



PATIENT INFORMATION

Our expert Medical Board will answer your questions and provide information on any issue. Call or write to Debbie Judy - she is standing by ready to help you!



ASK THE EXPERTS

Go to www.aamds.org to review the archive of patient's questions which have been answered by our distinguished panel of medical experts. You can also personally ask your own question of these experts at this site.



PATIENT CLINICAL TRIALS

We give you an updated list featuring doctor's name, phone number and explanation of treatment protocols.



PATIENT TRAVEL FUND

Families traveling to clinical trials can receive up to \$500 for travel expenses. Contact our office to receive an application form.



GLOBAL NETWORK OF VOLUNTEERS

You are not alone — patients and families will share their treatment experiences with you. Call us to make a friend!



PATIENT REGISTRY

Statistics on these diseases seem to be as rare as the diseases themselves. Please fill out our Patient Registry Form for surviving or deceased patients. The more data we collect, the more data we can use for research.



YOU CAN HELP

Please donate your blood & platelets, have your bone marrow tested, and financially donate to the AA&MDSIF's research & support efforts.



American Society of Hematology Meeting

In December 2004, nearly 20,000 clinicians, scientists, and various other professionals in the field of hematology attended the annual meeting of the American Society of Hematologists. Oral and poster presentations covered the latest developments in scientific research in hematology. Here are brief summaries of some of the most significant topics related to AA, MDS, and PNH.

The full abstracts of these items were published in the journal *Blood*, volume 104, issue 11, November 16, 2004 and can also be viewed online at http://www.abstracts2view.com/hem_sandiego2004/

Aplastic Anemia

Aplastic anemia patients who did not respond to immunosuppressive therapy were treated with Danazol, an anabolic steroid, for at least 3 months. Findings indicate that the drug, which may stimulate the growth of a small number of stem cells that survive, is useful in the treatment of a subset of patients without PNH-type cells. In particular, being both female and PNH-negative were associated with a good response to Danazol. [Abstract 2817]

A 15-year followup study of patients in Brazil with severe aplastic anemia who did not have suitable bone marrow donors and were treated with cyclosporine and prednisone showed that treatment to be effective. Data shows patients become free of infections and transfusion independent and are able to live normal lives even though their blood counts may remain subnormal. [Abstract 2816]

A prospective multi-national study in Germany, Austria, and Switzerland compared bone marrow transplantation and immunosuppressive therapy (IST) in children with aplastic anemia. Results showed very severe aplastic anemia patients who received IST did as well as those who had matched-sibling donor transplants as their first treatment. [Abstract 1439]

A study conducted by the Japan Childhood Aplastic Anemia Study Group compared the relative effectiveness of repeated immunosuppressive therapy vs. stem cell transplantation (SCT) from unrelated donor as a second-line treatment for children with aplastic anemia. Data showed that SCT offers a better chance of progression-free survival although overall survival was slightly lower due to treatment mortality. [Abstract 2815]

Myelodysplastic Syndromes

The results of a North American Phase III clinical trial of decitabine (Dacogen) vs. supportive care in adult MDS patients with IPSS intermediate and high-risk disease show decitabine to be a promising therapy with manageable toxicity. Patients who responded showed sustained improvements in several aspects of physical health, including transfusion independence, and quality of life measures such as physical functioning and fatigue. [Abstract 67]

The results of an international Phase II study of R115777 (Zarnestra™) shows this oral therapy to be gentle enough for use by high-risk MDS patients in their 70s or 80s. About one-third of 82 patients treated had durable responses with limited toxicity. Zarnestra

continued on page 3

FROM THE DIRECTOR...

Everything has its wonders, even the darkness and silence, and I learn, whatever state I may be in, therein to be content.

-Helen Keller

Last year I spoke to an MDS patient who told me how hysterically upset he was over his diagnosis. Three months later he called to say that he was still so upset that he couldn't get out of bed anymore. At 6 months, he reported that his depression was now joined by anger and fury. At 9 months, he let me know that his family had left him so he was spending his days alone and crying. After a year, he called to say that even though his disease hadn't worsened, he was so sick at heart that the stress was killing him. I couldn't help but think that an entire year of a precious



life was wasted because he couldn't accept that he had the blessing of being alive even though it wasn't exactly on his terms. In contrast is our Foundation's president, Robert Carroll. During his 15 years with MDS, Bob has been transfusion dependent on a bi-weekly basis and needs an 8-hour pump each night to treat his iron overload. Regardless of these challenges, Bob not only works full-time but does amazing work helping others. A recent example is his fundraising campaign that has already raised \$200,000 to build a new school in Sri Lanka which was destroyed during the recent Tsumani. An amazing man who has created an amazing life and legacy because of his illness.

