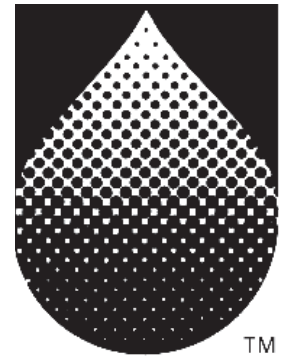


Aplastic Anemia & MDS International Foundation, Inc.

Fighting Bone Marrow Diseases through Patient Support & Research Since 1983



Patient Information

Our expert Medical Board will answer your questions and provide information on any issue. Call us – we are standing by ready to help you!



Ask the Experts

Go to www.aamds.org to review the archive of patients' 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.

Revlimid® approved by the FDA

Celgene Corporation's Revlimid® (lenalidomide) has been approved by the U.S. Food & Drug Administration (FDA) for patients with a subgroup of myelodysplastic syndromes (MDS).

Revlimid® was given priority review and fast track status by the FDA. It is an oral medication approved for the treatment of low- or intermediate-risk MDS associated with deletion of 5q, a chromosomal (cytogenetic) abnormality, with or without other cytogenetic abnormalities. "The clinical data from a Phase II trial of 148 patients demonstrated that Revlimid can reduce or even eliminate the need for transfusions in many patients with del 5q MDS," said Dr. Alan List, Professor of Oncology and Medicine, and Chief Division of Hematologic Malignancies Hematologic Malignancies at H. Lee Moffitt Cancer Center, Tampa, Florida, and the study's lead investigator. "I am extremely pleased with the FDA's action today."

Revlimid® is a member of a new class of drugs called immunomodulatory drugs (IMiDs), drugs that can modify or regulate the functioning of the immune system. IMiDs are a group of oral drugs that are chemically similar to thalidomide.

Revlimid® is expected to be available for distribution in early 2006. Since Revlimid® is chemically similar to Thalidomid® (thalidomide), it may cause severe birth defects. To ensure the safety of patients the FDA has required Celgene Corporation to market Revlimid® with a Black Box warning, and under a risk management program (a special, restricted distribution program) called RevAssist.

RevAssist is designed to educate patients, their physicians and pharmacists about the possible side effects. The FDA approved goals of RevAssist are as follows:

- Prevent fetal exposure to Revlimid® by registering and educating all physicians, pharmacists and patients and monitoring pregnancy prevention activities.
- Reduce the risk of fetal exposure from males taking Revlimid® who engage in sexual contact with a female partner of child bearing potential.
- Educate physicians, other healthcare providers, and patients about potential lowering in blood cell counts (cytopenias) associated with Revlimid® therapy.

Prescriptions of Revlimid® will be limited to a 28 day supply, only distributed to patients of registered and RevAssist educated physicians, and filled by specialty pharmacies. For more information about RevAssist please visit www.revlimid.com, or call (888) 4Celgene, or call the AA&MDSIF Information Specialists (800) 747-2820. ♦

President Signs Cord Blood Stem Cell Bill into Law

On December 16, the Senate voted unanimously to approve S. 1317, the Stem Cell Therapeutic and Research Act of 2005. This legislation provides \$79 million to establish a national registry of 150,000 umbilical cord blood units. This law reauthorizes the Bone Marrow Program through 2010 and authorizes \$158 million over the next five years for the program. The bill was signed into law by President Bush on December 20.

Thousands have been successfully treated with cord blood stem cells for more than 67 diseases, including bone marrow diseases. The infusion of federal funds will make this promising therapy available to more patients and will ensure that research continues so that this source of stem cells can treat many other debilitating diseases. ♦

From the Director...

*Life is not easy for any of us. But what of that?
We must have perseverance and above all confidence in ourselves.
We must believe that we are gifted for something
and that this thing must be attained.*

*-Madame Curie
died from aplastic anemia*



“Being diagnosed and treated wasn’t the hard part; it was dealing with my emotions that was the real battle for me.” This sentiment is expressed by many of the patients and caregivers who contact our Foundation for assistance. People dealing with bone marrow failure diseases are often unsure if the sadness they feel with their illness is normal or a sign of depression.

