

## A message from Kellie Martin...



In my more than ten years with AARDA as its national spokesperson, I have been privileged to present testimony at congressional briefings, take part in educational meetings, and speak one-on-one with congressional representatives. I have helped to lobby Congress for autoimmune disease research funding; and I have shared experiences with others, like myself, who have intimate knowledge of the grief and suffering inflicted by autoimmune diseases. I have talked with physicians and noted researchers who truly care about autoimmune disease patients and who work tirelessly toward finding the answers to the questions surrounding these merciless diseases.

My dedication to the autoimmune cause came after the death of my younger sister Heather who died at the age of 19 of late-stage lupus which had gone undiagnosed despite repeated trips to doctors and emergency rooms.

I am determined to do what I can to ensure the help for others that Heather didn't have. I want to support an organization that is working for early, life-saving diagnosis of autoimmune diseases; shouting to everyone, "Know Your Family AQ (Autoimmune Quotient)"; encouraging collaboration among researchers, physicians, and others; pushing for increased government funding for autoimmune research; and advocating for the establishment of a specialty of "auto-immunologist" so that an ailing person won't be dragged from specialist to specialist, needing someone to look at the **whole** problem, not just parts of the whole.

Yes, it will be great when and if Congress grants adequate funding for autoimmune research. But we can't wait for that to happen. We are the voices for Heather and millions of others like her. **Someone you know has an autoimmune disease.** Let's combine our efforts—spread awareness, contact our representatives, and lend financial support to AARDA—the best.

We are making a difference, but we have a way to go! Thank you for all you are doing—and will do.

Kellie Martin  
AARDA National Spokesperson  
and dedicated AARDA Volunteer

## AARDA FY 2009: View from the Top

### Chairman of the Board Stanley M. Finger, Ph.D. President and Executive Director Virginia T. Ladd

While AARDA is a forward-thinking organization, the end of a fiscal year is a great opportunity for a backward look. What do we see in the past fiscal year, from October 1, 2008, through September 30, 2009?

Given the current economy, we are pleased to see a financially stable organization. Thanks to loyal supporters and a strong corps of volunteers on all levels, plus generous in-kind contributions, our income on average has remained substantially the same as in recent years. Yes, an increase in contributions would allow us to raise our support for research and other areas of need, but we are grateful for all we've been able to accomplish during FY 2009. **Please read the "Major Accomplishments" section in this report.**

Meriting special attention are accomplishments in two areas of AARDA's mission: **collaborating** and **reaching out**. By collaborating with other national autoimmune disease organizations in the National Coalition of Autoimmune Patient Groups (NCAPG), we successfully lobbied Congress to increase support for autoimmune disease research within the National Institutes of Health (NIH), joined in national autoimmune disease awareness programs, and worked toward having March declared National Autoimmune Disease Awareness Month.

**Collaborating** has also been very evident in our support of scientific programs, both in the US and abroad, where AARDA's involvement has encouraged cross-fertilization of information among researchers and clinical professionals. One outstanding example is the annual Johns Hopkins Autoimmunity Day that promotes interaction among researchers not only on-site



AARDA President and Executive Director Virginia T. Ladd and AARDA Chairman of the Board Stanley M. Finger, Ph.D.

in Baltimore, Maryland, but also across the US and in other countries via Web cast. We also initiated the groundbreaking "Noel R. Rose Scientific Colloquium on Immunodeficiencies and Autoimmune Diseases," recognizing the overlapping etiology of these disease categories. Additional collaboration occurred through public education program grants to specific autoimmune disease groups.

**Reaching out** involved not only sponsoring our own AARDA public forums—"What Every American Needs to Know About Autoimmune Disease"—but also using the Internet to allow communication among our members and developing a new e-marketing strategy. AARDA also expanded its support to the Johns Hopkins Bloomberg School of Public Health's Diversity Summer Internship Program. Through that support, we were able to fund the research into autoimmunity and autoimmune disease by seven young investigators. Since early research opportunities strongly influence students' careers, this support will help alleviate the major shortage of medical researchers and physicians specializing in autoimmunity. If funds are available, we plan to expand this support to reach even more students in FY 2010.

