

NIH should create an Office of Autoimmune Disease Research, says new report

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While the quantity and quality of research that the National Institutes of Health (NIH) conducts on autoimmune diseases is impressive, a strategic plan and a well-funded office to support the coordination of all autoimmune disease research across NIH institutes and centers are

needed, says a new congressionally mandated report from the National Academies of Sciences, Engineering, and Medicine.

Enhancing NIH Research on Autoimmune Disease says there are major barriers to NIH's ability to maximize the outcomes of its research, such as the varying approaches to institutes' and centers' strategic plans regarding autoimmune diseases, and most significantly, the absence of a research plan that spans all institutes and centers to provide an overall NIH strategy for autoimmune diseases. Absent the latter, NIH lacks a comprehensive, transparent, and strategic approach to how it plans and evaluates progress made on autoimmune disease research.

The committee that wrote the report considered five options for enhancing autoimmune disease research and their expected outcomes, and it concluded that the best option for addressing these challenges would be for the director of NIH to create an Office of Autoimmune Disease/Autoimmunity Research within the Office of the Director. Such an office would facilitate cross-NIH multidisciplinary collaboration and stimulate innovation around autoimmune disease research; engage in priority setting, strategic planning, and implementation; budget for and allocate available research funds in alignment with the [strategic plan](#); work with institutes and centers to coordinate, manage, evaluate, and report on research efforts; communicate with key stakeholders; and provide visible leadership on autoimmune disease research. The report recommends that the new office should have its own research budget and substantially control certain key budgetary decisions about autoimmune disease research activities conducted across NIH in order to increase and strengthen collaborative efforts and accelerate research.

"NIH research has contributed significantly to advances in care of autoimmune disease, and it is important to continue to translate this knowledge into more precise diagnostic criteria and clinical interventions to achieve the best outcomes and benefit the lives of our

patients," said Bernard Rosof, professor, Donald and Barbara Zucker School of Medicine at Hofstra/Northwell, and committee chair. "Due to the number and complexity of autoimmune diseases, achieving this requires a concerted, strategic effort that leverages the many research activities across NIH's institutes and centers."

Autoimmune diseases occur when the immune system, which normally defends the body against disease and infection, malfunctions and mistakenly attacks healthy cells, tissues, and organs. These diseases are chronic, lifelong, and can cause significant physical and psychosocial impairment, impeding activities of daily living, productivity, and quality of life. Individuals with an autoimmune disease commonly develop more than one autoimmune disease. Some can be fatal, and there are no known cures.

There is no consensus on which illnesses are autoimmune diseases; counts range from over 80 to 150 diseases depending on the source. The committee chose 11 autoimmune diseases for special focus: Sjögren's disease, [systemic lupus erythematosus](#), antiphospholipid syndrome, rheumatoid arthritis, psoriasis, [inflammatory bowel disease](#) (Crohn's disease and ulcerative colitis), celiac disease, primary biliary cholangitis, multiple sclerosis, type 1 diabetes, and autoimmune thyroid disease (Graves' disease and Hashimoto's thyroiditis). The commonalities across autoimmune diseases, such as mechanistic pathways, genetics, and effects of environmental factors, may provide significant insights that can further the development of patient care and therapies, and offer the greatest opportunity for advancing the field, the report says.

There is a lack of long-term (20 years or more) population-based epidemiology studies on autoimmune disease, the committee found. Such studies would allow for, among other things, assessing trends, risk factors, and costs of disease; identifying differences among population subgroups; and determining the prevalence of under-researched

autoimmune diseases, such as celiac disease. The National Cancer Institute's Surveillance, Epidemiology, and End Results Program (SEER), which provides information on cancer incidence and survival in the U.S., is a model for such studies.

The report also includes recommendations for developing population cohorts for long-term data collection (20+ years) that extends from the period before the disease manifests to the development of symptoms and disease, including patient cohorts that allow for examination of disease progression, coexisting morbidities, and outcomes, as well as the timing of exposures that may contribute to disease.

In addition, NIH should provide funding and support for a national research agenda that, among other priorities, should:

- Dissect heterogeneity across and within autoimmune diseases to decipher common and disease-specific pathogenic mechanisms
- Study rare autoimmune diseases and develop supporting animal models
- Define autoantibodies and other biomarkers that can diagnose and predict the initiation and progression of autoimmune diseases
- Determine the biologic functions of genetic variants and gene-environment interactions within and across autoimmune diseases using novel, cutting-edge technologies
- Examine the role of environmental exposures and social determinants of health in autoimmune diseases across the life span
- Determine the impact of coexisting morbidities, including co-occurring autoimmune diseases and complications of [autoimmune diseases](#), across the life span, and develop and evaluate interventions to improve patient outcomes
- Foster research to advance health equity for all autoimmune

disease patients

The study—undertaken by the Committee for the Assessment of NIH Research on Autoimmune Diseases—was sponsored by the National Institutes of Health. The National Academies of Sciences, Engineering, and Medicine are private, nonprofit institutions that provide independent, objective analysis and advice to the nation to solve complex problems and inform public policy decisions related to science, technology, and medicine. They operate under an 1863 congressional charter to the National Academy of Sciences, signed by President Lincoln.

More information: Bernard Rosof et al, Enhancing NIH Research on Autoimmune Disease, *National Academies of Sciences, Engineering, and Medicine* (2022). [DOI: 10.17226/26554](https://doi.org/10.17226/26554). [nap.nationalacademies.org/catalog/26554/enhancing-nih-research-on-autoimmune-disease](https://www.nationalacademies.org/catalog/26554/enhancing-nih-research-on-autoimmune-disease)

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