



## 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!



## 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.



## Announcing *Two New Tools for Patients*

*A key part of our mission is to listen to the needs of patients, and then to do as much as we possibly can to address those needs. From newly diagnosed patients, we hear the need for help in getting a handle on all the information and medical data that comes with managing their disease. From existing patients we hear the need for information on all treatment medications. We have listened and we acted by adding these two new services.*

### Patient Organizer

Our new *Patient Organizer* is a durable three-ring binder that comes with pre-printed tabs, to serve as a guide for getting organized quickly and efficiently. It is designed to provide one convenient place to keep all the information patients need in these categories: medical contacts, patient support contacts, medication list, lab reports, transfusion history, lifestyle guidelines, research updates, questions for doctors, and miscellaneous. Thanks to a generous grant from Pharmion Corporation, makers of Vidaza, the *Patient Organizer* will be mailed free of charge to the first 2,000 patients or parents of patient who request one.

### Online Drug Information

Our new Drug Information page at the AA&MDSIF website provides information on drugs currently being used to treat bone marrow failure diseases and those that are being studied in clinical trials. Go to: [www.aamds.org](http://www.aamds.org) and click on the link for "Drug Information" to view this exciting new tool.

Each drug listing includes drug names and manufacturers, drug type (for example, immunosuppressant or hypomethylating agent), and whether it is considered standard therapy or is investigational. A brief summary discusses the diseases that the drug is used to treat, how it is given, and some of the possible side effects. Also covered are special concerns, such as age factors, implications for pregnancy/breastfeeding, and allergies. Links to current clinical trials, medical literature, and news reports are also provided.

Drugs approved by U.S. Food and Drug Administration (FDA) are identified at the FDA's website ([www.fda.gov](http://www.fda.gov)) and the National Library of Medicine's MedlinePlus ([www.medlineplus.gov](http://www.medlineplus.gov)). Information on investigational drugs comes from research published and indexed in medical journals. All drug entries are reviewed by an advisory group of medical doctors and pharmacists before being published on our website.

This Drug Information page is updated weekly. If you are looking for drug information and cannot find it, let us know by contacting Debbie Judy or Brianna Bedigian at (800)747-2820 or [judy@aamds.org](mailto:judy@aamds.org). As always, we strongly recommend that patients question their doctors regarding any drug therapy or treatment options suggested to them.

**And don't forget this valuable tool:** Our *Managing Treatment Decisions* booklet, contains an extremely helpful list of questions for patients to ask their physicians about treatment recommendations. Contact our office for a free copy of this booklet.

**Please help us to help you:** we want to know what you need to help you manage your disease and make treatment decisions that are right for you. Please speak up with suggestions, comments, or just to talk about what you are feeling...we are listening! Contact Marilyn Baker (800) 747-2820 or [baker@aamds.org](mailto:baker@aamds.org)

## FROM THE DIRECTOR...

*The possibility of stepping into a higher plane is quite real for everyone. It requires no force or effort or sacrifice. It involves little more than changing our ideas about what is normal.*

*-Deepak Chopra*

Many of us view our bodies as merely a vehicle to get us around each day, or as an ever expanding thing that prevents us from fitting into last year's clothes. Often we don't acknowledge the miracle and complexity of our bodies until something goes wrong. Only then do we rush to the nearest doctor and demand the quick fix for the problem to let us go back to our busy lives. Knowing that we may have to live the rest of our lives with illness and an unpredictable future is often the hardest part of dealing with a serious illness.



When a person becomes ill, all parts of them are hurt – body, mind, and spirit. All are parts of the whole, all are intrinsically related, and all need to be treated in order to heal the whole person. Doctors and nurses do their best to fix the body, but the care of the mind and spirit are in the hands of the patient and their loved ones. And care they must, because if our thoughts and feelings are ignored, then all the rest will suffer. This collaboration of treatment is necessary to enable a person to live a good life with physical illness, which millions are able to do every day.

