Mission Statement

The American Autoimmune Related Diseases Association, Inc., (AARDA) is dedicated to the eradication of autoimmune diseases and the alleviation of suffering and the socioeconomic 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.

2015 ANNUAL REPORT
A year ago I greeted AARD A Annual Report readers as a newly elected Chairman of the Board; and, not surprisingly, this past year has been a time of challenge and growth. I am pleased to give you a bit of my own "View from the Top" as an introduction to the more detailed view in this report. AARD A is definitely a national organization on the move.

With my own background in finance, management, community nonprofit involvement, and faith-building, I know that the foundation is important. Thus, I have been particularly cognizant of the effective leadership of members of the AARD A Board of Directors, utilizing their variety of backgrounds in their own goal-setting and overview while drawing on the Executive Director's experience and judgment.

Also, from its very beginning, AARD A has sought the wisdom of its Scientific Advisory Board. Led initially by internationally known researcher Noel R. Rose, M.D., Ph.D., now Chairman Emeritus, the Board is chaired by highly respected researcher Betty Diamond, M.D. Comprised of outstanding researchers representing six countries (Australia, France, Israel, Italy, Germany, and the U.S.A.), this widely scattered Board has been available in speaking, reviewing, advising, and teaching—simply ask!

With this combination of advisors and mentors, plus the dedicated volunteers carrying out fundraising, autoimmune awareness, and support across the country—and, indeed, into some other countries—we have maintained a firm foundation on which to build our work in advancing AARD A's mission of "facilitating collaboration in the areas of education, public awareness, research, and patient services in an effective, ethical and efficient manner."

We are grateful for the generous support of corporate and foundation grants and contributions plus the equally valuable individual donations that have enabled AARD A to move ahead steadily in those stated areas.

We are particularly pleased that we have been able to facilitate collaboration among diverse businesses and groups having a mutual interest in autoimmune diseases. With the establishment of the Autoimmune Partnership Council, offering memberships to the business community and institutions of learning, combined with the increasing effectiveness of the National Coalition of Autoimmune Patient Groups, we are encouraging a sharing of autoimmune information and goals.

While AARD A and friends have a long way to go toward achieving the eventual defeat of the category of autoimmune disease, we know that progress continues in all aspects of the fight, as interested readers can see in "Overview of Major Accomplishments" elsewhere in this report.

Not listed, however, but perhaps the most important part of our "View from the Top" is the genuine concern, the caring, shown among the supporters of AARD A's mission. Even when hurting on a personal basis, AARD A's supporters show compassion for the 50 Million Americans—and others throughout the world—who are afflicted by the life-threatening consequences of many of the autoimmune diseases.

Autoimmune diseases cross the boundaries of all ages, genders, races, and socioeconomic levels. As we say, someone you know has an autoimmune disease. Is it you? Is it a loved one? Or is it someone else who has touched your life? The need for support is great.

On behalf of the 50 Million whom we serve, I thank you for any support you have given—or will give.

President and Executive Director Virginia T. Ladd

One of the real joys of being both President and Executive Director—forget the paper work and endless e-mails—is viewing the organization from both the AARD A office and the stimulating meetings around the country in which I am included. Sometimes it's easy to be discouraged that no cure for autoimmune disease has been found. Then I see the excitement and learning generated by, for example, AARD A's "The State of Autoimmune Disease: A National Summit," and I see possibilities.

This National Summit featured leading physicians and researchers, plus patients and patient advocates, including our own National Spokesperson Kellie Martin. Together we learned about the past and looked into "Paths for the Future." The profound fatigue felt by many autoimmune disease patients was discussed. We heard about a possible "mapping process" in which physicians and their patients try to pinpoint when the fatigue starts and what factors, like stress, diet, and sleep patterns, may be at play.

We heard the suggestion for a directory of physicians who themselves have autoimmune disease or who have family members with autoimmune disease. Those physicians might help educate other physicians and advocate for improved diagnostic tools and treatments for patients. These are truly patient/people oriented topics for discussion, exciting stuff not only for organization administrators but also for researchers.

