

**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.





AMERICAN AUTOIMMUNE Related Diseases Association, Inc.

## AARDA FY 2014: View from the Top

## Chairman of the Board the Rev. Dr. Herbert G. Ford



After more than 12 years of involvement with AARDA, I am honored to have begun FY 2014 as its Chairman of the Board. My own personal and professional

backgrounds have included finance, banking, and economics, plus community service involvement.

My AARDA volunteer history has included serving as an informal advisor/consultant, participating in committee work, accepting appointment as a member of the Corporate Advisory Board, and being elected to the Board of Directors. Each step along the way has increased my respect for the work being accomplished by the AARDA leaders, staff, and volunteers who join forces not only across the United States but also in a number of other countries, e.g., in those countries represented by our Scientific Advisory Board.

One of the constant needs of a nonprofit organization is "financial refueling." In this respect, AARDA is dependent upon the generosity of individuals and foundations, aided by grants from corporations whose decision makers have either a corporate or, sometimes, a personal interest in autoimmune diseases. While contributions wavered a bit during the recent years of hurting economies, they did, for the most part, remain constant. That was a source of not only financial survival but also growth and, not to be minimized, encouragement.

By reading "Major Accomplishments During Fiscal Year 2014" in this Annual Report, you can see that AARDA has left tracks along the way. In autoimmune research, education, awareness, and advocacy, AARDA has been heard and seen. This was possible only with the support of generous donors, dedicated volunteers, and in-kind contributors.

Thinking of the 50 million Americans suffering from autoimmune diseases, we know that we must leave even more tracks in Fiscal Year 2015. You, too, can leave your tracks on the autoimmune trail. In advance, we thank you.

## President and Executive Director Virginia T. Ladd



Once more we can say, "It's been a great year," as our Strategic Plan for Fiscal Year 2014 has come alive in many ways. Let me share with you...

A much needed autoimmune survey/ registry project is now underway. For too long we have had to depend on incomplete data on the occurrences of various autoimmune diseases. With AARDA Informatics Director Aaron Abend leading the way and with the cooperation of the National Coalition of Autoimmune Patient Groups (NCAPG), we see promise that this data update will become reality. With accurate percentages for occurrences of the majority of autoimmune diseases, we can provide statistics to aid in education, advocacy, and research as well as funding efforts.

An autoimmune diagnostic and treatment center has been established on an exploratory scale in Midland, Michigan, with start-up funding from AARDA. Abid Khan, M.D., of Mid-Michigan Health, affiliated with the University of Michigan, heads this effort. Also, the AARDA Board of Directors approved a seed fund to expand the search for a major donor or major donors for a national autoimmune diagnostic and treatment center.

Advocacy days and congressional briefings, held with the assistance of the NCAPG, have proved to be so effective that "autoimmunity" is finding its place on Capitol Hill. Fiscal Year 2015 will see added effort on our part to increase basic autoimmune funding within the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Department of Defense.

# Issues arising from implementation of the Affordable Health Care Act have

shown signs of adversely affecting patients with autoimmune diseases. We have been active in aspects related to safety, access, and FDA issues; and we expect to increase our efforts in this area.

#### A physician education strategy

targeted toward family and/or medical home doctors is in the plans for FY 2015 to involve a search for a company capable of developing such a program. An AARDA survey conducted in FY 2014 shows the need for reaching out to physicians who offer autoimmune patient initial contact and follow-up care. We will expand our work in this area as we develop a plan for tying physician education into our advocacy program.

Autoimmune research support has continued, from summer research internships to basic and targeted research projects, e.g., liver research, in major institutions.

**Funding for AARDA's various proj**ects has been enhanced by Board efforts to reach out to foundations and corporations. Through the establishment of the Autoimmune Partnership Council, we have welcomed new corporate supporters and have seen renewed interest on the part of long-time corporate friends. Such a partnership unites the corporate and nonprofit worlds to the benefit of all autoimmune patients.

The basis for giving, of course, remains with the individual donors and foundations, plus our volunteers and in-kind contributors, who have maintained their loyalty through the years—and, for many, despite their own battles with autoimmune challenges.

Yes, 2014 has been a great year. And with the deeply appreciated help of our many friends, 2015 will be even better.