The AA&MDSIF has also created an important collaboration. For 22 years we have led a vital global team of thousands of patients, families, caregivers, hospitals, doctors, nurses, researchers, pharmaceutical companies, politicians, and government institutions. Driven by an unshakeable belief in what we can achieve together, we continue to work on improving the quality of patient's lives and to find a cure for bone marrow failure diseases.

And just as all parts of a person must work together as a whole, all parts of our collaboration must contribute for us to accomplish our goals. As you plan your life for the year ahead, please take time to do as much as you can to contribute to our team. Work within your community to increase blood, platelet and bone marrow donations. Spread awareness of the disease and our Foundation's work through your local hospital and news sources. And please continue giving generous financial contributions to help our fight against bone marrow failure diseases.

Your personal and financial involvement in our Foundation are critical parts of our global team. Please contact us today to find out how you can help. Remember, we can't work without your help.

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

## TIDBITS

**Comfort for a Child** A wonderful website for children and parents: Soaringwords is an online support network for sick children and their families. It will create a sense among children and their families that it is okay to talk about illness, and that sickness, and even death, over natural parts of life. Wonderful online activities for bedridden children and wonderful resource for their caregivers.  
[www.soaringwords.org](http://www.soaringwords.org)

### Helpful Reading

Riding the Dragon: 10 Lessons for Inner Strength in Challenging Times by Robert Wicks

10 Secrets for Success and Inner Peace by Wayne Dyer

The Miracle of Change by Dennis Wholey

Risking Everything: 110 Poems of Love & Revelation by Roger Housden

### AA&MDSIF Newsletters

Archived on website since 1997. They contain wonderful articles on patient's victory, helpful resources and readings as well as important medical information and listings of research articles. Go to our website at: [www.aamds.org](http://www.aamds.org) and click on "Newsletters." You can also ask a friend, family member or your librarian to print the newsletters for you.

### AA&MDSIFE-Bulletins

Are you on our ebulletin mailing list? Every month we send out the very latest in scientific news and research developments on bone marrow failure disease. These bulletins are also archived on our website along with our newsletters. If you would like to receive monthly updates, email us at: [Bedigian@aamds.org](mailto:Bedigian@aamds.org)

### Overheard at Patient Conference

- ☼ "I have a plastic anemia because I couldn't afford a real one"
- ☼ "I have a damn cell in distress"
- ☼ "Don't start dying until you're dead; keep living life to the fullest as long as you're alive"
- ☼ "If you aren't delighted then you aren't paying attention!"
- ☼ "Worrying ruins this day I've been given; I choose to feel grateful for having been given this day."
- ☼ "I find joy in every tiny blessing I've been given, and if I don't, I sit there and count them!"

---

---

## HELPFUL RESOURCES

### MEDICAL FLIGHT PROGRAMS

**Air Care Alliance** – [www.aircareall.org](http://www.aircareall.org) • 888.260.9707  
Links patients with numerous free flight programs.

**Angel Flight America** – [www.angelflightamerica.org](http://www.angelflightamerica.org)  
800.446.1231 : Patient and a support person fly free.  
The flights distance cannot be greater than 1000 miles.

**Mercy Medical Airlift**/ National Patient Air Transport  
[www.mercymedical.org](http://www.mercymedical.org) • 800.296.1217  
A referral service that connects patients to free flights.

**American Airlines** / MILESFOR KIDS  
817.963.8118 • Marie Ising  
One-time help for lifetime • Oxygen Available

**Continental Airline** / CAREFORCE  
281.360.5314 • Amelia Reed and Bob Jack  
Advanced notice is variable and based on resources available. Oxygen available with 48hrs advanced notice and \$100 fee. One time every six months.

**Delta Airline** / SKYWISH - 877.327.8211 • Jan McDaniel  
3-4 weeks advanced notice necessary  
1-2 times per year (Domestic Only) • Oxygen available

**Southwest Airlines** - 214.904.4103 • Tracy Martin  
2-3 weeks advanced notice necessary • No oxygen  
1 time per-year (Domestic Only)

### PATIENT AID & PATIENT ADVOCACY

**AA&MDSIF Patient Travel Fund** - Clinical Trials  
[www.aamds.org](http://www.aamds.org) • 800.747.2820  
For low income families, provided up to \$500 per family for travel expenses to clinical trials.