What about environment and autoimmunity? Speakers pointed out that over the past several decades, a significant number of autoimmune diseases have increased in frequency not only in the U.S. but also around the world. Mounting evidence for the role of environment comes from a variety of sources, including environmental agents that can alter the structure of cells, making them appear to be foreign invaders, resulting in either an activation or suppression of the immune system.

Speakers emphasized the difficulties in getting an autoimmune disease diagnosis. Surprisingly, one roadblock may be the way that patients describe their symptoms. As Dr. Abid Khan, Director of the MidMichigan Health Autoimmune Disease Center, suggested, patients should not describe the chronic fatigue afflicting them as "fatigue" but perhaps "function-impaired." The Center, the first such facility in the United States, has received support as an AARD A pilot program.

In the meantime, AARD A has developed and published a white paper on biologics and biosimilars to educate autoimmune organizations' leaders and individual patients. This will enable them to be well informed advocates of policies that protect patient safety issues related to the approval of biologics. Also, with the help of AARD A Board Advisor Stephanie Hales, we have submitted several comments to the FDA regarding biosimilar patient safety issues and CMS regarding Part D guidelines and essential benefits.

All this is simply a smattering of AARD A activities. For details, see "Major Accomplishments for FY 2015" in this Annual Report.

Scientific colloquia, congressional briefings, public forums, media exposure, research support, establishment of an Autoimmune Disease Patient Registry (ARNet), "Linking for the Cure" autoimmune walks across the country, grassroots fundraising with awareness opportunities, personal contacts—they involve both "lofty" views and real people issues. Yes, the current autoimmune disease picture is both disheartening and hopeful—but always exciting.

From a President/Executive Director's "View from the Top" and on a very personal level, I'm privileged to share the autoimmune fight with the many patients and others who definitely won't quit—and I am grateful to our many donors, sponsors, volunteers, and in-kind contributors who make every gain possible.

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.

Thank you—for doing and being.
Our awareness of autoimmune diseases continues to increase, and the number of conditions we now recognize as autoimmune continues to expand. In order to focus on these various aspects of autoimmunity, AARDA sponsored several meetings this past year.

One of these meetings addressed "Neuropsychiatric Manifestations of Autoimmune Diseases." Presentations ranged from new data on diseases already known to be autoimmune in origin, such as multiple sclerosis, to newly recognized autoimmune diseases, such as limbic encephalitis (the topic of the book Brain on Fire), to the potential contribution of maternal autoimmunity to autism spectrum disorder. Another conference was "Eosinophils, Types II Immunity and Autoimmune Disease" that focused on this neglected area of research in autoimmune diseases. A third meeting, "Pregnancy and Lactation in Women with Autoimmune Disease," addressed hormonal regulation of immune and autoimmune responses which needs to be better understood as well as the impact of transfer of maternal antibodies to the developing fetus and neonate. These meetings which are organized annually by AARDA help focus the research agenda in autoimmunity.

AARDA also continues to advocate on behalf of individuals with autoimmune diseases, holding in 2015 a national summit in Washington DC, and public forums in Tampa FL and West Bloomfield MI. While the major efforts of AARDA are directed to advocacy, public awareness of autoimmune diseases, and public access to information, AARDA also funds research trainees and early career investigators.

The autoimmunity field continues to learn about disease pathogenesis and therapy, sometimes from unexpected sources. The use of immune modulatory therapy in cancer has provided new insights into autoimmune disease.

We also know that it can take 3.5 years to obtain an accurate diagnosis, with visits to an average of five physicians before the diagnosis is made—and in the meantime, the disease is steadily progressing. That is where AARDA and I, with my media contacts, come in—AWARENESS! We know that awareness can lead to education which can lead to diagnosis which can lead to very possibly life-saving treatment. And this is where YOU, our interested reader, come in.

I am blessed to find opportunities to lend not only my time and talent but also financial support to the fight against autoimmune diseases. You, too, very likely have talents for creating donations, grants, bequests, and ideas or resources for raising funds. A little or a lot, it all makes a difference. Research, education, and awareness require money. No surprise there!

