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.
The year in autoimmunity has been one of opportunity and challenge. More and more, we appreciate that autoimmunity is not an isolated alteration in the function of immune cells. Rather, autoimmunity is a consequence of the genetics, the environment, and the physiology of an individual. Each of these component parts can drive or protect against autoimmunity and autoimmune disease. AARDA has long been interested in understanding environmental exposures that might trigger disease.

An environmental exposure only recently considered is the microbiome, or the universe of bacteria that live on and within us, on our skin, in our mouth, intestines, and other body cavities. It is now abundantly clear that the microbiome can alter risk of developing an autoimmune disease. This awareness opens a new arena for therapeutic intervention.

For these reasons, AARDA is organizing a meeting on autoimmunity and the microbiome to be held in 2014 to explore the opportunities that are emerging to understand the contribution of the microbiome to disease and the possibility of intervening in disease pathogenesis by manipulating the microbiome. This is an area of research that will explode with information over the coming years.

Clinical trials in autoimmune diseases continue to provide encouragement that insights into mechanisms of disease will, in fact, translate into new approaches to disease prevention and management. Therapeutic strategies range from conventional drugs, like the new family of Jak inhibitors, to cellular therapies. In particular, there is growing interest in mesenchymal stem cells and their potential for dampening immune responses. Groups are now being formed to standardize the isolation and identification of mesenchymal stem cells for clinical trials.

But challenges are increasing as well as opportunities. For decades, the U.S. government demonstrated a strong commitment to scientific investigation. The biomedical research enterprise in the U.S. flourished. However, over the past seven years, there has been an erosion of this national commitment to research. Funding has diminished, and investigators and patients are discouraged. It is critically important that all individuals with a stake in the success of biomedical research—and that, of course, is everyone—make certain that all representatives in Congress hear that research is vital to our health and our economy.

AARDA is an important voice for research and has a strong record of advocacy, but each individual voice must also be heard.

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A message from Kellie Martin...

When my family lost my beautiful young sister Heather to an autoimmune disease, diagnosed too late, I went through all the usual stages of grief. But I was determined that something good had to come out of that tragedy. That “something good” turned out to be AARDA, the only national organization dedicated to addressing the problem of autoimmunity, the major cause of chronic illness. It was too late to help Heather—but not too late to help others. Thus began my volunteer work with AARDA as National Spokesperson.

Through AARDA, I have advocated for autoimmune research monies for the National Institutes of Health; spread autoimmune awareness to thousands via TV, radio and print media interviews and PSAs; and shared Heather’s experience at public forums and scientific symposia. I have also raised funds for autoimmune research on my own and have been pleased to inspire others to do the same. Being a National Spokesperson is a multifaceted assignment!

Have you, too, been affected in some way by autoimmune disease? I invite you to step forward, in your own way, to join the fight. Can you raise funds? Can you contact your congressional representatives? Can you raise awareness? Can you let your friends and others know that autoimmune disease may appear in genetically prone families as any one (or more) of the 100+ autoimmune diseases? Will you save at least one life by talking about autoimmune diseases? Will you make sure that your physician hears the word “autoimmune” in some way?

You can help with awareness by liking AARDA on Facebook (www.facebook.com/autoimmunity). You can keep up with AARDA by signing up for ENews on the front page of AARDA’s Web site (www.aarda.org).

Thank you for being a friend of AARDA and the “50 million” with autoimmune diseases. You know at least one person with an autoimmune disease—maybe yourself. What role are you playing? We support you and THANK you, whatever role you choose.

Kellie Martin
National Spokesperson
and Dedicated AARDA Volunteer
Looking back...yes, that’s what an Annual Report sets out to do; but it also looks to the future. Let’s see what the View shows.

First, we call your attention to the list of “Major Accomplishments over the Past Year” published in this report. Please take a few moments to read those accomplishments—not with just a quick scan but with pauses to realize what each of those accomplishments means to the millions of autoimmune patients whom we represent and, perhaps, to you personally.

We also call your attention to the message from Dr. Betty Diamond, Chair of AARDA’s Scientific Advisory Board. This Board is comprised of an international group of outstanding physicians and researchers who stand ready to lend advice to the organization as needed while they actively work in their own fields on behalf of autoimmune patients.

