this transition and beyond, I'm confident that Randy and our dedicated staff will continue to make progress on the organization's long-term projects as well as continuing the growth of the organization to meet the demands of its all-important mission. Under Randy's leadership, the organization is poised to move confidently into the future by building on its strengths in the all-important areas of patient advocacy with programs such as "Let My Doctor Decide;" patient and physician educational programs which include creating educational modules and a robust website; and awareness programs which will include retooling AARDA messaging and collaterals, while enhancing the research program which includes AARDA's signature scientific colloquiums and young investigator research grants.

As founder, I'm very proud of the work AARDA has accomplished and am excited for AARDA's future growth and potential under new leadership. I would like to thank all of you for your support through the years. In so many ways, I have had reason to be grateful to you for your messages, your words of encouragement, and your active support through volunteer work and financial contributions. It has truly been a great run – an incredibly rewarding experience – both personally and professionally.

I leave the role of AARDA president and CEO in good hands, and look forward to my less demanding role with AARDA. With my heartfelt commitment to continue to make a difference to all of you, I send my best wishes to you for much joy and success.

With deep appreciation,  
**Virginia T Ladd.**



## AARDA FOUNDER VIRGINIA LADD HONORED WITH AARDA'S LIFETIME ACHIEVEMENT AWARD

As fiscal 2019 concluded, AARDA Founder and Immediate Past President and Executive Director, Virginia T. Ladd, was presented with AARDA's Lifetime Achievement Award. AARDA Board Officer Rich Hodge presented the award on behalf of the AARDA Board of Directors and staff, sharing the heart-felt message engraved on the award:

***"In recognition of her extraordinary vision, leadership, and advocacy for autoimmune disease patients throughout the world; for being the champion of research; the voice of hope; and the untiring standard bearer for awareness."***

AARDA sponsored an event to present the award to Virginia which was attended by AARDA Board Members, staff, Advisors, and dozens of patient advocates, health care leaders, corporate partners, and agency officials who celebrated her vision and nearly 30 years of leadership on behalf of people

living with autoimmune related diseases. Virginia also received letters of appreciation from colleagues across the world.

In accepting the award, Virginia spoke of the beginning years of her work on behalf of autoimmune patients, like herself, and the advancements she witnessed over the nearly 3 decades at the helm. She expressed her appreciation to the countless individuals who have been at the forefront in the struggle to have autoimmune disease receive recognition and support.

Having made her decision to step down from her longtime leadership position at AARDA, Virginia remains on the staff of AARDA as Advisor to the President, the strategic lead on medical research and science programs, and as a selected AARDA representative at various conferences, meetings and educational events.

***Thank you, Virginia!***



## INTRODUCTION OF RANDALL RUTTA

In August 2019, the AARDA Board of Directors selected Randall Rutta to succeed Virginia Ladd as AARDA President and Chief Executive Officer (CEO), effective October 1, 2019. Randy has been serving as AARDA's Federal Policy Consultant in Washington, D.C., promoting to Congress, the Administration, federal agencies, patient health advocates, and other stakeholders the policy priorities benefiting people living with autoimmune conditions. He is a seasoned healthcare executive with a long and extensive background in strategic and operational leadership across the nonprofit health policy, service, and delivery sectors.

AARDA Board Chair (2018-2019) Dr. Herbert Ford stated: *"We are fortunate to have recruited Randy Rutta as our next senior executive. Randy not only has a strong nonprofit background, but also a stellar reputation and a strategic understanding of AARDA's mission and its historical background."* Dr. Ford added: *"Randy and outgoing President/Executive Director Virginia Ladd established an outstanding working relationship that has enhanced AARDA's advocacy and government relations programs that has improved the environment for the autoimmune community. We are pleased to welcome Randy into this leadership role."*

Much of Randy's career was based at Easterseals, a global nonprofit service and advocacy organization dedicated to the health, well-being, and success of people with disabilities, veterans, seniors, and families. He served as Easterseals' President and CEO, Chief Strategy Officer, Executive Vice President, responsible for strategic insight and support in achieving objectives across the healthcare ecosystem. ■



AARDA President & CEO Randall Rutta

Randy serves as Board Chair of the Partnership to Fight Chronic Disease (PFCD), a national coalition of nearly 100 patient, provider, and community organizations, business and labor groups, and health policy experts committed to raising awareness of chronic disease in America and globally. He joined the PFCD Board early in its inception and served as its Chief Patient Advocacy Officer.

Since 2008, Randy has served on the Board of Directors of the American Eagle Lifecare Corporation, an Ann Arbor-based nonprofit organization providing assisted and independent living services in multiple communities nationwide.