The power of positive thinking is a scientifically proven fact of life. It is well documented that when a patient creates healing powers, instead of destructive negativity, they live longer and better lives. No matter what the circumstances, everyone can make a life that is rich with joy and wonderment. All it takes is daily effort to think positive thoughts, see optimistic affirmations, and choose inspirational activities instead of blind and empty bitterness.

Finding the extraordinary in an ordinary life is the secret to happiness.

If you change your thoughts about a situation, then you can change the situation. So, if you are sick or worried about someone who is, make some changes. Open your mind to new things. There's an entire world out there for you to enjoy! Meditate every day using a CD headset or join a class. Do daily yoga with a DVD or join a class. Listen to beautiful music. Watch what happens in your back yard instead of watching the news. Walk around your block every day, several times a day. Ride a bicycle in local parks. Get out there and explore new places. Feed the birds and squirrels. Get a telescope and watch the stars. Read poetry. Study all the religions of the world and create your own. Read

FOR KIDS

Serious Illness Camps - Medical Staff 24/7

Association of Hole in the Wall Gang Camps

<http://www.holeinthewallcamps.org/>
203.562.1203

Paul Newman founded this non-profit year round camping association in 1988; all stays at Hole in the Wall Camps are free of charge.

Camp Simcha

http://www.chailifeline.org/camp_simcha.asp
877.242.4543

Staying at Camp Simcha, including travel from anywhere in the world, is completely free of charge. Preference is given to children with hematological disorders.

Scholarship

Patient Advocate Foundation - Scholarships

<http://www.patientadvocate.org/events.php?p=69>

"The purpose of these scholarships, are to provide support to patients seeking to initiate or complete a course for study that has been interrupted or delayed by a diagnosis of cancer or other critical or life threatening disease."

Also please speak to your local librarian or school counselor for more resources.

self-help books every day by such authors as Wayne Dyer and Melody Beattie. See a therapist to help you sort out your thoughts. Grow, expand, change, give up being stubborn, let go and accept new thoughts and activities. Go to all the museums you can. Volunteer in an orphanage. Volunteer in an animal shelter. Volunteer in a homeless shelter. Cook in a soup kitchen for the poor. Make the world a better place thanks to the things you've done. Search hard for the positive in everything and smile every time you see a blessing. Smile a hundred times a day. Make everyone you come in contact with smile. Do something new everyday: knit, paint, sing, play the guitar, create an invention, write a children's book, bake bread. Take an art class. Take a music appreciation class. Take a cooking class. Dance. Rent funny movies. Go to the library for inspiring novels. Create a personal mantra and repeat it a hundred times a day, something like: "Accept and Adapt with Gratitude and Grace." Do something kind for someone every day. Help people, lots of people. Make new friends, lots of friends.

Doing all this may or may not prolong your time on earth, but it will absolutely make your life, and the lives of those around you, incredibly marvelous. Choose to have a marvelous life, no matter how long it is.

-- Marilyn Baker, M.S.
Executive Director & Editor

belongs to a group of drugs known as farnesyl transferase inhibitors, which block enzymes needed for the activation of cancer-promoting proteins. [Abstract 69]

Darbopoietin Alfa is a longer-lasting form of erythropoietin (EPO) that allows weekly administration (or even every second week). Results obtained with Darbopoietin Alfa alone (without G-CSF) on the anemia of low-risk MDS may be better than those obtained with conventional EPO alone, and the drug is well tolerated. Randomized studies are needed to compare the effect of the different types of EPO on the anemia of MDS patients. [Abstract 69]

A hospital-based case control study was conducted to investigate the association between lifestyle characteristics and MDS risk. Cases included 354 newly diagnosed adult de novo MDS cases diagnosed between 1996 and 2003 and 452 healthy control subjects. A validated questionnaire was used to collect demographic and epidemiological information, including lifetime history of smoking, alcohol consumption, and occupational history. Primary risk factors identified in this study are: (1) first degree relative diagnosed with blood-related cancer, (2) having ever smoked, and (3) having been exposed to agricultural chemicals or solvents. Wine drinkers showed a reduced risk. Risk profiles seem to differ by FAB classification. A joint effect between smoking and chemical exposures was found among smokers who were also exposed to solvents or agricultural chemicals as compared to people who never smoked and had no chemical exposure. [Abstract 71]

