## United States Senate

WASHINGTON, DC 20510

## April 12, 2019

The Honorable Richard Shelby Chairman Appropriations Subcommittee on Defense Committee on Appropriations 122 Dirksen Senate Office Building Washington, D.C. 20510

The Honorable Dick Durbin Vice Chairman Subcommittee on Defense Committee on Appropriations 122 Dirksen Senate Office Building Washington, D.C. 20510

Dear Chairman Shelby and Vice Chairman Durbin:

As you begin work on the Fiscal Year (FY) 2020 appropriations process, we write to respectfully request that you include language adding endometriosis to the list of Congressionally Directed Topic Areas in the Department of Defense Peer Reviewed Medical Research Program (PRMRP).

Endometriosis is one of the most common reproductive disorders, affecting approximately 190 million women worldwide and one in 10 women and girls of reproductive age in the U.S. It is a painful, chronic disorder in which tissue that normally lines the inside of the uterus (the endometrium) grows outside of the uterus—typically on the fallopian tubes, ovaries, and pelvic tissue. Symptoms of endometriosis can be debilitating and greatly affect the quality of life of individuals with endometriosis; they range in severity and can include infertility and increased risk of endometrial cancer.

Endometriosis has no known cure, and is often misdiagnosed because of the high costs of diagnosis and treatment in addition to the presence of confounding symptoms.<sup>3</sup> In addition, women's menstrual pain, a common symptom of endometriosis, has been normalized, leading to a lack of disease awareness.4 According to a multi-country study on the impact of endometriosis, on average, women 18-45 years old will experience pelvic pain for nearly seven years before

the world bank, "Databank, ropulation Estimates and Projections,

https://databank.worldbank.org/data/reports.aspx?source=Health%20Nutrition%20and%20Population%20Statistics: %20Population%20estimates%20and%20projections

<sup>2</sup> U.S. Department of Health & Human Services, Office of Women's Health, "Endometriosis," https://www.womenshealth.gov/a-z-topics/endometriosis

Parveen Parasar et al. "Endometriosis: Epidemiology, Diagnosis and Clinical Management." Curr Obstet Gynecol Rep. Author manuscript; available in PMC 2018 March 01, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5737931/pdf/nihms847220.pdf

Sawsan As-Sanie, Rebecca Black, et al. "Assessing research gaps and unmet needs in endometriosis," February 2019; American Journal of Obstetrics & Gynecology, https://www.ajog.org/article/S0002-9378(19)30385-0/abstract receiving a correct endometriosis diagnosis.<sup>5</sup> At present, an endometriosis diagnosis can only be confirmed through invasive surgery. The causes of endometriosis are also unknown, but recent research has indicated there may be a hereditary link: having a family member with endometriosis raises the risk of having the disorder sixfold.<sup>6</sup>

The most recent research assessing endometriosis in the U.S. Army was published over 30 years ago. In 1988, researchers reviewed the records of 6,456 women in the U.S. Army and found the prevalence of endometriosis amongst the female servicemembers to be 6.2% with an estimated lost duty time related to endometriosis of 21,746 days over 5 years. The costs of endometriosis to female service members, veterans, and family members has almost certainly grown over the years as the number of women serving in our armed forces has increased.

The PRMRP listed endometriosis as a Congressionally Directed Topic Area in FY18, but the disease was removed last year. The FY18 funding has enabled grant awards for key areas of endometriosis research including in genomics, identification of biomarkers to help develop a non-invasive diagnostic tool, the transformation of endometriosis into cancer, non-hormonal medical therapy, and the effects of chronic pain for women. Continued research will be needed to understand the causes of endometriosis, find a noninvasive diagnosis tool, and cure or better treat the disorder.

Endometriosis research may also provide further insight into many other diseases that have historically been studied through the Congressionally Directed Medical Research Program. According to researchers at the National Institutes of Health, women with endometriosis are more likely to have chronic fatigue syndrome, fibromyalgia syndrome, asthma, allergies, and eczema. Endometriosis is also associated with an increased risk of developing certain types of ovarian cancer, and limited research on the topic indicates that endometriosis may also be connected to breast cancer.

Institute of Child Health and Human Development, "Health research throughout the lifespan," https://www.nichd.nih.gov/health/topics/endometri/conditioninfo/at-risk

Nnoaham et al. "Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries". Fertil Steril 2011; 96(2):366-373, <a href="https://www.sciencedirect.com/science/article/pii/S0015028211008764">https://www.sciencedirect.com/science/article/pii/S0015028211008764</a>
U.S. Department of Health & Human Services, National Institutes of Health, Eunice Kennedy Shriver National

Boling, Abbasi, et al. "Disability from endometriosis in the United States Army." January 1988. J Reprod Med: 49-52, <a href="https://www.ncbi.nlm.nih.gov/pubmed/2965241">https://www.ncbi.nlm.nih.gov/pubmed/2965241</a>

Bepartment of Defense, Congressionally Directed Medical Research Programs, "Peer Reviewed Medical," <a href="https://cdmrp.army.mil/prmrp/awards/awards">https://cdmrp.army.mil/prmrp/awards/awards</a>

<sup>&</sup>lt;sup>9</sup> U.S. Department of Health & Human Services, National Institutes of Health, Eunice Kennedy Shriver National Institute of Child Health and Human Development, "Women with Endometriosis Have Higher Rates of Some Diseases," <a href="https://www.nichd.nih.gov/newsroom/releases/endometriosis">https://www.nichd.nih.gov/newsroom/releases/endometriosis</a>

<sup>&</sup>lt;sup>10</sup> Brilhante, Augusto, et al. "Endometriosis and Ovarian Cancer: an Integrative Review (Endometriosis and Ovarian Cancer)." 2017; Asian Pacific Journal of Cancer Prevention; 18(1): 11-16, <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5563086/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5563086/</a>

Pontikaki, Sifakis, and Spandidos. "Endometriosis and breast cancer: A survey of the epidemiological studies." January 2019; Oncology Letters Spandidos Publications; 11(1): 23-30, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4726942/

Including endometriosis as a PRMRP Congressionally Directed Topic Area will provide vitallyneeded research support to a women's health disorder that has been overlooked and underfunded. We appreciate your consideration of this request.

Sincerely,

Elizabeth Warren

United States Senator

Mitt Romney

United States Senator