*"Close collaboration with Virginia and AARDA over the years has helped me understand the variety of challenges facing people with autoimmune disease, their families, and practitioners, and the compelling need for increased research, awareness, education, and advocacy. I am energized to join AARDA at this critical time and look forward to contributing to advancing the important goals of this great organization and the autoimmune disease community."*

Randy holds a Bachelors of Arts degree in Sociology and a Masters of Arts degree in Politics, focusing on international health policy. He resides in Washington, D.C.

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**The Rev. Herbert G. Ford, D.Min.**

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**Richard M. Hodge****DIRECTORS****John Kaiser, Jr., CPA****Michael Linn****Michelle Ouellet****Robert Phillips, Ph.D.****Scott Selby****Lilly Stairs****SCIENTIFIC ADVISORY  
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BOARD CHAIRMAN EMERITUS****Noel Rose, M.D., Ph.D.****AARDA'S COMMITMENT TO SCIENTIFIC RESEARCH RUNS DEEP****AARDA's Scientific Advisory Board**

(SAB) is the cornerstone of AARDA's scientific research agenda, efforts, and operations. Specifically, the SAB is charged with assuring that the organization's mission and programs are thoroughly grounded in science and at the forefront of advancing research to better understand the cause and treatment of autoimmunity.

The SAB has members from across the United States and internationally. Each member actively participates in the work of the SAB through speaking, reviewing proposals, serving in advisory capacities, and representing AARDA as requested. These outstanding researchers and physicians form a truly working Scientific Advisory Board.

"AARDA is a unique and essential bridge between cutting-edge scientific research, the application of discovery in medical treatment, and the engagement of people with autoimmune related diseases," said Dr. Betty Diamond, who leads the work of AARDA's Scientific Advisory Board. "Through AARDA, the autoimmunity community is more effectively focused and successful in advancing the frontiers of science to best help autoimmune patients achieve their goals for health and well-being."

Advancing scientific research to better understand the underlying causes of autoimmunity, promote pathways to early diagnosis and treatment, and advocate for public and private support for research are fundamental priorities for AARDA. Dedication to science permeates organizational values and efforts.

In fiscal year 2019, AARDA's science portfolio includes the Dr. Noel R. Rose Scientific Colloquium series, which convened highly-regarded researchers to discuss current research related to autoimmunity underway in their respective labs. This past year, these topics represented a new area of immunologic research on resident memory T-cells and recent research on innate immunity. Following each colloquium, an article reporting on the discussion is peer-reviewed and published.

The SAB oversees applicants for the Virginia T. Ladd Young Investigators Program. In fiscal year 2019, the SAB recommended five young researchers for grants to support their work on autoimmune diseases. They were awarded two-year grants of \$20,000 each per year.

AARDA joined with Johns Hopkins University, a longtime partner to AARDA,

to support an Autoimmunity Day to raise awareness of the exemplary research underway. Additionally, AARDA provided grant funding to support the Autoimmune Research Diversity Summer Internship Program, which promotes interest in research careers among students from minority backgrounds.

SAB members regularly advised the AARDA Board and staff on matters pertaining to science and medical research, contributed to media articles and interviews, and participated on panels and hearings. Members lent their expertise and stature to raising public awareness, educating patients, shaping public policies, and influencing private-sector practices to better reflect an accurate basis in evidence-based science and the advance goals of the autoimmune community.

AARDA recognizes that opportunities to gain new knowledge continue to outpace resources available. In order to fully fund biomedical research central to AARDA's mission, they continually push the National Institutes of Health (NIH) and other organizations to support their mission in Washington, DC, and in communities throughout the country. ■

# MAJOR CONTRIBUTORS IN FISCAL YEAR 2019

## MAJOR IN-KIND CONTRIBUTORS

|                                       |                         |                           |                   |                                  |                     |
|---------------------------------------|-------------------------|---------------------------|-------------------|----------------------------------|---------------------|
| 4imprint                              | Cedra Pharmacy          | Grosse Pointe Run         | Motor City Casino | Michelle Ouellet                 | WCZ Electric        |
| Aliotta's Via Firenze                 | Tom Christie            | Hour Media, LLC           | NBC uni           | Southwest Magazine               | Washington Examiner |
| Amalfi Fine Art                       | Context Strategies, LLC | Richard Hodge             | Park West Gallery | The Cleveland Women's Journal    | Weekly Standard     |
| Portraiture                           | Echo Media              | JMR Media                 | Dr. Noel Rose     | The Westin Book Cadillac Detroit | Carrie Zehnpfennig  |
| Biotechnology Innovation Organization | Dr. Stanley Finger      | Lavida Massage of Livonia | NORM              | Todd Design                      |                     |
| Nona Bear                             | Google                  | Media Planet              | Penn Quarters     |                                  |                     |
|                                       | Grand Hotel             | Michael Linn              | Sidley Austin     |                                  |                     |

