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# The Cost Burden of Autoimmune Disease: The Latest Front in the War on Healthcare Spending



American Autoimmune Related Diseases  
Association (AARDA)  
National Coalition of Autoimmune Patient  
Groups (NCAPG)

# The Cost Burden of Autoimmune Disease: The Latest Front in the War on Healthcare Spending

**“The burden of a human disease should be counted not only in terms of dollars spent on health care for people directly affected, but as the total cost to society.”**

**National Institutes of Health (NIH), “Progress in Autoimmune Disease Research” Report**

## Summary

Autoimmune disease as a category affects 50 million Americans. It is one of the top ten causes of death in women under the age of 65<sup>1</sup>, is the second highest cause of chronic illness, and is the top cause of morbidity in women in the United States. Additionally, autoimmune diseases have been reported to be on the rise in the U.S. and around the world, making this poorly understood category of disease a public health crisis at levels comparable to heart disease and cancer. Because of a severe lack of awareness amongst the general public and medical practitioners and unequal allocation of research funding and focus at the National Institutes of Health (NIH), plus a lack of coordinated care and standardized diagnostic tests, the associated cost of autoimmune diseases has become a significant portion of the rising cost of healthcare in the U.S. Addressing the pressing concerns surrounding autoimmune diseases should be a major priority of the United States Congress as a means of reducing healthcare spending while ensuring improved public health.

## Autoimmunity and Autoimmune Disease

### The Common Thread

There are 100+ known autoimmune diseases, all caused by the common thread that is autoimmunity. The process of autoimmunity is initiated when one’s immune system becomes overactive and, rather than destroy invader cells, such as infections and viruses, targets one’s own healthy cells and tissues causing various autoimmune diseases. Autoimmune diseases can affect any system in the body. Symptoms vary widely among the diseases, making the diseases difficult to diagnosis. Exactly what triggers an autoimmune response is unknown; however, researchers do know that autoimmune diseases occur where there are a genetic predisposition in the family towards autoimmunity and the presence of an environmental trigger, such as, viruses, bacteria, medications, pollutants, hormones, or stress.

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<sup>1</sup> [Walsh SJ, Rau LM. Am J Public Health 2000;90:1463-6](#), PMID: 10983209

## Prevalence of Autoimmune Disease

A significant lack of epidemiological studies of many of the 100+ autoimmune diseases greatly increases the difficulty of developing accurate numbers for prevalence and cost for all autoimmune diseases. The National Institutes of Health estimates that up to 23.5 million Americans have an autoimmune disease<sup>2</sup>; however, this number reflects epidemiology studies pertaining to only 24 of the 100+ autoimmune diseases. According to the American Autoimmune Related Diseases

Association (AARDA), it is estimated that 50 million Americans have an autoimmune disease based on NIH epidemiology studies as well as individual patient group data through members of the National Coalition of Autoimmune Patient Groups (NCAPG). The prevalence chart to the right was published in a report first released at a global summit meeting, hosted by AARDA and the National Coalition of Autoimmune Patient Groups (NCAPG), in March 2010<sup>3</sup>.

Autoimmune diseases affect women 75 percent more often than men. The cause of this sex bias is not fully known. However, research suggests that estrogen tends to increase autoimmune responses. Also, researchers have found some connection with autoimmune diseases and pregnancy, in that pregnancy has been shown to trigger some autoimmune diseases as well as cause other autoimmune diseases to go into remission.

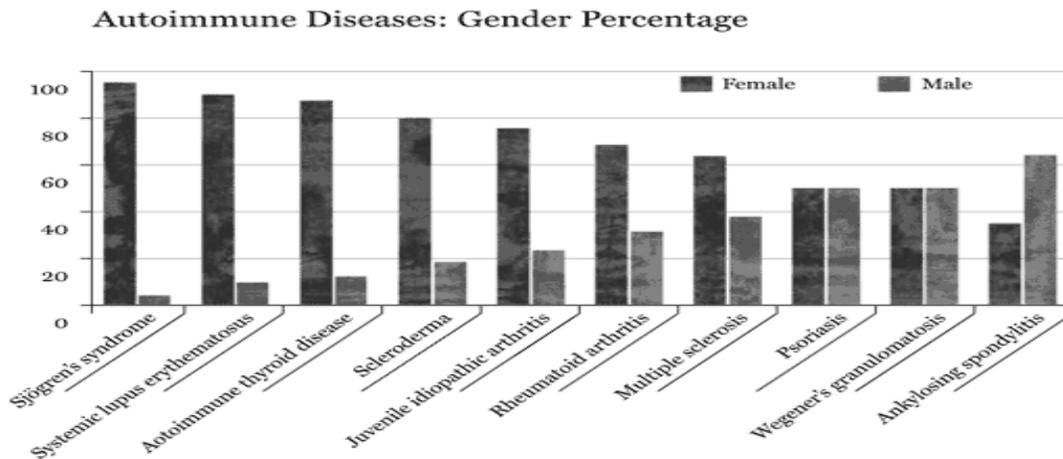
**Prevalence Data for Selected Autoimmune Diseases Listed Alphabetically**

