



The American College of
Obstetricians and Gynecologists
WOMEN'S HEALTH CARE PHYSICIANS



March 27, 2019

The Honorable Rosa DeLauro
Chair
House Labor-HHS Appropriations
Subcommittee
United States House of Representatives
Washington, D.C. 20515

The Honorable Tom Cole
Ranking Member
House Labor-HHS Appropriations
Subcommittee
United States House of Representatives
Washington, D.C. 20515

Dear Chairwoman DeLauro and Ranking Member Cole,

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 2020 LHHS appropriations bill and accompanying report language, you include report language addressing the lack of adequate public awareness and understanding of endometriosis. *For your consideration we are forwarding draft report language (attached).*

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 this chronic disease, 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 \$6M in 2019.

We applaud the leadership of the LHHS Appropriations Subcommittee for including language in the FY 2019 Report accompanying the LHHS Bill. Despite the report language, to date in 2019 NICHD has not issued a report on the state of endometriosis, nor are we aware of new initiatives

by NICHD or CDC to support education, outreach, or awareness aimed at promoting early and accurate diagnosis of endometriosis.

We believe that the more specific language in the FY 2020 bill is warranted and necessary. It would ensure that whatever report is issued on the current state of endometriosis includes topics such as disease prevalence, an evaluation of diagnostic standards, treatment options and outcomes.

As healthcare providers, patients and groups dedicated to improving access to quality healthcare for women, we are troubled that endometriosis has not been given appropriate attention and priority. Women, patients and healthcare providers need the most up-to-date information on diagnosing and treating this disease, as well as the identification of areas where more research and data can contribute to improved treatments and outcomes.

Thank you in advance for your consideration of our request. Your past support is tremendously appreciated. Working together we believe we can play a role in improving the health education and outcomes of women living with endometriosis.

Sincerely,

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

Lisa M. Hollier, MD, MPH
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President
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cc: House Labor-HHS Subcommittee Members
Congresswoman Nita Lowey, Chairwoman, House Committee on Appropriations
Congressman Kay Granger, Ranking Member, House Committee on Appropriations

Proposed FY 2020 Report Language

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 again in FY 2020 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.