As National Spokesperson for the American Autoimmune Related Diseases Association, I am proud to proclaim, “Happy 25th Anniversary, AARDA!”

While I haven’t been part of AARDA for the entire 25 years of its existence, I count my family and myself as proud supporters of AARDA. It’s definitely a life-saver for many, and it very possibly would have saved the life of my 19-year-old sister Heather if we had encountered it soon enough.

Over the past 25 years, “autoimmunity” has been thought of as AIDS (no, not related) or something to do with automobiles—or even airplanes! It was rare that anyone realized that autoimmunity is a family of diseases via a misdirected immune system. Health care professionals were puzzled when they encountered the symptoms (as with my sister). Even today, the road to diagnosis takes an average of 3.5 years after trips to at least five physicians. To AARDA, that is unacceptable.

As National Spokesperson for AARDA, I am fortunate to be able to use my name and media contacts to advocate on a national basis for autoimmune research, education, awareness, and support. AARDA is the only national organization dedicated to addressing the problem of autoimmunity, the major cause of chronic illness. It is our determined goal to conquer this illness which affects 50 million Americans—75 percent of whom are women, mostly in their childbearing years.

For my sister Heather, for my own little girls, for all the people not only in the United States but also throughout the world, I am putting my name, time, and money on the line against autoimmune disease. Can you—will you—join all of us in AARDA?

Perhaps you already are an active supporter, in your own special way, of AARDA and its mission. If so, we thank you. Or perhaps you are wondering how you could facilitate the AARDA mission. Maybe you could contribute time, talent, in-kind service, or financial help. We invite you to find your niche (Webster: “A situation or activity specially suited to one’s character or abilities”).

Yes, your AARDA niche is awaiting you. Are you ready to claim it? You can expect a warm-hearted welcome!

Kellie Martin, AARDA National Spokesperson and Dedicated AARDA Volunteer
Y es, this year marks the 25th anniversary for the American Autoimmune Related Diseases Association. It’s been quite a journey, from working to make “autoimmune” a household word to establishing a mission of “eradication of autoimmune diseases,” “alleviation of suffering, and “the alleviation of the socioeconomic impact of autoimmunity.” A major part of the mission was collaboration among researchers, health professionals, patients, and interested others. That mission still guides us.

The first epidemiology study, identifying only 24 autoimmune diseases, showed that 24 million Americans had at least one autoimmune disease. Today we estimate at least 50 million individuals afflicted by one or more of the 100+ known autoimmune diseases, but lack of up-to-date information is hampering autoimmune disease research and education. AARDA intends to change that.

Currently we are looking forward to the formal launching of an AARDA-developed autoimmune registry which has been in beta testing. Through this Autoimmune Disease Patient Registry Research Network (ARNet), diagnosed autoimmune disease patients can be identified for potential participation in the study. ARNet will help researchers answer epidemiological questions, identify trends, and track the number of patients with certain autoimmune diseases and their experiences in obtaining a correct diagnosis. This research will help improve time to diagnosis of these diseases as well as advance knowledge into causes, treatments, and perhaps cures.

Taking on an advocacy role for so many who suffer with such diverse diseases and recognizing the common threads uniting these diseases, AARDA leaders see clearly that autoimmune disease must be recognized as its own category—like cancer or heart disease—to form the basis of our work.

And what is AARDA’s work? You, the readers of this Annual Report, can peruse “What’s been happening in FY 2016? Overview of Major Accomplishments.” You will see the following areas:

• **Awareness and Advocacy** efforts can be the first steps.
  Many sufferers of unusual, nagging symptoms—including profound fatigue—have never heard of autoimmune diseases, and even their medical professionals may not think “autoimmune.” A recent study shows that too often it takes 3.5 years and five physicians to achieve a correct diagnosis of autoimmune disease. AARDA’s efforts are designed to remedy this problem (see “Awareness and Advocacy” in Major Accomplishments).

• **Education** of patients, the general public, and also physicians and other professionals is a major focus of AARDA. For too long, autoimmune disease has received only token coverage in professional curricula—although it was identified in the 1950s in the research of Dr. Noel Rose. Through forums, scientific symposia, congressional briefings, educational brochures, and publications in peer-reviewed journals, plus lay-friendly media, AARDA’s autoimmune education accomplishments provide another step forward.

