

Updates on OADR-ORWH

December 12, 2025
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 Nancy Rodrigo titled "Sea Suckle". The artist, from Brooklyn, NY, highlights the intersection of art and science through this work. Rodrigo lives with multiple autoimmune conditions, including psoriatic arthritis, Sjogren's disease, and autonomic neuropathy. She was first diagnosed at 35, became disabled at 38 and is now 62. Rodrigo's art, specifically her BIO series, uses vibrant watercolor compositions to explore the natural world through a magnifying lens. Her work serves a healing role, helping alleviate her symptoms and transform chronic pain into timeless imagery, informed by biology and physiology, depicting elements such as tidepools, kelp forests, moss, fungi, and the connection of life and matter.

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.

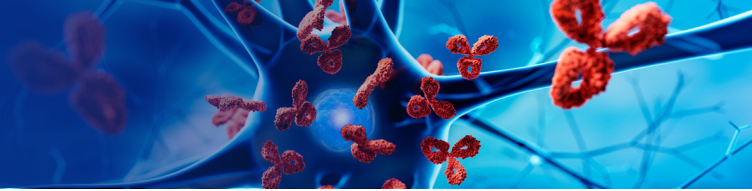
OADR-ORWH is a relatively new office, created by congressional mandate in alignment with the National Academies of Sciences, Engineering, and Medicine's 2022 report titled [Enhancing NIH Research on Autoimmune Disease](#), which highlighted the need for greater coordination across NIH regarding autoimmune 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.
- A study using United Kingdom data shows over 10% of the population affected and prevalence increasing over two decades.
- Autoimmune disease significantly increases cardiovascular risk, underscoring the need for integrative research and care that spans specialties.

Congressional Directive 1 - Strategic Planning

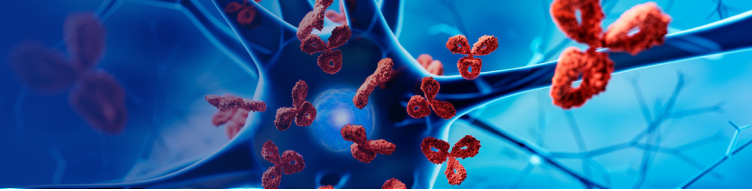
Dr. Shanmugam shared that the inaugural *NIH-Wide Strategic Plan for Autoimmune Disease Research Fiscal Years 2026-2030*, was launched in July 2025. For its creation, the office collected and collated input from scientific literature; portfolio analysis; a public request for information; community roundtables; 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. 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, Intramural Collaborative Research Awards targeted co-occurring autoimmune diseases across multiple ICs, 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 portfolio analysis efforts 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.

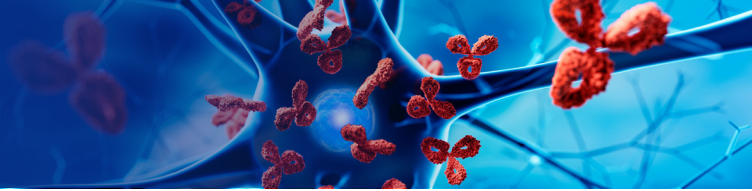
Congressional Directive 5. Provide Resources to Support Planning, Collaboration, and Innovation

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](#)
- Funded multiple efforts to create of Common Data Elements (CDEs) for Autoimmune Diseases
- Funded efforts leveraging the CARRA Registry (Dr. Marc Natter, Boston Children’s Hospital): The largest observational registry in North America for pediatric-onset rheumatic diseases, advancing long-term outcomes research and medication safety/effectiveness to treat pediatric rheumatic diseases.
- Funded AVERT Study (Dr. Jill Buyon, New York University School of Medicine): A prospective study testing the FDA-approved therapy rozanolixizumab, plus hydroxychloroquine, to prevent recurrence of cardiac neonatal lupus.
- [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 infrastructure linking multiple repositories (e.g., ImmPort, NIH intramural data and other existing datasets). ADAPTS will:



- Enable cohort discovery across distributed clinical and molecular datasets.
- Provide tools and workflows, including Artificial Intelligence/Machine Learning, for analysis.
- Explore topic modeling and swarm learning to identify autoimmune endotypes.
- This approach respects data stewardship and access controls while expanding researcher access and insight.

Communications and Outreach

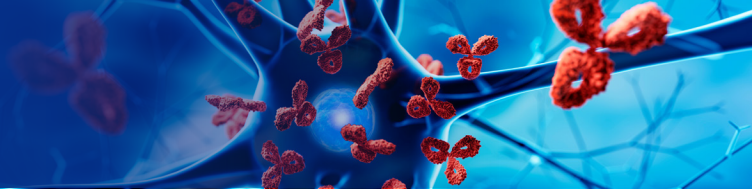
- [Report of the Office of Autoimmune Disease Research in the Office of Research on Women's Health \(OADR-ORWH\), fiscal years 2023-2024](#)
- Podcast [Century Lives "When Life Gives You Lemons"](#)
- Podcast [Autoimmune Association's "Threads of Hope"](#)
- OADR participation in congressional briefings (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](#)

NIH Funding Changes

- [A framework for leveraging funding policies beginning January 2026 council round](#)
- Replacement of Notices of Special Interest with [Highlighted Topics](#)
- 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 news and voiced interest in several areas, including the Growth Program for Inflammatory Bowel Disease from Children's National Hospital, the need for harmonization of autoantibody screening, and the advancement of CDEs across autoimmune diseases. There was also interest expressed in expanding access to the ADAPTS platform for extramural investigators and hopes for improving the infrastructure to support the research and broader implementation of CAR-T therapy.

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.