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of America  
Chevron Matching  
Employee Funds  
Dell Giving  
Exelon Corporation  
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Johnson & Johnson  
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Wells Fargo Community  
Support Campaign

### OTHER CONTRIBUTORS AND FRIENDS

Space does not allow  
us to include the names  
of all persons and  
organizations who gave  
their financial support to  
AARDA, but we say "Thank  
You" again as we give this  
recognition in honor of  
their generosity.

### MEMORIALS AND TRIBUTES

Since it is our policy not  
to release amounts given  
for these contributions,  
we take this opportunity  
to express our  
appreciation again to all  
the kind donors. Every  
contribution has been  
acknowledged to the  
donors, to those persons  
honored, and to the  
families of those held in  
memory.

## MAJOR ACCOMPLISHMENTS DURING FISCAL YEAR 2019



### EDUCATION, AWARENESS, AND COMMUNITY OUTREACH

**AARDA initiated a partnership with Canada-based iMD Health Global** to enhance AARDA's digital resources and make them available through iMD's online platform. Healthcare professionals in doctor's offices, hospitals, and other facilities will be able to access and share AARDA's materials with patients at the point of care. The partnership significantly increases AARDA's capacity to disseminate and report on the use of patient education materials across North America.

**AARDA endorsed a nursing education program sponsored by the Relapsing Polychondritis Foundation (RPF) which was held at Northern Michigan University.** The program offered CME credits for nurses and was very well-attended. Local media praised the program and called attention to AARDA priorities for autoimmune disease research, diagnosis, and treatment.

Twenty AARDA brochures were translated from English to Spanish for nationwide distribution to Spanish-speaking individuals with autoimmune diseases, their families, and community resources. Spanish language materials were disseminated through local libraries and community health and social service programs, posted online, and included information packets, as appropriate.

AARDA brochures were distributed at several events, including the 2019 International

Vasculitis Symposium (Minneapolis, MN), class project (Waterville, NY), and Metro Detroit CLUW, National Women's Health Week Forum.

**Autoimmune Disease Awareness Month (ADAM)** featured the distribution of AARDA educational materials in thirteen states. Over 800,000 total impressions were achieved on social media, there were over 13,000 link clicks, and 1,300+ new followers were gained on Facebook and Instagram.

AARDA held public forums on understanding and living with an autoimmune disease in Metro Detroit, Pittsburgh, and Los Angeles. Participants heard from leading national and local experts on a range of issues pertaining to early diagnosis, coordinated care, and coping with a chronic condition.

National Webinars were conducted by AARDA staff and external experts on **"The Autoimmune Research Network"** and **"Getting a Proper Diagnosis of an Autoimmune Disease."**

In July, **AARDA participated in PhRMA's WeWork Recognition event** to honor leading researchers for their commitment to improving patient health through discovery and better treatments for persons with autoimmune diseases and other health conditions.

In September, **AARDA moderated a panel at the National Press Club to present the 2019 National Report Briefing: *Riding the Rollercoaster of Intermittent Illness: A National Study of Caregivers of Individuals with Crohn's Disease and Ulcerative Colitis***, with the National Alliance for Caregiving, Crohn's and Colitis Foundation, and ImprovedCareNow.





## PUBLIC RELATIONS AND AWARENESS

**AARDA had multiple editorials published in Washington, DC newspapers** and was also featured in ads and stories in *US News and World Report* and *Southwest Airlines Magazine*, focusing on women's health and autoimmune diseases.



## RESEARCH

AARDA made grants totaling nearly \$15,000 to Johns Hopkins University to support the **19th Annual Autoimmunity Day** and supported a student research intern in its 2019 Diversity Summer Internship Program.

### **AARDA's Young Investigators Program**

extended support for five young researchers who received grants in 2018, with second year funding support provided in 2019. Researcher received awards \$20,000 annually for the two-year period, with a total of \$100,000 disbursed in 2019.

Dr. Noel Rose, Chairman Emeritus of AARDA's Scientific Advisory Board, convened Scientific Colloquia on key autoimmune disease research priorities.

AARDA participated in an array of research-related coalitions, consortia, and conferences that focused on the priorities and work of National Institutes of Health, Centers for Disease Control and Prevention, and other research institutions with an emphasis on autoimmune related diseases.



