

Updates on OADR-ORWH

January 29, 2026
12 p.m. EST

Victoria Shanmugam, MBBS, FRCP, FACR, CCD, Director of the National Institutes of Health (NIH) Office of Autoimmune Disease Research in the Office of Research on Women's Health (OADR-ORWH), opened the meeting with approximately 30 minutes of remarks.

Moment of Reflection

Dr. Shanmugam began with a moment of reflection and spotlighted a painting from Dee Hayward titled "[Living Beyond the Boxes](#)". The artist, from Delaware, OH, highlights how people living with autoimmune diseases are assigned labels by others, which can feel like being boxed into a characterization of what people are or can be. But the artist chooses to rise above this "boxing", even if some days the assigned labels fit, by being creative, analytical, compassionate, courageous, and strong. Hayward lives with lupus and Raynaud's disease. In her painting, purple represents lupus. The blues and white represent the colors of her fingers and toes when Raynaud's strikes. The butterfly represents the rash that often appears on the face of people living with lupus.

Information About the Office

Dr. Shanmugam introduced the OADR-ORWH Program Officers working under her directorship: Xinrui Li, Ph.D, and Carmen Ufret-Vincenty, Ph.D.

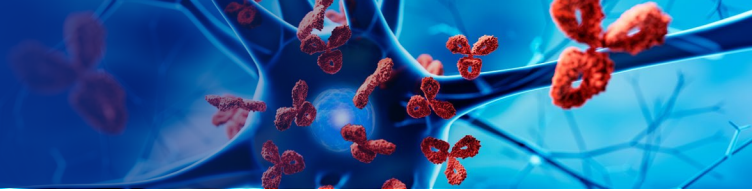
OADR-ORWH was created by congressional mandate in alignment with the National Academies of Sciences, Engineering, and Medicine's 2022 report titled [Enhancing NIH Research on Autoimmune Disease](#), which highlighted the need for greater coordination across NIH regarding autoimmune disease efforts. In the [Consolidated Appropriations Act, 2023](#) (Public Law 117–328), Congress directed the creation of OADR in the Office of Research on Women's health (ORWH) to:

- Coordinate the development of a multi-Institute and Center (IC) strategic research plan
- Identify emerging areas of innovation and research opportunity
- Coordinate and foster collaborative research across the ICs
- Annually evaluate the NIH autoimmune disease research portfolio
- Provide resources to support planning, collaboration, and innovation
- Develop a publicly accessible central repository for autoimmune disease research

Dr. Shanmugam shared an overview of the [autoimmune disease research portfolio](#), which comprises 144 diseases, and a timeline of OADR-ORWH activities. A printer-friendly and text searchable version of the full portfolio can be found [here](#).

Prevalence and Impact of Autoimmune Diseases

Data from several publications was shared to highlight the scale and trajectory of autoimmune diseases:



- Autoimmune diseases are highly prevalent globally.
- In the United States (U.S.), autoimmune diseases are reported to affect 7% to 8% of the population, or approximately 23.5 million Americans. However, recent estimates suggest that there are close to 50.0 million Americans living with autoimmune diseases. The exact prevalence of autoimmune diseases in the U.S. is unknown due to a lack of longitudinal data repositories.
- In the U.S., autoimmune diseases affect more Americans than many more widely recognized conditions such as coronary artery disease, chronic obstructive pulmonary disease, Alzheimer's Disease, human immunodeficiency virus (HIV), and most cancers.
- Nearly 80% of people with an autoimmune disease are women, with four times more women than men affected by an autoimmune disease. However, men with autoimmune diseases tend to have more severe disease and, in some cases, a higher risk of dying from their disease.

Congressional Directive 1 - Strategic Planning

Dr. Shanmugam shared that the inaugural *NIH-Wide Strategic Plan for Autoimmune Disease Research Fiscal Years 2026-2030*, was launched in July 2025. For its creation, the office collected and collated input from scientific literature; portfolio analysis; a public request for information; community roundtables; NIH Institutes, Centers, and Offices (ICOs) Directors; and subject matter experts via the NIH-wide Strategic Plan Working Group. The strategic plan's mission is to coordinate and advance efforts to support rigorous, high-priority, innovative, and collaborative autoimmune disease research. Dr. Shanmugam explained OADR-ORWH's vision for implementation of the strategic plan, which leverages a strong foundation from existing programs and research to create a unified approach for accelerating progress through research and partnerships that lead to bold ideas and a healthier future for people living with or at risk of autoimmune disease.