• **Research** forms the background. We at AARDA are proud of our support of research at major institutions, e.g., Johns Hopkins University, The Feinstein Institute for Medical Research, and Massachusetts General Hospital, plus grants to Summer Diversity Student Interns at Johns Hopkins and the Young Investigators at several universities. Also, the aforementioned ARNet will be a crucial tool in autoimmune research.

• **Diagnosis and Treatment**—Why do suffering patients need to trample all over—sometimes across the country—to obtain diagnosis and treatment? With a small but determined start, AARDA is accumulating funds for a National Autoimmune Diagnostic and Treatment Center, but “big money” is needed. At present, Israel is the only country having such a center. Why not the USA?

While much has been accomplished in AARDA’s history, more work awaits us—and we will not rest until autoimmunity is included in all medical school curricula, the public understands the debilitating nature of these chronic diseases, and most important, all patients can be diagnosed properly and have full access to life-saving treatments.

**Your continuing help is needed.** Someone you know has an autoimmune disease, perhaps you. For whatever you can give or do, we thank you.
This past year has seen more progress in our understanding of and ability to treat autoimmune disease. New biologic therapies and new drug therapies as well have been approved for clinical use. More are advancing through clinical trials with early promising results.

Genetic studies continue to identify new risk alleles, mutational forms of genes, for autoimmune diseases. A major advance of the past year has been the explosion of epigenetic analyses, the study of modifications in chromatin that determine the likelihood that a gene will be expressed. Chromatin is a substance present in the nucleus of a cell that contains the genetic material. These studies hold great promise for linking environmental factors which can alter epigenetic profile to genetic risk factors.

More progress has been made in understanding how the microbiome, those organisms that live in our gut or on our skin in symbiosis with us, can alter our susceptibility to autoimmune disease. These studies provide hope for the development of non-immunosuppressive therapies for autoimmune disease.

The new area of neuromodulation of the immune system has moved to the clinic with promising therapeutic benefit in inflammatory bowel disease and rheumatoid arthritis. This also represents a new, less immunosuppressive approach to therapy.

Finally, we have continued to dissect the metabolism of the immune system and have strong evidence from laboratory models and growing evidence from clinical trials that drugs which alter immune cell metabolism may constitute effective therapies for autoimmune diseases.

This past year, therefore, continues the strong progress being made in understanding and treating autoimmune disease. The studies continue to support the founding principle of AARD, that we learn more when we consider these to be related diseases than when we study each separately. Indeed, more and more communalities among autoimmune diseases are seen and provide opportunities to improve a multiplicity of disease with the same therapeutic interventions.

Against all this progress and opportunity, we now face a very real threat to the fabric of scientific discovery and medical advance in our country. The recommendation for decreasing the budget of the National Institutes of Health (NIH) will undermine our preeminence in biomedical research. American science has long led the world and been a source of national pride. Young investigators from around the world come to the United States to learn how to become creative and rigorous investigators. Our scientific infrastructure has served as a model for other countries, but it will not take more than a few years of drastically reduced funding to destroy what has been built.

As Chair of AARD's Scientific Advisory Board, I know that AARD supporters join with me in endorsing evidence-based health policies, universal access to the benefits of biomedical science, and the need to maintain the preeminence of our national biomedical research enterprise.


Noel R. Rose, M.D., Ph.D.
2016 AARD Champion

At the 25th anniversary celebration of the American Autoimmune Related Diseases Association (AARD), held on May 7, 2016, Noel R. Rose, M.D., Ph.D., was honored as the recipient of AARD’s highest honor, its 2016 Champion Award, in recognition of his invaluable and dedicated service to the Association.

In the earliest days of AARD’s history, Dr. Rose gave significant encouragement to Founder Virginia Ladd and the original planners. His faithful and wise support, continuing throughout AARD’s formative years to the present, has been instrumental in advancing the mission, growth, longevity, and standing of AARD.

Aptly called the “Father of Autoimmune Disease” for his breakthrough discovery of thyroid autoimmunity in 1956, Dr. Rose has gained international recognition. A listing of his academic achievements, awards, writings, and other accomplishments, including a Nobel prize nomination, covers many pages.