## ADVOCACY

Throughout the year, AARDA held dozens of meetings with U.S. Senators and Representatives that oversee FY 2020 federal appropriations by AARDA Board, CEO, and staff, to advocate for the resources it needs to be effective.

In addition, **AARDA moderated 500+ communications between AARDA online advocates**, and ongoing communications with congressional staff to promote itself. Because of this intensive advocacy work, Congress will allocate funds and support priorities for research at the National Institutes of Health, Department of Defense, and across the public and private sectors to enhance understanding of the underlying causes of autoimmunity and improve diagnosis, treatment, and management.

### **AARDA expanded Let My Doctors Decide (LMDD)**

from a Michigan pilot to a national campaign to raise awareness and promote the elimination of unwarranted step therapy and other health plan design barriers that too often prevent patients from accessing the medicines they need. These efforts included patient and physician education and building an Advisory Task Force by recruiting key patient, professional, and other stakeholder organizations. The LMDD National Campaign launched in the Spring with the publication of national study results on health plan practices that unduly restrict access to medicines for persons with autoimmune diseases. ➔

**In March, AARDA and the National Coalition of Autoimmune Patient Groups hosted a briefing for Members of Congress and congressional staff on The Hidden Epidemic of Autoimmune Disease**, with expert speakers including AARDA Board Member Lilly Stairs, and President, Virginia Ladd; Drs. Joseph Ahearn and Susan Manzi, AHN Autoimmunity Institute, and Candace DeMattieus, Ph.D. More than 60 Senate and House offices were represented in the audience, as were National Coalition of Autoimmune Patient Group (NCAPG) member organizations including Lupus Foundation of America, American Behcets Disease Association, and the Sjogren's Foundation.

**Throughout the Spring, AARDA collaborated with stakeholders across the healthcare eco-system, including: participation in the Nonprofit Summit: Patient Access to Care held by the National Organization of Rheumatology Managers (NORM)** joined the US Chamber of Commerce *Redesigning Wellness Summit* in Washington, D.C. to raise awareness of challenges for persons with autoimmune diseases with employers and the business community; and, participated in Center for Healthcare Innovation *Equitable Access to Rare Diseases Therapies* Forum in Washington, DC to raise awareness of issues affecting people with autoimmune diseases in accessing affordable and appropriate medicines and care.

**AARDA advanced autoimmune community interests in federal agency decision-making by submitting comments to CMS on proposed rules affecting access to medicines under Medicare Part D and Medicare Advantage Part B**, and recommending the preservation of formulary access to six protected classes of drugs, including immunosuppressants and other drugs important to people with autoimmune disease.

Additionally, **AARDA joined a letter authored by the Partnership for Safe Medicines to oppose legislative proposals to permit importation**

**of prescription drugs from foreign non-FDA approved sources**, which are often counterfeit, unreliable, and unsafe. AARDA joined the Value our Health Coalition to support a set of principles that address value assessment measures and QALYs, which too often fail to fully include the patient perspective and are increasingly used to limit access to care. AARDA strongly advocated for Congress to embrace proposals to cap out-of-pocket costs for Medicare Part D beneficiaries to reduce the financial burden on patients by joining the MAPRx Coalition, which promotes access and adherence to needed medicines. By authoring an op-ed expressing disappointment over the Administration's withdrawal of the proposed rebate rule, AARDA made it clear that the rule would have increased transparency regarding rebates and transfer a portion of rebate savings to patients.



## RESOURCE DEVELOPMENT

**Grassroots events and fundraisers, created and hosted by active supporters on behalf of AARDA, raised \$31,716 throughout the year.**

These included the Brave Dave Open led by Tom Branthover (\$10,000); a New York Marathon fundraiser led by Joe Geoghegan (\$5,370); 5 for the 50 5k event led by Jimmie Parten (\$4,276); a percentage of sales from Indie Lee skin-care products and Hannah's Homemade Nut Butters; and bake sales, dress-down days, tricky-tray raffles, and other inventive efforts.

**AARDA held Autoimmune Awareness Walks in Los Angeles, Detroit, New York City, and Pittsburgh.** The inaugural Pittsburgh Autoimmune Walk was part of an "autoimmune weekend" that included AARDA's signature in-person educational forum, "What Every American Needs to Know about Autoimmune Disease," in partnership with the AHN Autoimmunity Institute.

## ARNet

AARDA has continued to advance participation in the Autoimmune Research Network patient registry, adding an additional 1,800 new registrants to the database during 2019. New development initiatives have been ongoing in an effort to maximize the use and visibility of ARNet, not only for registrants, but for researchers alike. AARDA has continued cultivating new engagement strategies with participants and clinical researchers, as well as the development and enhancement of ARNet's data integrity management systems and data analysis reporting methods.