If you already are actively supporting AARDA in some way—money, in-kind contributions, volunteering—we thank you. If you see the autoimmune fight as a worthy cause, welcome aboard. We'll take the journey together.

Kellie Martin
AARDA National Spokesperson
and Dedicated Volunteer
What happened in FY 2015?
We present an “Overview of Major Accomplishments”....

Research
• Contributed, to date, a total of $4,762,310 to research
• Introduced a campaign to fund a National Autoimmune Diagnostic and Treatment Center
• Sponsored five students in the Johns Hopkins University Summer Diversity Student Internship Program, Baltimore MD
• Provided "Young Investigator" grants to three Postdoctoral Fellows: Massachusetts General Hospital, Boston MA; The Feinstein Institute for Medical Research, Manhasset NY; and Johns Hopkins University, Baltimore MD
• Sponsored 17th Annual Autoimmunity Day, Center for Autoimmune Disease Research, Johns Hopkins University Bloomberg School of Public Health, Baltimore MD
• Continued research support for the following:
  — O’Leary-Wilson Autoimmune Disease Fellowship, basic autoimmune research, Johns Hopkins University, Baltimore MD
  — Role of the innate immune system in lupus, The Feingold Institute for Medical Research, Manhasset NY
• Completed research study, "Autoimmune Disease and Fatigue: Patients Speak"

Education (Scientific, Public, Patient)
• Sponsored, cosponsored, or supported the following:
  — Scientific round table, "Eosinophils, Type II Immunity and Autoimmune Disease," Washington DC
  — Scientific colloquium, "Neuropsychiatric Manifestations of Autoimmune Disease," Washington DC
  — "Pregnancy and Lactation in Women with Autoimmune Disease: Sharing Knowledge Across Disciplines," San Diego CA
  — "The State of Autoimmune Disease: A National Summit," Washington DC
  — "What Every American Needs to Know About Autoimmune Disease," AARDA public forums, Tampa FL, West Bloomfield MI
  — "How to Dance in the Rain," Conference for the Autoimmune Community, Scleroderma Foundation Michigan Chapter and others, Grand Rapids MI
  — American College of Rheumatology Annual Meeting (AARDA provided staffed display booth), San Francisco CA
• Provided representation at Congressional Briefing on "Inflammatory Eye Diseases, Focus on Uveitis," Congressional Briefing sponsored by National Alliance for Eye and Vision Research
• 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
• Continued to offer "My Autoimmune Story" video on AARDA YouTube channel
• Maintained social networking sites (Facebook page, 88,582 "likes," Twitter account, 2,497 followers)
• Published quarterly lay-friendly, 12-page newsletter InFocus
• Made available informational brochure and PowerPoint presentation of AARDA's "Risk/Benefit" study
• 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)
• Maintained 24-hour toll-free request line
• Provided referrals and non-medical information during office hours via the Patient Educator
• Maintained Local Contact list with support groups as available

Noel R. Rose, M.D., Ph.D., addresses audience at AARDA Public Forum in Michigan

Young researchers, JHU Diversity Summer Internship Program 2015 - L to r: Alejandra Garcia, Chelsea Saumi, Mankaah Acho, Brandon Mallory, Felix Contreras-Castro
Advocacy and Awareness
- Continued facilitation of the 38-member National Coalition of Autoimmune Patient Groups (NCAPG)
- Provided representative at United Nations World Health Organization meeting on biologic and biosimilar drugs, Geneva, Switzerland
- Provided representative to Advocacy Day sponsored by the Partnership to Fight Chronic Disease
- Co-sponsored with the NCAPG a news briefing, "The State of Autoimmune Disease, A National Summit," at the National Press Club, Washington DC
- Continued development and information gathering for a first-of-its-kind National Autoimmune Disease Registry
- Co-sponsored 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 in national publications

