

APLASTIC ANEMIA & MDS INTERNATIONAL FOUNDATION, INC.

Fighting Bone Marrow Diseases through Patient Support & Research Since 1983



Winter 2007

Volume 20, Issue 1

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Marilyn Baker Retires After 17 Years

On behalf of the entire Board of Directors of the Aplastic Anemia & MDS International Foundation, I extend my congratulations and best wishes to Marilyn Baker on her retirement. We honor and congratulate Marilyn for 17 years of outstanding service to our community of patients and to our Foundation. She has personally supported patients like me, and she has ably led the Foundation with unconditional passion.

While it may be a surprise to many of you, Marilyn's announcement represents the end of yet another chapter in the life of a compassionate leader. All organizations, both big and small, grow and change and mature over time. Since 1990, Marilyn led the fight to find cures for bone marrow diseases and has been a key strategist who has been focused on supporting patients.

She is retiring after winning a championship, after achieving all personal goals, and after the equivalent of belting that "grand slam" in the bottom of the 9th in the last game of the World Series. Our Foundation is wiser, healthier, and much more sophisticated today than in any period of its history because of her efforts. The

Board of Directors has accepted Marilyn's decision to retire as of March 31, 2007. To insure a smooth transition, Marilyn has agreed to continue to support the Foundation as an Ambassador through the first quarter of 2007.

While the Foundation searches for a new leader through the McCormick Group (www.mccormickgroup.com), which has expertise in non-profit leadership, I have been selected to serve as Acting President. During this period of transition, the Foundation is in excellent hands. Our three Directors, Jennifer Krammes, Director of Patient Services; Terri Nyman, Director of Development; and Christin Engelhardt, Director of Health Professional Programs will continue to manage their departments, with Jennifer Krammes managing the overall office functions. The Directors will report to me and also take functional guidance from our Executive Committee. We thank all the Directors and the entire staff for their support during this transition. ■

Regards,
Neil Horikoshi, J.D., M.B.A.
Chairman of the Board and Acting President

"We honor and congratulate Marilyn for 17 years of outstanding service"

A Message From Marilyn Baker



The best and most beautiful things in the world cannot be seen or even touched. They must be felt with the heart."

- Helen Keller

about. To the thousands of patients and families who taught me how to see what is in our hearts, thank you. I am very grateful and honored to have had the privilege of working for such extraordinary heroes.

Good-bye and God Bless,

Marilyn Baker ■

There are some who look but never see. Sometimes it takes an illness, or the death of a loved one before we really see what life is all

Volume 20, Issue 1

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New Address

Please note that we
have changed our
mailing address (but not
our street address), so
we can send and
receive mail more
efficiently from the post
office in nearby
Churchton (see page 1).

**Another Way
to Help**

If you have all-inclusive
long distance phone
service, you can help
us reduce overhead so
we may better support
patients when you use
our 410 phone number
-- 410-867-0242.
(Note: Our toll-free
help line, 800-747-
2820, is still in service.)

Nutritional Concerns for Individuals with Hematological Disorders

Theresa B. Donohue, MHS, PA-C and Sara Bergerson, MS, RD
Hematology Branch, NHLBI, National Institutes of Health

Bone marrow disease patients have many health issues to confront every day. The following discusses issues regarding diet, food and medication interactions, and supplements. For further information, visit our web site at www.aamds.org and the NHLBI web site at www.nhlbi.nih.gov and, most importantly, discuss these issues with your own doctor.

Diet. Proper nutrition optimizes blood production. In general, a well-balanced diet with plenty of fruits and vegetables is recommended. However, nutritional needs and safety can be impacted by both disease and medications.