Dr. Rose is a Fellow of the American Academy of Allergy, the College of American Pathologists, the American Academy of Microbiology, and the American Association for the Advancement of Science. He is the recipient of the Abbott Award and the Award for Pioneering Research on Autoimmunity, both awarded by the American Society for Microbiology. In 2009, Dr. Rose received the Polish Academy of Sciences’ Nicolaus Copernicus Medal, the academy’s highest honor. He is co-editor of the renowned textbook *The Autoimmune Diseases*.

A member of The Wayne State University (Michigan) Academy of Scholars, he received the WSU Lamp Award for Excellence in Teaching (1976), the President’s Award for Excellence in Teaching (1979), and the Distinguished Service Award from the College of Medicine (1982).

In addition to serving as a professor of microbiology, pathology, and immunology at the Johns Hopkins University School of Medicine, Baltimore, Maryland, Dr. Rose directed the establishment of the the Center for Autoimmune Disease Research, Bloomberg School of Public Health, at Johns Hopkins, and served as its first director.

Dr. Rose now holds the titles of Emeritus Professor, Johns Hopkins University, and Senior Lecturer, Harvard Medical School, while he maintains a staff position in pathology at the Brigham and Women’s Hospital, Harvard Medical School, Boston, Massachusetts.

Still supporting AARD, Dr. Rose plans and coordinates AARD scientific symposia, teaches patients and others about autoimmune disease through AARD public forums, and serves as an active advisor to the AARD Board of Directors. He also serves as Chairman Emeritus of AARD’s Scientific Advisory Board.

Dr. Noel Rose is a true Champion for the good of autoimmune patients worldwide.
**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 to accomplish autoimmune research projects
- Continued campaign to fund the establishment of a National Autoimmune Diagnostic and Triage Center
- Beta-tested the Autoimmune Registry Network (ARNet)
- Funded five “Young Investigators” grants

**Education (Patient, Public, Scientific)**

- Sponsored, cosponsored, or supported the following:
  — AARD A 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 (AARD A staffed display booth), San Francisco, CA
  — Scientific Meeting, Novel Cellular Pathways in Autoimmunity, Washington, DC
- Federation of Clinical Immunology Societies (FOCiS) Annual Meeting, Boston, MA
- 15th International Congress on Antiphospholipid Antibodies, Istanbul, Turkey
- AARD A Neuropsychiatric Symposium, Washington, DC
- Welcomed new member to Scientific Advisory Board, Patrizio Caturegli, M.D., Incoming Director, Johns Hopkins University Center for Autoimmune Disease Research, Baltimore, MD
- Endorsed and staffed AARD A booth, Interdisciplinary Autoimmune Summit, New York, NY
- Began support for organizer/facilitator of AARD A scientific meetings, Noel R. Rose, M.D., Ph. D., Emeritus Professor, Johns Hopkins University; Senior Lecturer, Harvard Medical School; Pathology Dept., Brigham and Women’s Hospital, Boston, MA
- Continued to distribute Autoimmune 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

**Advocacy and Awareness**

- Continued to make available AARD A patient-friendly “Risk/Benefit” brochure
- Continued to provide AARD A “Three-Second Benefit Factor” study for physicians
- Maintained 24-hour toll-free request line
- Provided referrals and non-medical information to inquirers
- 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

**What’s been happening in FY 2016?**

We present an “Overview of Major Accomplishments”....

Volunteer Kim Radomski (left) and Assistant Director Pat Barber pose at AARD A’s Derby Fundraiser

Abid Khan, M.D. (left), Medical Director, Autoimmune Clinic, MidMichigan Health, and Noel R. Rose, M.D., Ph.D., Chairman Emeritus, AARD A Scientific Advisory Board and AARD A 2016 Champion Award recipient, attend AARD A’s 25th Anniversary celebration
• Provided comments to the Food and Drug Administration (FDA) in support of distinguishable names for biologics and biosimilars
• Received national recognition through the awarding to AARDA President/Executive Director Virginia Ladd the 2016 Research and Hope Award for “Excellence in Advocacy and Activism” by the Pharmaceutical Research Manufacturers of America (PhRMA)
• 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” special edition of USA Today, Modern Woman, and autoimmune disease insert in USA Today