Fundraising
- Continued to encourage and provide support for "grassroots fundraising," including the online Grassroots Newsletter
- Expanded the Autoimmune Disease Awareness Walks schedule and provided support for Virtual Walks
- Sponsored the AARDA Annual Fund Raiser in the Greater Detroit area ($59,817 profit)

Administration
- Maintained the following ratings:
  — Better Business Bureau Wise Giving Alliance Charity
  — Best in America Certified by Independent Charities of America
  — Charity Navigator Three Star Charity
- Maintained membership and active participation in the International Alliance of Patients’ Organizations (IAPO)
- Continued to meet all Standards of 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)
## AMERICAN AUTOIMMUNE RELATED DISEASES ASSOCIATION, INC.
### STATEMENT OF FUNCTIONAL EXPENSES
**For The Year Ended September 30, 2015**

<table>
<thead>
<tr>
<th>Program Services</th>
<th>Education</th>
<th>Public Awareness</th>
<th>Research</th>
<th>Total Program Services</th>
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<td>In-Kind Goods and Services</td>
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<td>$943,522</td>
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<td>$1,180,824</td>
<td>$361,884</td>
<td>$2,342,629</td>
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### AMERICAN AUTOIMMUNE RELATED DISEASES ASSOCIATION, INC.
### STATEMENT OF ACTIVITIES
**For The Year Ended September 30, 2015**

<table>
<thead>
<tr>
<th>Revenue and Other Support:</th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Total</th>
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<tr>
<td>Contributions</td>
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<td>Total Revenue and Other Support</td>
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<td>2,727,827</td>
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### Expenses:

<table>
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<tr>
<th>Expenses:</th>
<th>Program services:</th>
<th>Support &amp; Revenue</th>
<th>Management and General</th>
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<td>Research</td>
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<td>361,884</td>
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<td>Supporting services:</td>
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<td>Total Expenses</td>
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<td>Net Assets, Beginning of Year</td>
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<td>Net Assets, End of Year</td>
<td>$913,505</td>
<td>17,083</td>
<td>$930,588</td>
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Major Contributors in Fiscal Year 2015

Major In-Kind Contributors
- Aaron Abend
- Sidley Austin, LLP
- Nona Bear
- Carway Communications
- The Education Center
- Environmental Consulting and Investigations
  - Stanley M. Finger, Ph.D.
  - FoxKiser
- Richard M. Hodge
- Johns Hopkins University
  - Noel R. Rose, M.D., Ph.D.
- Google Ad Word
- John Kaiser, CPA
- Abid Khan, M.D.
- Kristi-Fundraising
- Natasha Leskovsek
- Kellie Martin
- National Cable TV Company
- Neutron Media
- Michelle Ouellet
- Julia Pandl
- Pennquarters Consulting
- Linda Pesonen Consulting, LLC
- PharmaNexus, Inc.
- Charles Pottinger
- Haley Ramm
- Saga Communications
- George Schusser
- USA Special Editions
- Todd Graphic Design

Individual, Corporate, and Foundation Donors

Contributions $20,000 and Over
- AbbVie Inc.
- Allergan USA, Inc.
- Amscan USA
- Anonymous
- BIO
- Genentech, Inc.
- Pfizer, Inc.
- PhRMA
- Mr. & Mrs. Joseph Scoby