Neutropenia (an abnormal decrease in neutrophils, one type of white blood cell that destroys bacteria) and immunosuppression can put patients at risk for developing infection, exponentially raising their susceptibility to fungal and bacterial infections. Food normally contains sizeable bacteria counts, including potentially pathogenic (disease causing) organisms. Dietary modifications for people with aplastic anemia, MDS and PNH are intended to minimize the introduction of pathogenic organisms from food. Diet guidelines for neutropenia are based on a two-pronged approach: **maintain food safety** and **avoid high-risk foods**. It is important to be attentive to safe handling, storage, and preparation of foods in the home, as well as those purchased in restaurants. More detailed food safety guidelines are available at www.foodsafety.gov.

Based on the most recent results available, it is typically recommended that the following high-risk foods should be avoided by those on a neutropenic diet:

- Raw and undercooked meat, fish, shellfish, poultry, game, eggs, hotdogs, tofu, sausage and bacon
- Cold-smoked fish and lox; pickled fish
- Unpasteurized, or raw milk and milk products, including unpasteurized yogurt and cheese
- Unpasteurized, *uncooked* cheeses e.g., brie, camembert, bleu, roquefort, extra

aged cheddar, stilton, feta and cheeses with foods like sweet peppers added to them)

- Refrigerated cheese-based salad dressings (e.g. bleu cheese) which are not shelf-stable
- Unwashed raw fruits and vegetables, those that can not be scrubbed well (such as raspberries), or those with visible mold
- Unpasteurized juices (fruit or vegetable)
- Raw or unpasteurized honey
- All miso products (e.g. miso soup) *unless* boiled for one minute; tempeh (fermented tofu)
- All moldy and out-dated food products
- Unpasteurized beer (e.g. microbrewery beers and those not shelf-stable)
- Raw, uncooked brewer's yeast
- Well water, *unless* tested yearly and found to be safe
- Luncheon meats, *unless* reheated until steaming.

Food and medication interactions. People who take cyclosporine or tacrolimus are generally advised not to drink grapefruit juice or eat grapefruit, because it can change the levels of these drugs in the blood. Too high a level of either drug can cause tremors, kidney damage and other side effects.

Some herbal products, especially St. John's Wort, can interact with and change cyclosporine levels. Always check with your doctor before starting ANY herbal remedies.

Many PNH patients are on the blood-thinner warfarin (Coumadin) and need to monitor their intake of foods containing Vitamin K which can change the level of Coumadin, and potentially increase the risk of bleeding. Foods that contain

(Continued on pg 9)

AA&MDSIF and Advocacy: Achievements in an Uncertain Era

On December 9, the 109th Congress adjourned quietly in the early hours of the morning, after a year of tumultuous events and electoral change. Congress adjourned without completing its budgetary business, thanks in large part to a year dominated by partisan politics. The House and Senate enacted only two spending bills – the Defense and Homeland Security appropriations bills – and left undecided the level of funding for agencies like the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Food and Drug Administration (FDA). Congress operated primarily in gridlock mode throughout the year, the war in Iraq persisted, and Democrats took control of both the House and Senate.

Despite these challenges, AA&MDSIF enjoyed a successful year marked by significant accomplishments in advocacy. Thanks in large part to relationships that we have forged with Republican and Democratic Senators and Representatives, we were able to secure new “directives” in the appropriations bills that provide funding to the NIH. The House bill includes directive language calling on NIH to conduct a study of the disproportionate prevalence of bone marrow diseases in Asian countries – with the goal of gaining a better understanding of the causes of these diseases in all individuals. The Senate bill includes language calling on NIH to focus greater research resources on iron overload.

The AA&MDSIF’s advocacy and awareness efforts were greatly aided by “Our Hike,” Patty Laatsch’s and Robin Grapa’s courageous mother-daughter hike across

America for bone marrow diseases. As they crossed through Congressional Districts, we brought their hike to the attention of Members of Congress and their staffs who previously had never heard of bone marrow diseases. Their hike also generated significant press coverage by local and regional media outlets.