Left to right: Author/Blogger Stacey Thureen, Virginia Ladd, and AARDA Board member Dr. Robert Phillips.

## A commentary from AARDA Scientific Advisory Board Chair Betty Diamond, M.D.



E ach year, our understanding of autoimmune disease grows and new therapeutics are brought to the clinic. This year has seen enormous growth in our appreciation of the contribution of the microbiome and immune activation in the gut in autoimmunity.

AARDA co-sponsored a workshop on the topic of the microbiome early this year. There are exciting data suggesting that the predilection for autoimmune disease in women may result from gender-specific differences in gut microbiome and intestinal immune activation. The role of specific gut bacteria in potentiating numerous autoimmune diseases offers exciting therapeutic opportunities. This avenue of research provides hope for non-immunosuppressive therapies for autoimmune disease; these are being aggressively pursued in animal models.

AARDA continues to be at the forefront of promising new insights into autoimmunity. This coming year, AARDA is sponsoring two additional meetings. The first addresses the role of eosinophils in autoimmune disease, raising awareness of a novel player in disease. The second focuses on neuropsychiatric manifestations of autoimmune disease, an area of increasing concern to patients. There is more and more evidence of neuropsychiatric impairments associated with autoimmunity and an increased frequency of neuropsychiatric problems in the children of women with autoimmune disease. The meeting will explore our current understanding of these issues and approaches that need to be explored.

New therapeutics continue to make their way into the clinical. IL-17 blockade currently appears to be a promising approach. Cellular therapies continue to progress to the clinic, both T regulatory cells and mesenchymal stem cells, both offering the hope of longterm drug-free remissions.

While opportunities are great, resources remain limited. Increasing funding for research is a priority. Stable funding levels threaten the work force. Indeed, funding has actually decreased over the past several years when inflation is considered. Young scientists and young physician-scientists are discouraged from embarking on careers as independent, creative investigators, raising concerns about the future cadre of creative scientists. AARDA plays a key role in raising awareness in Congress and in the public of the need for research funding. All AARDA supporters need to do likewise to maintain the excellence of the U.S. biomedical research enterprise.

## A message from Kellie Martin...

In the world of make believe, i.e., movies and television, I have been a little sister, a country school teacher, a detective, and a medical intern, among many roles. Nothing, however, compares in importance with the volunteer role I have held with AARDA for the past 16 years as its National Spokesperson.

Why does one become a spokesperson for a nonprofit organization? For me, it was a major way to bring some good out of tragedy. At the age of 19, my beautiful older sister Heather passed away from lupus that had remained undiagnosed despite our attempts to find a physician who could understand the meaning of her many symptoms. Finally, too late, we found that physician.

AARDA is the traditional "beacon of hope" for the 50 million Americans suffering from autoimmune diseases. As National Spokesperson, I am determined to shine that beacon on Congress, advocating for research dollars for the National Institutes of Health. I carry the



beacon when I speak at physician symposia, take part in media interviews, make public appearances on behalf of AARDA, advocate for a variety of research efforts, and sponsor my own AARDA fund raisers. For Heather, for all undiagnosed—and diagnosed autoimmune disease patients, for my own little Margaret "Maggie" Heather who has been born into a family with autoimmune diseases, I will continue to speak out. Do you know someone with an autoimmune disease? Do YOU have an autoimmune disease? I invite you to join me in the fight against this category of disease that appears as 100+ known autoimmune diseases. Together, through our financial contributions and our individual awareness efforts, we can promote collaborative research to find improved treatments and a cure for all autoimmune diseases.

If you already are a beacon of hope, thank you. If not, please shine your light in this fight against autoimmune disease. Every glimmer brightens a life somewhere. THANK YOU.

