



Solve M.E.

From: Emily Taylor
Vice President of Advocacy and Engagement
Solve ME/CFS Initiative (Solve M.E.)
350 N Glendale Ave., Suite B #368
Glendale, CA 91206
etaylor@solvecfs.org
(714) 296 1661

To: Dr. Vicki Shanmugam
Director, Office of Autoimmune Disease Research (OADR)
Office of Research on Women's Health (ORWH)
Email: oadr-orwh#rfi@od.nih.gov

February 7, 2024

Subject: Response to RFI NOT-OD-24-049

Dear Dr. Vicki Shanmugam,

On behalf of Solve M.E., we express our gratitude for the opportunity to contribute to the National Institutes of Health (NIH)-wide strategic plan for autoimmune disease research. This initiative by the Office of Research on Women's Health (ORWH) and the newly established Office of Autoimmune Disease Research (OADR) signifies a pivotal step towards enhancing research and outcomes for autoimmune diseases. We acknowledge the NIH's commitment to fostering innovation, collaboration, and inclusivity in research, as highlighted in the RFI NOT-OD-24-049.

OBJECTIVE 1: *OBJECTIVE 1: Research areas that would benefit from cross-cutting, collaborative research (these areas may include basic or translational research, clinical research, health services research, population science, data science, preventative research, biomedical engineering, and other areas of research).*

We advocate for the prioritization of cross-cutting, collaborative research endeavors that integrate basic, translational, clinical, and biomedical engineering approaches with a focus on diseases like Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Long COVID, and other infection associated chronic diseases. These conditions, which disproportionately affect women and involve complex immune system dysregulation, stand to benefit immensely from a multidisciplinary research strategy. By harnessing data science and health services research, we can uncover novel insights into their etiologies and interventions.

OBJECTIVE 2: *Opportunities to advance collaborative, innovative, or interdisciplinary areas of autoimmune disease research.*

www.SolveCFS.org

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Glendale, CA 91206
Street address: 611 N Brand Blvd Suite 13-120
Glendale, CA 91203



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The intersectionality of autoimmune and infection-associated chronic diseases presents untapped opportunities for collaborative and interdisciplinary research. Facilitating connections among researchers across these domains can dismantle existing silos, propelling forward innovative approaches to understanding and treating these conditions. We endorse initiatives that promote innovative methodologies and technologies in studying the intricate relationship between infectious agents and autoimmune disease processes.

OBJECTIVE 3: Opportunities to improve outcomes for individuals living with autoimmune diseases including NIH-designated health disparities populations, populations and individuals with rare diseases, and specific populations that have been historically underrepresented in research and clinical trials.

Ensuring equitable research opportunities and outcomes for individuals with autoimmune diseases, particularly those belonging to NIH-designated health disparities populations and historically underrepresented groups, is crucial. We strongly support the inclusion of ME/CFS cohorts in NIH research agendas. Addressing the unique challenges faced by individuals with ME/CFS, Long COVID, and related infection-associated chronic diseases will not only correct historical oversights but also enrich the body of autoimmune disease research with diverse perspectives and data.

We commend the NIH for seeking comprehensive input on advancing autoimmune disease research. Solve M.E. is committed to working alongside the NIH, leveraging our expertise and community connections to aid in the development of a strategic plan that recognizes the significance of inclusivity, innovation, and collaboration in research.

We look forward to the outcomes of this strategic planning process and the advancements it will bring to the field of autoimmune disease research. Thank you for considering our input.

All the best,

Emily Taylor
Vice President of Advocacy and Engagement

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