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ACMG Applauds Increase in Funding for Newborn Screening and Medical Genetics Workforce Study in FY 2019 LHHS Appropriations

On September 28, 2018, the President signed the Department of Defense and Labor (DOD), Health and Human Services, and Education (LHHS) Appropriations Act of 2019, an appropriations bill that provides FY2019 funding for several important federal agencies, including the National Institutes for Health (NIH), Health Resources and Services Administration (HRSA), and Centers for Disease Control and Prevention (CDC). ACMG, together with other organizations that support newborn screening, advocated for increased funding for HRSA's Heritable Disorders program and newborn screening activities carried out by CDC's Environmental Health Laboratory. We are pleased to report FY2019 funding levels of $16,383,000 for the HRSA's Heritable Disorders program, a $500,000 increase from FY2018, and $17,250,000 for CDC's newborn screening activities, a $2,600,000 increase from FY2018.

Additionally, ACMG is excited to announce that the 2019 LHHS appropriations bill also included a request for the U.S. Government Accountability Office (GAO) to perform a nationwide analysis of the medical genetics workforce that includes all medical genetics professionals. The study request is a direct result of ACMG's advocacy efforts and was presented to the House Appropriations Committee by Representative Jaime Herrera Beutler (Washington's 3rd District). Thanks to Rep. Herrera Beutler, the Committee recognized the important role that the medical genetics workforce plays in precision medicine, particularly given the unprecedented advances in genetic testing and the rapid and widespread application of these tests across all of medicine. The analysis will include a determination as to whether there are sufficient qualified medical genetics professionals as well as whether there are particular geographic areas of the country that lack access to genetic counseling. The results of the workforce analysis will help more clearly identify workforce needs and will serve as a starting point for implementation of programs and development of tools to fill workforce gaps and incentivize students and young professionals to enter the medical genetics workforce. ACMG looks forward to providing available data and assisting in the acquisition of additional data as needed to support the GAO's assessment.

Representative Herrera Beutler is no stranger to the field of medical genetics and genomics. In the FY2018 LHHS appropriations, she included a request for HRSA's Maternal and Child Health Bureau to convene a meeting of Federal and public stakeholders representing health care professionals, industry, and patient voices to discuss the purposes and definitions of noninvasive prenatal screening (NIPS), the status of research regarding the effectiveness of various practices regarding NIPS, other factors that should be considered in implementing NIPS, provider best practices and guidance, and patient and industry needs related to information dissemination and standards for screenings. The meeting, intended to establish consensus about next steps for provider and patient education, was held May 21st, 2018. As follow-up to the meeting, the Committee requested that HRSA provide a report outlining consensus recommendations for

education of women regarding NIPS, possible methods/timeline for implementing an education initiative related to prenatal screening, and a recommendation to the Secretary regarding a process by which materials related to specific conditions are created, disseminated, and updated on a routine basis.

“ACMG thanks Rep. Herrera Beutler for her ongoing support of medical genetics, the workforce, and the patients we support,” said ACMG Executive Director, Michael S. Watson, PhD, FACMG. “We look forward to continuing to work with Congress to increase awareness of the importance of medical genetics and advocate for policies that support the responsible application of genomics in medical practice.”