Autoimmune Disease	Hospital and Non-Hospital-Based Data	
	<b>Studies from Europe, North America, Australia, New Zealand</b>	
	<b>Rate per 100,000</b>	<b>Study Area</b>
Addison's disease	11-14	UK, Italy, Norway
Alopecia	1700	US
Chronic active hepatitis	11-17	Spain, Sweden, Norway
Crohn's disease	96-201	US, Spain, Denmark, New
Diabetes type 1 – age < 20 yrs.	227-355	US, New Zealand
Multiple sclerosis	177-358	US, Canada
Myasthenia gravis	8-15	Greece, Estonia, Croatia, Netherlands, Sweden, UK
Polymyalgia rheumatica – age ≥ 50 yrs.	739	US
Primary biliary cirrhosis	4-20	US, Australia
Psoriasis	696-1527	US, UK
Psoriatic arthritis	140-190	US, Iceland, Norway, Den-
Rheumatoid arthritis	310-380	France, Hungary, Spain, Turkey, Greece, UK
Sjögren's syndrome – ages 30-60	110	Denmark
Systemic lupus erythematosus	34-150	US, Spain, Greece
Systemic sclerosis	5-34	US, France, Greece, Spain,
Systemic vasculitis	9-14	France, UK
Thyroid-hyper	500	US
Thyroid-hypo	300	US
Ulcerative colitis	143-294	US, Hungary, Denmark,
Uveitis	69-115	US, Finland
Wegener's granulomatosis	2-10	France, Norway, Australia,

<sup>2</sup> Biennial Report of the Director, National Institutes of Health Fiscal Years 2006 & 2007, Summary of Activities by Disease Category, Autoimmune Diseases; [http://report.nih.gov/biennialreportfy0607/research\\_activities\\_by\\_disease\\_categories/autoimmune\\_diseases.asp](http://report.nih.gov/biennialreportfy0607/research_activities_by_disease_categories/autoimmune_diseases.asp)

<sup>3</sup> Tobias, L., A Briefing Report on Autoimmune Diseases and AARDA: Past, Present, and Future, 2010

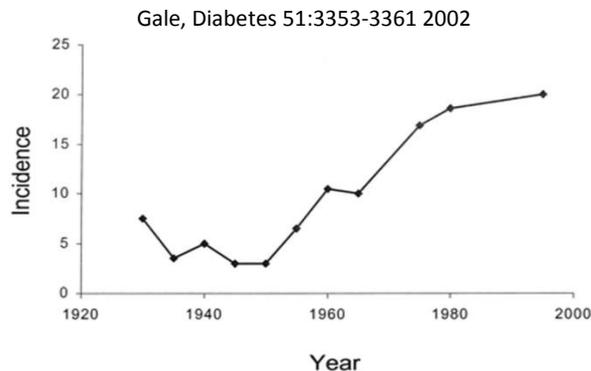
## Sex Distribution of the Major Autoimmune Diseases in the U.S.



### Rising Incidence of Autoimmune Diseases

Studies show that the incidence of multiple sclerosis in Italy has risen from fewer than one million cases in 1979 to just over four million in 1999. In Norway and Sweden, incidence of diabetes in children under ten has risen from eight million in 1930 to more than 20 million in 2000. In Finland, the incidence of type 1 diabetes has more than doubled in the past 30 years. In the United States, in Minnesota alone, incidence of celiac disease has tripled in the past decade.

### Incidence of diabetes in children under 10 in Norway



Researchers believe that this increase of autoimmune incidence around the world is due to a combination of genetic predisposition and environmental factors. However, too little is known regarding what elements in the environment today are triggering record increases in autoimmune diseases. With 50 million Americans currently living with an autoimmune disease and the prevalence rising at alarming rates, it is imperative that the effect on U.S. healthcare spending, as well as the financial burden on individual constituents faced with these diseases, become a major priority in the ongoing discussion regarding the future direction of healthcare in the U.S.

