

Rep. Doris Matsui Introduces Health Research Legislation Bill will expand research into bone marrow failure diseases

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WASHINGTON, D.C.—Today, Representative Doris O. Matsui (CA-05) introduced the Bone Marrow Failure Disease Research and Treatment Act of 2008. This critical legislation dramatically increases the Federal Government's commitment to finding and developing a cure for acquired bone marrow failure diseases, which affect thousands of families each year and which occur when stem cells inside the bone marrow stop making enough healthy blood cells.

"Bone marrow failure diseases impact families in cities, towns, and communities across our country, including my own," said Representative Matsui. "When a person is diagnosed with one of these often fatal conditions, their loved ones are forced to confront the fact that we know very little about what causes these diseases. We know even less about how to cure them, and the Bone Marrow Failure Disease Research and Treatment Act is a first step toward shedding light on these silent killers."

Every year, between 20,000 and 30,000 Americans are diagnosed with myelodysplastic syndromes (commonly known as MDS), aplastic anemia, paroxysmal nocturnal hemoglobinuria (known as PNH), and other acquired bone marrow failure diseases. These conditions take a debilitating and deadly toll on those diagnosed, forcing patients and families to deal with significant health, social, and economic hardships. While evidence exists suggesting that bone marrow failure diseases occur more often in minority groups than in the general population, a central database such as that envisioned in the legislation is needed to help researchers and epidemiologists understand these diseases' disproportionate racial impact.

"The Bone Marrow Failure Disease Research and Treatment Act is an important step toward finding new treatments and cures for these diseases," explained Aplastic Anemia and MDS International Foundation Executive Director John Huber. "Our patients and families greatly appreciate the hard work and leadership exhibited by Representative Matsui."

The Bone Marrow Failure Disease Research and Treatment Act directs the Health and Human Services Department to develop a comprehensive strategy to combat bone marrow failure diseases 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.

"I am committed to advancing research into bone marrow failure diseases, because I know the damage they can do and the pain they can cause," said Matsui. "The Bone Marrow Failure Disease Research and Treatment Act is a critical tool for our country's medical researchers as they continue to explore and examine the causes of these devastating illnesses. I am confident that the work this bill supports will one day yield a cure for bone marrow failure diseases, and I look forward to working with my colleagues in Congress to pass it into law."

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