



August 16, 2018

Dianne Post
Chapter Secretary
Inez Casiano NOW Chapter #0140
P.O. Box 32336
Phoenix, Arizona 85064

Dear Ms. Post:

Thank you for your letter to National Institutes of Health (NIH) Director Dr. Francis S. Collins sharing your interest in diseases and conditions primarily affecting women and your concerns about NIH funding for research on those diseases and conditions. Dr. Collins referred your letter to me for response as I serve as the NIH Associate Director for Research on Women's Health and the Director of the NIH Office of Research on Women's Health (ORWH).

ORWH provides a focal point for coordinating NIH women's health research and co-funds women's health research with the NIH Institutes and Centers (ICs). ORWH also supports the recruitment, retention, reentry, and advancement of women in biomedical careers. The ORWH website¹ provides up-to-date information on ORWH's support of women's health research, women in biomedical careers, and career enhancement for women's health researchers in general. ORWH also has the important role of helping to ensure that women are appropriately represented in clinical research funded by NIH. For many years, the aggregate enrollment of women in NIH-funded clinical research has equaled or exceeded 50 percent,² illustrating the emphasis that NIH gives to research on diseases affecting women.

Further, ORWH is involved in ongoing efforts to educate medical professionals and researchers about sex and gender differences in health and disease. For example, ORWH currently supports a web-based course on the major physiological differences between the sexes, their influence on illness and health outcomes, and their implications for policy, medical research, and optimal healthcare.³ The course is currently being expanded to include new modules that focus on incorporating epidemiologic observations, basic and preclinical research findings, and clinical research results with sex/gender-based influences for various diseases. In addition, ORWH is actively engaging with medical educators to better emphasize the many differences in health and

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disease between women and men, and to further integrate the consideration of those differences into medical curricula via interprofessional education.

On behalf of NIH, I assure you that supporting research on the health of women is one of our priorities. NIH recognizes that differences between women and men have important influences on the prevalence, causes, outcomes, treatment, and perception of many diseases. Indeed, autoimmune diseases, chronic pain, and a host of other diseases and conditions affect women more than men. NIH is committed to supporting research aimed at reducing the burden of those diseases in women as well as men and to enhancing the biomedical workforce engaged in research on diseases and conditions that primarily affect women.

Each NIH IC is involved in research of relevance to the health of women. For several ICs, particularly the National Institute of Allergy and Infectious Diseases⁴ and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS),^{5,6} autoimmune diseases are a priority. By conducting searches using the NIH Research Portfolio Online Reporting Tools, it is evident that several ICs aggressively fund research on autoimmune diseases, such as Sjögren's syndrome, systemic lupus erythematosus, rheumatoid arthritis, and multiple sclerosis, that affect more women than men. For instance, NIH awarded \$97 million and \$111 million in funding for research on multiple sclerosis (MS) in fiscal year (FY) 2016 and FY 2017, respectively, and it is estimated that NIH will spend \$118 million on MS research in FY 2018.⁷

Another example of coordinated efforts to support research on diseases that predominantly affect women is the Trans-NIH Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) Working Group, which is composed of 24 ICs.⁸ In FY 2017, the Trans-NIH ME/CFS Working Group supported the creation of three collaborative research centers and a data management coordinating center to conduct research and advance our knowledge on this debilitating disease.⁹ We look forward to new knowledge from the studies conducted by investigators at these centers.

In addition to ORWH's integrative website on women's health research, several ICs also maintain informative web resources on women's health topics specific to their mission areas (e.g., the National Heart, Lung, and Blood Institute (NHLBI)¹⁰, NIAMS¹¹; the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)¹²; and the National Institute of Environmental Health Sciences (NIEHS)¹³). Moreover, the National Library of Medicine's MedlinePlus page on women's health¹⁴ contains many links to useful information and resources for women on research news, disease prevention, risk factors, tools for

⁴ niaid.nih.gov/about/autoimmune-diseases-committee

⁵ niams.nih.gov/health-topics/autoimmune-diseases

⁶ niams.nih.gov/about/working-groups/lupus-federal

⁷ report.nih.gov/categorical_spending.aspx

⁸ nih.gov/mecfs/trans-nih-mecfs-working-group-members

⁹ nih.gov/news-events/news-releases/nih-announces-centers-myalgic-encephalomyelitis-chronic-fatigue-syndrome-research

¹⁰ nhlbi.nih.gov/science/womens-health

¹¹ niams.nih.gov/community-outreach-initiative/understanding-sex-gender-health/health-information-women

¹² nichd.nih.gov/health/topics/womenshealth

¹³ niehs.nih.gov/health/topics/population/whealth/index.cfm

¹⁴ medlineplus.gov/womenshealth.html

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finding specialist physicians, and so forth. I hope you will share these online resources with members of the National Organization for Women.

Finally, I am pleased to report that a new (2019-2023) Trans-NIH Strategic Plan for Women's Health Research will be completed by the end of the current calendar year. ORWH is developing this plan in collaboration with NIH's ICs and with input from almost 200 individuals and organizations, including scientists, patient advocates, and other external stakeholders responding to the public notice.¹⁵ During the strategic planning process, consideration was given to diseases that only or mostly affect women (ME/CFS, MS, and many others) and to career enhancement for biomedical scientists performing research on such diseases, with the hope of alleviating misconceptions and advancing sex- and gender-appropriate diagnoses and treatments for those diseases.

I encourage you to stay tuned to the ORWH website for the forthcoming strategic plan and to keep abreast of our efforts to improve the health of women. I sincerely hope that this letter provided you with useful information and resources regarding our strong commitment to research on diseases and conditions that adversely affect more women than men.

Respectfully yours,

Janine Austin Clayton, M.D.
NIH Associate Director for Research on Women's
Health and Director, Office of Research on
Women's Health

¹⁵ grants.nih.gov/grants/guide/notice-files/NOT-OD-17-108.html