<sup>4</sup> Rose, N.R. (2010). *Autoimmune Disease: The Common Thread* [PowerPoint slides]. File retrieved from the American Autoimmune Related Diseases Association (AARDA)

## Cost of Chronic Illness

Autoimmune diseases are the second leading cause of chronic illness in the United States; and as a category, they are the leading cause of morbidity in women<sup>5</sup>. According to a 2008 international survey<sup>6</sup>, chronically ill patients in the U.S. as compared with those in other countries are more likely to do without proper care due to the burden of cost. Additionally, these patients are more likely to experience the highest rates of medical errors, problems with coordination of care, and high out-of-pocket health care costs. Currently, AARDA estimates that 50 million Americans have an autoimmune disease. Epidemiological data are lacking to determine the full direct and indirect cost to the overall health care system due to autoimmune disease. However, in 2001, National Institutes of Allergy and Infectious Diseases (NIAID) Director Dr. Anthony Fauci estimated that annual autoimmune disease treatment costs were greater than \$100 billion. While \$100 billion is a staggering figure, it is likely a vast understatement of the true costs of autoimmune disease as the annual costs of only seven of the 100+ known autoimmune diseases, Crohn’s disease, ulcerative colitis, systemic lupus erythematosus (SLE), multiple sclerosis (MS), rheumatoid arthritis (RA), psoriasis, and scleroderma, are estimated through epidemiological studies to total from \$51.8-\$70.6 billion annually.

**The Estimated Cost of Selected Autoimmune Diseases**

Autoimmune Disease	Base Yr	Country	Indirect Costs	Direct Costs	Total Est'd Costs
Crohn’s disease	2008	US			\$10.9-\$15.5 billion
Ulcerative colitis	2008	US	Est’d at 40 percent of direct costs	\$3.4–8.6 billion	\$8.1–\$14.9 billion
SLE	2008	US	\$8,659/pt/yr	\$12,643/pt/yr.	\$2.2-\$9.6 billion
MS	1994	US			\$6.8 billion
RA	2005	US	\$8.4 billion	\$10.9 billion	\$19.3 billion
Psoriasis	2010	US	\$4.5 billion	\$6.7 billion	\$11.2 billion
Scleroderma	1997	US			\$1.5 billion

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## The Cost to Patients and Your Constituents

### Out-of-Pocket Cost

The importance of an early diagnosis and onset of treatment is key in minimizing life altering complications that can occur as a result of autoimmune disease, such as damaged internal organs, loss of physical mobility and possible disfigurement, as well as an increased likelihood of death. Therefore, obtaining the recommended care for autoimmune disease patients is paramount. However, according to an international 2008 survey which looked at cost trends amongst chronically ill patients in seven

<sup>5</sup> Faustman, D. Institute of Medicine Report, “Women’s Health Research: Progress, Pitfalls, and Promise, 2010

<sup>6</sup> C. Schoen, R. Osborn, S. K. H. How, M. M. Doty, and J. Peugh, In Chronic Condition: Experiences of Patients with Complex Health Care Needs, in Eight Countries, 2008, *Health Affairs* Web Exclusive, Nov. 13, 2008, w1-w16; <http://www.commonwealthfund.org/Content/Publications/In-the-Literature/2008/Nov/In-Chronic-Condition--Experiences-of-Patients-with-Complex-Health-Care-Needs-in-Eight-Countries--20.aspx>

<sup>7</sup> Tobias, L., A Briefing Report on Autoimmune Diseases and AARDA: Past, Present, and Future, 2010

countries, 54 percent of U.S. chronically ill patients did not get recommended care, fill prescriptions, or see a physician when sick because of the high cost of care. Nearly one-third of patients in the U.S., a higher rate than in any of the other seven countries surveyed, reported medical errors or poorly coordinated care. As a whole, according to the survey, 41 percent of U.S. patients spent more than \$1,000 in the previous year on out-of-pocket medical costs.

According to the National Psoriasis Foundation, people with psoriasis have significantly higher health care resource utilization and costs than the general population, and those with moderate to severe disease have higher costs than people with mild disease<sup>8</sup>.

**For all psoriasis patients as compared to control sample without psoriasis:**

- Total healthcare costs - (\$5,529 vs. \$3,509)
- Greater medical costs (\$3,925 vs. \$2,687)
- Drug costs (\$1,604 vs. \$822).

