Updates on OADR-ORWH

April 23, 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 Beatriz Fraga titled "Digested", which was displayed at the 2026 NIH RARE Diseases Day. The artist lives with neurosarcoidosis. Fraga describes digestion as a process meant to be simple, something people do not think much about. However, in her case digestion stopped "cooperating" and became pain, swallowing became nausea. Her issues started when she was 11 and obtaining a diagnosis took a year. She explains that she titled her piece "Digested" because that is how her illness feels. Symptoms affect her every day, the illness "destroys pieces of who I am". Art is a coping mechanism for Fraga, a way to find a voice and explain how she feels. "The tubes, the organs wrapping around my throat, my body feels against me sometimes, and drawing helps me fight back." "My illness will never be able to take my identity." Autoimmune diseases are not abstract biological problems alone. They reshape identity, daily function, and communication itself.

Information About the Office

Dr. Shanmugam started by introducing the OADR-ORWH Program Officers working under her directorship (Xinrui Li, Ph.D, and Carmen Ufret-Vincenty, Ph.D) and followed by explaining the office. 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 over 140 diseases and conditions. A printer-friendly and text searchable version of the full portfolio can be found here. Autoimmune diseases and conditions, which result from the immune system mistakenly attacking the body's own tissues, are a major public health issue.

Prevalence and Impact of Autoimmune Diseases

The presentation highlighted data from several publications showing that autoimmune diseases are highly prevalent globally and appear to be increasing in incidence. In the United States (U.S.), autoimmune diseases are reported to affect at least 7% to 8% of the population, or between 23.5 and 50.0 million Americans. However, the exact prevalence of autoimmune diseases in the U.S. is unknown due to a lack of longitudinal data repositories. Nearly 80% of people with an autoimmune disease are women, but men with autoimmune diseases tend to have more severe disease and, in some cases, a higher risk of dying from their disease.

It is clear that 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. Autoimmune diseases are underfunded relative to prevalence and disease outcomes, which can be severe and persistent. Challenges include:

- People may wait a long time to get the right diagnosis
- Some diseases remain poorly understood
- Treatments may work only for some patients
- Researchers may struggle to compare findings across diseases and across studies
- Opportunities for prevention may be missed both in research and treatments

Genetics alone does not explain the increasing incidence of autoimmune diseases. It is critical to advance understanding of the autoimmune prodrome, meaning the period when autoantibodies or immune activation become detectable but full disease is not yet obvious. This is important because earlier recognition of risk could eventually help doctors diagnose diseases sooner or even prevent some cases from becoming severe. Another priority is exposome research, or the study of various exposures experienced throughout people's lives, to elucidate how exposure mixtures impact the incidence, severity and outcomes of autoimmune diseases.

Strategic Planning (Congressional Directive 1)

The inaugural *NIH-Wide Strategic Plan for Autoimmune Disease Research Fiscal Years 2026-2030* was launched in July 2025. For its development, OADR-ORWH and the NIH-wide Autoimmune Disease Research Strategic Plan Working Group 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. 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 strategic plan implementation, 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 (for example, one-page overview of strategic plan)
- The Inaugural NIH-Wide Strategic Plan for Autoimmune Disease Research (Fiscal Years 2026–2030) - Publication
- NIH Highlighted Scientific Topic: Autoimmune Disease-specific – NOW LIVE
- NIH Highlighted Scientific Topic: Hidradenitis Suppurativa (HS)-specific – NOW LIVE
- Featured Funding Opportunities:
    - PAR-25-450: Clinical Trial Readiness for Rare Diseases, Disorders, and Syndromes (R21 Clinical Trial Not Allowed)
    - PAR-25-122: Pilot Projects Investigating Understudied Proteins Associated with Rare Diseases (R03 Clinical Trial Not Allowed)

Congressional Directive 2 -Identifying Emerging Areas and Opportunity

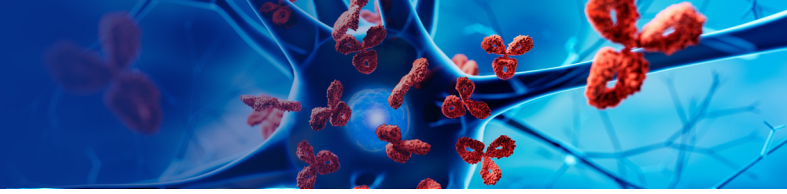
To support innovation in the field of autoimmune disease research, OADR-ORWH wants to update the community on the following events and publications:

- Restarted with the 12/12/2025, session, Updates on OADR-ORWH are held virtually on a quarterly basis. The goal is to exchange information and engage with people living with or at risk for autoimmune diseases, advocacy groups, researchers and community.
- Translational Autoinflammatory Research Network (TARN)-NIH 3rd annual Symposium: "Celebrating Autoinflammation: On the Shoulders of a Giant. The event convened scientists, clinicians, people living with autoimmune disease and advocates to discuss research and new therapies.
- A 2024 Nutrition Workshop at NIH focused on the state of nutrition science, knowledge gaps and life experiences of people living with autoimmune disease. The publication NIH–Wide Workshop: Impact of Diet on Mucosal Immunity and Immune-Mediated Inflammatory Diseases of the Gastrointestinal Tract summarizes the proceedings.
- Examples of past Community Engagement:
    - 2024 ScienceTALKS series
    - OADR-ORWH at Congressional Briefing to launch the NIH-wide Strategic Plan for Autoimmune Disease Research (presenter: Dr. Victoria Shanmugam; host: Autoimmune Association; July 22, 2025)

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

Dr. Shanmugam highlighted the broad breadth of catalytic OADR-ORWH funding during Fiscal Years 2023 through 2025, providing coverage across autoimmune diseases and ICs (both for NIH-based research and research across academic institutions). OADR-ORWH focused on collaboration and/or centralization since the need for integrated approaches is critical to advance autoimmune disease discoveries and translate them into better care.