FY 2013 has been a year of zeroing in, even more than usual, it seems, on specific concerns of the patients themselves.

One patient-centered concern, carried over from FY 2012 and mentioned in our FY 2012 Annual Report, has been the question of why only up to 30 percent of prescriptions are filled by autoimmune patients. We continue to reach out to patients and health care professionals with facts learned in our 2012 survey. The most important revelation of the risk-benefit survey was that, in a large percentage of cases, adherence went up significantly when the physician took more time than usual, it seems, on specific concerns of the patients themselves.

As mentioned in our previous Annual Report, we continue the search for a collaborator, developer, or institution that could support the establishment of a much needed Autoimmune Diagnostic and Treatment Center. Autoimmune patients are desperate for coordinated care afforded by having the necessary specialists sharing the same facility and communicating with each other. Currently only Israel has such a facility. Why not the United States?

And what about awareness of autoimmune diseases by the public in general? Our once-every-five-years survey found that we are reaching out, but we still have a long way to go. The number of people confusing autoimmune disease with AIDS dropped from 31.9 percent in 2008 to 20 percent in 2013—better, but not good enough. Only 19.3 percent of Americans could name at least one autoimmune disease (up from 12.8 percent in 2008); yet they do have autoimmune diseases in their families! Women are more likely than men to say they either have an autoimmune disease themselves or have a family member who has one (21.4 percent, women; 13 percent, men).

As we continue to carry out our Strategic Plan, we are encouraged by our progress while we are prepared to further the possibilities ahead.

As AARDA leaders, we know that we are very, very fortunate to have the support of many volunteers, in-kind contributors, donors, and patients themselves in carrying out AARDA’s mission.

Archbishop Desmond Tutu, of South Africa, said, “Do your little bit of good where you are; it’s those little bits of good put together that overwhelm the world.” Some of our gains are “little bits” and some, not so little; but with the help of our friends, we do indeed plan to “overwhelm the world.” Can we do less for the 50 Million counting on us?
Major Accomplishments During Fiscal Year 2013

Research
• Continued support of O’Leary-Wilson Autoimmune Disease Fellowship, Center for Autoimmune Disease Research, Johns Hopkins University, Baltimore, MD
• Provided grants for autoimmune research: University of California Los Angeles, CA, “Role of Sex Hormones in Regulation of Interferons Genes in Autoimmunity,” Los Angeles, CA; Johns Hopkins University, Baltimore, MD, ongoing autoimmune liver disease research and crosscutting autoimmune disease research
• Provided research support for six interns in the Summer Diversity Internship Program, Johns Hopkins University, Baltimore, MD
• Increased autoimmune disease research funding to more than $2.3 million

Education — Patient, Public, Scientific
• Sponsored, cosponsored, or supported the following:
  —AARDA Public forums in St. Louis, MO; Ann Arbor, MI; Charlotte, NC; Minneapolis, MN
  —15th Annual Autoimmunity Day, Johns Hopkins University, Baltimore, MD
  —“Biologic Therapies V Summit: Lessons Learned from the First Decade Focusing on New Targets and Agents,” Cleveland Clinic R.J. Fasenmyer Center for Clinical Immunology and Cleveland Society of Rheumatology, Cleveland, OH
  —16th International Congress on Mucosal Immunology, Society for Mucosal Immunology, Vancouver, B.C., Canada
  —Conference for the Autoimmune Community, “How to Dance in the Rain,” Scleroderma Foundation and others, Madison Heights (Greater Detroit), MI
  —International Society for Immunology of Reproduction Meeting, American Society for Reproductive Immunology, Boston, MA
  —AARDA Autoimmune Disease Forum for Physicians, University of Michigan, Ann Arbor, MI
  —Vasculitis International Symposium, Vasculitis Foundation, Philadelphia, PA
  —13th Annual Meeting, Federation of Clinical Immunology Societies (FOCIS), Boston, MA
  —5th International Conference on Neuroendocrine Immune Basis of the Rheumatic Diseases, Genova, Italy
  —MidMichigan Autoimmune Disorders Symposium, MidMichigan Health, University of Michigan Health System, Midland, MI
  • Became a source of autoimmune disease information on WebMD
  • Offered “My Autoimmune Story,” a video series on AARDA’s YouTube channel
  • Created and maintained social networking sites (Facebook page, twitter account)
  • Expanded disease-specific information on Web site
  • Published quarterly lay-friendly newsletter, InFocus
  • Maintained 24-hour toll-free request line
  • Provided referrals and non-medical information during office hours via the Patient Educator
  • Made available informational brochure and PowerPoint presentation of AARDA’s “Risk/Benefit” study
  • Provided free educational brochures and newsletters to numerous locally sponsored health centered meetings and events