**For moderate-severe psoriasis patients as compared to patients with mild psoriasis (even after excluding costs associated with direct treatment related to severity):**

- Total healthcare costs - (\$10,593 vs. \$5,011)
- Medical costs (\$5,854 vs. \$3,728)
- Drug costs (\$4,738 vs. \$1,283).

Current annual costs for systemic therapies typically used to treat moderate to severe psoriasis range from \$1,200 to \$27,600<sup>9</sup>. Additionally, recent analysis suggests that psoriasis patients with comorbid health conditions are more likely to experience urgent care, have greater rates of hospitalization, have more frequent outpatient visits, and incur greater costs than psoriasis patients without comorbidities<sup>10</sup>.

According to a survey by the National Adrenal Diseases Foundation (NADF), ongoing annual cost to a patient suffering from Addison's disease amounts to \$2,320 per patient per year. Additionally, to get an initial diagnosis, the cost would be \$1,680 per patient. Addison's disease occurs when the adrenal glands are damaged due to autoimmunity and cannot produce enough of the hormones cortisol and aldosterone. Addison's is a chronic disease; daily hormone replacement medication can never be stopped. Initial costs for diagnosis are amplified by the fact that progress of the illness is slow and diagnosis is difficult, requiring patients to see multiple physicians and specialists prior to diagnosis. For Addison's disease alone, five to six million patients live with this disease and have expended over \$8.4

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<sup>8</sup> Yu AP, Tang J, Wu EQ, Gupta SR, Bao Y, Mulani PM, Economic burden of psoriasis compared to the general population and stratified by disease severity. *Current Medical Research and Opinion*. 2009 Oct; 25(10): 2429-38

<sup>9</sup> Vivianne Beyer, MD; Stephen E. Wolverton, MD. Recent Trends in Systemic Psoriasis Treatment Costs. *Arch Dermatol*. 2010;146(1):46-54.

<sup>10</sup> Kimball A, Guérin A, Tsaneva M, Yu A, Wu E, Gupta S, Bao Y, Mulani P. Economic burden of comorbidities in patients with psoriasis is substantial. *J Eur Acad Dermatol Venereol*. 2011 Feb;25(2):157-163.

billion to obtain a diagnosis. Together these Americans spend annually \$11.6 billion to treat their chronic illness.

Both Addison's disease and psoriasis illustrate the plight of millions of patients with any of the 100+ autoimmune diseases who struggle to obtain a diagnosis and to maintain quality of life for themselves and their families. However, these costs reach beyond the patient and affect the whole country as many of these patients are uninsured, underinsured, or on disability, Medicaid, or Medicare.

### *Earnings Loss*

Due to the chronic nature of most autoimmune diseases, patients often miss extended periods of employment. Because of this, patients are faced with thousands of dollars in medical expenses that they can no longer afford due to lost wages. Due to the lack of studies investigating the varying costs of autoimmune diseases as a category, there is no current ability to calculate the total cost of all 100+ diseases. However, there are studies reflecting the cost to the patient and society that have been done by individual patient advocacy and research organizations who focus on individual autoimmune diseases. By highlighting the data from these individual organizations, the magnitude of the financial burden becomes clear as we consider the high cost of treatment and care amongst so few autoimmune diseases compared to the whole.

In the case of rheumatoid arthritis (RA), a survey published in the *Journal of Rheumatology* found that not only are estimated average earnings decreased in RA patients from \$18,409 to \$13,900 per year, but additionally the number of jobs patients could perform dropped from 11.5 million to 2.6 million. It's also been found that approximately 50 percent of RA patients become unable to work within ten years of disease onset<sup>11</sup>. Autoimmune diseases, such as RA, have a substantial impact on healthcare spending in the U.S. as they greatly affect the United States' ability to sustain a skilled work force. This impacts our ability as a nation to compete in the global marketplace.

Additionally, according to the publication "The Burden of Musculoskeletal Diseases," RA patients accounted for 1.1 million ambulatory care visits in 2004, representing 2.4 percent of the 44.2 million non-injury emergency room visits with a primary diagnosis of Arthritis and Other Rheumatic Conditions (AORC). Also, RA patients account for 18,000, or 2 percent, of the 922,100 non-federal, short stay hospitalizations for AORC in 2004. Decreasing non-injury emergency room visits is key to lowering the rising cost of healthcare in the U.S. These numbers demonstrate that the cost of autoimmune diseases as a whole, exemplified by RA, must be addressed if we are to make a lasting fiscal impact on healthcare spending in the U.S.<sup>12</sup>

Psoriasis is another autoimmune disease which adds heavily to the economic burden of autoimmune diseases in the U.S. The total annual health-related work productivity loss due to psoriasis was

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<sup>11</sup> Kochevar R.J., Kaplan R.M., Weisman M. Financial and career losses due to rheumatoid arthritis: a pilot study. *J Rheumatol.* 1997 Aug; 24(8):1527-30. Retrieved from <http://www.ncbi.nlm.gov/pubmed/9263146>.