Our advocacy efforts also enjoyed an increased level of support from the grassroots members of the Foundation – the patients and family members coping with bone marrow diseases. These efforts were primarily directed at securing support for H.Con.Res. 179, the Bone Marrow Disease Resolution. Despite the fact that this resolution enjoyed bipartisan

support, Energy and Commerce Committee Chairman Joe Barton (R-TX) refused to allow this resolution to come to the floor of the House prior to the adjournment of the 109th Congress. We look forward to the opportunities presented by the new leadership that will control this committee in the 110th Congress, and will begin working with incoming

Chairman John Dingell (D-MI) on a strategy for early passage of the resolution.

In 2007, the AA&MDSIF will work on a number of new federal government relations initiatives, all designed to increase awareness of bone marrow diseases and to find new cures. In addition to working in coalitions to preserve vital funding for NIH, we will be working to identify new sources of funding for research and awareness.

The AA&MDSIF looks forwarding to working with you on what we hope will be a productive year for advocacy in 2007. ■

*AA&MDSIF
enjoyed a very
successful year
marked by
significant
advocacy
accomplishments*

News You Should Know

Now you can sign up for our **Iron Overload Support Network** to connect with others. See the application on page 7 in this newsletter.

Patient 411

Have you visited our **Patient Resources** section on the website lately? It is located under "Support and Hope" and contains a new book list, citations of current articles, and an expanded section on Care Planning.

Travel Tip

Transportation for medical reasons, including the annual AA&MDSIF Patient & Family Conference, can be tax-deductible. For tips on maximizing medical deductions, visit www.bankrate.com or call your local I.R.S. office.

Need to Talk?

Contact Beth Bradley at 1.800.747.2820 or bradley@aamds.org to connect you with others living with bone marrow disease.

Have A Question?

Go to www.aamds.org and click on "Diseases and Drugs" for a Q&A of patients' questions which have been answered by our distinguished panel of medical experts. You can also ask your own questions and receive personalized responses from our patient information specialists.

News You Should Know

Attention Caregivers:

Need help keeping organized with family and friends. Make use of *Lotsa Helping Hands*. You can access this web-based service through our website under the "Care Planning" section.

Vehicle Donations

Now you can donate your used car, truck or boat to AA&MDSIF. Just call 866-332-1778 for information and pick up.



Information Archive

Read past issues of this newsletter and learn about health issues, helpful resources, and patients' victory stories at www.aamd.org.

A Memorable Year for Hikers Robin and Patty

Aplastic Anemia survivor Robin Grapa and her mother, Patty Laatsch, hiked across the United States last year to raise money and awareness for AA&MDSIF. Their 10 month, 5,000 mile adventure was a life altering experience that raised over \$118,000. Here's what Robin and Patty have to say about "Our Hike":

Q: What does it feel like to not to be hiking?

Robin: During the last month or so of the hike, I mostly wondered two things: What will it be like to NOT have to get up and hike 20+ miles? And, what will it be like to wake up and NOT have sore feet? I can say in all honesty, that it felt great to sleep in, and now the feeling has come back to my toes!

It has been very difficult cutting down on the amount I eat. On the hike I could get away with eating a lot more to keep up with how many calories we were burning. I gained about 10 pounds back right away.

Patty: I miss the freedom, overcoming the challenges, and the warm fuzzy feeling I would get everyday knowing I was making a difference. At the same time I'm enjoying the comforts of home.

Q: What are you doing now that you aren't hiking 24/7?

Robin: I took a little time off right away and tried to hibernate and do nothing — that was pretty easy. In December I went back to work. I'm having some really intense "flashbacks" of the hike, though.

Patty: I'm catching up with my husband, family and friends, and going to Curves.

AA&MDSIF: What was the first thing you did once you got home?

Robin: The first thing we did was to thank Wisconsin for the warm welcome. We had an awesome "Welcome Home" caravan when we drove into our home town. A big group of family, friends and the police department escorted us through the town.

Patty: Once home, I walked around our house looking at all the stuff I've gathered over the

years and realized how truly lucky I am to have so many possessions. I also realized how little I really need any of those possessions to survive.

Q: What was the most difficult part of the hike, other than being away from your family and friends?