The role of the p38 MAP Kinase (an enzyme involved in many cellular processes) in the pathogenesis of MDS was studied and its inhibition was identified as a potential source of therapies for the disease. [Abstract 470]

A large study analyzing the outcomes for MDS patients who underwent bone marrow transplants using HLA-matched unrelated donors vs. those who had stem cell transplants using HLA identical siblings showed that after high mortality at transplant, survivors with unrelated donors had a decreased rate of relapse. [Abstract 1427]

The preliminary results of an ongoing European multi-center Phase I/II study of arsenic trioxide (Trisenox®) in MDS patients indicate that the drug is generally well tolerated, even by elderly patients, and that it induces responses in all three hematopoietic lineages, in similar proportions for patients with higher risk and with lower risk MDS. Fourteen of 86 transfusion-dependent patients became transfusion independent. [Abstract 1433]

A Phase 1 study involving 53 patients to assess the tolerance and response rate in MDS patients receiving R115777 (Zarnestra™) alternating one-week on the drug

and one-week off the drug found it to be well tolerated with a response rate of 29%. This intermittent schedule would lend itself to combination or maintenance regimens. [Abstract 1436]

A Phase I/II study involving 19 MDS patients to evaluate the safety and efficacy of rapamycin (sirolimus) demonstrated that rapamycin might be effective in blocking T-cell activation and proliferation in advanced MDS. As new and possibly less toxic versions of rapamycin are developed, they could be candidates for future trials with MDS patients. [Abstracts 1449]

TLK199 (Telintra™), which improves hematopoietic cell proliferation and differentiation, is currently being evaluated in a Phase II trial for patients with refractory MDS. A significant increase in the number of cell colonies was seen in patients' peripheral blood and bone marrow early in the treatment cycle. Ten of 12 patients showed an increase in at least one colony type and 7 of 12 had an increase in all three colony forming types. Studies are underway to define the mechanism of bone marrow and peripheral blood count recovery. [Abstract 2372]

Preliminary clinical results were reported from an ongoing Phase II trial of REVLIMID in MDS patients with 5q deletion. Transfusion independence was achieved in approximately 2/3 of patients, hemoglobin counts were increased, bone marrow histology normalized in about 1/3 of patients, and some cytogenetic response was achieved in approximately 3/4 of patients. Complete cytogenetic response was achieved in more than 50% of the cytogenetic responders.

PNH

A two-year study of 10 patients given Eculizumab, a monoclonal antibody, for PNH shows that the drug is well tolerated and provides sustained control of hemolysis and reduces transfusion requirements. [Abstract 2823]

Researchers in the U.K. reported results from an ongoing study to monitor the size and type of granulocytes and red cells in PNH patients. Such measurements may help to predict the likelihood of spontaneous reduction in the PNH clones and the potential for spontaneous remission and so may allow doctors to manage the clinical course for individual patients more effectively. They identified those patients most likely to have a spontaneous decrease as having <90% GPI negative neutrophils at diagnosis. [Abstract 172]

PROTECTIONS FOR CLINICAL TRIAL PARTICIPANTS

Much of the progress made in medical research has come from patients choosing to participate in clinical trials. Through their participation, researchers learn more about how to diagnose diseases and discover new and better



treatment options. Carefully conducted clinical trials are the fastest and safest way to find treatments that work for patients and ways to improve health. To ensure that medical progress is made safely and ethically, the protections described below make certain that those who participate in clinical studies are protected from harm and unnecessary risk.

Protection for people participating in clinical research studies is of first and foremost importance to the United States government. *The Common Rule*, a Department of Health and Human Services regulation effective 12/13/01, mandates that clinical studies must be conducted under strict guidelines to protect participants' rights and welfare and to ensure that risks to participants are minimal compared to likely outcomes. This policy also enforces oversight by Institutional Review Boards (IRBs) and requires informed consent by all study participants. These rules apply to all clinical research involving human participants subject to federal regulation.

IRBs are independent committees established at each medical center conducting clinical research to ensure that the risks to study participants are minimal and are offset by the potential benefits of their participation in the study. Members of an IRB may include individuals such as doctors, other health care professionals, and community advocates who do not have any personal interest in the results of the study. It is the IRB's responsibility to ensure that the highest ethical standards are met and that participants' rights are protected.

