

Updates on OADR-ORWH

February 23, 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 (NIH) 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 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. The RFI seeks input 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. EDT
- Thursday, July 25, from 3:00 p.m. to 3:45 p.m. EDT
- Friday, November 8, from 12:00 p.m. to 12:45 p.m. EDT

Two additional opportunities for public engagement with NIH were highlighted:

- The NIH Office of Data Science and Strategy is hosting a hybrid event titled “[Advancing the Use and Development of Common Data Elements \(CDE\) in Research Workshop](#)” on March 6–7.
- The NIH National Institute of Allergy and Infectious Disease (NIAID) will be hosting a grant writing series, “[How to Plan for and Write Your First \(or Next\) NIH Grant Application](#)” from February 22 to July 18, 2024.

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. EDT. 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.

Academic Roundtable

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

- What are opportunities to advance collaborative, innovative, or interdisciplinary areas of autoimmune disease research?
- What would be the value of a publicly accessible central repository for autoimmune disease research? What should we consider as we plan this resource?

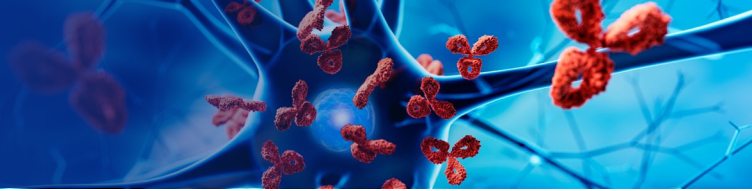
Participants who provided comments verbally or through the chat included autoimmune disease researchers, academics, and representatives from nonprofit organizations.

Participants strongly supported collaboration and the co-funding of collaborative efforts across various institutes, disciplines, and industries as avenues that would benefit autoimmune disease research and repository development. The Accelerating Medicines Partnership® – Autoimmune and Immune-Mediated Diseases Program (AMP®-AIM) was highlighted as a model. Respondents specifically called out the need for interdisciplinary work with respect to psychosocial aspects of autoimmune diseases, environmental exposures, and common genetic origins across autoimmune diseases. Data sharing was also indicated as a critical need.

Participants discussed the need for prevention strategies, screening, and research into common risk factors. Research focused on genetics, environmental exposures, and pathogenic exposures was highlighted, with several participants naming Epstein Barr Virus as a virus of interest.

Several researchers specializing in neurologic-related autoimmune diseases communicated the importance of further research into microglia and myelin.

Participants were enthusiastic about the concept of a centralized autoimmune disease research repository, with researchers proposing the following: a biofluid repository; a database with photographic representation of disease manifestation; and an integrated database with immune repertoire, genetic, clinical, and



phenotypic data, and environmental and pathogen exposure data. Participants noted expected challenges, including the enormity of project scope, patient confidentiality, patient engagement, and data curation and management. Ensuring diversity and representation from all populations was also emphasized.

The need for phenotyping technologies, guidelines for sharing phenotyping, and the development of prediction models was agreed on by several researchers.

Other study topics raised by participants included investigation into commonly utilized non-medical approaches to disease management, inflammatory responses as a driver of neurodegenerative diseases, development of biomarkers, and better approaches to medication termination.

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.