AARDA's reaching out continues through various media outlets to alert the autoimmune-unaware segment of the population. We have been fortunate that our national spokesperson, Kellie Martin, has joined us in our awareness activities.

Through this annual report, we give **you**, our AARDA members and supporters, your own "View from the Top." And while you are enjoying the View, please accept our THANK YOU—on behalf of the millions of autoimmune patients everywhere—for your interest and dedicated support.



Johns Hopkins University Diversity Summer Internship Program students: (back row, left to right) Oscar Nnoli, Andres DeLeon Medero, Farhan Quader, and James Morton; (front row, left to right) Cheyenne Harper, Sheila Boateng, and Sophia Uddin

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**AMERICAN AUTOIMMUNE  
RELATED DISEASES ASSOCIATION, INC.**  
*Virginia T. Ladd, Executive Director*

#### *National Office*

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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 Charities of America. As a Better Business Bureau Accredited Charity, AARDA meets the 20 Better Business Bureau Standards for Charity Accountability. AARDA also carries the seal "Best in America," certified by the Independent Charities of America, and has a Four Star Charity rating from Charity Navigator.



# 2009

## ANNUAL REPORT



AMERICAN AUTOIMMUNE  
RELATED DISEASES ASSOCIATION, INC.

*Dedicated to the  
eradication of  
autoimmune  
diseases and  
the alleviation  
of suffering  
through  
education,  
public  
awareness,  
research, and  
patient services*

# Major Accomplishments for Fiscal Year 2009

## Research

Provided research support for the following:

- Johns Hopkins University Center for Autoimmune Disease Research, Baltimore, MD, ongoing autoimmune liver disease research and crosscutting autoimmune disease research
- Johns Hopkins University, Baltimore, MD, vasculitis research (C. Lynne Burek, M.D.)
- Johns Hopkins University, Baltimore, MD, Summer Diversity Internship Program, seven interns
- Johns Hopkins University, Baltimore, MD, autoimmune disease research (Noel R. Rose, M.D. Ph.D.)
- Massachusetts General Hospital and Harvard Medical School, Boston, MA, (Denise Faustman, M.D.)
- Feinstein Institute for Medical Research, Manhasset, NY, crosscutting autoimmune disease research (Betty Diamond, M.D.)
- University of Pennsylvania, Philadelphia, PA, autoimmune disease research (Robert A. Eisenberg, M.D.)
- University of California, Davis, CA, autoimmune disease research (M. Eric Gershwin, M.D.)
- Yale University, New Haven, CT, autoimmune disease research (Joseph Craft, M.D.)

## Education (Patient, Public, and Scientific)

- Sponsored and provided a Web cast of the 11th Annual Autoimmunity Day, Johns Hopkins University Center for Autoimmune Disease Research, Baltimore, MD, to reach researchers across the Internet
- Sponsored AARDA Autoimmune Public Forums, "What Every American Needs to Know About Autoimmune Disease," Milwaukee, WI (with Endometriosis Association); Scottsdale, AZ; San Diego, CA; and Scranton, PA (with Lupus Foundation of Pennsylvania, Pocono/NE Branch)
- Provided speaker, Sjögren's Syndrome Foundation's 2009 National Patient Conference, Bethesda, MD
- Also sponsored, co-sponsored, or supported the following:
  - National Institute of Standards and Technology :Accelerating Innovation in 21st Century Biosciences: Identifying the Measurement, Standards and Technological Challenges," Gaithersburg, MD
  - Women's Health 2009: The 17th Annual Congress, Annual Meeting of American Medical Women's Association, Williamsburg, VA

- 9th Annual Meeting, Federation of Clinical Immunology Societies, "FOCiS 2009," Boston, MA
  - 9th International Symposium, Vasculitis Foundation, Long Beach, CA
  - 29th Annual Meeting, American Society for Reproductive Immunology, Orlando, FL
  - 4th Asian Congress on Autoimmunity, Singapore
  - 2009 Graves' Disease Foundation Patient Education Conference, Charlotte, NC
  - 4th International Conference on NeuroEndocrine Immunology in Rheumatic Diseases, Genova, Italy
  - Seattle Autoimmunity Day: "A Community Dialogue," Pat's Fund, Seattle, WA
- Assisted more than 400,000 inquirers approaching AARDA via telephone, e-mail, postal service, Web site, and personal contacts at meetings and conferences, by supplying information and referrals