Robin: Getting up very early every single day was difficult for me. Going to bed early; however, was rarely an issue after a long day hiking!

Patty: The discipline to hike every single day — rain or shine — for 20 miles or more!

Q: What do you miss most about "Our Hike"?

Robin: I miss meeting new people. I miss seeing the sky and feeling the fresh air around me. And even though the early mornings were tough, I miss them. Mom and I laughed the most together over our morning coffee.

Patty: I miss all the beautiful people and beautiful sights.

AA&MDSIF: Are there further plans for more awareness activities such as "Our Hike"?

Robin: Mom and I are in the very early planning stages of putting together a book about "Our Hike." *4imprint*, my employer, as well as a sponsor of "Our Hike," is helping me coordinate some speaking gigs around the state. I will be spreading further awareness of bone marrow disease, as well as inspiring others to get out and do something they've always dreamed of. Last but not least, we hold an annual fundraiser in Phillips to raise money for the fight against bone marrow diseases. It's a mini version of "Our Hike." We take a non-competitive 12.5-mile hike down a county road in Phillips. It's always a lot of fun! Mark your calendars! It's going to take place on September 8, 2007!

Fun and Easy Ways to Support AA&MDSIF

FirstGiving Web Sites for Fundraising

We've made it easier than ever for you to pursue your idea for supporting AA&MDSIF with your own fundraising web page.

FirstGiving makes it easy for supporters to create their own fundraising web sites, make contact with potential donors/participants, track donations, and raise lots of money for research, patient assistance, and operational support.



This program can support anything from a walk-a-thon to making donations to AA&MDSIF in lieu of wedding/birthday gifts, to a challenge (i.e., we'll shave our heads if we raise \$500,000!).

It's so easy -- just visit the AA&MDSIF start page (www.firstgiving.com/AAMDS) and create a fundraising page for your walk-a-thon, challenge, or other event*; send the link of your fundraising page to friends, family, and co-workers via email; and donors make donations directly to *your* fundraising web page. First Giving sends AA&MDSIF the funds.

E-Bay Auctions Using Mission Fish

We are now a part of the **Mission Fish** network for charitable online auctions. Mission Fish is the charitable arm of **E-Bay**. Recently, one of Robin Grapa's ("**Our Hike**") coworkers from **4Imprint** sold 13 hand-crafted stepping stones and raised \$1,259 for us! Sell your own stuff and help us find a cure for bone marrow failure diseases. It's easy to sell something to support our good cause -- go to www.missionfish.org; choose **Aplastic Anemia & MDS International Foundation** (keyword "Aplastic") as your recipient charity; and sell your stuff. MissionFish collects the donation from the seller, pays the Foundation and provides a tax receipt.

Shop Through iGive.com

If you shop on the internet, you can help support AA&MDSIF with the click of a mouse. Year 'round you can do your shopping through **iGive.com**, and AA&MDSIF will receive cash when you and your friends and family shop online. iGive.com links to major online shopping outlets such as Nordstrom, Barnes and Noble, Lobster Gram and many more. Check them out at www.iGive.com and be sure to list **Aplastic Anemia & MDS International Foundation** as your chosen charity. There is a link to iGive.com on our web site (www.aamds.org). Please take advantage of iGive.com to do your shopping this year -- and ask your friends and family to do the same.



Use GoodSearch.com To Surf the Web

Here's another new and easy way to raise money for AA&MDSIF just by searching the Internet with GoodSearch.com.

It's simple. You use GoodSearch.com like any other search engine -- the site is powered by Yahoo! -- but each time you do, money is generated for the Foundation.

Last year, search engines generated close to \$6 billion in revenue from advertisers. With GoodSearch part of this advertising revenue will now be directed to AA&MDSIF.



We hope that not only will you use GoodSearch as your main search engine from here on out, but will also pass this message on to your friends and family. The more people who use this, the more money will go to help find a cure for bone marrow disease.