Depression can go under-diagnosed in bone marrow disease patients because the two illnesses share symptoms. Patients can be confused or embarrassed about emotional issues and not let their doctors know they are having problems. Caregivers can feel guilty about feeling depressed because they aren’t the ones who are sick, even though caregivers may experience more stress than patients.

While it is normal to have feelings of sadness and fear because of an illness, chronic negative feelings and down-beat lifestyle habits are not normal. Studies show that only around 17 to 20 percent of cancer patients have clinical depression, regardless of their prognosis.

Depression is an illness of the brain, just like AA, MDS and PNH are illnesses of the bone marrow. No one “caused” either kind of illness and no one can “will” such illness away. There is scientific proof documenting the fact that treating depression is not only good for a patient’s mental health, but it can help patients recover faster from physical illnesses and help them live longer. Left untreated, depression can impair a patient’s ability to fight bone marrow disease and impact their will to live. In addition, it can reduce an entire family’s quality of life.

Depression can and should be treated. There are a variety of proven methods available to help you, including counseling, psychotherapy, support group participation, buddy systems, and medication.

If you or someone you love is experiencing emotional problems, please talk to your doctor or a therapist. Life, all the more precious when you are battling a bone marrow disease, should be enjoyed. ♦

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

New Book...

Myelodysplastic Syndromes: Clinical & Biological Advances, Edited by Peter L. Greenberg

A current major comprehensive reference on all aspects of the clinical classification underlying pathogenetic mechanisms and treatment of the Myelodysplastic Syndromes written for researchers and clinicians.

www.cambridge.org/0521496683

Make Sure You Read...

A free copy of the International Bone Marrow Scientific Symposium: Summary and Abstracts. This report is written in layman’s terms so patients can read the very latest in bone marrow research that was presented at this important AA&MDSIF scientific meeting in Washington, DC. Thanks to an unrestricted educational grant from Novartis, makers of Exjade®, we are able to send this report to anyone free of charge.

Make Sure You Hear...

A FREE copy of the 2005 Patient Family Conference scientific presentations from Drs. Marlene Haffner, Mikkael Sekeres, Pam Becker, Richard Childs, Lewis Silverman, Charles Parker on the latest in treatment and care for aplastic anemia, Myelodysplastic Syndromes, and Paroxysmal Nocturnal Hemaglobinuria. CDs include 2 hours of question and answer session.

\$1,000 Scholarship Award for Bone Marrow/Stem Cell Transplant Survivors

The Debono family honors the memory of their son, Matthew Debono, and his courageous fight against severe aplastic anemia by providing one deserving student with a scholarship each year. The idea for the scholarship came from Matt himself when he was dying. He was deeply disappointed when his education was cut short by his illness early in his freshman year of college. Since 1987, Matt’s family has honored his memory, his idea, and his desire to help others achieve their goals by offering this scholarship for post-high school study. The funds for the scholarship are maintained by donation. The Debono family is accepting applications for the 2006 academic year. To receive an application by mail, please contact: Matthew Debono Scholarship Fund, c/o Sara and Manuel Debono at 5257 Hinesley Avenue, Indianapolis, IN 46208 or e-mail them at mdebono@indy.rr.com. ♦

Robin Grapa Hikes Across America!

Yes, she REALLY is walking across our country!

Robin Grapa, a 26-year old aplastic anemia survivor, is embarking on a 5,000+ mile hike across America to raise money to help AA&MDSIF fight bone marrow diseases!

And as if this was not remarkable enough, Robin's mother, Patty Laatsch, decided she could not possibly let her baby girl venture across the country all by herself, so SHE WILL BE HIKING ALONGSIDE HER!

They will begin their hike at the Atlantic Ocean in Delaware on February 1st and ten months later will finalize their adventure at the Pacific Ocean in California.

Robin has been in remission since 1997. Most people would put the disease behind them and go have some fun, but Robin decided that surviving this disease was a blessing she wanted and needed to repay. Her goal is to raise one million dollars to fight bone marrow diseases. She and her mother will follow the American Discovery Trail traversing twelve states as they cross the country.