## Awareness

- Developed and arranged for nationwide TV distribution, including the Hallmark Channel and Lifetime Television, a PSA featuring Kellie Martin, "Do You Know Your Family AQ?"
- Continued Internet distribution of "Know Your Family AQ" and "Men Get Autoimmune Diseases, Too" PSAs, resulting in widespread placement reaching more than 34 million individuals
- Continued to sponsor the National Autoimmune Awareness Campaign "What Every American Needs To Know About Autoimmune Diseases"
- Provided materials for booth displays at the National Organization for Rare Disorders, Inc. (NORD) meeting
- Provided an awareness booth and representative at the 2009 American College of Rheumatology Annual Conference, Philadelphia, PA
- Provided an awareness booth and representative at FOCiS 2009 meeting



EL541 Covered Bridge Bike Tour participants travel along their Oregon route raising funds for AARDA

- (Federation of Clinical Immunology Societies), San Francisco, CA
- Presented 30-second video "Solving the Puzzle" at the 2009 Los Angeles County Fair (reached approximately 1.3 million patrons during course of the fair)
- Made available autoimmune information on the Web (social networking programs as well as its LinkedIn group)

## Advocacy

- Worked to significantly increase autoimmune research funding at the National Institutes of Health (NIH)
- Worked collaboratively with other patient groups through the National Coalition of Autoimmune Patient Groups (NCAPG) and the International Alliance of Patients' Organizations on issues of importance to patients
- Planned and facilitated an Autoimmune Awareness Advocacy program in conjunction with the National Coalition of Autoimmune Patient Groups (NCAPG)
- Provided testimony, NIH Office of Research on Women's Health, Regional Public Hearing and Scientific Workshop, St. Louis, MO; Chicago, IL; Providence, RI
- Helped introduce and continued to advocate for H.R. 2084, the "Prevention, Awareness, and Research of Autoimmune Diseases Act of 2009 (PARAiD)
- Conducted a survey of autoimmune disease patients to determine items of importance to them regarding Health Care Reform
- Conducted an advocacy campaign for member participation in advocacy efforts, including having a designated Autoimmune Disease Awareness Month

## Administration

- Contained administrative and fund-raising costs combined at only 6 percent of total expenses (up to 25 percent is considered acceptable for nonprofit organizations)
- Received \$1,972,014 in contributions and in-kind services, representing 99 percent of total support and revenue (65 percent, in-kind services)
- Conducted annual Victorian Tea fund raiser to realize a profit of \$63,124
- Continued to expand autoimmune education and awareness through publication of *InFocus*, AARDA's quarterly newsletter
- Maintained membership in the National Health Council and continued to meet all NHC standards
- Maintained status as a Better Business Bureau Accredited Charity, continued "Best in America" certification by Independent Charities of America, and received a Four Star Charity rating from Charity Navigator

## A commentary from AARDA Scientific Advisory Board Chair

Betty Diamond, M.D.



This year has been a busy and productive one for AARDA. The annual scientific program focused on the relationship between immunodeficiency and autoimmunity, highlighting the fact that these are related conditions, not opposites. Of importance to a therapeutic agenda, the connections suggest that improving autoimmunity will improve immunocompetence and vice versa. The meeting ended with some critical agenda items, most importantly maintaining a registry of immunodeficient patients and their autoimmune manifestations.

New therapeutics continue to fill the pipeline. It is necessary to recognize that clinical trials of these agents must include a diverse population of patients to determine whether there is a subset of patients who might benefit from a particular drug. In an age of personalized medicine, it is important that clinical trials be designed to identify both those who will benefit from a particular intervention and those who might be put at risk by that same intervention.

Studies of disease pathogenesis continue to yield remarkable discoveries. Hopefully the Obama administration and Congress will continue to recognize the importance of biomedical research to our nation's health and to our nation's economy.