For more information about how you can help support AA&MDSIF, call or email Terri Nyman at 410-867-0242. (nyman@aamds.org). ■

Wish List

We asked our staff what they need to better support bone marrow disease patients, families, caregivers and healthcare professionals.

If you can help our wishes come true through financial support for any of these items, please call Terri at 410.867.0242, x 106 or send an email to: nyman@aamds.org.

√ Postage & Shipping Costs for one month's patient information kits: \$1,200

√ Access to health-related on-line databases: \$800

√ *AHFS Drug Information 2007* ("The Big Red Book"): \$250

√ Digital camera and accessories: \$650

√ AA&MDSIF Awareness Pins for Nurses: \$1,500

√ 200 copies of a Jazz CD by the late, great Michael Brecker to share with patients at this year's patient and family conference: \$3,400.

Thank you!

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



Support A Research Fund

Join us in the search for cures for bone marrow diseases. Families or individuals who raise \$30,000 can help us to support the world's leading scientists as they seek cures. Call Terri at 410-867-0242 to find out how or to make a donation to an established fund.

Patient Clinical Trials

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

Patient Travel Fund

Families traveling to clinical trials can receive up to \$500 for travel expenses. Contact our office to receive and 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!

Report on the 2006 ASH Conference

Each December, the American Society of Hematology (ASH) holds its annual meeting which provides hematology clinicians and researchers from around the world with a forum for discussing critical issues in hematology and to introduce and hear about the latest and most exciting developments in the field. Here are summaries of just a few of the presentations that show possible advancement and, best of all, hope for the future. *As you read these, please keep in mind that much of this research is in its infancy and may never reach patients. The papers presented often deal with ongoing research, so results may not be final and may not have been peer-reviewed. For more information about the ASH conference and the latest research go to <http://www.asheducationbook.org/current.dtl>*

Multi-Center Studies Show Positive Outcomes in Treatments with Revlimid

Raza, Azra et al. *Long Term Clinical Benefit of Lenalidomide (Revlimid) Treatment in Patients with Myelodysplastic Syndrome without Del 5q Cytogenetic Abnormalities.*

Final results in a Phase II multi-center study were reported. In a 2-year follow up on 214 patients **without** the del 5q chromosomal abnormality who were treated with Revlimid, 56 patients (26%) became transfusion independent for a median duration of 41 weeks. An additional 36 patients had a greater than 50% reduction on transfusions. Revlimid does not have FDA approval for this use.

List, Alan et al. *Long term Clinical Benefit of Lenalidomide (Revlimid) Treatment in Patients with Myelodysplastic Syndrome and Chromosome Deletion 5q.*

Final results in a Phase II multi-center study were reported by the Moffitt Cancer Center. This study focused on the long-term care of patients with the del 5q chromosomal abnormality who are being treated with Revlimid. 67% of the 148 enrolled patients became transfusion-independent. The median duration of response was greater than 2 years.

Report on MDS Epidemiology

Rollison, Dana E. et al. *First Report of National Estimates of the Incidence of MDS and Chronic Myeloproliferative Disorders from the U.S. SEER Program.*

The incidence of MDS in the United States has been an estimate only, as it has not been formally tracked. MDS was added to the National Cancer Institute's *Surveillance, Epidemiology, and End Results* (SEER) program in 2001. With this first report, it is estimated that in 2003 there

was an overall incidence rate of 3.1 per 100,000 people in the U.S. The incidence rate for the U.S. is quite similar to that of European countries. The study cautions that this may be an underestimation of the total annual incidence of MDS in the U.S. due to differences in recording diagnoses.

Study on Dacogen After Vidaza for MDS Patients

Borthakur, Gautam, et al. *Decitabine Induces Responses in Patients with Myelodysplastic Syndromes (MDS) after Failure of Azacitidine Therapy.*

This goal of this study was to see if decitabine would be effective in treating MDS patients for whom azacitidine had not worked.

In this small study of only 14 patients, 3 achieved complete remission and 1 achieved partial remission. The median duration of remission was 5.3 months, thus far. The researchers conclude that some MDS patients, who don't respond to azacitidine therapy, may respond to decitabine.