**Bone Marrow Foundation**  
[www.bonemarrow.org](http://www.bonemarrow.org) • 800.365.1336  
The BMF patient aid program provides coverage for many of the costs associated with bone marrow transplant. These grants are limited to specific institutions, please speak with your hospital social worker or contact BMF for more information.

**First Hand Foundation** – Pediatric Charity  
[www.firsthandfoundation.org](http://www.firsthandfoundation.org) • 816-201-1569  
"First Hand is a philanthropic, nonprofit foundation established by the associates of Cerner Corporation. [Through grants] First Hand helps the families of children with health problems address the financial aspects of their child's healthcare."

**Healthcare Advocates** - Charges a fee  
[www.healthcareadvocates.com](http://www.healthcareadvocates.com) • 215.735.7711  
"Healthcare Advocates is a nationwide company designed to help people navigate through today's healthcare system."

**The Marrow Foundation**  
[www.themarrowfoundation.org](http://www.themarrowfoundation.org) • 202.638.6601  
"The Marrow Foundation...is committed to securing resources from the private sector to ensure that every patient who needs an unrelated marrow transplant has equal access to the procedure."

**National Transplant Assistance Fund**  
[www.transplantfund.org](http://www.transplantfund.org) • 800.642.8399  
Along with small grants the NTAf provides information and support for fundraising and patient awareness.

**Patient Advocate** – Equal Access to Health Care  
[www.patientadvocate.org](http://www.patientadvocate.org) • 800.532.5274  
"Patient Advocate Foundation seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability."

**Social Security Disability Programs**  
[www.ssa.gov/disability](http://www.ssa.gov/disability) • 800.772.1213  
"The Social Security and Supplemental Security Income disability programs are the largest of several Federal programs that provide assistance to people with disabilities."

### HOSPICE

**Children's Hospice International**  
[www.chionline.org](http://www.chionline.org)  
"CHI provides care for children from the time of their diagnosis with a life-threatening condition with hope for a cure, through bereavement follow-up if cure is not attained."

**Hospice International**  
[www.nhpc.org](http://www.nhpc.org) • 800.646.6460  
"The organization is committed to improving end of life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones."

**Hospice Net**  
<http://hospicenet.org>  
This non-profit internet resource provides information and support to patients and families facing a life-threatening illness.

**Palliative Care for Veterans**  
[www.hospice.va.gov](http://www.hospice.va.gov)  
The Veterans Administration has joined forces with hospice to better serve and meet the needs of its terminally ill veterans.

*continued*

(continued from previous page)

## CAREGIVERS

### **Family Caregivers Alliance (FCA)**

[www.caregiver.org](http://www.caregiver.org) • 800.445.8106

The first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care at home. Offers programs at national, state and local levels to support and sustain caregivers.

### **National Family Caregivers Association (NFCA)**

[www.thefamilycaregiver.org/about](http://www.thefamilycaregiver.org/about) • 800.896.3650

Supports, empowers, educates, and speaks up for those who care for a chronically ill, aged, or disabled loved one. NFCA reaches across the boundaries of different diagnoses, relationships and life stages to address the common needs and concerns of all family caregivers.

### **Well Spouse Foundation**

[www.wellspouse.org/information.html](http://www.wellspouse.org/information.html) • 800.838.0879

National not for profit membership organization which gives support to wives, husbands, and partners of the chronically ill and/or disabled. Monthly group meetings.

## LODGING

### **National Association of Hospital Hospitality Housing-**

[www.nahhh.org](http://www.nahhh.org) • 800.542.9730

A referral service for organizations that provide lodging for families supporting their loved ones far from home. Cost per family ranges from free to \$15 per night.

### **Ronald McDonald House • [www.rmhc.com](http://www.rmhc.com)**

Provides a "home-away-from-home" for families while children receive medical treatment. A donation of \$5 - \$20 dollar donation per night is asked; free if not possible.