On AARDA's calendar for the next fiscal year is an Autoimmune Summit, in Washington, DC, to map a direction for improving the lives of individuals with autoimmune diseases. Attention will be given to developing a needs assessment focused on such problems as obtaining a more accurate assessment of the health burden of autoimmune disease, encouraging and funding more scientific investigations and more clinical trials, and exploring the needs for a more diverse work force and better patient education.

The efforts by AARDA to extend the scientific focus of investigators and to inform policy makers of the extraordinary burden of autoimmune diseases are both critical and unique to this organization, and AARDA leadership should be applauded for their vision.

Finally, it appears that health care reform may become reality in the coming year. We can all hope that, with its arrival, all Americans will have access to state-of-the-art medical care.

### AMERICAN AUTOIMMUNE RELATED DISEASES ASSOCIATION, INC. STATEMENT OF ACTIVITIES For The Year Ended September 30, 2009

#### Support and Revenue:

Contributions	\$ 690,932	
Contributions in-kind	1,281,082	
Net investment return	11,419	
Total Support And Revenue		\$1,983,433

#### Expenses:

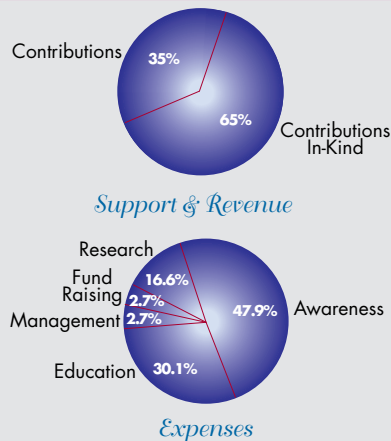
Program services:		
Education	576,365	
Public awareness	917,609	
Research	317,503	
Total program services		1,811,477
Supporting services:		
Management and general	52,348	
Fund raising	50,851	
Total supporting services		103,199
Total Expenses		\$1,914,676
Excess Of Support And Revenue Over Expenses		68,757
Fund Balance, Beginning Of Year		772,615
Fund Balance, End Of Year		\$ 841,372

#### In-Kind:

Services \$1

#### Expenses:

Wages  
Professional fees  
Postage and shipping  
Public relations  
Printing and stationery  
Office supplies  
Operating supplies  
Dues and subscriptions  
Filing fees  
Equipment rental and  
maintenance  
Telephone  
Insurance  
State and national  
meetings  
Travel  
Depreciation  
Payroll taxes  
Insurance – health  
Fund raising  
Grants  
Repairs and maintenance  
Utilities  
Retirement plan  
contributions  
Miscellaneous



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**AMERICAN AUTOIMMUNE  
RELATED DISEASES ASSOCIATION, INC.**

**STATEMENT OF FUNCTIONAL EXPENSES  
For The Year Ended September 30, 2009**

<u>Total</u>	<u>Program Services</u>			<u>Supporting Services</u>	
	<u>Education</u>	<u>Awareness</u>	<u>Research</u>	<u>Management and General</u>	<u>Fund Raising</u>
281,082	\$ 317,002	\$ 733,845	\$ 175,139	\$ 27,994	\$ 27,102
288,185	164,196	105,075	-	9,328	9,586
7,600	-	-	-	7,600	-
12,446	7,232	4,403	-	171	640
41,045	6,822	28,866	-	-	5,357
16,320	7,991	6,950	-	122	1,257
1,936	910	910	-	77	39
1,409	793	484	-	16	116
7,176	3,108	3,293	600	175	-
1,914	396	396	-	426	696
2,419	1,634	657	-	64	64
5,196	2,442	2,442	-	208	104
2,888	722	722	-	722	722
32,243	18,259	3,993	8,914	725	352
21,409	9,955	2,905	8,075	219	255
8,421	3,214	2,497	1,931	310	469
22,841	9,377	6,439	5,344	854	827
14,547	7,160	6,164	-	727	496
2,163	-	-	-	-	2,163
1,567	-	-	-	1,567	-
124,000	6,500	-	117,500	-	-
1,457	801	510	-	73	73
4,081	1,918	1,918	-	163	82
12,331	5,933	5,140	-	807	451
-	-	-	-	-	-
<u>633,594</u>	<u>259,363</u>	<u>183,764</u>	<u>142,364</u>	<u>24,354</u>	<u>23,749</u>
<u>914,676</u>	<u>\$ 576,365</u>	<u>\$ 917,609</u>	<u>\$ 317,503</u>	<u>\$ 52,348</u>	<u>\$ 50,851</u>

