

## Updates on OADR-ORWH

November 8, 2024  
12 p.m. EST

### Dr. Shanmugam's Updates

Vicki Shanmugam, MBBS, MRCP, 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 20 minutes of remarks.

### Moment of Reflection

Dr. Shanmugam began with a moment of reflection and spotlighted artwork by [Kate Snow](#) whose art has been influenced by her diagnosis with Sjögren's syndrome and fibromyalgia. Noting the similarities to science, Dr. Shanmugam shared one of Ms. Snow's quotes, "If you want gold, you've got to be willing to go down in the mine. I can't think of a better way to explain the process of making art; it's hard, it's painful, and gold is never guaranteed."

### Information About the Office

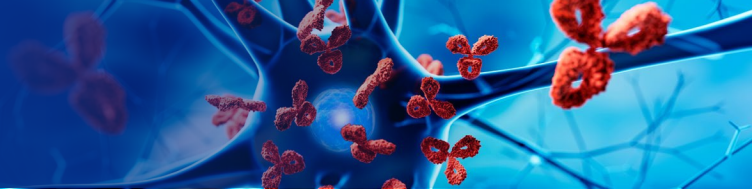
Dr. Shanmugam announced that two new federal staff have joined the OADR-ORWH team, Carmen Ufret-Vincenty, Ph.D., and Xinrui Li, Ph.D.

Autoimmune diseases affect 7% to 8% of the United States (U.S.) population, or approximately 23.5 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, with four times more women than men affected by an autoimmune disease.

In 2022, to align with recommendations from the [National Academies of Sciences, Engineering, and Medicine](#) report, [Enhancing NIH Research on Autoimmune Disease](#), Congress enacted [Public Law 117-328](#) that directed NIH to establish OADR-ORWH. 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 an overview of the [autoimmune disease research portfolio](#), which comprises 144 diseases, and a timeline of OADR-ORWH activities.



*Congressional Directive 1. Coordinate the Development of a Multi-Institute and Center Strategic Research Plan*

Dr. Shanmugam shared that the *NIH-Wide Strategic Plan for Autoimmune Disease Research* is well underway. The office collected and collated input from scientific literature; an ongoing 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 priorities and objectives have been drafted, and publication is anticipated for August 2025.

*Congressional Directive 2. Identify Emerging Areas of Innovation and Research Opportunity*

OADR-ORWH works closely with collaborators across NIH to identify emerging areas of innovation and research opportunity. Dr. Shanmugam highlighted the new OADR-ORWH ScienceTALKS series as one of the initiatives supporting this directive. The inaugural [ScienceTALKS](#) in April 2024 examined the role of the XIST molecule in sex-biased autoimmune diseases. OADR-ORWH hosted the second [ScienceTALKS](#) in August 2024, which focused on viral triggers of autoimmune diseases. ScienceTALKS sessions are open to the public and available online.

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

Dr. Shanmugam reviewed Fiscal Year (FY) 2024 data, highlighting the broad spread of funding across ICs. OADR-ORWH funding in FY23 and FY24 addressed conditions in 14 of the 15 subportfolios, with only the auditory/ear subportfolio not receiving funding. In response to this gap, Dr. Shanmugam presented the new Notice of Special Interest (NOSI): [Autoimmune Inner Ear Disease](#) (AIED) that was published by the [National Institute on Deafness and Other Communication Disorders](#) in collaboration with OADR-ORWH. The NOSI promotes research to better understand AIED and identify strategies that will prevent and treat this disease. The NOSI's first due date is February 16, 2025.

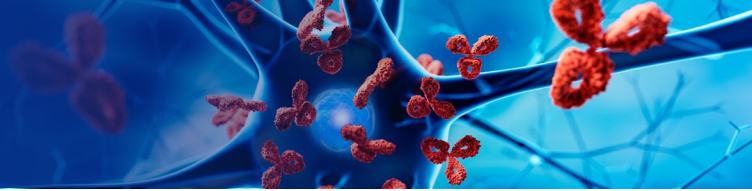
*Congressional Directive 4. Annually Evaluate the NIH Autoimmune Disease Research Portfolio*

OADR-ORWH is currently curating a 5-year baseline portfolio and evaluating its year 1 portfolio. Dr. Shanmugam noted that this portfolio work has been an extremely valuable exercise that has generated a detailed understanding of ongoing NIH autoimmune disease research. The office will subsequently perform annual portfolio evaluations.

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

Dr. Shanmugam reviewed the resources that OADR-ORWH is providing to support planning, collaboration, and innovation in autoimmune disease research.