This research was funded by MGI Pharma.

Several Vidaza Studies Unveiled Including Alternate Dosing Schedules and Combination Therapies

Lyons, Roger M, et al. *Hematologic Improvement, Transfusion Independence, and Safety Assessed Using 3 Alternative Dosing Schedules of Azacitidine in Patients with Myelodysplastic Syndromes.*

Results of a Phase II study designed to evaluate treatment response to alternative dosing, each of which eliminated weekend

(Continued on Pg. 9)



APLASTIC ANEMIA & MDS INTERNATIONAL FOUNDATION, INC.

P.O. BOX 613 ANNAPOLIS, MARYLAND 21404-0613 U.S.A.

www.aamds.org • (800) 747-2820 • help@aamds.org

Fighting Bone Marrow Diseases through Patient Support & Research Since 1983

IRON OVERLOAD SUPPORT NETWORK

The AA&MDSIF Iron Overload Support Network is a community of patients with bone marrow disease affected by iron overload. Through this network patients connect with others, ask questions, share treatment experiences, discuss emotional aspects, side effects, insurance and financial issues, special topics related to iron overload, and new research. The Iron Overload Support Network communicates through an Internet forum and by telephone and email. AA&MDSIF supports group members by offering information on iron overload, current treatments, and new treatments being studied. After registering you will receive a packet of information on iron overload and access to the online discussion forum. Contact Beth Bradley, Support Network Coordinator, with questions at (800) 747-2820 or bradley@aamds.org.

DATE: _____

CURRENT AGE: _____

DIAGNOSIS:

(check all that apply)

Aplastic Anemia

Paroxysmal Nocturnal Hemoglobinuria

Myelodysplastic Syndrome

Pure Red Cell Aplasia

(MDS Subtype): _____

Other: _____

PATIENT NAME: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

PHONE: _____ ALT. PHONE: _____

EMAIL: _____

BEST TIME TO CALL *(please circle)*: anytime morning afternoon evening

AGE AT DIAGNOSIS: _____ YEAR DIAGNOSED: _____

CURRENT HEALTH STATUS: _____

TREATMENT(S) FOR IRON OVERLOAD: _____

OTHER TREATMENT(S): _____

YEAR, HOSPITAL & CITY/STATE OF TREATMENT: _____

PERSONAL EXPERIENCES THAT MAY BE HELPFUL TO SHARE WITH OTHER PATIENTS AND FAMILIES:

FOREIGN LANGUAGE SKILLS: _____

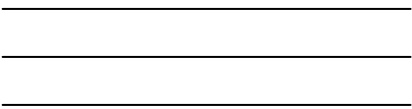
I HEREBY GIVE permission to the Aplastic Anemia & MDS International Foundation, Inc., (AA&MDSIF) to distribute any of the information that I have provided on this questionnaire to any individual or organization wanting to contact me regarding my treatment experiences. I understand that the information is not confidential and AA&MDSIF is not responsible for any of the interactions I may have with individuals or organizations that have used the information to contact me. I also acknowledge that the AA&MDSIF is not responsible for anything that such an individual or organization may subsequently do with the information provided. I HEREBY RELEASE the AA&MDSIF from any liability associated with the use and distribution of such information. By signing this form I consent to this disclaimer.

SIGNATURE: _____ DATE: _____

SUBMIT FORM BY

Mail: AA&MDSIF, PO Box 613, Annapolis, MD 21404-0613 or Fax: (410) 867-0240 or Online: www.aamds.org

(fold here)



Place
Stamp
Here

Aplastic Anemia & MDS International Foundation, Inc.
PO Box 613
Annapolis, Maryland 21404-0613

(fold here)

Nutrition, (Cont. from page 2)

large amounts of Vitamin K include green leafy vegetables (broccoli, spinach, brussels sprouts, and many others). It is important to keep your Vitamin K intake fairly consistent to maintain a steady INR (International Normalized Ratio) level. Alcohol (more than 3 drinks/day) can increase the effect of Coumadin, making the blood thinner, which can lead to life-threatening bleeding. Some herbal products, such as ginkgo, can do this as well. Other herbal products including ginseng, St. John's Wort and green tea can decrease Coumadin effects and lead to blood clotting.