Awareness
• Featured in independent supplement from Media Planet to the Washington Post
• Continued “3-Second Adherence” Public Service Campaign explaining AARDA’s “Risk/Benefit” study and available materials

Advocacy
• Held Congressional Staff Briefing, “Women and Autoimmune Disease—the Truth About Care, Access, and Treatment,” in collaboration with National Coalition of Autoimmune Patient Groups, Washington, DC

Autoimmune Walk participants Chanda, Jennifer, and Michelle Simkin celebrate their fundraising Simkin Sisters Stride honoring their uncle and mother.
• Was included in a BBB Wise Giving Alliance Seal Holders full-page ad in USA Today, “Dear Mr. President and Members of Congress”: letter—Don’t Push Charities Over the Fiscal Cliff
• Had article published in The Sentinel Newspapers, “Marylanders deserve low-cost biotech, high safety standards,” by AARDA Executive Director Virginia Ladd
• Editorial published in the Baltimore Sun, “The Biosimilar Debate: Losing Sight of What’s Really at Stake,” by former AARDA Board Member and current Advocacy Committee member Abby Bernstein
• Accepted invitation to join the Coalition for Accessible Treatments (encouraging patients and physicians to ask lawmakers to support and cosponsor the Patient’s Access to Specialists Act of 2013 (HR 460)

• Accepted invitation to join the Alliance for Safe Biologic Medicines
• Continued to distribute the AARDA-published white paper, “The Cost Burden of Autoimmune Disease: The Latest Front in the War on Healthcare Spending”
• Continued to work for the reintroduction and passage of HR 6218, to establish an Autoimmune Diseases Interdepartmental Coordinating Committee
• Continued to work in collaboration with other organizations on the following: Reauthorization of the Prescription Drug User Fee Act, NIH research funding, Essential Health Benefits, Independent Payment Advisory Board (IPAB), Medicare and Medicaid issues, Fight Fraud First, and protection of charitable contribution deduction
• Advocated for “Access to Specialist” in Affordable Health Care Act
• Continued involvement in issues surrounding access to specialty treatments in Virginia, New York, and Vermont
• Continued researching essential benefits offered by several states, such as California, which have opted out of the Federal Program
• Had an op-ed piece (written by AARDA Executive Director Virginia Ladd) concerning essential benefits that ran in The Hill’s Congress Blog
• Signed onto coalition letter in New York on access to specialty treatments

Fundraising
• Sponsored 13th Annual Fund Raiser, Derby Luncheon & Auction at the Dearborn Inn, which earned $57,739 for AARDA, Dearborn, MI

Administration
• Maintained the following ratings:
  • Four Star Charity Rating with Charity Navigator
  • Better Business Bureau Wise Giving Alliance Charity
  • Best in America Certified by Independent Charities of America
• Remained recognized Member Organization of Health & Medical Research Charities of America
• Continued to meet all Standards of National Health Council and maintain long-time membership
• Continued standing in Combined Federal Campaign (CFC)
• Held combined management and fundraising costs at 7 percent of total expenses (25 percent acceptable for nonprofit organizations)
• Continued to facilitate the National Coalition of Autoimmune Patient Groups
• Maintained membership and active participation in the International Alliance of Patients’ Organizations

AARDA and NCAPG members at Congressional Briefing: (Left to right) Sharon L. Harris, AARDA Project Manager; Virginia T. Ladd, AARDA President/Executive Director; Tracy Evans, AARDA volunteer; Kathleen A. Amstsen, Lupus Foundation of Mid & Northern New York President/CEO; Sandra Frear, Lupus Foundation of Mid & Northern New York Program Director