Kilii Martin

Kellie Martin AARDA National Spokesperson and Dedicated Volunteer

## What happened in FY 2014? We present an "Overview of Major Accomplishments"....

## Research

- Continued research support for the following:
  - —O'Leary-Wilson Autoimmune Disease Fellowship, basic autoimmune research, Johns Hopkins University, Baltimore, MD
  - —Autoimmune liver research, Johns Hopkins University, Baltimore, MD
  - —"Role of Sex Hormones in Regulation of Interferon Genes in Autoimmunity (SLE)," University of California, Los Angeles, CA
  - ---Role of the innate immune system in lupus, The Feinstein Institute for Medical Research, Manhasset, NY
  - —Pilot study, Autoimmune Diagnostic and Triage Center, MidMichigan Physicians Group, University of Michigan, Midland, MI
  - —Project to map and identify the specificity of newly created monoclonal antibodies to TNGR2 for the expansion of human Tregs, "Young Investigator" grant, Massachusetts General Hospital, Charlestown, MA
  - —"Neutrophil Extracellular TrapsRegulate Autoreactive T Cell Responses," Johns Hopkins University, Baltimore, MD
  - —"Clg-based therapeutic opportunities to block HMGB1 and RAGE in SLE," Feinstein Institute for Medical Research, Manhasset, NY

## Education (Patient, Public, Scientific)

- Sponsored, cosponsored, or supported the following:
  - —"The Microbiome and Autoimmune Disease," Leesburg, VA

- —9th International Congress on Autoimmunity, Nice, France
- —16th Annual Autoimmunity Day, Center for Autoimmune Disease Research, Johns Hopkins University
- —Federation of Clinical Immunology Societies Annual Meeting "FOCiS 2014"
- —AARDA public forums, "What Every American Needs to Know About Autoimmune Disease," St. Louis, MO; Charleston, SC; Los Angeles, CA; Midland, MI; Atlanta, GA
- —"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 staffed display booth), Boston, MA
- —3rd USA Science & Engineering Festival, Washington, DC
- —Interdisciplinary Autoimmune Summit, Las Vegas, NV

- Launched Autoimmunity Curriculum for Elementary and Middle School 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, twitter account)
- Published quarterly lay-friendly newsletter *InFocus*
- Made available informational brochure and PowerPoint presentation of AARDA's "Risk/Benefit" study
- Maintained 24-hour toll-free request line
- Provided referrals and non-medical information during office hours via the Patient Educator
- Provided free educational brochures and newsletters to numerous health-centered meetings and events
- Maintained Local Contact list



### Advocacy and Awareness

- Continued facilitation of the National Coalition of Autoimmune Patient Groups (NCAPG)
- Co-sponsored with the NCAPG a news briefing at the National Press Club, Washington, DC
- Unveiled plans to create a new, first-of-its-kind National Autoimmune Disease Registry
- Conducted a Web-based survey to collect data on how the Affordable Care Act is affecting autoimmune disease patients
- Provided interviews and information for news media
- Resumed work on development of AARDA's "Advocacy Tool Kit" with designated grant

### Fundraising

- Continued to encourage and provide support for "grassroots fundraising," including the online *Grassroots Newsletter*
- Expanded the Autoimmune Disease Awareness Walks

INDEPENDENT AUDITOR'S REPORT Board of Directors American Autoimmune Related Diseases Association

#### **Report on the Financial Statements**

We have audited the accompanying financial statements of American Autoimmune Related Diseases Association (a Michigan nonprofit corporation), which comprise the statement of financial position as of September 30, 2014 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. schedule and provided support for establishment of Virtual Walks (raised \$66,145)

• Sponsored the AARDA Annual Fund Raiser in the Greater Detroit area (\$54,877 profit)

### Administration

- Appointed an Assistant Director to oversee AARDA's national office (Michigan) in conjunction with Executive Director
- 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

#### 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 from 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 organization'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 organization's internal control. Accordingly, we express no such

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 7 percent of total expenses (compared with 25 percent acceptable for nonprofit organizations)



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, 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, 2014, 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.

Dolfy Hannel, Dannels & Loughang, P.C.

Godfrey Hammel, Danneels & Company, P.C. St. Clair Shores, Michigan March 17, 2015