Robin Grapa and Patty Laatsch

Your personal involvement is critical to the success of "Our Hike." There are many ways to support Robin and her cause as she and Patty cross our nation, including:

- Sponsor Robin and Patty in order to help them reach their goal of \$1 million. Donations may be made online at www.ourhike.com/donate.html, or checks may be sent by mail to "Our Hike for AA&MDSIF", P.O. Box 613, Annapolis, MD 21404-0613.
- Challenge your friends, family members, neighbors, and colleagues, to sponsor Robin and Patty.
- Write a letter to your local newspaper informing their readers about Robin's hike, asking them to donate to her cause, and raising awareness about bone marrow disease. Contact Jennifer Krammes for more information: krammes@aamds.org or (800) 747-2820.

If you live in a community that Robin and Patty are walking through, you can also help by:

- Coordinating a fundraising event in your community to help raise dollars. Contact Jennifer Krammes, AA&MDSIF Development Director, at (800) 747-2820 or krammes@aamds.org, for more information. Fundraising events along the way will not only help boost dollars raised and bring Robin closer to her goal, but will also increase bone marrow disease awareness within your local community.
- Offering your home to these weary travelers! If you live in one of the cities that Robin and Patty will be passing through, please offer your home as their overnight stay, complete with a hot meal and a warm shower! This will save them the cost of a hotel, plus it will give them the added boost they just may need to keep hiking along! To coordinate these overnight stays, contact Jennifer Krammes.
- Encouraging local media outlets to cover "Our Hike".
- Encouraging your elected officials to meet with Robin and her mother.
- Telling your friends and family members to get involved.
- HIKING WITH ROBIN and PATTY!

For details on how you can make a difference, visit our website www.aamds.org or contact Jennifer Krammes at (800) 747-2820 or by email krammes@aamds.org.

Don't let Robin and Patty make this brave journey alone – show them your support through sponsorship. Your tax-deductible donation will fund the necessary search for cures and treatments, while at the same time lifting the spirits and hopes of so many patients suffering with bone marrow disease. Together we can ensure that Robin's heroic walk will have a lasting impact on our mission to improve the lives of everyone suffering from these deadly diseases. ♦

Husbands and Wives and Illness

I am a pretty tough person and try to keep a positive attitude. That and the support I received in boatloads is what kept me kicking and alive. I was grateful to let people help me, pray for me, be with me in the down times and laugh with me when we recognized the absurdity in a situation. One particular person was the main reason I could smile, make jokes, keep working and deal with the pain and aggravation.

I met my significant other a year before my second illness surfaced. We had an affectionate, close relationship that grew stronger every day. He treated me like the most beautiful woman in the world. I felt treasured, valued and deeply loved. The future seemed brighter than it had in years. Then came the day when I got sick again. Thus began my journey through two years of what could have been hell had it not been for my man. He went to every appointment with me. He was at the hospital every time I was admitted. He changed bandages, made sure I took my medicine, brought me milk shakes and told me I was a very sexy bald lady. In the middle of it all, he proposed and we were married in a lovely church wedding with all our friends and family. He didn't seem to notice that the bride had no hair. Two days later, I was back in the hospital having emergency surgery related to the staph infection. He never complained about having to cancel a very expensive honeymoon.

A year after our wedding, I had what we both prayed was my last surgery. It was celebration time. Then, the day before Thanksgiving in 2004, he stood in front of my desk in my home office and simply said to me, "I have a life-threatening illness."

Emotions flooded my brain and my body went limp. How could it be? That is when I began to see that, for me, being the patient was much easier than being the caregiver. The chemo didn't work. Panic once again set in for my dear husband. I prayed while he "what if"ed and worried. I tried to remember that I am an optimistic person. My positive attitude usually serves me well, but I was being deeply tested. The lesson I had to learn is that optimism is not transferable. When he was not nauseated after a chemo session, I would suggest that was a good thing and we should celebrate, while he decided it was because the doctors weren't giving him a high enough dosage of chemo and he was going to die in four months. Every positive idea I offered up was met with, "yes, but...."

I also learned that being a caregiver with nothing to do is the worst kind of frustration. He didn't want to be held because his skin felt "creepy" and he didn't want to talk because the medicine made him cry a lot. Since I'm being honest here I can admit that I sometimes snore, which kept him awake, which made him cranky the next day, which was my fault. You get the drift. My job was to be there for him, but to stay out of the way. This lovely man who took such tender, complete care of me either didn't know how or really didn't want to let someone care of him. He didn't want to be told "it will be all right," because he believed it was not going to be all right. He didn't believe in prayer because "it doesn't work." God was punishing him and being mean to him.

