

Updates on OADR-ORWH

February 2, 2024

12 p.m. EST

Dr. Shanmugam's Updates

Vicki Shanmugam, MBBS, MRCP, FACR, CCD, Director of the Office of Autoimmune Disease Research in the Office of Research on Women's Health (OADR-ORWH) at the National Institutes of Health opened the meeting with approximately 15 minutes of remarks.

Establishment of the Office

In 2022, aligned with contents of the [National Academies of Sciences, Engineering, and Medicine](#) report [Enhancing NIH Research on Autoimmune Disease](#), the U.S. Congress enacted [Public Law 117-328](#) directing NIH to establish an Office of Autoimmune Disease Research in the Office of Research on Women's Health (OADR-ORWH). The Consolidated Appropriations Act, 2023 directs OADR-ORWH to:

- Coordinate the development of a multi-institute and center strategic research plan
- Identify emerging areas of innovation and research opportunity
- Coordinate and foster collaborative research across the institutes and centers
- 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.

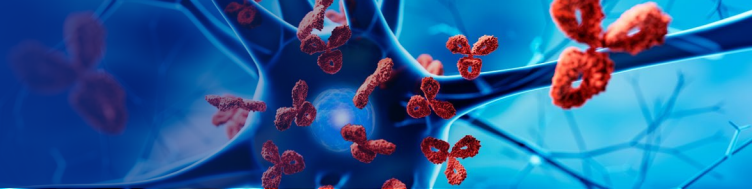
OADR-ORWH Activities

OADR-ORWH has developed an initial autoimmune disease research portfolio, categorized into 15 research areas that encompass 144 autoimmune diseases. These diseases are being evaluated as part of the landscape analysis of the NIH autoimmune disease research portfolio.

In fiscal year 2023, OADR-ORWH supported a total of 41 awards across 12 separate NIH institutes and centers. This included 15 extramural co-funding awards, 3 R56 bridge funding awards, 2 Accelerating Medicines Partnership® Autoimmune and Immune-Mediated Diseases ([AMP® AIM](#)) awards, 10 intramural co-funding awards, 5 intramural scientific fellowships, and 6 [EXACT-PLAN](#) (EXposome in Autoimmune Disease Collaborating Teams PLANning) awards. The EXACT-PLAN Awards were developed by OADR-ORWH with the [National Institute of Arthritis and Musculoskeletal and Skin Diseases](#), the [National Institute of Environmental Health Sciences](#), and additional NIH institute, center, and office (ICO) partners to support the design, development, and implementation of a future, national, interdisciplinary, collaborative, team science research network that will advance the study of the exposome in autoimmune disease. These awards spanned basic to translational, clinical, and public health research focused on autoimmune diseases.

OADR-ORWH currently has an active Request for Information (RFI): Inviting Input on an NIH-Wide Strategic Plan for Autoimmune Disease Research ([NOT-OD-24-049](#)). Responses will be accepted through March 1, 2024. Comments received will be curated and considered during OADR-ORWH's strategic planning process. OADR-ORWH hopes to hear broadly from the community of researchers, patients and those affected by autoimmune diseases, and advocates interested in autoimmune disease research.

The overall strategic planning process will be informed by the autoimmune disease research portfolio analysis results, input collated from the Updates on OADR-ORWH public meetings, responses to the RFI, contributions from NIH ICOs, feedback from members of an internal NIH working group, and relevant academic literature and reports.



Staying Involved

OADR-ORWH plans to host quarterly Updates on OADR-ORWH virtual meetings to provide updates on Office activities and listen to input from the community. Upcoming events in 2024 will be held on:

- Friday, May 3, from 12:00 p.m. to 12:45 p.m. EST
- Thursday, July 25, from 3:00 p.m. to 3:45 p.m. EST
- Friday, November 8, from 12:00 p.m. to 12:45 p.m. EST

Additionally, the [8th Annual Vivian W. Pinn Symposium](#) will feature autoimmune disease research. This virtual event will be held on Wednesday, May 15, from 1 p.m. to 5 p.m. EST. Stay tuned to the [event webpage](#) for additional details as they become available.

[Sign up for emails from OADR-ORWH](#) to receive updates on pertinent items such as events and funding opportunities.

Community Roundtable

For the remainder of the meeting, participants were prompted to provide input on the following topics:

- What research opportunities could improve outcomes for individuals with autoimmune disease?
- How can NIH improve participation of individuals with autoimmune diseases from historically underrepresented groups in relevant research and clinical trials?
- What would be the value of a publicly accessible central repository for autoimmune disease research? What should we consider as we plan this resource?

Participants that provided comments verbally or through the chat included autoimmune disease patients, researchers, and representatives from nonprofit organizations. The nature of the Office, reaching across all autoimmune disease areas, was highlighted as a potential strength in supporting research seeking commonalities across disease mechanisms and treatments. Continued research funding to investigate molecular mechanisms of disease, identify biomarkers for faster time to diagnosis, and study new drug candidates was emphasized. Meeting participants also encouraged OADR-ORWH to perform a gap analysis.

Representatives from nonprofit organizations asked for OADR-ORWH to continue bidirectional engagement, and to work with their organizations to reach their patient and researcher communities. Additionally, there was general consensus that the number of autoimmune disease patients is undercounted. Identifying accurate disease prevalence is a complex issue, but contributing factors may include lack of diversity in the health care workforce leading to missed diagnoses in patients from underrepresented groups, autoimmune disease-specific clinical training, and validated biomarkers for many autoimmune diseases. Length of time to diagnosis also influences the likelihood that instances of autoimmune diseases are underreported.

The concept of a publicly accessible central repository for autoimmune disease research was applauded as a need. Many participants noted that individual disease groups have their own form of a registry, and the strength of an OADR-ORWH repository may lie in harmonizing these disparate, but robust, resources.

OADR-ORWH thanked everyone for sharing their comments and encouraged participants to [respond to the RFI](#). The meeting concluded after approximately 45 minutes, and Dr. Shanmugam looks forward to connecting with the community again on May 3.