## Major Contributors in Fiscal Year 2014

#### Major In-Kind Contributors

Aaron Abend AI Virtual Solutions Marilyn White Assiff Nona Bear Abby Bernstein Carway Communications Althea Cices Dr. Betty Diamond Donna DiSante The Education Center Environmental Consulting and Investigations Dr. Stanley M. Finger Dr. Herbert G. Ford FoxKiser Chuck & Susan Gaidica Google Ad Word Advertizing and Check-Out Service Stephanie P. Hales Richard M. Hodge Johns Hopkins Hospital John Kaiser, CPA Key Bridge Associates Dr. Abid Khan Ruth Kibler Natasha Leskovsek Linda Pesonen Consulting, Inc. Kellie Martin National Cable TV (Hallmark, Lifetime) Neutron Media Michelle Ouellet Julia Pandl Pennquarters Consulting PharmaNexus, Inc. Dr. Robert H. Phillips Charles Pottenger J. Michael Quinlan, LLM Dr. Noel R. Rose Saga Communications, Inc. George Schussler Scientific Advisory Board Members Sidley Austin LLP Todd Graphic Design Carolyn Ugval USA Special Editions

#### Individual, Corporate, and Foundation Donors Contributions \$20,000

*and Over* AbbVie, Inc. Anonymous Bayer USA Foundation Mary K. Gardner Estate Genentech, Inc. Pfizer, Inc. PhRMA The Scoby Foundation

## Contributions \$5,000 thru \$19,999

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#### Payroll Campaigns & Matching Gifts

Aetna Foundation Agilent Technologies Alliance Data Allstate American Endowment Foundation American Express America's Charities AT & T Benevity Community Impact Fund Boeing Chevron Humankind Cigna Foundation City of Seattle Clorox Donatic GE Foundation Give with Liberty Halliburton IBM Maryland Charity Campaign Merck Microsoft Morgan Stanley Pepsico Foundation Pfizer Foundation Thomson Reuters Truist United Way — Allegheny County; Southeastern Pennsylvania Wells Fargo

# Other Contributors and Friends

Space does not allow us to include the names of all the persons and organizations who generously gave their financial support to AARDA, through individual donations and fundraising projects, but we say "Thank you" again as we give this recognition in honor of their kindness.

#### Memorials and Tributes

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

#### AMERICAN AUTOIMMUNE RELATED DISEASES ASSOCIATION, INC. STATEMENT OF FUNCTIONAL EXPENSES For The Year Ended September 30, 2014

	Pi	rogram Service		Supporting Services			
	Public		Total Program	Management Fund			
	<b>Education</b>	<u>Awareness</u>	<u>Research</u>	<u>Services</u>	and General	<b>Raising</b>	<u>Total</u>
In-Kind Goods and Services	\$ 417,812	\$ 749,829	\$204,054	\$1,371,695	\$38,737	\$ 45,293	\$1,455,725
Other Expenses:							
Wages	170,354	102,028	8,549	280,931	5,310	14,912	301,153
Temporary help	1,094	9	-	1,103	1	1	1,105
Professional fees	2,963	8,501	-	11,464	11,515	2,659	25,638
Postage and shipping	5,410	3.765	13	9.188	100	1.792	11,080
Public relations	19,033	25,487	-	44,520	-	33	44,553
Printing and stationery	8,795	8,253	-	17,048	51	2,130	19,229
Office supplies	1,360	1,360	-	2,720	110	105	2,935
Operating supplies	821	573	-	1,394	31	394	1,819
Dues and subscriptions	2,451	2,685	500	5,636	75	-	5,711
Filing fees	556	556	-	1,112	465	556	2,133
Equipment maintenance	1,928	1,858	-	3,786	17	171	3,974
Telephone	2,730	2,730	-	5,460	228	166	5,854
Insurance	1,137	1,137	-	2,274	1,009	1,137	4,420
State and national meetings	24,150	12,197	20,566	56,913	1,087	1,066	59,066
Travel	14,815	5,070	16,274	36,159	914	482	37,555
Depreciation	3,520	2,167	1,719	7,406	325	381	8,112
Payroll taxes	10,606	6,559	5,201	22,366	987	1,154	24,507
Insurance - health	7,658	6,443	268	14,369	771	576	15,716
Fundraising -							
Derby	-	-	-	-	-	6,739	6,739
Board expenses	-	-	-	-	6,154	-	6,154
Professional training	58	38	-	96	4	-	100
Grants	23,000	-	56,569	82,569	-	-	82,569
Repairs and maintenance	1,246	793	-	2,039	113	113	2,265
Utilities	2,037	2,037	-	4,074	173	87	4,334
Miscellaneous	23	23	-	46	-	9	55
Retirement plan contributions	5,460	4,539	-	9,999	486	335	10,820
Total Other Expenses	311,205	198,808	112,659	622,672	29,926	34,998	687,596
Total Functional Expenses	\$ 729,017	\$ 948,637	\$ 316,713	\$ 1,994,367	\$68,663	\$ 80,291	\$ 2,143,321

