April 5, 2018

The Honorable Roy Blunt  The Honorable Patty Murray
Chairman  Ranking Member
Senate Labor-HHS Appropriations  Senate Labor-HHS Appropriations
Subcommittee  Subcommittee
United States Senate  United States Senate
Washington, D.C. 20510  Washington, D.C. 20510

Dear Chairman Blunt and Ranking Member Murray,

As organizations dedicated to advancing and improving the health of women, we are writing to draw your attention to endometriosis, a disorder that impacts approximately 1 in 10 women in the US between the ages of 18 and 49.

We respectfully request that, in drafting the FY 19 LHHS appropriations bill and accompanying report language, the LHHS Subcommittee include report language addressing the lack of adequate public awareness and understanding of endometriosis.

While endometriosis is one of the most common of gynecological conditions, it far too often goes undetected and untreated. Women suffering from endometriosis frequently experience infertility, as well, and diagnosing the disorder takes an average of four years for women trying to conceive. For women whose main complaint is pelvic pain, the average time to diagnosis is almost seven and a half years.

Despite the number of women suffering from endometriosis, there are too few treatment options available to patients. The serious emotional, physical, and financial burdens associated with endometriosis affect not only the women living with the disorder, but their families and society as a whole.

NIH research dollars dedicated to endometriosis have dropped from $16M in 2010 to $7M in 2018. There is a need for a comprehensive assessment of the current state of endometriosis and the identification of areas where more research and data can contribute to improved treatments and outcomes.

We urge you to include report language in the LHHS bill that addresses this issue and ensures that this disease is given appropriate attention and prioritized as an important women’s health issue. For your consideration draft report language we feel would be appropriate is attached.
Thanks in advance for your attention to this unmet women health need.

Sincerely,

Richard Reindollar, MD  
Chief Executive Officer  
American Society for Reproductive Medicine

Hal C. Lawrence, III MD, FACOG  
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Dr. Sandra Gelbard, MD  
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Debra Ness  
President  
National Partnership for Women and Families

Gay Johnson  
Chief Executive Officer  
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cc: Senate Labor-HHS Subcommittee Members

   Senator Richard Shelby, Incoming Chairman, Senate Committee on Appropriations

   Senator Patrick Leahy, Vice Chairman, Senate Committee on Appropriations
Endometriosis.—The Committee is aware that endometriosis is a serious chronic condition that impacts an estimated one in 10 women in the United States between the ages of 18 and 49. Women with this condition can suffer up to 10 years before being properly diagnosed, often due to lack of awareness, invasive methods of diagnosis, and limited treatment options. The Committee encourages the National Institute of Child Health and Human Development (NICHD) at the NIH to develop a report on the current state of endometriosis, including topics such as disease prevalence, an evaluation of diagnostic standards, treatment options, and outcomes. The report should also identify remaining knowledge gaps in understanding this disease and recommendations for filling these gaps. Further, the Committee encourages NICHD/NIH, in collaboration with the CDC, to continue to support education, outreach, and awareness to promote early and accurate diagnosis of endometriosis.