What I know so far is that when I was ill, I was in control. I had control over how I reacted to what was happening to me. I made the decision to try a positive approach to my illness, looking at treatment as my army that was fighting the disease. I was in charge of choosing when to call medical providers about a problem and if and when I needed to head straight for the ER. When the love of my life was ill, I had to understand that I had no control. Sometimes, when his illness decided to take charge for a while, he didn't even have control. I could suggest he needed to call the doctor when he was feeling "funny," but I couldn't make him do it. I could assure him that everything was going to be all right, but I couldn't make him believe it. There were no bandages to change, no special comfort food to prepare that would ease the fear and no particular nursing skills were needed — except maybe patience with the patient.

What it finally boiled down to for me was to honestly understand that true love is sometimes learning to let go of trying to force my way of coping on my life partner — and to trust in his ability to arrive at hope and peace with his illness at his own pace. I also learned that while I felt agonizingly ineffective at making a smooth road for him through this ordeal, I was actually being supportive by not pushing him into being a Pollyanna. While we each have our own way of getting through illness, it is still a whole lot easier facing the challenges together — two distinct parts of an illness-fighting warrior. ♦

– Kathleen Neal, APR, is President of Arnold Neal Communications, Inc. and author of *A Primer on Nonprofit PR: If Charity Begins at Home* (www.pineapplepress.com)

Highlight on Clinical Trials: The Bone Marrow Transplant Clinical Trials Network

A major challenge when studying a rare disease is researchers' ability to evaluate large numbers of patient participants. "A network conducting clinical trials across multiple centers allows researchers to see many patients and to learn much more about a disease," says Dr. Mary Horowitz, Data Coordinating Center Representative of the BMT CTN. The Bone Marrow Transplant Clinical Trials Network (BMT CTN) is a network that offers this capability for several diseases, including aplastic anemia and myelodysplastic syndromes.

According to their website, "The BMT CTN was established in October 2001 to conduct large multi-institutional clinical trials to address important issues in hematopoietic stem cell transplantation (HSCT). These trials will further the understanding of the best possible treatment approaches." The BMT CTN is funded through the National Heart, Lung and Blood Institute (NHLBI) and the National Cancer Institute (NCI).

Dr. Paolo Anderlini of MD Anderson Cancer Center in Houston, Texas is the Protocol Chair for the BMT CTN aplastic anemia study, *Fludarabine-based Conditioning for Allogeneic Marrow Transplantation from HLA-compatible Unrelated Donors in Severe Aplastic Anemia*. According to Dr. Anderlini, "Being a rare disease, it is important to use a multi-center approach when studying bone marrow transplants to treat aplastic anemia. This allows the ability to test a hypothesis in a consistent manner with a larger number of study participants, and to ultimately optimize and improve the way that aplastic anemia patients go through bone marrow transplants."

For more information about the BMT CTN and for detailed descriptions of each protocol, patients and physicians can visit <http://spitfire.emmes.com/study/bmt/index.html>. For more information about clinical trials, contact Elizabeth Bradley, AA&MDSIF Clinical Trials Educator at (800) 747-2820 or bradley@aamds.org. She is here to help you learn about clinical trials, how they work, answer your questions, and provide you with educational resources. Also, visit www.aamds.org for information about clinical trials and a listing of current protocols for aplastic anemia, PNH, and MDS. ♦

Patients Need to Keep Moving!

Regular exercise is crucial for the emotional and physical wellbeing of patients and their caregivers. Exercise has the power to effect change emotionally, mentally and physically. Keeping the body strong, without a doubt, reaches far beyond keeping your waistline in check. In people who suffer from depression, regular exercise is a proven an effective treatment.

Dr. Sekeres, a bone marrow disease specialist and assistant professor at the Cleveland Clinic Lerner College of Medicine, advises his patients to

"...continue exercising, whether they are receiving treatment or not. If a person is not currently receiving any treatment for his or her bone marrow disorder, exercising will enable him or her to be in the best possible physical shape to face any treatment head-on if and when it becomes necessary. If one of my patients is receiving therapy, exercise helps to prevent that person from becoming de-conditioned [out of shape], and some of the complications that go along with it. My general rule is to exercise freely until your body tells you to stop; this is NOT the time to follow the principle of, 'No pain, no gain!' If a patient has heart disease, exercise should only be undertaken under the guidance of a cardiologist or a cardiac rehabilitation program. Anyone experiencing chest pain or shortness of breath while exercising should consult his or her doctor immediately."

