

Updates on OADR-ORWH

May 3, 2024

12 p.m. EDT

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 20 minutes of remarks.

Background Information about the Office

Dr. Shanmugam began by providing background about autoimmune diseases and the establishment of OADR-ORWH. Autoimmune diseases affect 7% to 8% of the United States population, meaning approximately 23.5 million Americans are affected by autoimmune diseases. Nearly 80% of people with autoimmune disease are women, and four times more women than men are affected by autoimmune diseases. The exact prevalence of autoimmune disease in the U.S. is unknown due to a lack of longitudinal data repositories.

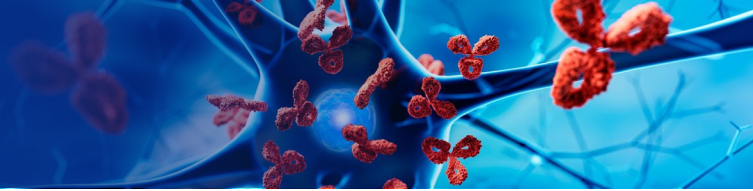
In 2022, aligned with contents of the [National Academies of Sciences, Engineering, and Medicine](#) report, [Enhancing NIH Research on Autoimmune Disease](#), Congress enacted [Public Law 117-328](#) directing NIH to establish an Office of Autoimmune Disease Research in the Office of Research on Women's Health. The Consolidated Appropriations Act, 2023 directs OADR-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 a brief timeline of OADR-ORWH activities that have been underway to address the congressional directives. A [Notice of Special Interest](#) (NOSI) was published in spring 2023 on developing a network for studying the exposome in autoimmune diseases. During Fiscal Year (FY) 2023, OADR-ORWH supported 41 awards across 12 NIH ICs. Dr. Shanmugam was named director in November 2023, and in December 2023 OADR-ORWH's [Request for Information](#) (RFI) inviting input on an NIH-wide strategic plan for autoimmune disease was released. Strategic planning, partially informed by responses to the RFI, is ongoing, and efforts to assess the NIH autoimmune disease research portfolio are underway. More than 144 diseases have been collated in the autoimmune disease research portfolio and are being evaluated as part of the landscape analysis of the NIH autoimmune disease research portfolio.

Website Updates

Dr. Shanmugam shared that OADR-ORWH has a recently revitalized [website](#). The website now has a navigational pane with individual webpages for strategic planning, funding opportunities, news and updates, autoimmune disease research across NIH, and events.



Arthritis & Rheumatology Article

Dr. Shanmugam and Janine Austin Clayton, M.D., FARVO, associate director for Research on Women's Health and director of the Office of Research on Women's Health, coauthored an [article](#) for *Arthritis & Rheumatology*, the official journal of the American College of Rheumatology, introducing the Office of Autoimmune Disease Research. The article provides an overview of OADR-ORWH and its FY23 activities. The FY23 activities summary can also be found on OADR-ORWH's [funding opportunities webpage](#).

EXACT-PLAN Awards

OADR-ORWH, in partnership with the National Institute of Arthritis and Musculoskeletal and Skin Diseases and the National Institute of Environmental Health Sciences, awarded six programs as part of the Exposome in Autoimmune Disease Collaborating Teams PLANing Awards (EXACT-PLAN) [NOSI](#). The EXACT Network is a national research collaborative team that conducts research to discover the environmental exposures that influence disease susceptibility, onset, and outcomes and will develop a systems-level approach to understand the mechanisms underlying how exposures perturb cellular, organ, and tissue function across autoimmune diseases. Learn more about the [six awardees](#).

Strategic Planning

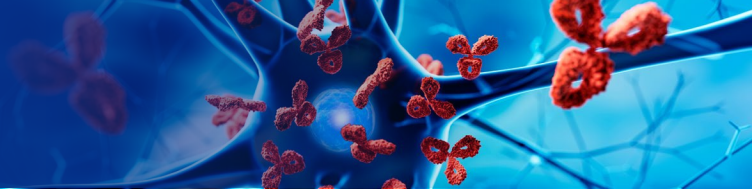
OADR-ORWH is incorporating many sources into its strategic planning process, with key input received from responses to the RFI, which closed on March 1, 2024. Eighty unique, nonblank responses were received, 68% of which were submitted on behalf of the responder, and 32% on behalf of an organization. OADR-ORWH received submissions from a wide variety of responder categories including academic, advocacy, patient, academic institution, scientific society, research organization, and industry. Analysis of RFI responses is ongoing.

Areas of Innovation, Fostering Collaboration, and Repository for Autoimmune Disease Research

Foundational to all these components of OADR-ORWH's work are common data elements (CDEs). Dr. Shanmugam presented a concept clearance at the 60th meeting of the [NIH Advisory Committee on Research on Women's Health](#) with the purpose to build consensus around generation of autoimmune disease-related CDEs as a means to help advance research and build the foundation for an autoimmune disease research repository.

Speaking Engagements

Dr. Shanmugam has been engaged in the community, giving talks to promote OADR-ORWH co-funding opportunities, share office updates, discuss CDEs for autoimmune disease research, and present scientific topics related to autoimmune diseases. She shared a list of audiences that she has connected with, including intramural NIH scientists, the Foundation for NIH, the Society for Women's Health Research, Women's Health Access Matters, the Pediatric Inflammatory Bowel Disease Research meeting, and the workshop on Immunotherapies and Cellular Therapies for Systemic Sclerosis and Chronic Graft-Versus-Host Disease, among others.



ScienceTALKS

On April 23, 2024, OADR-ORWH hosted the inaugural ScienceTALKS public webinar, “Xist-ing Data: Why Might Autoimmune Diseases Be More Common in Women?” With talks by Montserrat Anguera, Ph.D.; Diana R. Dou, Ph.D.; and Brendan Antiochos, M.D., the audience learned about the mechanism by which the X chromosome is inactivated. In people with more than one X chromosome it is now thought this mechanism may be a driver of increased frequency of autoimmune diseases in women. A panel discussion was moderated by Stacy Ferguson, Ph.D., and Marie Mancini, Ph.D., where the speakers discussed future aspects of this research topic. This event was attended by hundreds of participants, with a worldwide reach. The archived recording can be [viewed via NIH VideoCast](#).

8th Annual Vivian W. Pinn Symposium and National Women's Health Week

Dr. Shanmugam closed her remarks by promoting the [8th Annual Vivian W. Pinn Symposium](#) on May 15, and additional events for National Women's Health Week hosted by [ORWH](#) and the [Office of the Assistant Secretary for Health](#).

Community Roundtable

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

- What autoimmune disease research issues are high priority that you would you like the Office of Autoimmune Disease Research to be aware of?
- Do you have areas of autoimmune disease scientific research that you or your organization would like to see OADR-ORWH highlight in a future ScienceTALKS webinar?

Participants who provided comments verbally or through the chat included autoimmune disease researchers, academics, and representatives from nonprofit organizations. The primary topics addressed were areas of research interest. Community members raised: the connection between gynecological cancer and autoimmune diseases; molecular epidemiology of autoimmune diseases; pregnancy and women of childbearing age and autoimmune diseases; gastrointestinal, neurological, and lung involvement in autoimmune diseases; Epstein-Barr virus as a trigger and driver of autoimmune diseases, and potential anti-retroviral therapeutics; how symptoms across different autoimmune diseases are similar or how they have different etiopathogenesis; and concern for potential increases in autoimmunity in pediatric populations.

OADR-ORWH thanked everyone for sharing their comments and encouraged participants to [sign up for emails](#). The meeting concluded after approximately 36 minutes.