### AMERICAN AUTOIMMUNE RELATED DISEASES ASSOCIATION, INC. STATEMENT OF ACTIVITIES

For The Year Ended September 30, 2014

Tor the rear Ende				
	<b>Unrestricted</b>	Temporarily Restr	icted <u>Total</u>	
Support and Revenue: Contributions Less: Donor designations Net Contributions In-kind goods and services Fundraising income Interest income Total Support and Revenue Before Net Assets Released From Restrictions	\$ 604,705 (75,000) 529,705 1,455,725 140,920 790 2,127,140	\$ 54,000 - 54,000 - - - - 54,000	\$ 658,705 (75,000) 583,705 1,455,725 140,920 790 2,181,140	Contributions Contributions 28% 66%
Net Assets Released From Restrictions	36,825	(36,825)	-	Fundraising
Total Support and Revenue	2,163,965	17,175	2,181,140	Support & Revenue
Expenses: Program services: Education Public awareness Research Total program services	729,017 948,637 316,713 1,994,367		729,017 948,637 <u>316,713</u> 1,994,367	Research Awareness
Supporting services: Management and general Fund raising Total supporting services <b>Total Expenses</b>	68,663 <u>80,291</u> 148,954 2,143,321	- - -	68,663 <u>80,291</u> 148,954 2,143,321	Fund Raising Management and General 34%
Change In Net Assets	20,644	17,175	37,819	Education
Net Assets, Beginning of Year	721,758	36,825	758,583	Expenses
Net Assets, End of Year	\$ 742,402	\$ 54,000	<u>\$ 796,402</u>	

## **Officers and Board Members**

The Rev. Herbert G. Ford, D.Min. Chairman of the Board President, NECABA Management Group, Inc. Detroit, Michigan Pastor, Good Shepherd Missionary Baptist Church Southfield, Michigan

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## Scientific Advisory Board

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Retired The University of the West Indies Mona, Kingston, Jamaica, West Indies

Steven A. Krilis, Ph.D.

Head, Department of Immunology, Allergy and Infectious Disease The St. George Hospital Kogarah, New South Wales, Australia

#### Parviz Lalezari, M.D.

Clinical Professor Department of Medicine and Pathology Albert Einstein College of Medicine Montefiore Medical Center Bronx, New York President, The Biomedical Research Institute Scarsdale, New York

#### Ian Reay Mackay, A.M., M.D., F.A.A.

Professor (Honorary) Department of Biochemistry and Molecular Biology, Monash University Clayton Victoria, Australia

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

Lawrence Damian Tobias Founder and President PharmaNexus, Inc. Montville, New Jersey

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#### Michelle Petri, M.D., M.P.H.

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

Robert H. Phillips, Ph.D

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 Schwarz-Kipp Chair for Research of Autoimmune Diseases Tel-Aviv University Tel-Hashomer, Israel

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#### Hartmut Wekerle, M.D.

Professor, Direktor Department of Neuroimmunology Max-Planck-Institut für Neurobiologie 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



### American Autoimmune Related Diseases Association, Inc.

Virginia T. Ladd, Executive Director

National Office

22100 Gratiot Avenue • Eastpointe • East Detroit, Michigan 48021-2227 Phone: (586) 776-3900 • Fax: (586) 776-3903 • Web Site: www.aarda.org Washington, D.C., Office Phone (586) 292-1919

The American Autoimmune Related Diseases Association, Inc., (AARDA), DBA Autoimmune Diseases Association, is a 501(c)(3) national voluntary health organization founded in 1991. AARDA is a member group and meets all standards of the National Health Council, in Washington DC, and of the Health & Medical Research Charities of America. AARDA is a member group of the Combined Federal Campaign (CFC). As a Better Business Bureau Accredited Charity, AARDA meets the strong and comprehensive standards of the Better Business Bureau Wise Giving Alliance. AARDA also carries the seal "Best in America," certified by the Independent Charities of America, and has a Three Star Charity rating from Charity Navigator.