Informed Consent is the process of patients learning about a study to help them decide whether or not to participate. The doctors and nurses involved explain the protocol (details of the study) to potential participants and answer all of their questions. The research team then provides an informed consent document that includes information about the study such as: purpose, duration, procedures, risks and potential benefits and key contacts. While informed consent is not a legally binding contract, participants must sign the informed consent document to both acknowledge their understanding of the clinical study's protocol and to agree to participate in the study. Informed consent continues throughout the

study because new information gained by researchers is constantly communicated to participants. Participants in any clinical study are of course free to leave the study at any time without compromising their future medical care.

AA&MDSIF Medical Board Chairman, Dr. Richard Stone of the Dana Farber Cancer Center, says "Our primary ambition as researchers is to find better methods to treat patients and improve their quality of life. These essential protections provide the platform for safe and ethical research to produce promising and life-changing outcomes for patients."

For more information, please contact Elizabeth Bradley, Clinical Trials Educator, at the AA&MDSIF. Elizabeth is available to talk to you by phone or email and can answer your questions about clinical research studies, the risks and benefits to consider, what to expect during participation in a clinical research study, and to give you referrals to centers conducting clinical research studies.

Other links:

The Department of Health and Human Services

The Common Rule

<http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm#46.101>

The Department of Clinical Bioethics at the NIH

<http://www.bioethics.nih.gov/about/index.html>

The National Institutes of Health

www.nih.gov

Office for Human Research Protections

<http://www.hhs.gov/ohrp/>

Search Clinical Trials

www.clinicaltrials.gov

View the NIH Patient Bill of Rights

http://clinicalcenter.nih.gov/participate/patientinfo/legal/bill_of_rights.shtml

Food and Drug Administration

www.fda.gov

-Elizabeth Bradley
Clinical Trials Educator
(800) 747-2820

RECENT MEDICAL LITERATURE

Listed below are a few recently published journal articles indexed in the National Library of Medicine database MEDLINE: www.pubmed.gov. These articles include published results of clinical studies, review articles, letters or comments on previously published articles. To obtain complete articles, contact your public or hospital library. These articles are listed for general information purposes only.

Aplastic Anemia

Eisenberg S. Reader comments on antithymocyte globulin use for aplastic anemia. *Clinical Journal of Oncology Nursing*. 2004 Dec; 8(6):583; author reply 583.

Marsh JC. Management of acquired aplastic anaemia. *Blood Review*. 2005 May;19(3):143-151.

Morimoto Y, Niwa H, Imai Y. et al. Dental management prior to hematopoietic stem cell transplantation. *Special Care in Dentistry*. 2004 Nov-Dec; 24(6):287-92.

[No authors listed]. Severe aplastic anaemia. *Bone Marrow Transplant*. 2005 Mar;35(S2):S378-S392.

Kurre P, Johnson FL, Deeg HJ. Diagnosis and treatment of children with aplastic anemia. *Pediatric Blood Cancer*. 2005 Feb 10; www3.interscience.wiley.com [Epub].

Myelodysplastic Syndromes

Andersen MK, Christiansen DH, Pedersen-Bjergaard J. Amplification or duplication of chromosome band 21q22 with multiple copies of the AML1 gene and mutation of the TP53 gene in therapy-related MDS and AML. *Leukemia*. 2005 Feb; 19(2):197-200.

Bader P, Niemeyer C, Willasch A, et al. Children with myelodysplastic syndrome (MDS) and increasing mixed chimaerism after allogeneic stem cell transplantation have a poor outcome which can be improved by pre-emptive immunotherapy. *British Journal of Haematology*. 2005 Mar;128(5):649-58.

Bowen D, MacIlwaine L, Cavanagh J. et al. Thalidomide therapy for low-risk myelodysplasia. *Leukemia Research*. 2005 Feb; 29(2):235-6.

Cazzola M, Malcovati L. Myelodysplastic syndromes--coping with ineffective hematopoiesis. *New England Journal of Medicine*. 2005 Feb 10;352(6):536-8.

Chen B, Zhao WL, Jin J, et al. Clinical and cytogenetic features of 508 Chinese patients with myelodysplastic syndrome and comparison with those in Western countries. *Leukemia*. 2005 Mar 10; www.nature.com [epub].