Supplements. While a healthy balanced diet should contain most of the necessary nutrients, taking a multivitamin is generally fine. Patients with aplastic anemia, MDS and PNH who are receiving red cell transfusions may be told to take a multivitamin *without iron*. Those who are not receiving transfusions should have their iron checked by their doctor before starting a vitamin with iron.

If you are taking Coumadin and you choose to take a multivitamin, it is usually best to take one every day so that the Vitamin K level in the body stays the same and the level of anticoagulation is less likely to change.

Both cyclosporine and tacrolimus cause the kidney to excrete magnesium, so the body's magnesium may need to be replaced. When taking these medications, it is often difficult to meet magnesium needs with diet alone. A person taking cyclosporine or tacrolimus may need to take a magnesium supplement (magnesium oxide or other formulation). Low magnesium levels can cause weakness, muscle cramps, and even seizures. However, it is wise not to take large doses of magnesium, unless ordered by a doctor. Large doses of magnesium supplements can cause diarrhea.

Two vitamins that the body needs to make cells are Vitamin B12 and folic acid. A well-balanced diet typically contains enough of these nutrients, but your doctor can check your blood levels to be sure. People with increased cell turnover, like PNH patients with chronic hemolysis, may benefit from taking extra folic acid, but most people with MDS and aplastic anemia have acceptable folic acid levels. Ask your doctor to check your folic acid level and about replacing it if it is low.

Communication with your doctor is vital to your health. Always discuss diet and supplements with him or her before making changes. ■

ASH Conference (Cont. from page 6)

dosing. Hematologic improvement was seen in 57% of patients.

Nand, Sucha, et al. *Azacitidine Plus Gemtuzumab Ozogamicin (GO): A Novel Combination in the Treatment of Acute Myeloid Leukemia (AML) and High-Risk Myelodysplastic Syndromes (MDS) in the Elderly.*

Phase II trial for elderly, newly diagnosed MDS or AML patients. Out of 13 patients 10 received complete response with a median duration of remission of 7 months.

Promising Results After One Year Aranesp Study

Gabrilove, Janice, et al. *The Efficacy and Safety of Darbepoetin Alfa for Treating Anemia in Low-Risk MDS Patients: results after 53/55 Weeks.*

This data was the final result from a Phase II Study of 206 patients who were treated with Aranesp for one year. 59% had a major response which was defined as greater than or equal to 2 g/dL increase in hemoglobin from a baseline, or transfusion independence. Aranesp has not been approved by the FDA for the treatment of MDS. ■

Traveling to Washington or Baltimore?

If you are traveling to NIH, Johns Hopkins or to the Washington/Baltimore area for any other reason, give us a call. We'd love to meet you and have a cup of coffee, do lunch, or give you a tour of our offices.

You Can Help!

Please donate your blood and platelets, have your bone marrow tested, and financially donate to the AA&MDSIF's research and support efforts! Call Terri at 410-867-0242.

E-Bulletin

Sign up for the AA&MDSIF E-Bulletin to receive regular updated medical research updates on bone marrow disease and treatments. Patients, caregivers, nurses, and doctors should send their enrollment request to: finne@aamds.org.

The Aplastic Anemia & MDS International Foundation has been awarded a 4-Star rating by Charity Navigator



Thanks to our 2006 Donors!

Each dollar you donate to AA&MDSIF helps us fulfill our mission to support patients, families, caregivers, and healthcare professionals whose lives have been touched by bone marrow diseases. You are the key to our efforts to provide vital, life saving resources; to advocate with the government, hospitals and drug companies; and fund ground-breaking research to improve treatments and find cures for bone marrow diseases. We truly can not help our thousands of patients and their caring circles of support without your generous donations. Thank you. Your support means the world to us and those we serve.

