How Federal Agencies Support Women Navigating Life with Autoimmune Diseases and Conditions

Within the U.S. government, there are hundreds of federal agencies that are charged with overseeing, implementing, and administering public policy. These agencies have specific responsibilities and serve critical roles, whether regulating commerce, tackling certain issues, defending the nation, or advancing the welfare of the American people.

Among these many responsibilities, federal agencies provide support—ranging from education and awareness campaigns to research to health insurance coverage—for individuals with autoimmune diseases and conditions. Autoimmune diseases, a group of more than 80 chronic and often disabling diseases that develop when the immune system mistakenly attacks the body’s own healthy organs, tissues, and cells, are a leading cause of death and disability in the United States and take a significant economic toll on patients, their families, and the U.S. health care system.

The U.S. government—through its programs and initiatives—has an important role to play in improving the lives of those living with autoimmune diseases and conditions and in addressing the significant public health concerns that are associated with these conditions.

* Note: Immune-mediated inflammatory diseases (IMIDs) are diseases where the causes and mechanisms of action are not fully understood, but a malfunction of the immune system is involved. Autoimmune diseases are a subset of IMIDs and are characterized by antigen presence. For the purposes of this document, “autoimmune diseases” refers to diseases and conditions across both classifications.
Issue Overview

Autoimmune diseases are a significant public health concern—and one with great gender disparity. Within the United States, autoimmune diseases are estimated to affect anywhere between 23.5 million and 50 million individuals, and women represent 80 percent of patients diagnosed with autoimmune diseases. While symptoms vary among various autoimmune diseases, they can cause inflammation, pain in joints or muscles, skin rashes, fevers, and fatigue. They are a leading cause of death and disability in the United States.

“Autoimmune diseases are heterogeneous and long-lasting conditions. The impact on physical health—which can include pain and fatigue, an increased risk of developing a wide variety of other conditions, impaired growth and development, disfigurement, disability, functional impairment, and death—is substantial... Autoimmune diseases can have adverse effects on social interaction and development, mental health, the capacity to have children, and education and employment.”

–Enhancing NIH Research on Autoimmune Disease (2022), National Academies of Sciences, Engineering, and Medicine

Unfortunately, federal research investments and the supply of specialty health care providers—namely rheumatology providers—are not keeping pace with the growing presence of autoimmune biomarkers in the United States. The availability of rheumatologists is especially limited in more rural, less populated areas.

Beyond the impact of autoimmune diseases on health, these diseases also have a substantial economic impact on patients and their families as well as on society. For example, a 2018 literature review of the direct medical costs associated with rheumatoid arthritis (RA) patients in the United States found that annual direct health care costs for these individuals are estimated to range from $12,509 to $36,053. In 2011, the National Institutes of Health’s National Institute of Allergy and Infectious Diseases (NIAID) estimated that the cost of treating autoimmune diseases in the United States exceeds $100 billion annually, and even that number—according to a subsequent report of the American Autoimmune Related Diseases Association (now the Autoimmune Association)—is likely a vast understatement of the true cost of autoimmune disease.

Currently, the U.S. government provides several types of support for women with autoimmune diseases and conditions—spanning several federal agencies, programs, and initiatives. These agencies often engage with one another to ensure optimal outcomes for the populations they serve and may also engage in collaborative programs, such as working groups, research networks, and partnerships. It is vital that federal agencies continue to prioritize programs and initiatives that support women with autoimmune diseases and conditions and that, in parallel, patients and their families are aware of and can utilize the federal resources available to them.

Types of support provided by the U.S. government for women with autoimmune diseases and conditions include the following:

▶ **Research Funding.** Several federal agencies including the National Institutes of Health (NIH), the National Science Foundation (NSF), the Department of Defense (DoD), the U.S. Centers for Disease Control and Prevention (CDC), and more, fund research into autoimmune diseases and conditions. This research advances our understanding of these conditions and allows for the development of diagnostic tools and new therapies and treatments. Read more about federal autoimmune disease research in the SWHR Policy Brief, “Prioritizing Federal Research on Autoimmune and Immune-Mediated Diseases and Conditions.”

