

April 4, 2024

The Honorable Tammy Duckworth
U.S. Senate
524 Hart Senate Office Building
Washington, DC 20510

The Honorable Shelley Moore Capito
U.S. Senate
170 Russell Senate Office Building
Washington, DC 20510

Dear Senators Duckworth and Moore Capito:

On behalf of the physician and medical student members of the American Medical Association (AMA), I want to express our support for S. Res. 90, a resolution recognizing the significance of endometriosis as an unmet chronic disease for women that requires far greater attention, public awareness, and education. S. Res. 90 encourages the Administration to provide information to women, patients, and health care providers concerning endometriosis, including available screening tools and treatment options, and asks the Administration to conduct additional research on endometriosis and possible clinical options. In addition, the resolution asks the Administration to update information, tools, and studies currently available that help women live with endometriosis.

Endometriosis is a condition caused by tissue that resembles the lining of the uterus growing outside of the uterus in places that it should not be, often resulting in chronic pain due to this tissue growing on organs, such as the ovaries, intestines, and bladder, leading to inflammation and potential scarring.¹ As a result of this excess tissue, endometriosis can significantly decrease the quality of women's lives and "can cause constant and intense pelvic pain, fatigue, depression, anxiety, and infertility."²

Unfortunately, this condition is pervasive and impacts at least 11 percent of women globally and more than 6.5 million women in the U.S. alone.³ Despite the significant number of women who suffer from endometriosis, there is still a considerably small amount of knowledge about this disease which has resulted in 47 percent of endometriosis patients having to see at least five physicians before being diagnosed or referred for this condition.⁴ This results in the average diagnosis time taking about seven years, with some patients not being diagnosed for up to 12 years.⁵ These findings align with a 2021 French study finding that 25 percent of general practitioners did not believe they knew enough about endometriosis.⁶ Moreover, there is a disparity in how endometriosis is diagnosed and treated in patients of color with "with elevated complication rates experienced by Hispanic, Black or African American, Native

¹ <https://swhr.org/closing-gaps-in-physician-endometriosis-education/>.

² <https://www.ox.ac.uk/news/2023-03-14-global-study-shows-experience-endometriosis-rooted-genetics>.

³ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9127440/>.

⁴ *Id.*

⁵ <https://swhr.org/closing-gaps-in-physician-endometriosis-education/>.

⁶ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9127440/>.

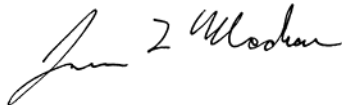
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Hawaiian or Pacific Islander, and American Indian or Alaska Native patients.”⁷ This is in part due to the lack of research that has been conducted concerning patients of color with endometriosis.⁸

Notwithstanding the widespread impact of this condition, the funding for research in this space has remained very low. In 2023, only \$29 million were allocated in the federal budget for endometriosis research which equates to only about \$4.46 of funding per patient per year.⁹ This extremely low funding allocation for endometriosis “means knowledge gaps are not being filled, making the development of effective diagnosis and treatment options more complicated, more time consuming, and less enticing for researchers.”¹⁰ As a result, treatment options for women with endometriosis remain extremely limited and only moderately effective with about half of women experiencing recurrence of this condition regardless of treatment.¹¹

The AMA believes that there should be increased endometriosis research that addresses health disparities in the diagnosis, evaluation, and management of endometriosis as well as increased funding for endometriosis related research for patients of color. Therefore, we support passage of S. Res. 90 to increase the endometriosis research that is desperately needed. We appreciate your leadership on this important issue and look forward to working with you to advance this resolution.

Sincerely,

A handwritten signature in black ink that reads "James L. Madara". The signature is written in a cursive style with a large initial "J" and "M".

James L. Madara, MD

⁷ <https://pubmed.ncbi.nlm.nih.gov/35101410/>.

⁸ <https://raf.bioscientifica.com/view/journals/raf/3/2/RAF-21-0106.xml>.

⁹ <https://report.nih.gov/funding/categorical-spending#/>.

¹⁰ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9127440/>

¹¹ <https://www.michiganmedicine.org/health-lab/experts-research-gap-stalls-improvements-endometriosis-care>.