Cortes J, Faderl S, Estey E, et al. Phase I Study of BMS-214662, a Farnesyl Transferase Inhibitor in Patients With Acute Leukemias and High-Risk Myelodysplastic

Syndromes. *Journal of Clinical Oncology*. 2005 Feb 22; www.jco.org [epub].

Giagounidis AA, Germing U, Wainscoat JS. et al. The 5q-syndrome. *Hematology*. 2004 Aug;9(4):271-7.

Kurzrock R. Thrombopoietic factors in chronic bone marrow failure states: the platelet problem revisited. *Clinical Cancer Research*. 2005 Feb 15;11(4):1361-7.

List A, Kurtin S, Roe DJ. et al. Efficacy of lenalidomide in myelodysplastic syndromes. *New England Journal of Medicine*. 2005 Feb 10; 352(6):549-57.

McKenna RW. Myelodysplasia and myeloproliferative disorders in children. *American Journal of Clinical Pathology*. 2004 Dec;122 Suppl:S58-69. Review.

[No authors listed]. Azacitine (Vidaza) for myelodysplastic syndrome. *The Medical Letter on Drugs and Therapeutics*. 2005 Jan 31; 47(1201):11.

Platzbecker U, Haase M, Herbst R, et al. Activity of sirolimus in patients with myelodysplastic syndrome--results of a pilot study. *British Journal of Haematology*. 2005 Mar;128(5):625-30.

Steensma DP, Gibbons RJ, Mesa RA. Somatic point mutations in RUNX1/CBFA2/AML1 are common in high-risk myelodysplastic syndrome, but not in myelofibrosis with myeloid metaplasia. *European Journal of Haematology*. 2005 Jan; 74(1):47-53.

Paroxysmal Nocturnal Hemoglobinuria

Cornetta K, Laughlin M, Carter S. et al. Umbilical cord blood transplantation in adults: Results of the prospective cord blood transplantation. *Biology of Blood and Marrow Transplantation*. 2005 Feb; 11(2):149-60.

Masuda T, Morishita Y, Homma S. et al. Acute renal failure in a patient with paroxysmal nocturnal hemoglobinuria and autoimmune hemolytic anemia. *American Journal of Hematology*. 2005 Feb; 78(2):159.

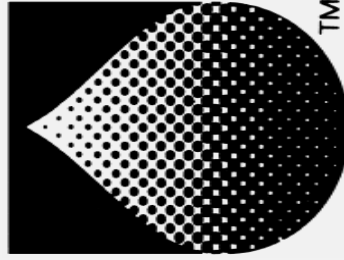
Risitano AM, Maciejewski JP, Muranski P. et al. Large granular lymphocyte (LGL)-like clonal expansions in paroxysmal nocturnal hemoglobinuria (PNH) patients. *Leukemia*. 2005 Feb; 19(2):217-22.

van den Heuvel-Eibrink MM, Bredius RG, te Winkel ML, et al. Childhood paroxysmal nocturnal haemoglobinuria (PNH), a report of 11 cases in the Netherlands. *British Journal of Haematology*. 2005 Feb;128(4):571-7.

Young NS. Paroxysmal nocturnal hemoglobinuria: current issues in pathophysiology and treatment. *Current Hematology Reports*. 2005 Mar;4(2):103-9.

APLASTIC ANEMIA & MDS INTERNATIONAL FOUNDATION, INC.

2005 ANNUAL PATIENT & FAMILY CONFERENCE



**Research and Treatment Updates for
Aplastic Anemia, Myelodysplastic Syndromes & PNH**

**July 28 - July 30, 2005
Denver Airport Marriott, Colorado**

ABOUT DENVER:

Denver has an altitude of 5,280 feet above sea level. Most commercial airplane cabins are pressurized to the same altitude, 5,000 feet. Doctors on the AA&MDSIF Medical Advisory Board say that the altitude is okay for most patients as long as they do not engage in strenuous activities. And the only strenuous activity we have planned for you is waiting in line for the breakfast buffet! As with any travel, patients receiving regular blood or platelet transfusions should consult with their doctor. For patients receiving regular transfusions, timing one prior to traveling is advised. In most cases, there should not be any danger.