▶ **Medication Safety and Access.** The U.S. Food and Drug Administration (FDA) regulates the approval and safety of drugs, biologics, and medical devices that may be used to treat autoimmune diseases. FDA’s drug approval process involves a review by FDA’s Center for Drug Evaluation and Research and a subsequent determination that the drug provides benefits that outweigh the potential risks for the intended population, increasing the number of treatment options available to autoimmune disease patients.

▶ **Worker Protections.** The Americans with Disabilities Act (ADA) prohibits discrimination against people with disabilities, including discrimination related to employment. This law requires employers to provide reasonable accommodations for employees who meet certain conditions, namely “a physical or mental impairment that substantially limits one or more major life activities...” The U.S. Department of Labor’s Office...
of Disability Employment Policy offers publications and technical assistance on the basic requirements of the law. Other federal agencies, including the U.S. Equal Employment Opportunity Commission, the U.S. Department of Justice, the U.S. Department of Transportation, and many others, have a role in enforcing or investigating claims involving the ADA.

- **Disability Benefits.** The Social Security Administration (SSA) provides disability benefits—through the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs—to individuals who are unable to work due to a medical condition, including autoimmune diseases and conditions. The SSDI program pays benefits to individuals and certain family members if they are “insured,” meaning they have worked long enough and recently enough and paid Social Security taxes on their earnings. The SSI program “pays benefits to adults and children who meet our requirements for a qualifying disability and have limited income and resources.”

- **Education and Awareness.** The U.S. Department of Health and Human Services (HHS) and its Office of Women’s Health provide resources and educational information about a range of health topics, including autoimmune diseases and conditions. Activities of the agency include conducting public education campaigns that share information about symptoms, diagnosis, and treatment of certain diseases and conditions. Further, research entities, such as the NIH’s National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) offer patient resources, including information on diagnosis, treatment, and prevention options related to autoimmune diseases and conditions as well as information pertaining to participating in clinical trials.

- **Health Insurance Coverage.** The Affordable Care Act (ACA), the comprehensive health care reform law passed in 2010, guarantees that individuals with pre-existing conditions, including autoimmune diseases, cannot be denied coverage. The ACA also requires that certain health insurance plans cover 10 “essential health benefits,” which include preventive and wellness services and chronic disease management, such as treatments for autoimmune diseases. Medicare and Medicaid are also two services that provide health insurance coverage to low-income individuals, including those with autoimmune diseases and conditions.

### Recommendations

Individuals living with autoimmune diseases face myriad challenges, including challenges with diagnosis, high health care costs, complex courses of treatment, and difficulty finding access to specialists—all of which can affect their physical, emotional, and social well-being. While the U.S. government provides critical support for women navigating these diseases and conditions, there are policies that federal agencies could implement to better support women with autoimmune diseases and conditions. These include:

- **Increased, Targeted Investments in Autoimmune Disease Research.** There is still much to learn about autoimmune diseases, and increased funding for research could lead to better understanding, prevention, and treatment of autoimmune diseases, including better understanding the gender-specific risk factors for autoimmune diseases.

- **Expand Clinical Education to Increase Awareness.** Many people are not aware of the signs and symptoms of autoimmune diseases, which can lead to delays in diagnosis and treatment. Increasing the focus of the autoimmune-related content taught within medical programs as well as efforts to address the gender bias in care are key to improving awareness among providers and leading to reduction in diagnostic delays.

- **Increase Access to Health Care Services.** Federal agencies can improve access to health care services in several ways, including by providing incentives for health care providers to specialize in autoimmune diseases, increasing the number of medical professionals who are trained in treating autoimmune diseases and conditions, and expanding access to telehealth services. Additionally, given the role of health insurance coverage in improving access to care and to better health outcomes, the federal government should continue to explore how it supports and encourages utilization of insurance coverage programs, including Medicare, Medicaid, and employer-sponsored coverage.

- **Provide Support for Disability Accommodations.** Policies should be in place to provide support and reasonable accommodations for individuals with autoimmune diseases.