<sup>12</sup> The Burden of Musculoskeletal Diseases in the United States: Prevalence, Societal, and Economic Cost: <http://www.boneandjointburden.org/about/usbjd.htm>

estimated in 2006 to be over \$16 billion. Annually, lost productivity (“presenteeism”) of patients with psoriasis is estimated to be approximately \$9.9 billion, or \$2,961 per worker with psoriasis.<sup>13</sup>

According to a Lupus Foundation of America (LFA) survey, it was found that the mean annual productivity cost (lost hours of productive work) for participants of employment age (between the ages of 18 and 65) was \$8,659 per patient per year<sup>14</sup>. With lupus alone affecting 1.5 million Americans<sup>15</sup>, this study estimates that lost hours of work cost these Americans nearly \$13 billion annually.

The Vasculitis Foundation of America reports that patients experience a 26 percent reduction in income within the first year of diagnosis, or \$9.7 billion per year in total annual income loss for vasculitis patients. Vasculitis affects 1 in 20 Americans.

The following chart shows the annual indirect and direct cost of Sjögren’s syndrome and rheumatoid arthritis (RA) against a control group. This data was published by the Sjögren’s Syndrome Foundation and was produced by two independent UK studies<sup>16</sup>. The studies found that indirect costs totaled \$21,369 per patient per year. These included time lost from current work, inability to work at all, or to work full-time, as well as costs associated with the necessity to hire outside help within the home to assist with tasks no longer possible due to disease progression, such as housework and yard work. With four million patients suffering from Sjögren’s syndrome in the U.S. today, this adds billions more to the already staggering financial burden faced by patients, your constituents, in the U.S. today.

#### Annual Indirect and Direct Costs of SS, RA and Controls

	INDIRECT COSTS		DIRECT COSTS	TOTAL COSTS
	Low Range	High Range	<i>Not including cost of biologics</i>	
Control Group	£892 or US \$1,418	£3,382 or US \$5,353	£949 or US \$1,509	£1,841 - £4,331 or US \$2,927 – \$6,862
SS Patients	£7,677 or US \$12,150	£13,502 or US \$21,369	£2,188 or US \$3,479	£9,865 - £15,690 or US \$12,185 – \$24,848
RA Patients	£10,444 or US \$16,530	£17,070 US \$ 27,061	£2,693 or US \$4,282	£13,137 - £19,763 or US \$20,812 - \$31,343

**Notes:**

US \$ is based on £1.00 = \$1.59; All figures rounded up or down to the nearest whole number.

**Direct Costs** = The costs paid to health services by patient and insurance companies (includes lab work, medications, any inpatient care by doctor or hospital)

**Indirect Costs** = All non-medical costs due to autoimmune disease, including time lost from current work (lower range) and time lost from inability to work at all or to work full-time (higher range). Indirect costs also include the cost of hiring help for tasks that the patients cannot do due to their illness (such as housework and yard work).

<sup>13</sup> Schmitt JM, Ford DE. Work limitations and productivity loss are associated with health-related quality of life but not with clinical severity in patients with psoriasis. *Dermatology* 2006; 213:102-10.

<sup>14</sup> Economic Impact of Lupus. (2010). Retrieved January 25, 2011, from [http://www.lupus.org/webmodules/webarticlesnet/templates/new\\_aboutintroduction.aspx?articleid=247&zzoneid=9](http://www.lupus.org/webmodules/webarticlesnet/templates/new_aboutintroduction.aspx?articleid=247&zzoneid=9)

<sup>15</sup> Cases of lupus. (2010). Retrieved January 25, 2011, from [http://www.lupus.org/webmodules/webarticlesnet/templates/new\\_aboutintroduction.aspx?articleid=247&zzoneid=9](http://www.lupus.org/webmodules/webarticlesnet/templates/new_aboutintroduction.aspx?articleid=247&zzoneid=9)

<sup>16</sup> Bowman S. the Cost of Sjögren’s Syndrome. *Sjögren’s Quarterly*. Spring 2007, Vol.2, Issue 2.