### **Fisher House - Supporting Military Families**

[www.fisherhouse.org](http://www.fisherhouse.org) • 888.294.8560

There is at least one Fisher House at every major military and VA medical center. Cost per family ranges from free to \$10 per night.

## SCHOLARSHIPS

### **Patient Advocate Foundation - Scholarships**

[www.patientadvocate.org/events.php?p=69](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."

## MEDICATION ASSISTANCE

### **Medicaid - Prescription Drug Program**

[www.cms.hhs.gov/medicad/drugs/drughmpg.asp](http://www.cms.hhs.gov/medicad/drugs/drughmpg.asp)

Medicaid will cover most prescription drugs.

### **Needy Meds**

[www.needymeds.com](http://www.needymeds.com)

This site, run by both an MD and a social worker, provides information and links to pharmaceutical prescription programs.

### **National Organization of Rare Disorders (NORD) -**

[www.rarediseases.org/programs/medication](http://www.rarediseases.org/programs/medication)

203.744.0100 or 800.999.6673 (voicemail only)

NORD works with pharmaceutical companies to ensure that vital medications are available to those in need.

### **Pharmaceutical Manufactures Association**

[www.helpingpatients.org](http://www.helpingpatients.org) • This organization "offers a single point of access to more than 275 public and private patient assistance programs, including more than 150 offered by pharmaceutical companies."

### **Pillbot - Pillbot Drug Index**

[www.pillbot.com](http://www.pillbot.com) • 800.505.7279

Pillbot's database provides pricing comparisons for prescriptions and is updated daily.

### **RX Outreach - Volunteers in Health Care**

[www.rxassist.org/default.cfm](http://www.rxassist.org/default.cfm) • 877-844-8442

RX Outreach provides access to generic drugs for low income individuals.

### **Medicare - Prescription Drug Program**

[www.medicare.gov/default.asp](http://www.medicare.gov/default.asp)

"This section provides information on public and private programs that offer discounted or free medication, programs that provide help with other health care costs, and Medicare health plans that include prescription coverage."

## INSURANCE

### **Insure Kids Now - Every state in the Union**

[www.insurekidsnow.gov](http://www.insurekidsnow.gov) • 877.543.7669

A national campaign to link the nation's uninsured children to free and low-cost health insurance.

Please contact Debbie Judy ([judy@aamds.org](mailto:judy@aamds.org)) or Brianna Bedigian ([bedigian@aamds.org](mailto:bedigian@aamds.org)) regarding more information on helpful resources at 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](http://www.pubmed.gov). To obtain complete articles, contact your public or hospital library. These articles are listed for general information purposes only.

### APLASTIC ANEMIA

Bevans MF, Shalabi RA. Management of patients receiving antithymocyte globulin for aplastic anemia and myelodysplastic syndrome. *Clinical Journal of Oncology Nursing*. August 2004; vol. 8 no. 4: pp. 377-82.

Brodsky RA, Jones RJ. Riddle: what do aplastic anemia, acute promyelocytic leukemia, and chronic myeloid leukemia have in common? *Leukemia*. October 2004; vol. 18 no. 10: pp. 1740-2.

Goldenberg NA, Graham DK, Liang X, Hays T. Successful treatment of severe aplastic anemia in children using standardized immunosuppressive therapy with antithymocyte globulin and cyclosporine A. *Pediatric Blood & Cancer*. December 2004; vol. 43 no. 7: pp. 718-22.

Hirano N, Butler MO, Guinan EC, et al. Presence of anti-kinectin and anti-PMS1 antibodies in Japanese aplastic anaemia patients. *British Journal of Haematology*. January 2005; vol. 128 no. 2: pp. 221-3.

Howard SC, Naidu PE, Hu XJ, et al. Natural history of moderate aplastic anemia in children. *Pediatric Blood and Cancer*. October 2004; vol. 43 no. 5: pp. 545-51.