“AARDA and NCAPG members at Congressional Briefing: (Left to right) Sharon L. Harris, AARDA Project Manager; Virginia T. Ladd, AARDA President/Executive Director; Tracy Evans, AARDA volunteer; Kathleen A. Amstsen, Lupus Foundation of Mid & Northern New York President/CEO; Sandra Frear, Lupus Foundation of Mid & Northern New York Program Director

“Women and Autoimmune Disease,” Spirit of Justice. Left to right: AARDA representatives Sharon Harris, Tracy Evans, Pat Barber
Major Contributors in Fiscal Year 2013

**Major In-Kind Contributors**

Marilyn White Assiff  
Dr. Thomas Assiff  
Rita Barron-Faust  
Nona Bear  
Abby Bernstein  
Carway Communications, Inc.  
Althea Cicces  
Dr. Betty Diamond  
Donna DiSante  
Denis Dorf  
Environmental Consulting and Investigations  
Dr. Stanley M. Finger  
Dr. Herbert G. Ford  
FoxKiser  
Susan and Chuck Gaidica, Jr.  
Google Ad Word Advertising  
Howard E. Hagon  
Richard M. Hodge  
Hallmark Channel  
John Kaiser, CPA  
Ruth Kibler  
Natasha Leskovsek  
Kellie Martin  
Sharon Mengel  
Julia Pandl  
Linda M. Pesonen  
Dr. Robert H. Phillips  
Charles Pottinger  
J. Michael Quinlan, LL.M  
Dr. Noel R. Rose  
Sage Communications, Inc.  
Michelle Simkin  
Lawrence Damian Tobias  
Todd Graphic Design  
Carolyn Ugal  
Barbara Willett

**Individual, Corporate, and Foundation Donors**

**Contributions $20,000 and Over**

Anonymous  
Genentech, Inc.  
GlaxoSmithKline  
Linked Fore A Cure Golf Outing  
Pfizer, Inc.  
PhRMA  
The Scoby Family Foundation

**Contributions $10,000 thru $19,999**

Anonymous  
Harry Debes Family Foundation  
Howl at the Moon Fundraiser

**Contributions $1000 thru $999**

Anonymous

**Contributions $250 thru $999**

Katie Alford  
Emily Alter  
Annelie Herrmann’s Concert With A Cause  
Brian Anderson  
Anonymous  
Marilyn & Dr. Thomas Assiff  
Elaine Belter  
Ben Clark Marathon  
Bieske & Associates  
Edna Carol Blue  
Joan & William Boddie  
Buffalo Wild Wings  
Century Lending Company  
Althea & Simon Cicces  
Gena Conti, Inc.  
Mary DeBruycker  
Anthony DePaul  
Destiny World Church  
Mary Claire Dougherty  
Nigel Drepaul  
Nathan Espe  
Andrew Fawer  
Dr. Stanley M. & Shelley Finger  
Akiva Flesher  
Dr. Herbert & Margaret Ford  
Linda & Peter Fredo  
The Gardner Family Foundation  
Suzanne & Ron Geer  
David, Flora, Ali & Shlomo Goldsmith  
Sharon & Donald Gordon  
Greatest Commandments Foundation, Inc.  
Gregory Middle School  
Student Council Cash for a Cure Fundraiser  
Alan & Doreen Griffin  
Sandra Haney  
Peter Harrington  
Nancy Harris  
The Richard Hille Charitable Fund  
Ralph & Shirley Hitchcock  
Constance, Naomi, Jessica, & Alan Kadish  
Geoffrey Karmy  
Melinda & Roy Kelley  
Steve & Lynn Kieffer  
Pamela & Kendall Kipps  
Kevin Kitzke  
Jill Kiviat  
Suzanne Klein  
Mark Kratz  
Robert & Jeri Krueger  
Karen Levine  
Howard Lifshitz  
Ma’Ayanot Yeshiva High School for Girls  
Douglas & Marta Mayer  
Rina Mayer  
Angela McFarlin  
Gail McGreavy & Harmon & Pamela McGreavy  
Melanie Merriman  
Bill Mitchell  
Kevin Mitchell  
Nancy Monaghan  
Marvin & Rosalie Waltuch  
Yolanda Walker  
Lauren Wallerstein  
Marvin & Rosalie Waltuch  
Loudoun County Public Schools Wear Jeans to Work Fundraiser  
Jennifer Wells  
Louis & Hetty Wesly  
Carol Lynn White  
Brian & Carol Williams  
Charles Wofford  
Carol Wood