VISIONARIES

\$30,000 and over

Alexion
Celgene Corporation
Cleveland Clinic Health System
Florentine Camenish Trust
Housewares Charity Foundation
Jim and Lois MacGillivray
Novartis
Pharmion Corporation
TIAA-CREF

BENEFACTORS

\$10,000-\$29,999

4 Imprint, Inc.
AA&MDSIF Michigan
James L. Anderson
Drew Carmichael Foundation
Estate of Joanne M. Hanson
Herman Goldman Foundation
Maui Masterminds, LLC
MGI Pharma, Inc.
Shizue Spielberg
Vibratex, Inc
Allen Womack

PATRONS

\$5,000-\$9,999

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Volunteers

Very special thanks to our volunteers who serve on the Board of Directors, participate on our Global Volunteer Network, and organize blood and platelet drives. Kudos to those grassroots fundraising volunteers who organize events to raise money for our services and research.



An Update on Bob Carroll's Legacy

Dear Friends:

I attended the Connecticut Chapter of the American Red Cross' "Annual High School Recognition Luncheon" at which they presented the "Dr. Robert F. Carroll Awards of Excellence" to the top 5% of Connecticut high schools with respect to blood drive frequencies and collections. Due largely to Bob's arm twisting and storytelling about his "gift" and how American Red Cross blood was keeping him alive, approx. 98% of high school in Connecticut, and 25% of elementary schools have one to four blood drives a year.

Last year alone, more than 51,000 units of blood were collected through school drives, with approx 48,000 lives being helped. I was in awe of these accomplishments and wanted to share them with you. Bob's replacement is now working on elementary school stats. His legacy lives on!

Marie Carroll

NFL Hall of Fame Star Starts Scholarship Fund



AA&MDSIF is pleased to announce the creation of the **Harry Carson Scholarship Fund** to support the financial needs of young adults whose lives have been impacted by bone marrow disease. It is designed to help lift the financial burden faced by these young people who are pursuing higher education or professional school. NFL Hall of Fame linebacker Harry Carson is supporting the scholarship fund named in honor of his son, Donald, who was diagnosed with severe aplastic anemia in December 2005, just 5 days after he graduated from Savannah State University.

The Harry Carson Scholarship Fund will kick off with a fundraising dinner in New York City, hosted by Donald and Harry Carson. The event will be held at Ben Benson's Steakhouse in Manhattan on Thursday, March 8. Guests at the \$500 a plate fundraising dinner will include sports figures, prominent businesspeople, and others interested in supporting this good cause. Seats are available by calling 800-747-2820.

Harry Carson, known as one of the New York Giants greatest linebackers, was inducted into the NFL Hall of Fame earlier this year after a 13-year career with The Giants. Since leaving

the NFL as a player, Carson has been a sportscaster, ambassador, spokesperson, motivational speaker and a mentor to young people. Today the retired football star is CEO and President of Harry Carson Inc., a Sports Consulting and Promotions Company.

On his son's diagnosis with aplastic anemia Carson says, "In those five days we went from the highs of life (college graduation) to a scary low (being diagnosed with a rare blood disorder). I'm so happy to say that Donald is progressing very well!" This scholarship fund is the father and son team's way of giving back to help other students with bone marrow diseases.

Families often fall into financial difficulties when faced with a life-threatening disease. According to research carried out by Harvard and supported by a grant from the Robert Wood Johnson Foundation, illness and medical bills cause half of all bankruptcies – noting an increase of 2,200% since 1981. Families with children are especially hard hit; about 700,000 children live in families that declared bankruptcy in the aftermath of serious medical problems. (For more information, see www.hms.harvard.edu/news/releases.) ■

Working To Find A Cure

The Aplastic Anemia & MDS International Foundation is a resource for patient assistance, advocacy and support; provides educational materials and medical information; and supports research to improve treatments and find cures for bone marrow diseases.



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