New York Walk Ambassador Nika Beamon, author Rita Baron-Faust, and Dr. Ashira Blazer of NYU Langone Health, appeared on the "Here and Now" program on WABC-7 to discuss the walk and the impact of autoimmune disease on women and people of color. Major walk sponsors during the year included Lilly, Horizon, Intercept, Allegheny Health Network, and WABC-7 New York.

**AARDA's 19th annual spring fundraiser — "Bound by a Common Thread" — was held May 11, 2019 at the Detroit Athletic Club.** This event, sponsored by Level One Bank, MidMichigan Health, Michigan Health and Hospital Association, and Hour Detroit, raised more than \$50,000 and featured the presentation of the AARDA Champion Award to race car driver Kyle Marcelli. Marcelli was honored for driving autoimmune awareness to new heights with the AARDA logo emblazoned on his winning vehicles.

**AARDA continued to advance its online fundraising efforts through Facebook Fundraisers,** an ongoing source of donor support, which generated more than **\$80,000**. AARDA also established a Giving Tuesday campaign, an online endeavor which occurs every November.

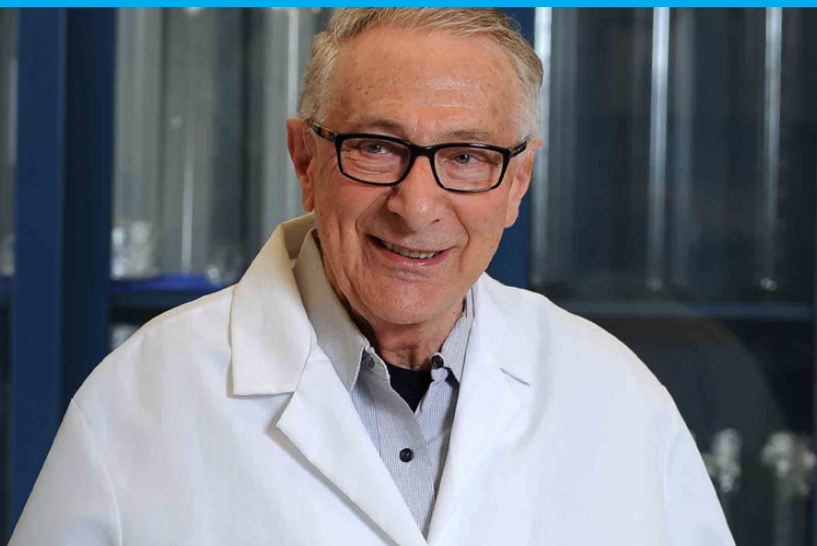
**AARDA's 2018 Annual Appeal** was supported by 193 friends of AARDA who donated **\$57,211** to help sustain our mission in 2019.

AARDA benefited from the engagement of leading companies and foundations in support of our cause in 2019, including through financial contributions and program-related

consultation and insight. Six companies serving the autoimmune community through access to innovative and effective medicines participated on AARDA's Autoimmune Partnership Council, collectively contributing \$200,000 to support capacity, patient-centered programs, and research initiatives including AARDA's collaboration with three-dozen national autoimmune disease-specific patient groups on public policy, research, best-practices, and other matters of mutual interest.

**Many of these companies, together with a number of foundations, contributed some \$400,000 in support of specific projects of critical interest and benefit to people with autoimmune diseases, including Let My Doctor Decide,** a national campaign dedicated to raising awareness and promoting reform of step therapy and other practices that prevent people with autoimmune disease from getting the medicines prescribed by their doctors. Funds were also targeted to support AARDA's national messaging to broaden autoimmune disease awareness and to conduct webinars and in-person forums to engage physicians, researchers, patient advocates, and other experts in educational programs for patients. Forum topics included Autoimmunity 101 and Getting to a Diagnosis and were presented in day-long sessions with partner organizations including the Allegheny Health Network Autoimmunity Institute in Pittsburgh, PA, a multi-specialty center providing integrated and coordinated diagnosis, treatment, and research. ■

## DR. NOEL ROSE RECOGNIZED FOR PIONEERING RESEARCH IN ADVANCING AUTOIMMUNITY



In September 2019, the American Academy for the Advancement of Science hosted the 2019 Golden Goose Award ceremony at the Library of Congress hosted by the American Association for the Advancement of Science. The annual award celebrates ground-breaking, federally funded basic research that has had a significant impact on human life, scientific advances, and societal needs.