## Impact on Disability and Medicare

Innate problems exist for autoimmune patients regarding getting a diagnosis and onset of treatment which add unnecessarily to the cost of having these illnesses. According to an AARDA study, on average patients spend upwards of four years seeking an effective diagnosis. Visits to more than four physicians are typically needed; and because of poor physician training and education in this category, the AARDA study found that 46 percent of patients were told that they are constant complainers or too concerned with their health. The cost ramification of this is that the illness continues to progress throughout this process, extending the time to which patients begin to obtain proper treatment and care for their illness. Disease progression, unchecked with treatment, has major consequences, such as organ damage and physical disability that often lead to earnings losses and financial distress due to high out-of-pocket costs. Ultimately, after becoming unable to work and support themselves and their families, patients are forced to apply and obtain disability payments. In the case of lupus, a chronic autoimmune disease that can damage any part of the body (skin, joints, and/or organs inside the body), a Lupus Foundation of America (LFA) study found that:

- Approximately 35 percent of people with lupus who responded to an LFA survey said they received disability benefits in the past, and 28 percent are presently receiving disability benefits, with the majority receiving government-sponsored payments (such as Social Security Disability).
- Another 38 percent of those surveyed have stopped working due to health complications of lupus.
- Tragically, most of the individuals disabled by lupus are impacted at a young age, which means that they likely will be on disability for a lifetime<sup>17</sup>.

Additionally, according to Noel R. Rose, M.D., Ph.D., Director, Johns Hopkins Center for Autoimmune Disease Research, and Dana K. Cassell, co-authors of *The Encyclopedia of Autoimmune Diseases*, “Autoimmune diseases present a significant disease problem in the United States, Canada, and many other countries.” As examples, they state the following costs to the U.S. government:

- Insulin dependent diabetes mellitus (IDDM) costs the U.S. Medicare program more than \$2 billion per year just for renal dialysis.
- The direct medical cost of rheumatoid arthritis approaches \$5 billion annually, with nearly 70 percent of this cost attributable to hospitalizations and home care nursing.

## Easing the Burden: Solutions for the Future

### Streamlining the Process of Diagnosis

The autoimmune disease treatment puzzle is complex. To obtain proper treatment, patients must visit a wide variety of specialties within medicine. Because autoimmune diseases affect multiple organs and systems in the body, teams of physicians ranging from rheumatologist, ophthalmologist, neurologist, and gastroenterologist often are needed to treat an individual’s symptoms separately. This method of treatment is time consuming and often fiscally wasteful as there is typically no model for proper

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<sup>17</sup> Lupus Foundation of America Impact of Lupus online survey. Retrieved January 25, 2011, from [http://www.lupus.org/webmodules/webarticlesnet/templates/new\\_newsroomnews.aspx?articleid=1615&zoneid=59](http://www.lupus.org/webmodules/webarticlesnet/templates/new_newsroomnews.aspx?articleid=1615&zoneid=59)

coordinated care amongst medical systems and physicians to monitor adequately diagnostic testing and prescription drug treatments. Also, the addition of new cutting edge biologic treatments for autoimmune patients requires an even higher level of coordination and expertise from physicians as these treatments, while revolutionary as lifesaving and quality of life-enhancing tools, must be heavily monitored for short-term and long-term adverse side effects and dosage issues.

In essence, the overall “system” is broken for autoimmune disease patients, putting patient safety at risk and opening the door for the following additional barriers to care and wasteful healthcare expenditures:

- ▶ Medical practitioners do not recognize autoimmune diseases as a disease category.
- ▶ Medical history questionnaires do not inquire whether patients have a family history of autoimmune diseases.
- ▶ There are very few standardized tests for many of the 80-100 autoimmune diseases.
- ▶ Medical education provides minimal training about autoimmune diseases.

### **Coordinated Care Through Community-Based Triage Centers**

According to Drs. Yehuda Shoenfeld, Carlo Selmi, Eyal Zimlichman, and M. Eric Gershwin, co-authors of “The Autoimmunologist: geoeidemiology, a new center of gravity, and prime time for autoimmunity,” published in the *Journal of Autoimmunity* (2008), the creation of a new specialty of physician is necessary, coined the “Autoimmunologist.” This new specialist would serve as the head of a multi-disciplinary team of physicians within autoimmune triage centers in order to, according to the *Journal* article, “lower the overall economic burden due to autoimmune diseases. Indeed, patients will be diagnosed at early stages, thus enabling effective therapies to be initiated earlier in the course of the disease.” The authors note that while this approach may appear on the surface to add to the expense of care for autoimmune patients, it would require a shift by government to encourage a change from hospital- centered care to a community-based triage center model which would offer services in all fields of medicine. In this break from hospital-focused to community-based models, cost savings would abound as the majority of patients attending these new triage centers would utilize a daycare model lessening the need for extended hospitalization and lowering cost<sup>18</sup>.

