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Friday, February 11, 2011

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## **Congresswoman Matsui Introduces Acquired Bone Marrow Failure Diseases Research and Treatment Act**

**WASHINGTON, D.C.** – Today, Congresswoman Doris Matsui (CA-05) introduced the [Acquired Bone Marrow Failure Disease Research and Treatment Act of 2011, H.R. 640](#), in the House of Representatives. Matsui’s legislation will expand the research, treatment, and education available about acquired bone marrow failure diseases, which although rare, are often fatal. Little research on these set of diseases have been pursued to date, which leaves patients unnecessarily struggling from what could be preventable or treatable diseases.

“Though thousands suffer from bone marrow failure diseases every year, little has been done to address these illnesses,” said Congresswoman Matsui. “My legislation will support long overdue research and improve treatment options for those that suffer from bone marrow diseases. As someone who has a deeply personal connection to these diseases, I understand the toll they can take and the potentially life-threatening consequences they have.”

Every year, at least 20,000 Americans are diagnosed with some form of acquired bone marrow failure disease, and while individuals stricken with these conditions can take some action to prolong their lives, this diagnosis offers little hope that affected patients will ever fully recover. H.R. 640 would enhance and intensify current and future efforts in the fight against bone marrow failure diseases by supporting increased research on these still relatively unstudied diseases, including what genetic and environmental factors may be associated with the condition and best practices for the diagnosis and treatment of these diseases.

The Bone Marrow Failure Disease Research and Treatment Act of 2011 would direct the Department of Health and Human Services (HHS) to develop a comprehensive strategy that includes:

- A national bone marrow failure disease registry so that researchers can combine their data in

one place, yielding more effective research designs and better results;

- Pilot studies through the Agency for Toxic Substances and Disease Registry to determine which environmental factors cause people to acquire bone marrow failure diseases;
- Minority-focused programs to make information on treatment options and clinical trials available to minority communities, particularly Hispanic and Asian American communities;
- Agency for Healthcare Research and Quality grants to help improve diagnostic practices and quality of care for patients with bone marrow failure diseases.

The Matsui legislation would also authorize coordinated outreach and informational programs targeted to minority populations affected by these diseases, including information on treatment options and clinical trials research. Although almost identical legislation passed the House last Congress with bipartisan support, the legislation was not considered by the Senate prior to adjournment.

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