AARDA executive leadership attended the ceremony for this well-deserved recognition of Dr. Noel Rose and his colleague, the late Dr. Ernest Witebsky, for “Advancing Autoimmunity” with the discovery that the human immune system could produce antibodies that attack itself. Their research gave rise to the study of autoimmunity in animals and humans, including human diseases such as lupus, multiple sclerosis, and Crohn’s. NIH funded the research by Dr. Rose, who is known as “the father of autoimmunology.”

Dr. Rose is a long-time leader and partner to AARDA in advancing its mission. He is the Chairman Emeritus of AARDA’s Scientific Advisory Board and hosts AARDA’s highly regarded Scientific

Colloquia that convenes leading autoimmune and related researchers on emerging topics of interest to advancing understanding and treatment of autoimmune diseases.

Also recognized as 2019 Golden Goose honorees were Dr. David Sacher for his development of a lifesaving cholera treatment—oral rehydration therapy—credited with saving far more than 50 million lives from diarrheal disease; and Drs. Jack Levin and the late Frederik Bang, for research that led to the development of a screening procedure, known as the *Limulus* amebocyte lysate test, which can detect minute concentrations of bacterial endotoxin, a component of all dangerous Gram-negative bacteria.

The Golden Goose Award was conceived by Representative Jim Cooper (D-TN) to highlight the ingenuity and talent of the U.S. scientific research community, long supported by federal research funding. In 2012, a nine-member coalition of businesses, universities, and scientific organizations founded the award to salute scientific research’s unexpected and consequential discoveries. ■

***Dr. Noel Rose passed away on July 30, 2020. His family established a memorial fund in his honor through AARDA. Donations can be made by mail or by visiting the memorial gift page on the AARDA website.***



# INDEPENDENT AUDITORS' REPORT

## The Board of Directors,

### American Autoimmune Related Diseases Association

Eastpointe, Michigan

We have audited the accompanying financial statements of American Autoimmune Related Diseases Association (a nonprofit organization) which comprise the statement of financial position as of September 30, 2019, and the related statements of activities, functional expenses and cash flows for the year then ended, and the related notes to the financial statements.

## MANAGEMENT'S RESPONSIBILITY FOR THE FINANCIAL STATEMENTS

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

## AUDITOR'S RESPONSIBILITY

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

## OPINION

In our opinion, based on our audit, the financial statements referred to above present fairly, in all material respects, the financial position of American Autoimmune Related Diseases Association as of September 30, 2019, and the changes in its net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

*Gordon Advisors, P.C.*

January 31, 2020



## AMERICAN AUTOIMMUNE RELATED DISEASES ASSOCIATION

# STATEMENT OF ACTIVITIES

*For the Year Ended September 30, 2019*

|  | WITHOUT DONOR<br>RESTRICTIONS | WITH DONOR<br>RESTRICTIONS | 2019 TOTAL          |
|--|-------------------------------|----------------------------|---------------------|
| <b>Revenue and Other Support</b>                 |                               |                            |                     |
| Contributions                                    | \$ 909,135                    | \$ 333,500                 | \$ 1,242,635        |
| In-kind goods and services                       | 558,987                       | 0                          | 558,987             |
| Fundraising income - net of expenses of \$15,213 | 123,165                       | 0                          | 123,165             |
| Loss on disposal of asset                        | (150)                         | 0                          | (150)               |
| Interest income                                  | 8,247                         | 0                          | 8,247               |
|  | <b>1,599,384</b>              | <b>333,500</b>             | <b>1,932,884</b>    |
| Net assets released from restrictions            | +257,494                      | (-257,494)                 | 0                   |
| <b>Total Revenue and Other Support</b>           | <b>1,856,878</b>              | <b>76,006</b>              | <b>1,932,884</b>    |
| <b>Expenses</b>                                  |                               |                            |                     |
| <i>Program services</i>                          |                               |                            |                     |
| Education  | 861,932                       | 0                          | 861,932             |
| Public awareness                                 | 943,145                       | 0                          | 943,145             |
| Research   | 366,304                       | 0                          | 366,304             |
| <b>Total program services</b>                    | <b>2,171,381</b>              | <b>0</b>                   | <b>2,171,381</b>    |
| <i>Supporting services:</i>                      |                               |                            |                     |
| Management and general                           | 178,628                       | 0                          | 178,628             |
| Fundraising                                      | 124,437                       | 0                          | 124,437             |
| <b>Total supporting services</b>                 | <b>303,065</b>                | <b>0</b>                   | <b>303,065</b>      |
| <b>Total Expenses</b>                            | <b>2,474,446</b>              | <b>0</b>                   | <b>2,474,446</b>    |
| <b>Change In Net Assets</b>                      | (617,568)                     | 76,006                     | (541,562)           |
| <b>Net Assets, Beginning of Year</b>             | <b>\$ 973,252</b>             | <b>\$ 244,626</b>          | <b>\$ 1,217,878</b> |
| <b>Net Assets, End of Year</b>                   | <b>\$ 355,684</b>             | <b>\$ 320,632</b>          | <b>\$ 676,316</b>   |

