



# Hon. Doris O. Matsui

## Member of Congress

*Doris O. Matsui*

### The Bone Marrow Failure Disease Research and Treatment Act

#### One-Page Summary

#### **BONE MARROW FAILURE DISEASES**

Between 20,000 and 30,000 Americans are diagnosed with acquired bone marrow failure diseases every year. These painful and often fatal diseases include myelodysplastic syndromes (MDS), aplastic anemia, and acute myeloid leukemia (which can progress from MDS).

Bone marrow failure diseases have exacted a significant toll on society, taking the lives of former Representatives Robert T. Matsui and Joe Moakley, Eleanor Roosevelt, Madame Curie, and Carl Sagan. Thousands more perish from these diseases every year, but we still know relatively little about what causes these disorders or how to treat them.

#### **WHAT THE BILL DOES**

The Bone Marrow Failure Disease Research and Treatment Act 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.

The legislation directs the Health and Human Services Department to develop a comprehensive strategy to combat these diseases, which include:

- **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.

In total, the legislation authorizes \$8 million annually for fiscal years 2010 through 2014.

#### **NEXT STEPS**

To co-sponsor the Bone Marrow Failure Disease Research and Treatment Act, contact [Sam Stefanki](#) in Congresswoman Doris O. Matsui's office by e-mail or over the phone at 5-7165. For more information on acquired bone marrow failure diseases, visit the [Aplastic Anemia and MDS International Foundation's website](#).