Contributions $5000 thru $19,999
- 50 Cents for 50 Million Fundraiser
- Aaron Abend & Shelley Orenstein
- Anonymous
- Nona Bear
- Brave Dave Foundation
- Celgene Corporation
- Howl at the Moon 1K Fundraiser
- Gerald & Virginia Ladd Partnership to Fight Chronic Disease
- Henry Riordan
- Contributions $1000 thru $4999
  - Althea & Simon Cices
  - Anonymous
  - Arbor Assays
  - Scott & Ann Barnhouse
  - Dr. Marvin Bellin
  - Ed & Judy Christian
  - Kellie & Keith Christian
  - Conyngham Family Charitable Foundation
  - Denim and Donations Fundraiser
  - Mary Deters
  - Nigel Drepaup
  - Enterprise Holdings Foundation
  - Louis and Helen Fanaroff Foundation Ltd.
  - The Farkas Family Foundation
  - Greatest Commandments Foundation, Inc.
  - Oxford Autoimmune Race
  - Across America Fundraiser
  - JG Interests, LLC
  - Peggy Lichter & David DiDomenico
  - Douglas & Marta Mayer
  - Daniel & Diana McCoy
  - Nancy Monaghan
  - Diane Moss
  - National Institute of Environmental Health Sciences (NIEHS)
  - NECTABA Management Group, Inc.
  - Ann Pearson
  - Sibella Pedder
  - Kenneth Pullig
  - Mike & Mary Quinlan
  - Raising awareness fund raiser
  - in honor of Cara Lian Lebedda
  - Ron & Diana Shepard
  - Step by Step Dance Studio
  - Valerie Thomas
  - Robert A. Waller Foundation
  - Brad & Erin Yoho

Contributions $250 thru $999
- Kevin Andersen
- Anonymous
- Marilyn Assiff
- Diane Becker
- Elaine Belter
- Joan Boddie
- Dave & Michelle Brown
- Marilyn Clague
- Andrew & Maryan Dunnet
- Duro Dyne National Corporation
- Shirin Emami
- Lawrence Eppolito
- Andrew Fawer
- Sandra Filbert
- Stanley & Shelley Finger
- Akua Flesher
- Floralia Decorators
- Herbert & Margaret Ford
- Linda Fredo
- The Gardner Family Foundation
- Dinh Ha
- Anne Hammell
- Judith & Charles Harris
- Nancy Harris
- Barbara Hayes
- Dr. & Mrs. Edward & Carolyn Hecker
- Jan Hewlett
- Ellen Hipsky
- Gloria Jones
- Jake Jones
- Geoffrey Kary
- William & Lisa Keller
- Melinda & Roy Kelley
- Suzanne Klein
- Robert & Jeri Krueger
- Heather Kupets Harris
- Ferne Lambert
- Karen Langdon
- Howard Lifshitz
- Erica London
- Lord & Taylor Coupon Book Fundraiser
- Merrill Magner
- Marovato Industries Inc.
- Marovato Italian Imports
- James & Patricia Miller
- Marilyn & Alan Morris
- Michael & Kara Mozena
- NYU Hospital for Joint Diseases
- Harriet & Richard Orkand
- Family Educational & Charitable Foundation
- William & Margy Kaye Padnos
- Daniel Panzer
- Jeffrey Parker
- Peony Flowers, Inc.
- Richard Rath
- Anne Remington
- James Ryan
- Saks Fifth Avenue
- Sample Czar Inc.
- Jennifer Seaman
- Karen Sheridan
- William Spiteri
- Spoonful of Hearts Fundraiser
- T & L Fabricators
- Joseph & Rebecca Taylor
- David Teague
- Kathleen & Daniel Thornberry
- Louise Torri
- Jayashree Vangala
- Mark & Mary Beth Vogt
- Alex & Iris Wagman
- Dennis Weiss
- Carol Lynn White
- Carol Williams
- Charles Wolford
- Payroll Campaigns & Matching Gifts
- AT & T
- Agilent Technologies
- Allstate Giving Campaign
- Ally Financial
- American Express
- Boeing
- Chevron Humankind
- Cigna Foundation
- City of Seattle
- Clorox
- GE Foundation
- Give with Liberty
- Goldman, Sachs & Co.
- Halliburton
- IBM
- Markel Corporation
- Maryland Charity Campaign
- Merck
- Morgan Stanley
- Shell Oil Company
- United Way California Capital Region
- United Way of Greater Philadelphia and Southern New Jersey
- United Way of Northern New Mexico
- Wells Fargo

Other Friends and Contributors
Space does not allow us to include the names of all the other persons and organizations who gave their financial support to AARDA, but we want to 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 donations, we take this opportunity to express our appreciation once more to those kind donors. Every contribution has been acknowledged to the donors and to those persons honored or to the families of those held in memoriam.
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