Conference Update… Nearly a dozen leading experts, three hundred patients and their families will gather at the Holiday Inn BWI in Linthicum, Maryland July 8 – 10, 2004 to discuss the latest developments in the treatment of bone marrow failure diseases at the AA&MDSIF 2004 Patient and Family Conference. Presenters include: David Araten, M.D. of Memorial Sloan-Kettering Cancer Center; Carlos de Castro M.D. of Duke University Medical Center, MD; Kristine Doney M.D. of Fred Hutchinson Cancer Research Center; John Eaton, Ph.D of J.G. Brown Cancer Center; Marlene Haffner, M.D., M.P.H. of FDA Office of Orphan Product Development; Jaroslav Maciejewski M.D., Ph.D of Cleveland Clinic Foundation; Mikael Sekeres M.D., M.S. of Cleveland Clinic Foundation; Elaine Slaud M.D. of NIH, NHLBI; and Richard Stone, M.D. of Dana-Farber Cancer Institute. Physicians will answer patient questions and lead panel discussions on the latest research findings on treatment options for bone marrow failure diseases. Clinical trial information and managing treatment options are a few of the topics to be discussed at the conference. The conference also will include workshops on coping techniques and a variety of other educational, networking and social activities. Visit the patient conference page at www.aamds.org or call 800.747.2820.

We need YOUR help…The AA&MDSIF is preparing for another successful Silent Auction during the 2004 Patient Conference. To help offset conference costs, please donate items that can be carried on the plane or shipped home. The silent auction form can be found on the patient conference information page at www.aamds.org. For more information, contact Monica Grover at grover@aamds.org or call her at the office.

WANTED: Experienced Development Director…The AA&MDSIF is looking for a results-oriented development officer with 5-7 years of proven fundraising experience and the ability to secure major gifts. We offer a friendly office with an outstanding staff, all the delights of the nearby Chesapeake Bay, moderate pay with great benefits, and an extraordinary cause to work for! If you, or someone you know, is interested and qualified then come join us in Annapolis, Maryland! Send resume to: baker@aamds.org or fax to: (410) 867-0240.

We Need a New Copy Machine…If you have ties to Xerox, Toshiba, Ikon or any other copier/printer technology company, and are interested in donating or discounting a new copy machine to the foundation, please contact Julie Bast: bast@aamds.org or call her at the office.

Results from SuperGen Study…Results from a phase III study of Dacogen™ (decitabine) for myelodysplastic syndromes were reported in an April 1 press release from SuperGen, Inc. The study enrolled 170 patients. Dacogen™ with supportive care was compared to supportive care only. The overall response rate of patients randomized to Dacogen™ was 22 percent compared to 0 percent in patients on supportive care only. Side effects observed in patients randomized to Dacogen™ were decreased white blood cells, fever, nausea, constipation, vomiting, diarrhea, joint pain, headache and insomnia. Fast Track status for Dacogen™ was granted by the FDA on May 9, 2003. More information can be found on the company’s website at www.SuperGen.com.

Revlimid’s on a "Fast Track"… This FDA designation of Celgene Corp's Revlimid (CC-5013) means the drug possibly be approved sometime next year. Dr. Alan List, researcher at Moffitt Cancer Center in Tampa, FL and part of an NIH grant to study bone marrow failure diseases, has played an integral part in Revlimid's successful climb. Dr. List says, "This new agent shows exciting promise for the management of anemia in patients with lower risk MDS." Dr. List is the only researcher to continue studies, using the drug. Learn more at: www.usforacle.com. Also visit: http://www.healthcentral.com/news/NewsFullText.cfm?id=8008146.

PNH Clinical Trial Results… One year cumulative results of Alexion Pharmaceuticals’ ongoing clinical trial in PNH were presented at the British Society of Haematology annual meeting by Dr. Hillmen, M.B. Ch.B., Ph.D., The General Infirmary at Leeds, Leeds, UK. The phase Ib trial is evaluating the use of eculizumab in 11 paroxysmal nocturnal hemoglobinuria (PNH) patients. Results showed that eculizumab administration for one year was associated with statistically significant reductions in the need for blood transfusions, a key clinical objective of the trial, as well as in hemolysis. Learn more at: www.alexionpharmaceuticals.com.

Drugs for MDS Patients… The FDA’s Oncologic Drugs Advisory Committee will meet on May 3 and 4 to discuss two pending new drug applications, safety concerns associated with Aranesp and Procrit. These drugs treat anemia in MDS patients. Learn more at: www.fda.gov/opacom/hpmeetings.html.

FDA Information… For information on FDA Drug Approvals, drug information sheets, generic drugs, drug safety, and more, visit www.fda.gov/opacom/hpmeetings.html.

A New Patient Resource… Devices@FDA is a new tool for locating medical device information from the FDA. You can either enter a specific device name or a generic name (i.e. pacemaker) to retrieve useful information. Search Devices@FDA through www.fda.gov.

Symposium on Diabetes… Planned by the FDA & NIH, the symposium on diabetes intends to provide assistance to FDA, clinical and basic scientists, and the interested pharmaceutical industry in their efforts to reduce the burden of diabetes and improve the health of all people with diabetes. Go to: http://www.niddk.nih.gov/fund/other/FDA-NIH/index.htm.


Summer Camps for Kids… If your child suffers from AA, MDS, PNH or any other bone marrow failure disease, look into a fun summer adventure for him or her.


The Don Imus Ranch for Children (New Mexico) - Phone: 505-421-4687.

Camp Sunshine (Maine) - www.campsunshine.org Phone: 207-655-3825.