

Committee on Framework for the Consideration of Chronic Debilitating Conditions in Women

MEETING 2

May 31st, 2023
10:00-2:20pm ET

WEDNESDAY, MAY 31ST, 2023

10:00–10:05 Welcome and introductions; conduct of the open session

Eve Higginbotham, SM, MD, ML, Committee Chair

10:05–11:35 Perspectives on Women’s Health Research on Chronic Debilitating Conditions

10:05-10:35 Janine Clayton, MD, FARVO, NIH Office of Research on Women’s Health

10:35-11:05 Holly Moore, PhD, National Institute on Drug Abuse

11:05-11:35 Marjorie Jenkins, MD, MEdHP, FACP, University of South Carolina School of Medicine Greenville

11:35–12:05 Break

12:05–1:35 Advocacy and Policy Perspectives

12:05-12:35 Denise Hyater-Lindenmuth, MBA, MA, National Women’s Health Network

12:35-1:05 Kathryn G. Schubert, MPP, CAE, Society for Women's Health Research

1:05-1:35 Carolee Lee, Women’s Health Access Matters

1:35–2:20 Panel: Patient Perspectives and Lived Experiences

Diana Falzone, The Endometriosis Foundation of America

Annika Ehrlich, MS, FNP-C, AQH, CNRN, Alliance for Headache Disorders Advocacy

Ayesha Patrick, Autoimmune Association

Wendy Rodgers, MEd, MPH, Lupus Foundation for America

2:20 Open Session Adjourns

A NOTE TO ATTENDEES

This meeting is being held to gather information to help the committee conduct its study. This committee will examine the information and material obtained during this, and other public meetings, in an effort to inform its work. Although opinions may be stated and lively discussion may ensue, no conclusions are being drawn at this time, and the committee will deliberate thoroughly before writing its draft report. Moreover, once the draft report is written, it must go through a rigorous review by experts who are anonymous to the committee, and the committee then must respond to this review with appropriate revisions that adequately satisfy the Academies' Report Review Committee and the NAS president before it is considered an official Academies report. Therefore, observers who draw conclusions about the committee's work based on today's discussions will be doing so prematurely. Furthermore, individual committee members often engage in discussion and questioning for the specific purpose of probing an issue and sharpening an argument. The comments of any committee member may not necessarily reflect the position he or she may actually hold on the subject under discussion, to say nothing of that person's future position as it may evolve in the course of the project. Any inference about an individual's position regarding findings or recommendations in the final report is therefore also premature.

COMMUNICATION

At any time throughout the study, members of the public may submit written comments for consideration by the study committee (as individuals or on behalf of an organization) via email to ChronicConditionsWomen@nas.edu through December 1, 2023.

All materials and comments received will be placed in the committee's Public Access File and may be provided to the public upon request. Materials and comments received may also be included in the committee's report.

To receive notification about future committee events and the report release, sign up for the listserv [here](#).

STATEMENT OF TASK

An ad hoc committee of the National Academies of Sciences, Engineering, and Medicine will:

1. Review the existing literature on chronic debilitating conditions specific to women. The review will consider:

- The epidemiology of chronic debilitating conditions including gender and racial and ethnic differences in clinical presentation and outcomes
- How the development and accumulation of chronic debilitating conditions in women are influenced by factors such as menopause, aging-related skeletal muscle dysfunction (loss of muscle mass, muscle strength, and muscle function), and frailty
- Prevention, diagnosis, and treatment of female-specific gynecologic conditions
- To the extent possible, the social and economic impact of chronic debilitating conditions

2. Assemble evidence-based findings on chronic debilitating conditions in women.

- The findings should incorporate the influence of social determinants of health, including but not limited to gender, race and/or ethnicity, socioeconomic status, sexual and gender minorities, and underserved rural population

3. Produce a report that describes current gaps in evidence and provides a suggested research agenda for the future.