

Hon. Doris O. Matsui

Member of Congress



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The Bone Marrow Failure Disease Research and Treatment Act

Section-by-Section Summary

SECTION 1. SHORT TITLE.

Names the legislation the “Bone Marrow Failure Disease Research and Treatment Act of 2009.”

SEC. 2. FINDINGS.

Makes a number of findings about the significant impact that acquired bone marrow failure diseases have on the thousands of people diagnosed annually.

Outlines a strategy to increase research into myelodysplastic syndromes, aplastic anemia, paroxysmal nocturnal hemoglobinuria, and other acquired bone marrow failure diseases.

SEC. 3. NATIONAL ACQUIRED BONE MARROW FAILURE DISEASE REGISTRY.

Creates an acquired bone marrow failure disease registry at the Centers for Disease Control and Prevention (CDC), which shall store and make the following information available to researchers in accordance with the CDC’s standard practices:

- The incidence and prevalence of acquired bone marrow failure diseases in the United States;
- The age, race, ethnicity, sex, and geographic location of those people who acquire a bone marrow failure disease;
- The genetic and environmental factors that may be associated with these diseases;
- Strategies for treating these disorders;
- Outcomes for Americans treated for bone marrow failure diseases.

Creates an advisory committee to make public recommendations to the CDC on how to set up and maintain this registry.

The advisory committee shall consist of at least one representative from each of a national bone marrow failure disease patient advocacy organization; the National Cancer Institute; the National Heart, Lung, and Blood Institute; the National Institute of Health’s Office of Rare Diseases; the C.W. Bill Young Cell Transplantation Program and its associated database; and the CDC. The advisory committee must also include at least one clinician with experience in the field of acquired bone marrow failure diseases, at least one epidemiologist with experience managing data registries, and at least one researcher who has examined acquired bone marrow failure diseases.

Authorizes the Director of the CDC to award grants to public or nonprofit entities to collect, analyze, and report the data that will be stored in the registry.

Authorizes \$3 million annually for fiscal years 2010 through 2014 for the acquired bone marrow failure disease registry.

SEC. 4. PILOT STUDIES THROUGH THE AGENCY FOR TOXIC SUBSTANCES AND DISEASE REGISTRY.

Authorizes \$1 million annually for fiscal years 2010 through 2014 for pilot studies conducted by the Agency for Toxic Substances and Disease Registry, in cooperation with the C.W. Bill Young Transplantation Program's Radiation Improvement Network, to improve information on the environmental factors that may cause people to acquire bone marrow failure diseases.

SEC. 5. MINORITY-FOCUSED PROGRAMS ON ACQUIRED BONE MARROW FAILURE DISEASES.

Charges the Health and Human Service Department's Office of Minority Health (OMH) with establishing and coordinating program to make information available to minority populations about acquired bone marrow failure diseases.

Authorizes grants through the OMH to finance research on the incidence of acquired bone marrow failure diseases in minority populations.

Authorizes \$2 million annually for fiscal years 2010 through 2014 to carry out this section.

SEC. 6. DIAGNOSIS AND QUALITY OF CARE FOR ACQUIRED BONE MARROW FAILURE DISEASES.

Authorizes \$2 million annually for fiscal years 2010 through 2014 for the Agency for Healthcare Research and Quality to award grants aimed at improving diagnostic practices and quality of care for acquired bone marrow failure disease patients.

SEC. 7. DEFINITION.

Defines "acquired bone marrow failure diseases" as myelodysplastic syndromes (commonly known as "MDS"), aplastic anemia, paroxysmal nocturnal hemoglobinuria (commonly known as "PNH"), pure red cell aplasia, acute myeloid leukemia that progress from MDS, or large granular lymphocytic leukemia.