TO REGISTER:

- 1) Complete and return this form to the AA&MDSIF, along with your check or credit card information. You may also call our office to register by phone, or register online through our website. Once you register, an information packet will be mailed to you. If you register the day of the Conference, you will have to pay full registration rate and meals may be not available to you.
- 2) Book your room with the Denver Airport Marriott at Gateway Park, Colorado, call (800) MARRIOTT. Specify you are with the Aplastic Anemia & MDS International Foundation. Special room rate of \$82.00 for reservations made before June 8, 2005. After this date room rates will be increased. If you must cancel your registration, it is your responsibility to also cancel your hotel room.

CANCELLATION POLICY:

Thanks to a generous grant from the Pharmion Corporation, we are able to offer this conference free of charge to the first 200 people who register. Because many financially challenged families want to take advantage of this offer, it is important that you tell the AA&MDSIF of your cancellation as soon as possible. If you use this free registration and do not notify the AA&MDSIF of your cancellation within 24 hours of the Conference, your credit card **WILL BE CHARGED** the full registration amount. The AA&MDSIF is not responsible for reimbursing any hotel or travel costs in the event of any Conference cancellation.

SEND REGISTRATION AND CHECK TO:

AA&MDSIF
P.O. Box 613
Annapolis, MD 21404-0613

Or make reservations by credit card (800) 747-2820



APLASTIC ANEMIA & MDS INTERNATIONAL FOUNDATION, INC.
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TEL: 410.867.0242 800.747.2820 FAX: 410.867.0240
help@aamds.org www.aamds.org

REGISTRATION FORM

Name(s): _____
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Aplastic Anemia Myelodysplastic Syndromes PNH
 Include my name and address in the roster distributed at the Conference: Yes No

ATTENDANCE

Thursday Presentation - Number of people attending: _____
Thursday Dinner - Number of people attending: _____
Friday Breakfast - Number of people attending: _____
Friday Lunch - Number of people attending: _____
Friday Coping Workshops - Choose one workshop per person:
 Patient Name: _____
 Spouse Name: _____
 Parent Name: _____
 Family Member Names: _____
Friday Dinner - Number of people attending: _____
Saturday Breakfast - Number of people attending: _____
Saturday Lunch - Number of people attending: _____
Saturday Dinner - Number of people attending: _____

REGISTRATION FEE INCLUDES ALL MEALS

FREE to the first 200 participants - only 2 per family. \$(No Charge)
 \$100 for each additional participant. \$ _____
 If you can afford the registration fee, please donate \$ _____
 so that a needy family can use this free registration offer.
 If you wish to give a tax-deductible donation to help offset Conference costs we sincerely appreciate your gift! \$ _____

TOTAL AMOUNT ENCLOSED \$ _____

Make Checks Payable to AA&MDSIF

Or Call (800) 747-2820

YOU MUST COMPLETE THE FOLLOWING TO SECURE FREE REGISTRATION.

MasterCard VISA American Express

Card #: _____
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APLASTIC ANEMIA & MDS INTERNATIONAL FOUNDATION, INC. 2005 PATIENT & FAMILY CONFERENCE AGENDA

Important Note: frequent schedule changes may occur without warning

THURSDAY, JULY 28

11:00am All Day Registration
 noon-1:00pm PNH Support Group Luncheon
 1:30pm Welcome Introduction of Board Members and Staff
 2:00pm Educational Video - Explanation of diseases, treatment options, and research by leading medical experts
 3:30pm Break
 3:45pm-4:45pm Healthy Exercise Program and Stress Management for Patients and Caregivers
 6:00pm Cocktail Party and Dinner
 7:00pm Victory Stories

FRIDAY, JULY 29

7:30am Breakfast
 9:00am Research & New Drug Approval Process
 Dr. Marlene Haffner, Rear Admiral and Director of the Food & Drug Administration (FDA) Office of Orphan Products Development; Dr. Mikkael Sekeres, Cleveland Clinic Lerner College of Medicine
 10:00am Break
 10:15am Panel Discussion - Research & Clinical Trials
 Beth Bradley & Debbie Judy, AA&MDSIF; Marlene Haffner, FDA; Olga Nunez, National Heart Lung & Blood Institute; Dr. Mikkael Sekeres, Cleveland Clinic Lerner College of Medicine; Susan Sunkle, Cleveland Cancer Clinic
 11:30am Lunch
 12:30pm-3:30pm Patient & Family Networking Workshops
 5:00pm Cocktail Party and Dinner