GODFREY HAMMEL, DANNEELS & COMPANY, P.C.  
Certified Public Accountants & Business Consultants

INDEPENDENT AUDITOR'S REPORT

To The Board Of Trustees

American Autoimmune Related Diseases Association, Inc.

We have audited the accompanying statement of financial position of American Autoimmune Related Diseases Association, Inc. (a Michigan not-for-profit corporation) as of September 30, 2009, and the related statements of activities, functional expenses, and cash flows for the year then ended. These financial statements are the responsibility of the Association's management. 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 includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our 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, Inc. as of September 30, 2009, and the changes in its net assets and its cash flows for the year then ended in conformity with accounting principles generally accepted in the United States of America.

*Godfrey Hammel, Danneels & Company, P.C.*

Godfrey Hammel, Danneels & Company, P.C.  
St. Clair Shores, Michigan  
March 2, 2010

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**Other Contributors and Friends**

Space does not allow us to include the names of all the 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 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.



Organizers Janet DeAustria (left) and Kristina Bachelor (right) await the start of the Oregon EL541 Covered Bridge Bike Tour for AARDA.

**AMERICAN AUTOIMMUNE  
RELATED DISEASES ASSOCIATION, INC.  
STATEMENT OF FUNCTIONAL EXPENSES  
For The Year Ended September 30, 2009**

	<u>Program Services</u>			<u>Supporting Services</u>		
	<u>Total</u>	<u>Education</u>	<u>Awareness</u>	<u>Research</u>	<u>Management and General</u>	<u>Fund Raising</u>
<b>In-Kind:</b>						
Services	\$1,281,082	\$ 317,002	\$ 733,845	\$ 175,139	\$ 27,994	\$ 27,102
<b>Expenses:</b>						
Wages	288,185	164,196	105,075	-	9,328	9,586
Professional fees	7,600	-	-	-	7,600	-
Postage and shipping	12,446	7,232	4,403	-	171	640
Public relations	41,045	6,822	28,866	-	-	5,357
Printing and stationery	16,320	7,991	6,950	-	122	1,257
Office supplies	1,936	910	910	-	77	39
Operating supplies	1,409	793	484	-	16	116
Dues and subscriptions	7,176	3,108	3,293	600	175	-
Filing fees	1,914	396	396	-	426	696
Equipment rental and maintenance	2,419	1,634	657	-	64	64
Telephone	5,196	2,442	2,442	-	208	104
Insurance	2,888	722	722	-	722	722
State and national meetings	32,243	18,259	3,993	8,914	725	352
Travel	21,409	9,955	2,905	8,075	219	255
Depreciation	8,421	3,214	2,497	1,931	310	469
Payroll taxes	22,841	9,377	6,439	5,344	854	827
Insurance – health	14,547	7,160	6,164	-	727	496
Fund raising	2,163	-	-	-	-	2,163
Board expenses	1,567	-	-	-	1,567	-
Grants	124,000	6,500	-	117,500	-	-
Repairs and maintenance	1,457	801	510	-	73	73
Utilities	4,081	1,918	1,918	-	163	82
Retirement plan contributions	12,331	5,933	5,140	-	807	451
Miscellaneous	-	-	-	-	-	-
	<u>633,594</u>	<u>259,363</u>	<u>183,764</u>	<u>142,364</u>	<u>24,354</u>	<u>23,749</u>
	<u>\$1,914,676</u>	<u>\$ 576,365</u>	<u>\$ 917,609</u>	<u>\$ 317,503</u>	<u>\$ 52,348</u>	<u>\$ 50,851</u>