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



Dr. Shanmugam described how portfolio analysis efforts continue at OADR-ORWH. Autoimmune disease research touches every NIH IC while remaining underfunded relative to its prevalence and impact.

NIH-wide updates in fiscal year 2025 that benefit autoimmune disease research portfolio analysis include:

- The Research, Condition, and Disease Categorization (RCDC) category for Autoimmune Disease was revised to more accurately reflect the Autoimmune Disease Portfolio.
- Sjogren's Disease was added as an RCDC category.
- NIH uses RCDC categories to track and categorize funding, therefore these updates will improve OADR-ORWH portfolio analysis capabilities.

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

Dr. Shanmugam highlighted progress related to several investments and partnerships. The most significant update was that, with the completion of the NOURISH Autoimmunity Challenge, OADR-ORWH has demonstrated efforts to address **all** strategic plan priorities in 2025-2026. The NOURISH Autoimmunity Challenge was a community ideation competition (Fall 2025–Spring 2026) to generate bold ideas integrating diet and nutrition into autoimmune disease research. Winning Concepts were announced on March 30th, 2026 (visit the Nourish Challenge website to watch a recording of the Winners Presentation Webinar). Four major themes emerged from the submitted ideas:

1. **Effectiveness of Dietary Interventions in Autoimmune Disease:** Including submissions for interventional studies testing specific dietary patterns or therapeutic diets.
2. **Microbiome, Immune, and Multi-Omics Mechanisms:** Submissions focused on mechanistic and biomarker-driven approaches linking diet, the gut microbiome, and immune activity.
3. **Personalized, Data-Driven and Predictive Nutrition:** Concepts and submissions that propose the use of innovative data-driven methods for personalization, diet optimization, and real-world, real-time data capture and modeling to improve lived experience for people living with autoimmune diseases.
4. **Community Voice, Landscape Assessment, and Patient-Centered Frameworks:** Submissions proposing patient centered frameworks that bring lived experience to the forefront of the research paradigm.

Taken together, these themes suggest that nutrition is emerging as a topic requiring further study, careful trial design, and close collaboration with patients.

Other investments and partnerships highlighted by Dr. Shanmugam include:

- 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

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

In collaboration with the National Library of Medicine (NLM), 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

The broad idea is to make autoimmune disease data easier to use while still respecting ownership, privacy, and oversight. Highlighted benefits include:

- one access point to distributed datasets
- near real-time access
- data stewards retain control
- stronger governance, protections and security
- lower storage and analysis costs

The goal is to include distributed datasets such as:

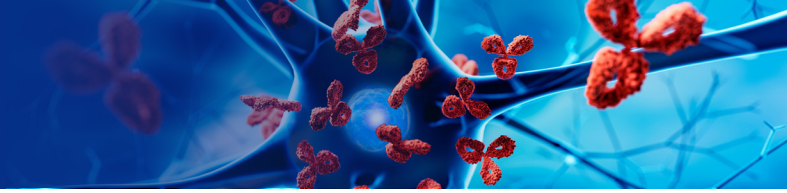
- ImmPort
- NIH Intramural
- other phenotypic, molecular, and clinical data

As part of these efforts, OADR-ORWH and the NLM co-hosted an ADAPTS Hackathon on January 15 and 16, 2026. Additionally, OADR-ORWH continues to support 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.
- Myositis-specific CDEs were developed through a collaboration of myositis researchers in the National Institute of Environmental Health Sciences (NIEHS) and data science expertise in the NLM, supported by consensus of myositis multi-specialty experts and its patient communities. The following publication describes this work and provides a broadly applicable workflow for the creation of CDEs for other autoimmune diseases: Standardized Interoperable Data Collection for Myositis Research: Developing Expert Consensus on Common Data Elements for Myositis Outcome Measures

Communications and Outreach

- OADR-ORWH attended a Congressional Briefing hosted by the American Association of Immunologists (AAI) on March 18, 2026
- Dr. Shanmugam presented at the Women's Health Access Matters (WHAM) Roundtable: The Longevity Connection: Inflammation, Autoimmunity, and the Future of Healthy Lifespan
- Dr. Shanmugam presented at the Benaroya Research Institute Cross-Autoimmunity Prevention Symposium in Seattle, WA, on March 26, 2026



- The Translational Autoinflammatory Research Network (TARN)-NIH 3rd annual Symposium on April 16-17, 2026, "Celebrating Autoinflammation: On the Shoulders of a Giant" honored Dr. Dan Kastner, the founding father of autoinflammation, for his important contributions in establishing and advancing the field. Dr. Kastner was recently a member of the NIH-wide Autoimmune Disease Research Strategic Plan Working Group and his leadership was instrumental for the development of the inaugural *NIH-wide Strategic Plan for Autoimmune Disease Research*.
- Highlighted media mentions:
  - Woman With 3 Autoimmune Diseases Enters Remission After Immune 'Reset'
  - Can a "Living Drug" Cure Autoimmune Diseases?
  - A Cancer Treatment That Does More Than Scientists Thought
  - How autoimmune conditions can unexpectedly drive mental illness

Latest NIH Funding Policy Updates

- Achieving NIH's Mission: Leveraging Funding Policies
- 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
- Replacement of Notices of Special Interest with Highlighted Topics
- Funding opportunities are now accessed through grants.gov
- 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.

Closing

Dr. Shanmugam thanked everyone for sharing their comments and encouraged participants to sign up for OADR-ORWH emails. The meeting concluded after approximately 65 minutes.