

# Support for the Office of Autoimmune Disease Research within NIH

## Request

We urge Congress to support the Office of Autoimmune Disease Research (OADR) by including report language in Fiscal Year (FY) 2023 appropriations to meaningfully execute the establishment of the office by:

- Understanding the totality of what research is currently underway;
- Defining what the best options are for achieving research priorities as identified through the OADR's consulting with advocacy organizations, patients and industry partners; and
- Instituting a coordinated effort that includes establishing an overarching strategic plan.

## Draft Report Language:

### NIH/Office of Autoimmune Disease Research

Autoimmune Diseases—The Committee recognizes the important role the new Office of Autoimmune Disease Research will play in coordinating and fostering collaborative research across Institutes and Centers. As the OADR develops a strategic research plan, the Committee strongly encourages OADR to seek input from external stakeholders including patient advocacy organizations that represent the populations affected by autoimmune and immune-mediated diseases. In addition, the Committee urges OADR to utilize targeted grant announcements to drive research on areas of innovation and opportunity, particularly the research recommendations identified in the 2022 National Academies Consensus Study Report on this topic.

## Rationale:

Early in 2022, the Congressionally mandated report by the National Academies of Sciences, Engineering, and Medicine (NASEM) contained a primary recommendation that an office of autoimmunity be established to increase research and clinical efforts, resources, and coordinate overlapping efforts addressing autoimmune diseases on a scale not undertaken previously. The office would:

- Establish strategic research planning to set priorities;
- Coordinate efforts across institutes and centers (ICs) and promote collaborative research;
- Evaluate the autoimmune research portfolio to determine progress made across NIH, as well as other agencies;
- Focus on new promising, innovative research methods;
- Establish long-term systems to collect and ensure optimum usability of population-based surveillance and epidemiological data;
- Ensure the resources are available to support planning, collaboration, and innovation.

## Background:

### 15-year-old Data

- According to the NASEM report, the previous study that considered autoimmune diseases in the United States was published in 2009, using data tabulated through 2008.

### 15-year-old Numbers

- The study estimated the prevalence of autoimmune diseases to be 7.6 to 9.4 percent—or 25 to 31 million people today. However, this estimate was based on only 29 autoimmune diseases and does not account for increases in prevalence in the last decade. The estimated number of patients cited by the 11 autoimmune and immune-mediated disease advocacy groups totals over 41 million.

### 15-year-old Funding

- Total spending on autoimmunity within the NIH, the largest single funder of research, has remained relatively static since 2008 and, in actual dollar value, has decreased over time if inflation is taken into account.

# Join the Autoimmune Congressional Caucus

## Request

We are requesting a member of Congress to lead the Autoimmune Congressional Caucus.

The mission of the Congressional Autoimmune Caucus would be to serve as a clearinghouse for information on autoimmune and immune-mediated conditions, a forum to aid Members of Congress in working together to address autoimmunity. The Caucus would work toward educating all Members of Congress about how autoimmune impacts their communities and how to help support federal and local efforts to address these chronic diseases.

## Rationale:

Autoimmune diseases are a significant cause of millions of Americans' severe and chronic health conditions. There are over 100 autoimmune diseases, and seventy-eight percent of those with autoimmune diseases are women. Autoimmune Diseases cost the United States more than \$100 Billion annually. Rheumatoid arthritis and other autoimmune diseases affect more than 50 million Americans. Coordinated care is the key to reducing direct and indirect costs.

Misdiagnoses and delayed diagnoses are common as the cause of autoimmune diseases is unknown. Autoimmune and immune-mediated diseases occur when the immune system malfunctions and mistakenly attacks healthy cells, tissues, and organs. Due to their complexity, autoimmune diseases are often difficult to diagnose and treat.

We want to raise awareness on Capitol Hill. A challenge in conquering autoimmune and immune-mediated diseases helps to teach everyone on the Hill about these conditions.