



AA & MDS International Foundation Electronic Bulletin

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Headline News...

The AA&MDSIF Medical Advisory Board, Executive Director, and President, met with senior representatives from funding institutions and prestigious international hematologist, scientists and researchers during the annual American Society of Hematology conference in San Diego to discuss the efforts of the newly created bone marrow clinical trials research network. This global forum was a perfect setting for AA&MDSIF to create a new Clinical Trials Study Group Consortium. The immediate task at hand for the Consortium is to identify the compelling questions that will lead to clinical trials best served by the multi-center approach. Stay tuned for more news in January on the Consortium efforts and how health care practitioners and patients can participate in these efforts.

More Headline News....

On December 8, President Bush signed into law the Medicare Prescription Drug and Modernization Act of 2003. The bill is the culmination of nearly a year of debate and compromise by Congress. The new law has been called the largest expansion of Medicare since its creation in the mid-1960's. The most sweeping provisions create a new Medicare drug benefit for seniors and also disabled individuals, who have qualified for Medicare. Because so many patients with AA, MDS and PNH are part of the Medicare program, the Foundation's patient advocate, Steven Grossman, has offered to answer questions about the impact of this law. E-mail grossman@aamds.org to pose a question. The most frequently asked questions will be published in the February issue of the e-bulletin.

Community News...

The AA&MDSIF Ohio Chapter members played Secret Santa stuffing and delivering holiday stockings to more than 100 bone marrow failure patients in their state. What is your community up to?

Advocacy Update....

Kudos to the many aplastic anemia, MDS and PNH patients, Board members, and family and support group members who helped us raise awareness by writing 75 awareness letters to the editors. Letters were printed in papers across the United States, Canada, the United Kingdom, Mexico and Australia. We hope you'll help us encourage blood and platelet donations in January by writing more letters.

Thank you...

Many thanks to the family and friends of Holly Cataldo who raised nearly \$4,000 for AA&MDSIF, through their annual Caring Car Cruise in the town of Jeannette, Pennsylvania. And thank you **Dr. Mikkael A Sekeres** for revising and updating the Foundation's "Myelodysplastic Syndromes Basic Explanations" booklet in 2003.

From the Doctor's Corner...

"Should a patient get a flu shot?"

There is disagreement among doctors as to whether or not aplastic anemia and myelodysplastic syndromes patients should get a flu shot. Some doctors advise patients not to get flu shots as this may worsen blood counts. However, other doctors feel the risk of the flu's illness outweighs potential harm from the flu shot. There is minimal data on this subject. Therefore the decision to get a flu shot or not should be discussed with the patient's hematologist to determine individual risks and benefits. Learn more from the experts, <http://aplastic.eyemg.com>

Calendar Notes...

January is "National Volunteer Blood Donor Month." Visit www.aamds.org to see how you can help thank volunteer blood donors and encourage new donors.

February 2-3, 2004 – BIO will host a partnering forum to introduce US and European clinical stage drug development companies to Japanese, and other Asian pharmaceutical companies in Tokyo, Japan. Contact: bioasia@bio.org

Words of Wisdom...

"Twenty-five years ago, 80-90% of patients with severe aplastic anemia would be dead within a year of diagnosis," says Neal Young, MD, Chief of Hematology with the National Heart, Lung and Blood Institute at the National Institutes of Health. Dr. Young, also a medical advisory board member for the Aplastic Anemia & MDS International Foundation (AA&MDSIF) notes that, "today, a great majority of patients are effectively treated by bone marrow transplants or immunosuppressive drug therapies, and survival rates of 5 or more years are at 70-90%."