### **Focus on Research Funding: Knowledge Limits Waste**

According to the American Autoimmune Related Diseases Association (AARDA), 50 million Americans are estimated to have an autoimmune disease. Together as a category, autoimmune diseases are one of the top ten causes of death in women under the age of 65. Women are more susceptible to the diseases, as they are affected 75 percent more often than men. Even with these statistics, not enough has been invested into the basic research and diagnostic tools when measured against comparable health crises in the U.S., such as heart disease, which affects 81 million Americans<sup>19</sup>, and cancer, which

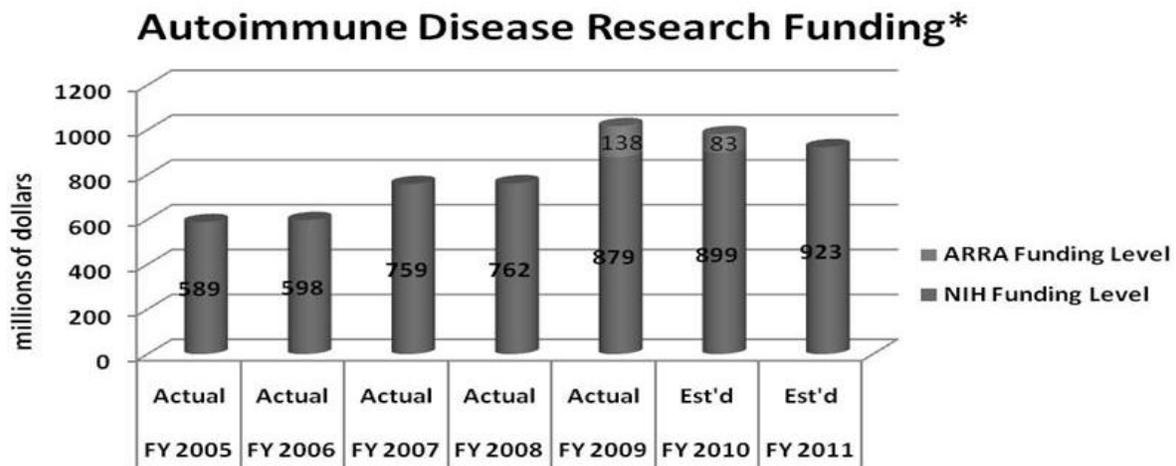
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<sup>18</sup> Shoenfeld Y., Selmi C., Zimlichman E., Gershwin E.M. The autoimmunologist: geoeidemiology, a new center of gravity, and prime time for autoimmunity. *Journal of Autoimmunity*. August 2008. Retrieved from <http://www2.kenes.com/autoimmunity/Documents/Articles/Autoimmunologists.pdf>

<sup>19</sup> American Heart Association *Prevalence of Heart Disease*. Retrieved January 25, 2011 from <http://www.americanheart.org/presenter.jhtml?identifier=4478>

affects 11 million<sup>20</sup>. Additionally, according to the Institute of Medicine (IOM), the U.S. is behind other countries in research on immune system self-recognition (the process involved in autoimmune disease)<sup>21</sup>. Also, the Canadian Institutes of Health Research reports that Canada also outspends the U.S. in the area of autoimmune disease research by approximately 15 percent<sup>22</sup>.

**NIH Funding for Autoimmune Disease Research (2005-2010).**



*\*Note that FY 2009 and FY 2010 include \$138 million and \$83 million, respectively, in American Recovery & Reinvestment Act (ARRA) Funding.*

Some progress has been made. For example, the United States Congress has recognized autoimmune diseases as a disease category; and the National Institutes of Health (NIH) has increased research funding for autoimmune diseases from \$587 million in 2007 to \$879 million in 2009. However, even with these increases, NIH funding for basic autoimmunity research does not begin to reflect the severity of the health crisis that is autoimmune diseases in the U.S.

