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**Rep. Doris Matsui Introduces Bone Marrow Research and Treatment Expansion Bill
*Legislation Will Give Hope to Patients Across the Country***

WASHINGTON, D.C. – Representative Doris Matsui (CA - 05) introduced the Bone Marrow Failure Disease Research and Treatment Act of 2009 in the U.S. House of Representatives today, and is urging Congress to act quickly on this important measure.

“Bone marrow failure diseases impact families in communities across the country, and right now we know very little about how to treat them. The Bone Marrow Failure Disease Research and Treatment Act is an important step toward finding new treatments and cures for these diseases. It will allow us to better understand how we can prevent, diagnose and treat bone marrow failure diseases,” said Congresswoman Matsui.

Each year, between 20,000 and 30,000 Americans are diagnosed with acquired bone marrow failure diseases. These are painful and often fatal diseases, including aplastic anemia, myelodysplastic syndrome (MDS), and paroxysmal nocturnal hemoglobinuria (PNH).

The legislation increases the federal government’s commitment to researching and treating acquired bone marrow failure diseases, which occur when the body’s bone marrow stops working properly. In total, the legislation authorizes \$8 million annually for fiscal years 2009 through 2013.

“Our patients and families greatly appreciate the hard work and leadership exhibited by Representative Matsui,” said Aplastic Anemia and MDS International Foundation (AAMDSIF) Executive Director John Huber.

The Bone Marrow Failure Disease Research and Treatment Act directs 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.