Fundraising
• Worked with volunteers through personal contacts and AARDA’s digital Grassroots Newsletter to encourage and provide support for their “grassroots fundraising” projects
• Expanded the Autoimmune Disease Awareness Walks schedule (Cleveland, Ohio; McLean, VA; Atlanta, GA; Manhattan, NY; Detroit, MI; Los Angeles, CA; St. Louis, MO) and provided 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
• Continued to meet the Standards of Excellence Certification Program for Voluntary Health Agencies of the National Health Council
• Remained recognized Member Organization of Health & Medical Research Charities of America
• Maintained membership and active participation in the International Alliance of Patients’ Organizations (IAPO)
• Continued standing in the Combined Federal Campaign (CFC)
• Held combined management and fundraising costs at 5 percent of total expenses (compared with 25 percent acceptable for nonprofit organizations)

Board member Althea Cices shows Certificate of Appreciation given to her and other outgoing Board members Linda Pesonen and Lawrence Tobias
**AMERICAN AUTOIMMUNE RELATED DISEASES ASSOCIATION, INC.**  
**STATEMENT OF FUNCTIONAL EXPENSES**  
*For The Year Ended September 30, 2016*  

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<th>Program Services</th>
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<th>Research</th>
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<th>Management and General</th>
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**Total Expenses**  
$455,468 $1,435,153 $1,015,643 $2,906,264 $69,723 $95,605 $3,071,592
Officers and Board Members

The Rev. Herbert G. Ford, D.Min.,
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Detroit, Michigan
Pastor, Good Shepherd Missionary
Baptist Church
Southfield, Michigan

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Vice Chairman
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Bluffton, South Carolina

Virginia T. Ladd, President,
Executive Director
American Autoimmune Related Diseases Association
Clinton Township, Michigan

Nona Bear, Secretary
Health Care Consultant
Fall Church, Virginia

Richard M. Hodge, Treasurer
Fairfax Station, Virginia
John P. Kaiser, Jr.
Partner, RSM US, LLP
Peoria, Illinois

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Varadero Capital, LLP
New York, New York

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CACP International
Vienna, Virginia

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Director, Center for Coping
Long Island, New York

J. Michael Quinlan, I.I.M.
Attorney & Corporate Executive
McLean, Virginia

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Head, Enterprise Development
Varadero Capital, LLP
New York, New York

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Lilly Stairs
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Clara Health
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Department of Biochemistry and Molecular Biology,
Clayton University
Clayton, Victoria, Australia

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Hunter College
New York, New York

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Division of Molecular and Clinical Rheumatology
Department of Medicine
Johns Hopkins University
Baltimore, Maryland

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Director, Center for Coping
Long Island, New York

Yehuda Shoenfeld, M.D.
Head, Department of Medicine B’ and Center for Autoimmune Diseases
Chaim Sheba Medical Center
(Affiliated to Tel-Aviv University)
Incumbent of the Laura Schwartz-Kipp Chair
for Research of Autoimmune Diseases
Tel-Aviv University
Tel-Hashomer, Israel

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Anita and Jack Saltz Chair in Diabetes Research
Professor and University Chair,
Department of Medicine
Albert Einstein College of Medicine
Montefiore Medical Center
Bronx, New York

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HERTIE Senior Professor
Department of Neuroimmunology
Max Planck Institute for Neurobiology
Planegg-Martinsried, Germany

Caroline Whitacre, Ph.D.
Vice President for Research
Office of Research
Professor, Department of Microbial Infection and Immunity
The Ohio State University
Columbus, Ohio

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Chair, Scientific Advisory Board
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Professor & Head
Center for Autoimmune & Musculoskeletal Diseases
The Feinstein Center for Medical Research
Northwell Health
Professor of Molecular Health & Medicine
Hofstra Northwell School of Medicine
Manhasset, NY

Chairman Emeritus
Noel R. Rose, M.D., Ph.D.
Emeritus Professor
Johns Hopkins University
Senior Lecturer
Harvard Medical School
Dept. of Pathology
Brigham and Women’s Hospital
Boston, Massachusetts

Jean-François Bach, M.D., D.Sc.
Secrétariat perpétuel
Académie des Sciences
Paris, France

Patrizio Caturegli, M.D.
Director, Center for Autoimmune Disease Research,
Bloomberg School of Public Health
Department of Pathology, School of Medicine
Department of Molecular Microbiology and Immunology
School of Public Health, Johns Hopkins University
Baltimore, Maryland

Nicholas Chiorazzi, M.D.
Head, Karches Center for CLL Research
The Feinstein Institute for Medical Research
Professor, Molecular Medicine and Medicine
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