Increased funding through NIH can make a significant difference in advancing autoimmune disease diagnosis, treatment, and care. As reported in the “Biennial Report of the Director, National Institutes of Health Fiscal Years 2006 & 2007,” “NIH recognizes that more needs to be done to close the gaps in knowledge and achieve the overall goal of reducing the rising toll of autoimmune diseases. The major tasks facing researchers in autoimmune diseases are:

- Development of a mechanism-based, conceptual understanding of autoimmune diseases

<sup>20</sup> American Cancer Society *Cancer Prevalence: How Many People Have Cancer?* Retrieved January 25, 2011 from <http://www.cancer.org/cancer/cancerbasics/cancer-prevalence>

<sup>21</sup> WOMEN’S HEALTH RESEARCH, PROGRESS, PITFALLS, AND PROMISE, 2010 Committee on Women’s Health Research, Board on Population Health and Public Health Practice, INSTITUTE OF MEDICINE; Chapter six, “Synthesis, Findings, and Recommendations,” page 279; [http://www.nap.edu/catalog.php?record\\_id=12908](http://www.nap.edu/catalog.php?record_id=12908)

<sup>22</sup> Finger, S. (2010). Autoimmune Disease Costs [PowerPoint Slides]. File retrieved from the American Autoimmune Related Diseases Association (AARDA)

- Translation of this knowledge into new, broadly applicable strategies for treatment and prevention of multiple diseases
- Development of sensitive tools for early and definitive diagnosis, disease staging, and identification of at-risk individuals “

Reduction of costs associated with autoimmune diseases would be feasible if these goals were met. New diagnostic tools would greatly lessen the time to diagnosis, shortening the number of specialist visits by patients seeking a diagnosis. The reality today is that there is no standardization of testing; and, for many of the 100+ autoimmune diseases, no reliable and effective diagnostic tests exist. Expanding knowledge of the mechanism of autoimmune diseases and decreasing the time-frame of research going from bench to bedside would also bring down the time to diagnosis, limit excessive diagnosis times, and increase effectiveness of treatment, allowing more patients to continue being productive members of society.

Ultimately, better autoimmune disease costs and epidemiological studies are necessary to improve assessment of the prevalence of all 100+ autoimmune diseases so that the U.S. can allocate, in fairness, resources in funds for research and drug development, focus on research and medical training, and provide accurate information for developing public health policy.

### Increasing Awareness

One of the most considerable barriers to patients’ getting diagnosed sooner and being better stewards of their own care, thus ensuring less waste in duplication of testing and physician visits, is directly related to the American public’s and the medical community’s level of awareness regarding autoimmune disease. According to an AARDA study, fewer than 13 percent of Americans can name an autoimmune disease. Nearly one-third of Americans (31.9%) continue to name incorrectly AIDS as an autoimmune disease. Also, adding to a severe awareness gap are physicians. Many are poorly trained in this area and typically do not ask about a family history of autoimmune diseases on patient intake forms. It has been scientifically proven that these diseases are genetically linked; therefore, family history plays a major role. If the patient doesn’t know to tell the physician of a family history of autoimmune disease and the physician doesn’t know to ask, patients are destined for years of misdiagnosis or no diagnosis; and billions of dollars are spent that could have been saved with an increase in awareness. Further illustrating this need for awareness is a study published in the *Journal of Insurance Medicine*, 2008, in which large managed care databases revealed reduced health care costs after the diagnosis of celiac disease. According to Peter H.R. Green, M.D., Professor of Clinical Medicine and Director, Celiac Disease Center at Columbia University Medical Center, “We now have evidence that the increased awareness and diagnosis of celiac disease would benefit not only the patients but would result in health care costs savings<sup>23</sup>.”

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<sup>23</sup> A.R. Lee, D.L. Ng, J. Zivin, P.H.R. Green, Research Paper, “Economic burden of a gluten-free diet”, Celiac Disease Center, Department of Biological Science, Department of Health Policy and Management, Mailman School of Public Health, Columbia University, New York, NY, USA; <http://www.ncbi.nlm.nih.gov/pubmed/17845376>

## Conclusion

Autoimmune diseases will continue to be a mounting public health concern in the U.S. and around the world for the foreseeable future. The cost associated with these diseases, while difficult to pin down accurately for all 100+ diseases, has clearly been illustrated to be a major component in the healthcare spending picture, adding perhaps hundreds of billions of dollars to healthcare spending through cost to individual patients and Medicare/Medicaid, as well as loss of productivity in the U.S. workforce. It is imperative that autoimmune diseases become a public health priority that is recognized throughout NIH institutes as well as amongst the congressional representatives who must represent the pressing needs of this growing constituency of Americans who live with autoimmune diseases. The solutions are wide-ranging; ultimately, however, the true immediate need is for Americans to become aware of the vastness of this issue as a public health concern and for its overall financial burden to be understood by Congress as a means to motivate our representatives to make addressing these solutions a high priority agenda item today.



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