**Payroll Campaigns & Matching Gifts**

ADP  
Aetna Foundation  
Agilent Technologies  
American Express  
America’s Charities  
Aptargroup Charitable Foundation  
AT & T United Way  
Boeing  
Chevron Humankind  
Give with Liberty  
Goldman, Sachs & Co.  
Google  
IBM  
Maryland Charity Campaign  
Microsoft  
Morgan Stanley  
Pfizer Foundation  
Trust  
United Way of SE Pennsylvania  
United Way of the Columbia-Willamette  
Wells Fargo

**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.

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, 2013, and the changes in its net assets and its cash flows for the year then ended, and the related notes to the financial statements.

**Management’s Responsibility for the Financial Statements**

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

**Auditor’s Responsibility**

We express the opinion that 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, 2013, and the changes in its net assets and its cash flows for the year then ended, and the related notes to the financial statements.

We have audited the accompanying financial statements of the American Autoimmune Related Diseases Association (a Michigan nonprofit corporation), which comprise the statement of financial position as of September 30, 2013, and the related statements of activities, functional expenses and cash flows for the year then ended, and the related notes to the financial statements.

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, 2013, and the changes in its net assets and its cash flows for the year then ended, and the related notes to 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, 2013, and the changes in its net assets and its cash flows for the year then ended, and the related notes to the financial statements.
### AMERICAN AUTOIMMUNE RELATED DISEASES ASSOCIATION, INC.
**STATEMENT OF FUNCTIONAL EXPENSES**
**For The Year Ended September 30, 2013**

<table>
<thead>
<tr>
<th>In-Kind Goods and Services</th>
<th>Education</th>
<th>Public Awareness</th>
<th>Research</th>
<th>Total Functional Expenses</th>
<th>Supporting Services</th>
<th>Management and General</th>
<th>Fund Raising</th>
<th>Total</th>
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<tbody>
<tr>
<td></td>
<td>$142,276</td>
<td>$67,662</td>
<td>$92,197</td>
<td>$802,335</td>
<td>$11,387</td>
<td>$26,377</td>
<td>$840,099</td>
<td></td>
</tr>
</tbody>
</table>

**Other Expenses:**

- **Wages:** 172,145
- **Temporary help:** 3,557
- **Professional fees:** 6,077
- **Postage and shipping:** 9,904
- **Public relations:** 10,019
- **Printing and stationery:** 13,916
- **Office supplies:** 1,531
- **Operating supplies:** 893
- **Due and subscriptions:** 2,445
- **Filing fees:** 330
- **Equipment maintenance:** 1,682
- **Telephone:** 2,160
- **Insurance:** 1,176
- **State and national meetings:** 16,105
- **Travel:** 8,203
- **Depreciation:** 3,724
- **Payroll taxes:** 9,575
- **Insurance - health:** 8,470
- **Repairs and maintenance:** 979
- **Utilities:** 2,078
- **Employee insurance:** 1,176
- **Equipment maintenance:** 1,682
- **Operating supplies:** 893
- **Filing fees:** 330
- **Insurance:** 1,176
- **State and national meetings:** 16,105
- **Travel:** 8,203
- **Depreciation:** 3,724
- **Payroll taxes:** 9,575

**Contributions:** $544,927

**Net Contributions:** $494,927

**In-kind goods and services:** $840,099

**Funding income:** $171,501

**Interest income:** $2,400

**Total Contributions:** $802,335

**Total Other Expenses:** $284,446

**Total Functional Expenses:** $1,414,368

**Net Assets, End of Year:** $721,759

**Net Assets Released From Restrictions:** $1,540,853

**Total Support and Revenue:** $3,000

**Total Support and Revenue Before Management and General:** $1,545,652

**Fundraising Income:** $3,026

**Total Expenses:** $1,530,179

**Net Assets Released From Restrictions:** $32,026

**Net Assets Released From Restrictions:** $1,540,853

**Net Assets, Beginning of Year:** $710,856

**Net Assets, End of Year:** $758,584
The American Autoimmune Related Diseases Association, Inc. (AARDA) 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, D.C., 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 Four Star Charity rating from Charity Navigator.