**Health Equity and Accountability Act of 2016 (HR 5475, 114th Congress)**

Among other aims, seeks to improve the health of minorities, women and children, by addressing genetics.

Updated last **August 15, 2016**
for the 6/14/16 version of H.R. 5475

**WHAT IT DOES**

**H.R. 5475** focuses on improving the health of minority individuals, women and children by expanding research and implementing programs to investigate diseases and their causes. This brief focuses on the genetics-centric aspects of the bill, including:

Improving health outcomes for women, children, and families (Sec. 509):

- Adds a new section to the Public Health Service Act (42 U.S.C. 243 et seq.) requiring the Secretary of Health and Human Services to develop a multisite gestational diabetes research project within the Centers for Disease Control and Prevention. This project aims to expand surveillance data and public health research on gestational diabetes.
- The project will address factors, including genetic, that influence risk and identify culturally sensitive interventions to reduce the incidence of gestational diabetes and related complications during childbirth.

Addressing high impact minority diseases by:

- Directing the Center for Disease Control and Prevention to develop a system to collect data on acquired bone marrow diseases and establish and maintain a publicly available National Acquired Bone Marrow Failure Disease Registry. This registry shall identify the incidence and prevalence of acquired bone marrow failure diseases in the US and will be used to collect and store data on such diseases, including associated genetic and environmental factors (Sec. 721).
- Developing guidelines, through the Agency for Healthcare Research and Quality, for disease screening of minority patient populations, which have higher than average risk for chronic diseases/cancer. Guidelines will be developed for numerous diseases, including genetic diseases and their related conditions (Sec. 731).
- Amending the Public Health Service Act (42 U.S.C. 285c et seq.) by adding that the Director of the National Institutes of Health shall expand, intensify, and support ongoing research and other activities regarding prediabetes and diabetes (emphasis on type 2) in minority populations. This research shall include investigation into the genetic causes and factors of diabetes that contribute to increased rates of diabetes in minority populations (Sec. 771).
- Conducting public education and awareness activities through the National Heart, Lung, and Blood Institute (NHLBI) and coordinating with patient and professional organizations to facilitate earlier diagnosis and improve patient outcomes from treatment of chronic obstructive pulmonary disease. The education and awareness activities will reflect the differences in chronic obstructive pulmonary disease due to varying causes, including genetic (Sec. 779).
- Conducting research relating to sleep and circadian rhythm through the NHLBI. The institute will develop study methods and analytical approaches to explain and predict determinants of sleep health, including biological or genetic determinants (Sec. 792).

Addressing Social Determinants and Improving Environmental Justice:

- Title X of H.R. 5475 defines “personal determinants of health” as reference to “an individual’s behavior, biology, and genetics.” Within this Title, the bill’s findings state that diabetes has a social and communal origin, as opposed to placing exclusive responsibility on individual choice and genetic predisposition.
Bone marrow failure syndromes are rare diseases characterized by an inability to make enough blood - either red cells, which carry oxygen; white cells, which fight infection; or platelets, which help the blood clot. The disorders can either be acquired or inherited. The most common cause of acquired bone marrow failure is aplastic anemia; exact U.S. incidence rate is unknown, although some sources say that approximately 500-1,000 new cases of aplastic anemia are diagnosed each year.

Gestational diabetes is a type of diabetes that develops only during pregnancy. The hormonal changes to the body during pregnancy resulting in the body using insulin less effectively. There is a higher risk of developing gestational diabetes in women of African American, American Indian, Asian American, Hispanic/Latina, or Pacific Islander American descent. These family backgrounds are also at higher risk for developing type 2 diabetes. Type 1 and Type 2 diabetes can be caused by inheriting a predisposition to the disease and triggered by environmental factors. The true prevalence of gestational diabetes is unknown. The closest estimates are based on data collected from birth certificates and Pregnancy Risk Assessment Monitoring System questionnaires, which reveal that 1-14% of pregnant women in the US could develop gestational diabetes annually.

Chronic obstructive pulmonary disease (COPD) is a progressive disease that hinders breathing ability. Less air flows in and out of airways due to either the airways and air sacs lose elasticity, the walls between air sacs are destroyed, the airway walls become inflamed, or the airways produce abnormal amounts of mucus. The leading cause of COPD is cigarette smoking. Long-term exposure to other lung irritants, such as pollution, chemical fumes and dust are also contributing factors. COPD affects over 24 million Americans. Rarely, a genetic condition triggers COPD, which impacts approximately 100,000 people.

Sleep disorders chronically affect 50 to 70 million Americans. There are approximately 90 distinct sleep disorders such as sleep loss, insomnia, breathing irregularities and narcolepsy. The long-term effects of sleep disorders have been associated with various negative health consequences. These include hypertension, diabetes, obesity, depression, heart attack, and stroke. The extent of the effect of genetics on sleep disorders remains widely unknown, however genome-wide association studies have revealed around 14 different chromosome locations (loci) that increase susceptibility to sleep disorders such as narcolepsy and restless leg syndrome.

Endorsements & Opposition

Endorsements:

- The American Psychological Association (APA) released a letter on June 15, 2016 in support of the bill, stating “APA supports HEAA’s aim to decrease disparities [in mental health access]. This effort is timely and essential in order to improve the quality of life among all Americans. Even with advancements made possible by the enactment of the Affordable Care Act, the path to health equity for minority and underserved communities is not complete. The HEAA recognizes that additional steps are needed to build upon the ACA’s solid foundation.” The APA represents the largest scientific and professional organization of psychologists in the U.S.

- The National Family Planning & Reproductive Health Association released a statement of support for the bill: “While the ACA makes significant advances in extending access to coverage, achieving health equity and addressing health disparities experienced by communities remains a fundamental challenge and standalone legislation is needed to address these challenges. HEAA dedicates more resources to safety-net providers, programs, and community partners who are called upon to provide preventive care to underserved communities across the country.” The National Family Planning & Reproductive Health Association (NFPRHA) is a “non-profit membership organization established to ensure access to voluntary, comprehensive, and culturally sensitive family planning and reproductive health care services and to support reproductive freedom for all.”

Opposition:

- At present, there has not been publicly reported opposition to this bill.

Status
H.R. 5475 was introduced in the House on June 14, 2016. On June 29, 2016, the bill was referred to the Subcommittee on Military Personnel, which is part of the Committee on Armed Services.

RELATED POLICIES

H.R. 2651, “Eliminating Disparities in Diabetes Prevention, Access, and Care Act of 2015,” was referred to Subcommittee on Health on June 5, 2015. The bill amends the Public Health Service Act to require the National Institutes of Health expand and support activities regarding diabetes in minority populations (similar to H.R. 5475).

S. 2114, “A bill to correct inconsistencies in the definitions relating to Native Americans in the Patient Protection and Affordable Care Act,” was referred to the Committee on Finance on October 1, 2015. The bill amends Title I of the Patient Protection and Affordable Care Act to add a definition of “Indian,” including individuals of Indian descent, members of an Indian community served by the Indian Health Service, and individuals considered by the Department of Health and Human Services to be Indian for purposes of eligibility in Indian health care services.

SPONSORS

Sponsor: Robin Kelly (D-IL-2)

Co-Sponsors: Michelle Lujan Grisham (D-NM-1), Linda Sanchez (D-CA-38), Barbara Lee (D-CA-13), Judy Chu (D-CA-27), Donald Payne, Jr. (D-NJ-10), and G.K. Butterfield (D-NC-1).

PRIMARY AUTHOR

Allyson Luo

EDITOR(S)

Brian Langloss, PhD Candidate & Aubrey Incorvaia, MPP

RECOMMENDED CITATION