Exercise is an amazing way to keep your body moving, your mind flowing and your emotions on an even keel. Talk to your doctor before exercising to create a plan of action. Once your doctor gives you permission, start small, 5 or 10 minutes of walking, do gentle leg lifts in bed or in a chair, stretch in front of the television or in bed, dance or even just tap out a beat. You should exercise everyday. Recruit family and friends to help keep you motivated and join you on your quest for wellness.

Remember that getting in shape is a process and therefore, be reasonable and try to keep your expectations in check. Remember that any exercise everyday is far better than no exercise at all. For more information please contact AA&MDSIF Patient Information Specialist and Yoga Instructor, Brianna Bedigian. ♦

Special Thanks to our 2005 Donors!

On behalf of the thousands of patients and their families suffering from bone marrow disease, our most heartfelt thanks to the many donors who made donations to AA&MDSIF over the past year. It is only through the generosity of your donations that we are able to continue to fulfill our mission of serving as a resource for patient assistance and to fund the medical research necessary to discover a cure for bone marrow disease. We are most grateful to all those who have supported AA&MDSIF throughout the past year, and hope that we can count on your continued support in the upcoming year. Together we can make a difference.

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Asbury Solomons Retirement
Community – hours & hours!
Charles & Catherine Baker – hours &
hours!
Doyle Printing – printed material
Neil Horikoshi – IBM computer
Jeff & Jennifer Krammes – office supplies
Novartis – patient conference attendee gifts
Pete Seidl – office furniture
Stephany's Chocolate – patient gifts
John Theriault – conference gifts
Tower Records – conference speaker gifts

Advocacy Updates

National Institutes of Health Budget Update

Last November, the Aplastic Anemia & MDS International Foundation signed on to a letter spearheaded by Research!America calling on Congress to approve \$29.4 billion for the National Institutes of Health (NIH) in fiscal year 2006. This funding level represents a modest 3.7 percent increase over the fiscal year 2005 level.

Unfortunately, the budget bill cleared by Congress in late December includes only \$28.6 billion for NIH – a mere \$253 million increase. Congress also approved a one percent across-the-board cut to all federal programs, including NIH. This means that, after accounting for this one percent cut, NIH funding will for the first time in three decades be cut below the previous year's level.

NIH is the nation's leading government research agency for rare diseases like aplastic anemia, MDS and PNH. The agency is one of the world's largest single sources of funding for bone marrow failure diseases. Next year, the Foundation will work more aggressively to restore these misguided cuts.

Support Grows for Bone Marrow Failure Disease Resolution

H.Con.Res. 179, the Bone Marrow Failure Disease Resolution, now enjoys the support of 39 cosponsors in the House of Representatives. Thanks to the patients and families across the nation who are writing and calling Congress, the bill enjoys support from Representatives in 20 U.S. states and territories. AA&MDSIF will continue to work for passage of this legislation when the House reconvenes in late January. ♦

SAVE THE DATE!

2006 Patient Family Conference!

String up yer guitars 'cuz we're going to NASHVILLE!

Nashville, Tennessee, August 3, 4, 5

Nearly 300 patients and their families will share treatment experiences, exchange medical information, make friends and listen to leading medical experts present the very latest in research and treatment options. Also available will be representatives from pharmaceutical companies and health organizations who will answer your questions on drugs and other health issues.

In addition, we are organizing a very special tour of the Country Music Hall of Fame and a show at the famous Grand Ole Opry. Agenda, registration form and hotel information will be included in the Spring Newsletter and on our website at www.aamds.org.



Aplastic Anemia & MDS International Foundation

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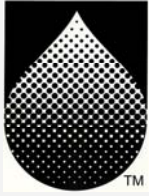
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donations@aamds.org ♦ www.aamds.org

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.

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

If paying by credit card, FAX this form to (410) 867-0240. If paying by check, mail check along with this form to the above address.