Locasciulli A, Bruno B, Rambaldi A, et al. Treatment of severe aplastic anemia with antilymphocyte globulin, cyclosporine and two different granulocyte colony-stimulating factor regimens: a GITMO prospective randomized study. *Haematologica*. September 2004; vol. 89, no. 9: pp. 1054-61.

Marsh JC, Gordon-Smith EC. Insights into the autoimmune nature of aplastic anemia. *Lancet*. July 24, 2004; vol. 364 no. 9431: pp. 308-9.

Shah C, Lemke S, Singh V, Gentile T. Case reports of aplastic anemia after vaccine administration. *American Journal of Hematology*, October 2004; vol. 77 no. 2: pp 204.

Viollier R, Passweg J, Gregor M, Favre G, Kuhne T, Nissen C, Gratwohl A, Tichelli A. Quality-adjusted survival analysis shows differences in outcome after immunosuppression or bone marrow transplantation in aplastic anemia. *Annals of Hematology*. January 2005; vol. 84 no. 1: pp. 47-55.

### MYELODYSPLASTIC SYNDROME

Bagby GC, Lipton JM, Sloand EM, et al. Marrow failure. *Hematology (Am Soc Hematology Education Program)*. 2004; pp. 318-36.

Bain B. The WHO classification of the myelodysplastic syndromes. *Experimental Oncology*. September 2004; vol. 26 no. 3: pp.166-9.

Bevans MF, Shalabi RA. Management of patients receiving antithymocyte globulin for aplastic anemia and myelodysplastic syndrome. *Clinical Journal of Oncology Nursing*. August 2004; vol. 8 no. 4: pp. 377-82.

Casadevall N, Durieux P, Dubois S, et al. Health, economic, and quality-of-life effects of erythropoietin and granulocyte colony-stimulating factor for the treatment of myelodysplastic syndromes: a randomized, controlled trial. *Blood*. July 15, 2004; vol. 104 no. 2: pp. 321-7.

Deeg HJ, Jiang PY, Holmberg LA, Scott B, et al. Hematologic responses of patients with MDS to antithymocyte globulin plus etanercept correlate with improved flow scores of marrow cells. *Leukemia Research*, November 2004; vol. 28 no.11: pp.1177-80.

Gore S. Classification, treatment goals, and management principles for myelodysplastic syndromes. *Cancer Control*. November-December 2004; vol 11(6 Suppl): pp. 3-6.

Hofmann WK, Baldus C, Uharek L, etc. Therapeutic spectrum in the treatment of myelodysplastic syndromes. *Expert Opin Pharmacother*. December 2004; vol. 5 no. 12: pp. 2451-8.

List A. Methyltransferase inhibitors: changing the treatment algorithm for myelodysplastic syndromes. *Cancer Control*. November-December 2004; vol. 11(6 Suppl): pp. 16-9.

List A. New paradigm in the management of myelodysplastic syndromes. *Cancer Control*. November-December 2004; vol. 11(6 Suppl): pp. 2.

List AF, Vardiman J, Issa JP, etc. Myelodysplastic syndromes. *Hematology (American Society of Hematology Education Program)*. 2004; pp. 297-317.

Lubbert M, Daskalakis M, Kunzmann R, et al. Nonclonal neutrophil responses after successful treatment of myelodysplasia with low-dose 5-aza-2'-deoxycytidine (Decitabine). *Leukemia Research*, December 2004; vol. 28, no.12: pp. 1267-71.

Marisavljevic D, Rolovic Z, Boskovic D, et al. Long-term survivors in myelodysplastic syndromes: clinical and biological characteristics. *Medical Oncology*. 2004; vol. 21 no. 4: pp. 333-8.

Raza A, Candoni A, Khan U, et al. Remicade as TNF suppressor in patients with myelodysplastic syndromes. *Leuk Lymphoma*. October 2004; vol. 45 no. 10: pp. 2099-104.

Silverman LR. The role of methyltransferase inhibitors in the management of the myelodysplastic syndromes. *Cancer Control*. November-December 2004; vol. 11(6 Suppl): pp. 11-5.

Stone R. Treatment options for myelodysplastic syndromes. *Cancer Control*. November-December 2004; vol. 11(6 Suppl): pp. 7-10.