SATURDAY, JULY 30

7:30am Breakfast
 9:00am-9:45am Iron Overload Management
 Dr. Pam Becker, University of Washington School of Medicine
 9:45am-10:00am Break
 10:00am-10:45am Physician Discussion of Aplastic Anemia, MDS & PNH
 AA - Dr. Richard Childs, National Heart, Lung & Blood Institute
 10:45am-11:30am MDS - Dr. Lewis Silverman, Mount Sinai Hospital
 11:30am-12:15pm PNH - Dr. Charles Parker, VA Medical Center Salt Lake City
 12:15pm-1:00pm Lunch
 1:00pm-3:30pm Physicians Answer Patient Questions
 5:00pm Cocktail Party
 6:00pm Dinner and Entertainment

CUT HERE AND RETURN LEFT SIDE

PNH - PURSUING NEW HOPE RESEARCH AWARD

Matching Challenge!

PURSUING NEW HOPE is the name of the research grant created by a loving father in honor of his daughter who is battling paroxysmal nocturnal hemoglobinuria (PNH). This research was announced on Valentine's Day when he presented his wife and two daughters with a dozen roses and certificate verifying the research study. Truly a meaningful Valentine's gift filled with love and hope.

And now the family has issued a challenge:

THEY WILL MATCH ANY DONATION MADE FOR THIS PURSUING NEW HOPE RESEARCH STUDY!

"We are making this generous offer because of our determined vision that one day those with bone marrow failure diseases, like our daughter, may be completely liberated of the hindrances that come with PNH. It is our hope and prayer that one day we hope that all patients will be cured and enjoy a healthy life."

This study is being conducted by Dr. Jaroslaw Maciejewski at the Cleveland Cancer Center to find effective treatment and cure for PNH. Dr. Maciejewski comments on his research. "Because PNH is an orphan disease, finding sources of funding for research in this area is a difficult task. Therefore, it came as a big surprise when we heard the news that PNH research in our laboratory and clinic will be helped by this incredible gift of the heart. This is a gift to all the patients. We strive to make the best use of this generous donation and to amplify the impact it will make on patient care. Since the award, we have devised a research plan and initiated several lines of investigation. They include studies on predisposition to PNH, development of experimental models allowing for the testing of new drugs and finally the development of tests to predict which patients will benefit from immunosuppression. We thank you from the depth of our hearts for this gift and any form of support."

PNH also strikes nearly 30% of aplastic anemia patients and an estimated 15% of MDS patients.

Please donate today and DOUBLE YOUR GIFT to PNH research! Simply write on your check, or include a letter with your donation, specifying "PNH - Pursuing New Hope Research Award." For more information contact Jennifer Krammes at the AA&MDSIF.



Aplastic Anemia & MDS
International Foundation, Inc.
P.O. Box 613
Annapolis, Maryland 21404-0613
(800) 747-2820 fax (410) 867-0240
help@aamds.org www.aamds.org

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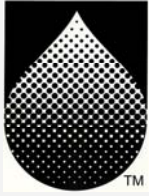
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If you would like to be taken off of our mailing list or have an address change, please inform us by referring to the spelling of your last name as it appears on this label. Thank you!



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donations@aamds.org ♦ www.aamds.org

Your donation helps AA&MDSIF fund medical research and assist patients, families, and caregivers affected by bone marrow failure disease. Working together with donors such as you, the Foundation continues working towards a cure. On behalf of all the families who will benefit from your kind and continued support, we thank you.

Enclosed is my tax-deductible gift of:

\$35 \$50 \$100 \$500 Other _____

PAYMENT OPTIONS:

♦ Make your check, money order or traveler's check payable to: ***Aplastic Anemia & MDS International Foundation, Inc.***

♦ By Credit Card:

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Exp. Date: _____

Signature: _____

♦ Monthly Payment – Amount \$ _____

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Email Address: _____

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Name: _____

Address: _____

City: _____

State: _____

Zip: _____

Daytime Phone: (_____) _____

Email Address: _____

I have enclosed my company's Matching Gift Form in order to increase my giving to AA&MDSIF.

I am interested in obtaining information regarding the AA&MDSIF Planned Giving Program. Please contact me with information on ways of giving by means of wills, trusts, stock, life insurance, real estate, etc.

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All annual donations totaling \$500 or more received by December 31, 2005 will be acknowledged in the Annual Report and End-of-Year Thanks published in our Winter Newsletter.

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AA&MDSIF is solely supported through individual contributions and is a non-profit charitable organization as described under the Internal Revenue Code, Section 501(c)(3).