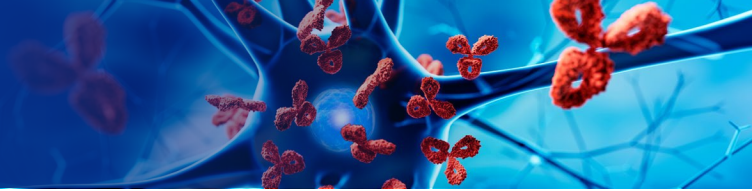
To learn more:

- [NOT-OD-24-049: Request for Information: Inviting Input on an NIH-Wide Strategic Plan for Autoimmune Disease Research](#)
- [Request for Information: Summary of Responses](#)
- [Strategic Planning for Autoimmune Disease Research at NIH –NIH-Wide Strategic Plan for Autoimmune Disease Research Fiscal Years 2026-2030](#), an inaugural video, and supplemental materials
- [The Inaugural NIH-Wide Strategic Plan for Autoimmune Disease Research \(Fiscal Years 2026–2030\) - Publication](#)

Congressional Directive 2 -Identifying Emerging Areas and Opportunity

To support innovation in the field of autoimmune disease research, OADR-ORWH:

- Issued RFI Inviting Input on an NIH-Wide Strategic Plan for Autoimmune Disease Research ([NOT-OD-24-049](#)): [Summary of RFI Responses](#)



- Hosted quarterly “[Updates on OADR-ORWH](#)” sessions with constituency groups, researchers, and community to exchange information and engage. This series was temporarily placed on hold during 2025 but restarted with the Dec 12, 2025 session.
- Convened “[Science Talks](#)”, targeting a research-focused audience, to examine cutting-edge science relevant to autoimmune disease. This series is currently on hold but expected to be reinstated soon.
- Hosted National Meeting. Engaged partners at the 8th Annual Vivian W. Pinn Symposium focused on “[Synergy in Science: Innovation in Autoimmune Disease Research and Care.](#)”

Congressional Directive 3. Coordinate and Foster Collaborative Research Across the ICs

Cross-NIH collaboration is central. In Fiscal Year FY25, eight Intramural Collaborative Research Awards targeted co-occurring autoimmune diseases across multiple ICs and teams, with projects spanning lupus, Sjögren’s, myocarditis, endocrine autoimmunity, gut inflammation, and immunopathology. This portfolio illustrates the breadth of biology involved and the need for integrated approaches. Dr. Shanmugam also highlighted the broad distribution of catalytic OADR funding across ICs and autoimmune diseases from Fiscal Years 2023 through 2025.

Congressional Directive 4. Annually Evaluate the NIH Autoimmune Disease Research Portfolio

Dr. Shanmugam described how portfolio analysis efforts continue and noted that autoimmune disease research touches every NIH IC yet remains underfunded relative to its prevalence and impact. A coordinated structure is needed to accelerate discoveries and translate them into better care.

Congressional Directive 5. Provide Resources to Support Planning, Collaboration, and Innovation

The office highlighted several investments and partnerships:

- [EXposome in Autoimmune Disease Collaborating Teams PLANning \(EXACT-PLAN\)](#)
- [Accelerating Medicines Partnership® Autoimmune and Immune-Mediated Diseases \(AMP® AIM\) Program](#)
- [Autoimmunity Centers of Excellence \(ACE\)](#)
- [NEXUS: Network for Exposomics in the U.S. Coordinating Center](#)
- [Nourish Challenge](#): A community ideation competition (Fall 2025–Spring 2026) to generate bold ideas integrating diet and nutrition into autoimmune disease research.

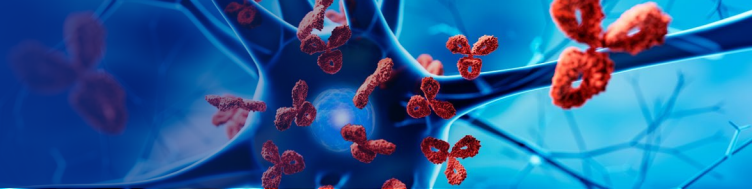
Congressional Directive 6. Develop and Oversee a Repository for Autoimmune Disease Research

OADR-ORWH is developing the Autoimmune Disease Analysis Platform Testing Space (ADAPTS), a federated data platform that:

- provides a single, unified view across multiple data sources
- allows different datasets to function like one database without moving the data
- reduces the need for complicated data transfer pipelines
- supports governance, privacy, and speed

Highlighted benefits include:

- one access point to distributed datasets



- real-time access
- data stewards retain control
- stronger governance and security
- lower storage and analysis costs

The goal is to include distributed datasets such as:

- ImmPort
- NIH Intramural
- other phenotypic, molecular, and clinical data

The broad idea is to make autoimmune disease data easier to use while still respecting ownership, privacy, and oversight. As part of these efforts, OADR-ORWH and the National Library of Medicine co-hosted an ADAPS Hackathon on January 15 and 16, 2026.

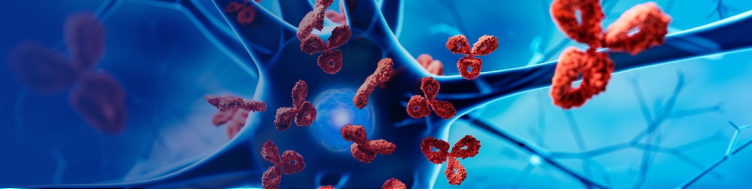
Additionally, OADR-ORWH is supporting multiple efforts to create Common Data Elements (CDEs) for Autoimmune Disease research. The following editorial explains this work: [Common Data Elements in Autoimmune Disease Research](#).

Communications and Outreach

- [Report of the Office of Autoimmune Disease Research in the Office of Research on Women's Health \(OADR-ORWH\), fiscal years 2023-2024](#)
- Podcast [Century Lives "When Life Gives You Lemons"](#)
- Podcast [Autoimmune Association's "Threads of Hope"](#)
- OADR participation in congressional briefings (e.g., Sjogren's Foundation on 3/25/25, Autoimmune Association on 7/22/2025) and constituency organization visits to NIH (e.g., Hidradenitis Suppurativa Foundation with NIAMS and NIAID on 9/30/2025).
- Highlighted media mentions:
 - [Disease of 1,000 faces shows how science is tackling immunity's dark side](#)
 - [Autoimmune diseases can strike any part of the body and mostly affect women. Here's what to know](#)
 - [Lifelong drugs for autoimmune diseases don't work well. Now scientists are trying something new](#)
 - [Kids get diseases like lupus, too. As researchers hunt better treatments, this camp brings joy](#)
 - [An autoimmune disease stole this man's memory. Here's how he's learning to cope](#)
 - [Why Autoimmune Diseases Rise Sharply After 50](#)
 - [5 Autoimmune Diseases Men Should Keep on Their Radar](#)

NIH Funding Changes

- [A framework for leveraging funding policies beginning January 2026 council round](#)
- Replacement of Notices of Special Interest with [Highlighted Topics](#)
- Funding opportunities are now accessed through [grants.gov](#)
- Removal of Letters of Intent requirements and pre-approval for unsolicited applications requesting \$500,000+ in direct costs: [NOT-OD-26-019](#)



- Implementation of common forms for bio-sketch and current/pending support for due dates on or after January 25, 2026: [NOT-OD-26-018](#)
- Guidance on reopening extramural activities after the October 1, 2025 lapse in appropriations: [NOT-OD-26-012](#)
- [Notices of Policy Changes](#)

Community Roundtable

A community roundtable invited brief, structured input from attendees on research, care, and organizational updates relevant to autoimmune disease. Participants provided comments, including representatives from constituency and consulting organizations and scientists. OADR-ORWH encouraged ongoing engagement, questions, and suggestions, and directed participants to the strategic plan and resources on the [OADR-ORWH](#) website. Community members shared updates and perspectives on patient needs, including a new set of [clinical practice guidelines for peripheral nervous system manifestations in Sjögren's disease](#), as well as upcoming reports highlighting the experiences of individuals living with multiple sclerosis. Participants expressed interest in emerging areas such as “food is medicine”, menopause as a modifier of autoimmune disease, environmental triggers, and expanding the ADAPTS platform to include extramural data sources. There was also discussion of broader issues, including understanding the economic impact of autoimmune diseases, gaps in autoimmune pain research, and the importance of continued engagement between patient organizations and NIH.

Closing

Dr. Shanmugam thanked everyone for sharing their comments and encouraged participants to [sign up for OADR-ORWH emails](#). The meeting concluded after approximately 55 minutes.