Visani G, Malagola M, Piccaluga PP, et al. Low dose Ara-C for myelodysplastic syndromes: is it still a current therapy? *Leukemia & Lymphoma*. August 2004; vol. 45 no. 8: pp. 1531-8.

### PAROXYSMAL NOCTURNAL HEMOGLOBINURIA

Grunewald M, Grunewald A, Schmid A, et al. The platelet function defect of paroxysmal nocturnal haemoglobinuria. *Platelets*. May 2004; vol. 15 no. 3: pp. 145-54.

Moyo VM, Mukhina GL, Garrett ES, et al. Natural history of paroxysmal nocturnal haemoglobinuria using modern diagnostic assays. *British Journal of Haematology*. July 2004; vol. 126 no. 1: pp. 133-8.

Risitano AM, Maciejewski JP, Muranski P, et al. Large granular lymphocyte (LGL)-like clonal expansions in paroxysmal nocturnal hemoglobinuria (PNH) patients. *Leukemia*. February 2005; vol. 19 no. 2: pp. 217-22.

Smith LJ. Paroxysmal nocturnal hemoglobinuria. *Clinical Laboratory Science*. Summer 2004; vol. 17 no.3: pp. 172-7.

---

---

# *Thank You to our 2004 Donors!*

On behalf of the entire AA&MDS International Foundation family, we would like to thank the following donors for their support. It is only because of these generous people that the AA&MDSIF can continue to fulfill its mission of serving as a resource for patient assistance & fund medical research to find a cure for bone marrow failure diseases - aplastic anemia, myelodysplastic syndromes, and paroxysmal nocturnal hemoglobinuria. We are truly grateful to all those who are helping us to assist thousands of patients and their families around the world who are so desperately asking for support.

## *Thank You!*

### **VISIONARIES – \$30,000 & over**

Anonymous - Jane's Research Study  
Anonymous - JHCL Memorial Research Study  
Anonymous - Pursuing New Hope Research Study  
Earl J. Goldberg, AA&MDSIF Affiliate – Research Study  
Pharmion Corporation – Patient Conference, Patient Notebooks & Physician Brochures  
Howard Stephenson – Research Study

### **PATRONS - \$10,000 - \$29,999**

AA&MDSIF Michigan Affiliate  
Alexion Corporation – Patient Conference  
Camenisch Trust – Camenisch Research Study  
Celgene Corporation – Patient Conference  
Eileen Michaely  
Marica Miller  
Shizue Spielberg & Vibratex, Inc. – Harold Spielberg Research Study  
Oliver & Jamie Wyss Soccer For Hope – Children's Network  
Donald & Joann Yahn Annual Barbeque – Tory Yahn Research Study

### **BENEFACTORS - \$5,000 - \$9,999**

Even & Malama Collinsworth Advised Fund Sarasota County - Research Study  
Herman Goldman Foundation – AA&MDSIF Quarterly Newsletters  
Vaughn & Heather Hardin  
Jim & Lois MacGillivray  
John Minelli - Lindsay Minelli Research Study  
Doris Moreland  
Anthony & Briget Sanfilippo  
George Smoot  
Carol Stewart – Funding for Patient Travel  
Stephanie Vendig – AA&MDSIF Website “Ask the Experts”  
Lois Walter

---

### **GIFTS IN KIND**

Neil Horikoshi of Maryland - *An Incredible IBM Printer*  
Office Depot of Florida - *Envelope Folding Machine*  
Rays Envelopes of Maryland - *Patient Information Packet Envelopes*  
Renee Sussman of New Jersey - *Office Supplies*