## AMERICAN AUTOIMMUNE RELATED DISEASES ASSOCIATION

## STATEMENT OF FUNCTIONAL EXPENSES

For the Year Ended September 30, 2019

|  | PROGRAM SERVICES  |                     |                   | TOTAL<br>PROGRAM<br>SERVICES | SUPPORTING SERVICES       |                   | TOTAL               |
|--|-------------------|---------------------|-------------------|------------------------------|---------------------------|-------------------|---------------------|
|  | Education         | Public<br>Awareness | Research          |                              | Management<br>and General | Fundraising       |                     |
| In-Kind Goods and Services   | \$ 149,618        | \$ 254,872          | \$ 66,092         | \$ 470,582                   | \$ 66,607                 | \$ 21,798         | \$ 558,987          |
| Other Expenses:  |                   |                     |                   |                              |                           |                   |                     |
| Wages  | 246,942           | 175,478             | 0                 | 422,420                      | 19,932                    | 53,458            | 495,810             |
| Professional fees  | 308,790           | 263,032             | 65,075            | 636,897                      | 76,342                    | 4,011             | 717,250             |
| Postage and shipping   | 6,475             | 4,373               | 0                 | 10,848                       | 192                       | 1,740             | 12,780              |
| Public relations   | 0                 | 22,750              | 0                 | 22,750                       | 0                         | 0                 | 22,750              |
| Printing and stationery  | 10,526            | 7,408               | 466               | 18,400                       | 161                       | 17,293            | 35,854              |
| Office supplies  | 1,724             | 1,711               | 0                 | 3,435                        | 146                       | 73                | 3,654               |
| Operating supplies   | 4,140             | 2,334               | 0                 | 6,474                        | 23                        | 6,574             | 13,071              |
| Dues and subscriptions   | 5,263             | 11,239              | 15,660            | 32,162                       | 749                       | 748               | 33,659              |
| Filing fees  | 1,750             | 1,750               | 0                 | 3,500                        | 1,174                     | 1,750             | 6,424               |
| Equipment maintenance  | 4,721             | 2,862               | 0                 | 7,583                        | 48                        | 2,576             | 10,207              |
| Telephone  | 4,380             | 4,380               | 0                 | 8,760                        | 367                       | 254               | 9,381               |
| Insurance  | 1,651             | 1,651               | 0                 | 3,302                        | 1,401                     | 1,651             | 6,354               |
| State and national meetings  | 26,351            | 11,581              | 8,224             | 46,156                       | 155                       | 1,135             | 47,446              |
| Travel   | 15,484            | 6,355               | 16,635            | 38,474                       | 307                       | 1,489             | 40,270              |
| Depreciation   | 1,403             | 1,403               | 1,403             | 4,209                        | 1,403                     | 1,403             | 7,015               |
| Payroll taxes  | 15,096            | 11,502              | 6,110             | 32,708                       | 1,078                     | 2,157             | 35,943              |
| Insurance - Health   | 14,506            | 8,832               | 0                 | 23,338                       | 1,253                     | 4,159             | 28,750              |
| Fundraising -  |                   |                     |                   |                              |                           |                   |                     |
| Bound by a Common Thread   | 0                 | 0                   | 0                 | 0                            | 0                         | 15,213            | 15,213              |
| Other  | 0                 | 0                   | 0                 | 0                            | 0                         | 0                 | 0                   |
| Board expenses   | 0                 | 0                   | 0                 | 0                            | 6,362                     | 0                 | 6,362               |
| Professional training  | 35                | 22                  | 0                 | 57                           | 0                         | 0                 | 57                  |
| Grants   | 7,000             | 11,400              | 167,747           | 186,147                      | 0                         | 0                 | 186,147             |
| Repairs and maintenance  | 2,934             | 1,867               | 0                 | 4,801                        | 267                       | 267               | 5,335               |
| Utilities  | 2,426             | 2,426               | 0                 | 4,852                        | 206                       | 103               | 5,161               |
| Miscellaneous  | 1,365             | 8                   | 0                 | 1,373                        | 1                         | 295               | 1,669               |
| Retirement plan contributions  | 4,076             | 3,159               | 0                 | 7,235                        | 331                       | 464               | 8,030               |
| Website  | 3,565             | 2,336               | 0                 | 5,901                        | 123                       | 123               | 6,147               |
| Advertising and development  | 21,711            | 128,414             | 18,892            | 169,017                      | 0                         | 916               | 169,933             |
| <b>Total Expenses By Function</b>  | <b>\$ 861,932</b> | <b>\$ 943,145</b>   | <b>\$ 366,304</b> | <b>\$ 2,171,381</b>          | <b>\$ 178,628</b>         | <b>\$ 139,650</b> | <b>\$ 2,489,659</b> |
| Less expenses included with<br>revenues on the statement of<br>activities                    | 0                 | 0                   | 0                 | 0                            | 0                         | (15,213)          | (15,213)            |
| <b>Total expenses included in<br/>the expense section on the<br/>statement of activities</b> | <b>\$ 861,932</b> | <b>\$ 943,145</b>   | <b>\$ 366,304</b> | <b>\$ 2,171,381</b>          | <b>\$ 178,628</b>         | <b>\$ 124,437</b> | <b>\$ 2,474,446</b> |

