Updates on OADR-ORWH

July 25, 2024 3 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.

Moment of Reflection

Dr. Shanmugam began with a moment of reflection and spotlighted artwork by <u>Shelley</u> <u>Lowenstein</u> whose art has been influenced by her daughter's diagnosis with type I diabetes. Her work was recently featured on the cover of <u>Diabetes Care</u>.

Background Information About the Office

Autoimmune diseases affect 7% to 8% of the U.S. population, or approximately 23.5 million Americans. However, the exact prevalence of autoimmune diseases in the United States is unknown because of a lack of longitudinal data repositories. Nearly 80% of people with autoimmune disease are women, and four times more women than men are affected by autoimmune diseases. However, men with autoimmune diseases often experience more severe disease as compared to women.

In 2022, aligned with contents of the <u>National Academies of Sciences</u>, <u>Engineering</u>, <u>and Medicine</u> report <u>Enhancing NIH Research on Autoimmune Disease</u>, Congress enacted <u>Public Law 117-328</u> 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 an overview of the <u>autoimmune disease research portfolio</u>, which consists of 144 diseases, and a timeline of OADR-ORWH activities. In April and May 2024, OADR-ORWH published an <u>article</u> in *Arthritis and Rheumatology* spotlighting the establishment of the office and hosted the inaugural <u>ScienceTALKS</u> and the <u>8th Annual Vivian W. Pinn Symposium</u>.

Notice of Special Interest (NOSI)

Dr. Shanmugam shared that OADR-ORWH recently published a NOSI (NOT-OD-24-145) to stimulate development of NIH-endorsed common data elements applicable to autoimmune diseases as a means to help advance research and build the foundation for an autoimmune

disease research repository. The first due date is August 12, 2024, with additional upcoming due dates in December 2024 and April 2025.

EXACT-PLAN Awards

Dr. Shanmugam provided a brief overview and update on the Exposome in Autoimmune Disease Collaborating Teams PLANning Awards (EXACT-PLAN). The EXACT Network is a national research collaborative team that conducts research to discover the environmental exposures that influence autoimmune diseases and will develop a systems-level approach to understand the mechanisms underlying how exposures perturb cellular, organ, and tissue function across autoimmune diseases. In May 2024, researchers and personnel supporting the EXACT-PLAN Awards gathered in Seattle during the EXACT-PLAN Summit to learn about groundbreaking research and engage in discussions regarding approaches to integrating the exposome into autoimmune disease research. Learn more about the EXACT-PLAN.

Arthritis Care & Research Editorial

Dr. Shanmugam and partners across NIH coauthored an <u>editorial</u> for *Arthritis Care & Research* examining the critical role of the exposome in shaping current and future autoimmune disease research at NIH. The editorial explores the impact of environmental exposure on autoimmune diseases and ongoing NIH efforts to elucidate these complex interactions.

Strategic Planning

OADR-ORWH is in the midst of writing the inaugural NIH-wide Strategic Plan for Autoimmune Disease Research. The strategic plan is being prepared with input from many sources, including the strategic plan Request for Information, Updates on OADR-ORWH, NIH institute, center, and offices, portfolio analysis, and scientific literature. A working group of autoimmune disease subject matter experts is drafting the strategic plan, ensuring that it is evidence-based and science-driven.

Speaking Engagements

Dr. Shanmugam has continued to be engaged in the autoimmune disease community, both external and internal to NIH, giving talks to promote OADR-ORWH activities and presenting on scientific topics related to autoimmune diseases. She shared a list of audiences with whom she has connected, including congressional staff, Women in Scleroderma, the NIAID Autoimmunity Centers of Excellence, and the AMP-AIM Leadership Scholars Program.

Funding Opportunities

Dr. Shanmugam shared funding opportunities relevant to the autoimmune disease community, spotlighting two opportunities:

- NOSI: Research Supplements to Promote Re-entry, Re-integration into, and Re-training in Health-related Research Careers
- NOSI: Women's Health Research

All funding opportunities are linked on the OADR-ORWH Funding Opportunities Webpage.

ScienceTALKS

Dr. Shanmugam announced that the next <u>ScienceTALKS webinar</u> is scheduled for Tuesday, August 27, 10 a.m.—12 p.m. EDT. The webinar topic is "Going Viral: Exploring Viral Triggers of Autoimmune Diseases" and will touch on multiple autoimmune diseases and commonalities across autoimmune diseases. This webinar spotlight on viral triggers and data pertaining to these viral triggers was inspired by discussion during multiple Updates on OADR-ORWH sessions. ScienceTALKS are open to the public and visible online.

Community Roundtable

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

- 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 who provided comments verbally or through the chat included representatives from advocacy organizations. Community members expressed interest in opportunities for advocacy groups to support OADR-ORWH, viral triggers of autoimmunity, progressing drug trials for autoimmune diseases, and inclusion of populations exposed to diethylstilbestrol in autoimmune disease research.

OADR-ORWH thanked everyone for sharing their comments and encouraged participants to <u>sign</u> <u>up for emails</u>. The meeting concluded after approximately 34 minutes.