The EXposome in Autoimmune Disease Collaborating Teams PLANning (EXACT-PLAN) awards represent a collaborative effort between OADR-ORWH, the [National Institute of Arthritis and Musculoskeletal and Skin Diseases](#), the [National Institute of Environmental Health Sciences](#) (NIEHS), and other NIH ICOs engaged in autoimmune disease research. The EXACT Network is a national research collaborative team that aims to discover the environmental exposures that influence autoimmune diseases and develop a systems-level approach to understand the



mechanisms that underly how these exposures perturb cellular, organ, and tissue functions across autoimmune diseases.

Dr. Shanmugam and partners across NIH coauthored an [editorial](#) for *Arthritis Care & Research* that examines the exposome's critical role in shaping current and future autoimmune disease research at NIH. The editorial explores the impact of environmental exposure on autoimmune diseases and NIH's ongoing efforts to elucidate these complex interactions.

Additionally, OADR-ORWH has supported the *Network of EXposomics in the U.S. (NEXUS)* Coordinating Center, which is led by NIEHS. Columbia University received the award whose goals are to advance the understanding of the various exposures that people encounter across the lifespan and analyze how these exposures trigger autoimmune diseases and other diseases.

#### *Congressional Directive 6. Develop a Publicly Accessible Central Repository for Autoimmune Disease Research*

To advance research and build the foundation for an autoimmune disease research repository, Dr. Shanmugam shared that OADR-ORWH published a NOSI ([NOT-OD-24-145](#)) to stimulate the development of NIH-endorsed common data elements applicable to autoimmune diseases. The NOSI's next due dates are in December 2024 and April 2025.

Additionally, OADR-ORWH has been working with Richard Scheuermann, Ph.D., Scientific Director at the [National Library of Medicine](#), on a new pilot project that will assess the feasibility of a federated data platform that can analyze distributed datasets and intramural/extramural research activities.

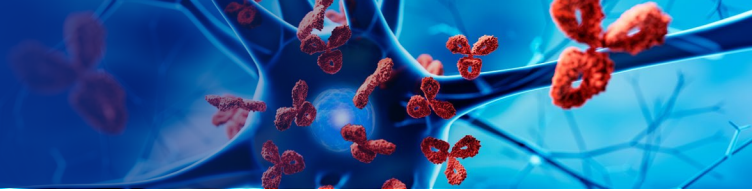
#### *Office Updates Wrap-Up*

Dr. Shanmugam has been engaged in the autoimmune disease community, both external and internal to NIH. Dr. Shanmugam has participated in 7 consortia and working groups, 5 collaborative workshops, 16 events/meetings, and 17 speaking engagements.

Dr. Shanmugam announced that the next [ScienceTALKS](#) session is Thursday, December 5, 12–2 p.m. EST. The webinar topic is “The Cancer Autoimmune Connection: Decoding the Paradox.” It will focus on the connection of the pathways involved in cancer and autoimmune disease development by bringing together experts in the field to generate discussion and identify opportunities to advance research in this area.

Dr. Shanmugam shared funding opportunities relevant to the autoimmune disease community, all of which are linked on the “OADR-ORWH [Funding Opportunities](#)” webpage.

Lastly, Dr. Shanmugam highlighted that March is Autoimmune Disease Awareness Month, and OADR-ORWH is planning several exciting events. More information will be forthcoming.



### **Community Roundtable**

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

- What areas of autoimmune disease scientific research would you like to see OADR-ORWH highlight in a future ScienceTALKS webinar?
- What emerging or topical areas of autoimmune disease research, care, and/or advocacy would you like OADR-ORWH to be aware of?
- What methods of engagement, information exchange, or communication with/from OADR-ORWH are most beneficial or helpful to you or your organization?
- Are there any additional comments you wish to share with OADR-ORWH?

Participants provided comments verbally or through the chat and included representatives from advocacy and consulting organizations. Community members voiced interest in several disease areas, including type 1 diabetes, Grave's disease, Hashimoto's disease, other endocrine gland-focused diseases, lupus, and neurological symptoms of autoimmune disease. Misdiagnosis was raised as a major concern in the autoimmune disease field. Participants would like to hear more about OADR-ORWH's scientific collaborative efforts with ICOs. Audience members also expressed appreciation for OADR-ORWH's autoimmune disease [funding table](#), interest in the upcoming [ScienceTALKS](#) on the cancer-autoimmune connection, and excitement for Autoimmune Disease Awareness Month, noting that it will be a great opportunity for patient engagement.

OADR-ORWH thanked everyone for sharing their comments and encouraged participants to [sign up for OADR-ORWH emails](#). The meeting concluded after approximately 35 minutes.