# INCOMING PRESIDENT & CEO VIEWPOINT: GREAT EXPECTATIONS FOR THE YEAR AHEAD

By Randall Rutta

**A**ARDA strives to improve the lives of people living with autoimmune diseases and their families. And for nearly three decades, under the leadership of AARDA Founder Virginia Ladd, AARDA has been breaking down persistent challenges to health and well-being through research, public awareness, patient education, and advocacy. Transitioning to the role President and CEO at the start of fiscal 2020 marks a welcome personal and professional milestone to make a difference across the autoimmune community.

I am awed and energized by the passion of patients to secure a diagnosis and proactively improve their health, and will support them on this journey by expanding AARDA's education and assistance offerings that connect patients to world-class subject matter experts including physicians, allied health professionals, patient advocates, and peers, on timely and relevant topics of interest to their health and well-being and to the autoimmune community.

I applaud the commitment of researchers from highly-regarded institutions across the U.S. and internationally who participate in ground-breaking scientific colloquia planned and facilitated by AARDA's Scientific Advisory Board Chairman Emeritus Dr. Noel R. Rose. This includes a strategic discussion with a vibrant group of researchers about their progress and that of their colleagues to advance the understanding of the impact of metabolic defects on autoimmunity. I am confident that the seeding of

important discoveries will continue at AARDA's Scientific Colloqui.

I marvel at the progress of Let My Doctors Decide (LMDD) in raising awareness among patients, practitioners, other healthcare providers, policymakers, and regulators of the frustrations associated with step therapy and "fail first" protocols that so often prevent access to the medicines patients need. LMDD expanded its efforts from a highly-successful pilot to a national campaign. The national effort, fully launched at the American College of Rheumatology Annual Conference in November 2019 where there, these stakeholders experienced our Escape the System by navigating our maze of obstacles, stories, and facts about the challenge of step therapy facing physicians and patients. I am confident this led to a better-informed community and call to action including endorsing the LMDD principles, signing our petition, and joining us to change government policies and harmful insurance company practices.

I welcome the opportunity to engage and expand AARDA's National Coalition of Autoimmune Patient Groups (NCAPG), which was founded and is facilitated to convene and support nearly forty national patient groups who come together to discuss policy issues of importance to people living with autoimmune disease. AARDA will continue to convene the NCAPG to feature experts on research, policy, and organizational topics of mutual interest and to showcase Coalition

member achievements in support of collective actions on legislative and regulatory actions affecting people with autoimmune diseases. I invite additional autoimmune patient groups to join NCAPG to enhance their unique, disease-specific missions and advance our collective impact benefitting all patients.

Lastly, I am energized by the community of AARDA's donors and partners that consistently contribute to our financial capacity to advance our mission, our impact and the resources necessary to move forward to enhance progress and results. Even as we celebrate this past year's accomplishments, we know that there remains much for us to do to understand the underlying causes of autoimmunity, shorten the time to diagnosis, raise awareness, help patients, and increase access to life-saving treatment and care. All of us in the AARDA family are grateful to those who contribute to our financial strength and ability to make a positive difference together. Your friendship, funds, and loyalty drive our passion, our work, and our collective impact.

The year ahead holds great promise for AARDA's expanded mission, direct impact, and sustainable growth. As the nation's only national non-profit focusing on all autoimmune related diseases-affecting 50 million Americans, their families, and their stakeholders-we are ideally positioned and highly motivated to achieve success for and with the entire autoimmune community. I am truly honored to do my part. ■