---

---

**FRIENDS - \$1,000 - \$4,999**

AA&MDS Association of Canada  
AA&MDSIF New England  
Anonymous from North Carolina  
Evan Ardavanis  
Luis & Paula Ayala  
BBR Contracting Corp  
Charles & Catherine Baker  
Marilyn Baker  
Susan & Larry Benson  
Christina & David Beranek  
David Bird  
Michael & Irena Blessent  
Bob's Discount Furniture  
Mark & Kimberly Bockman  
John & Kristen Byrne  
Jack Canetti  
Robert & Marie Carroll  
Anne Carry  
Ardith Chism  
Doug & Maureen Cohn  
John & Deborah Cook  
Judy Cottle  
Jerome & Barbara Eisner  
Bob & Dori Ellinger  
George & Eleanor Filowick  
Edward & Agata Gliwa  
Dorothy Goldmeier  
Michael Greenberg, MD  
Ralph & Sally Hamaker  
Suzanne Hedge Fund  
IBM Corporation  
Illinois Tool Works Foundation  
Abraham & Kimberly Kader, M.D.'s  
Amnuay & Usa Komalahiranya  
Debra & Davis Krekelberg  
Rita Kunofsky  
Vivian & Raymond Locke  
William & Mary Ellen Madden  
Bruce & Barbara Marshall  
Gina & Andy Montroy  
Mel Murray  
Netjac Corporation Limited  
Steve & Martha Nicholas  
Bill Nottingham  
Novartis Corporation  
Janet & Kevin O'Leary  
Oz Architects, Inc.  
Linda Hicks Payne  
Jeffrey Pearlman  
Pfizer Foundation  
John Powers  
Susan Morse Poynter  
John Cohn & Jeanne Raisler  
Roger & Nancy Rathke  
Sidney & Phyllis Rodbell  
Arnold & Adrienne Rubin  
Crawford Sandefur  
Lori & Bob Saunders  
Jeffrey Schultz  
Coleen & Elton Shuknecht  
Split Rock Realty  
Scott Stoddard  
Margie Ward  
Westlake Group

Winter Livestock  
Andrea & Larry Wolfe  
Allen & Linda Womack  
William & Deborah Yahn  
Adrianna Zabrosky  
Kim Ziegner Bepler

**PARTNERS - \$500 - \$999**

Judith & Luther Albert  
Jay & Susan Anderson  
Ashtabula Area City Schools  
Ashley River Baptist Church  
Robert & Suzanne Baker  
Neloise Bell  
Lois Benda  
Don & Gale Bennett  
Madaleine Berley  
Malcolm Berman  
Robert & Debbie Bingham  
Blank Charitable Foundation, Inc  
Harry Brancheau  
Cars 4 Causes  
Daniel Cherry  
J. Churchill  
Clark Enterprises, Inc  
Lorraine Cronin  
Linda D'Amico  
Anthony Dobranski  
Cathy Sue Downing  
Denise Ehlert & Family  
Nicholas Stuart Elfner  
Fairfield Prep  
Feil Family Foundation  
Mark Fielding  
Donald & Sarann Foster  
Janice & Robert Gale  
Patricia Fawne  
Mickela Gay  
Robert Geary & Christine Triessl  
Nicholas & Mary Georgatsos  
Gina Goldberg  
Steven Gordon  
Jean Wixson Gowen  
Gwen Haertling  
Julie & Peter Hains  
Rita & Paul Halpern  
Bill & Stephanie Hamm  
Patricia Herron  
Richart Hetland  
Julie Homza  
HSP Direct  
Jacqueline Hunt  
Robert & Eleanor Hunter  
Jason Janisch  
Janus Foundation  
Shirley & Harold Jarvis  
Gail & Dale Johnson  
JP Morgan Chase  
Just Give org  
Robert Kaplan  
Kathleen Keenan  
Dorothy Kelso  
James Knight  
Frank Krenek

Brian Levine  
Steve & Diane Liga  
Taisen Lin  
Al Loeb  
Kathy Loeb  
Phyllis Madden  
Carole McCurdy  
Edward & Patricia McIntire  
Sharon Goodman & Scott McNeilly  
Brian & Nancy Meehan  
Memorial Gold Tournament  
Israel Menchero  
Steven Miller  
Daniel Minnick  
Lynda & Dennis Morrison  
Mcginnis Partnership  
Jay & Leann Muschenheim  
Rita & Alan Orlosk  
Merrill Osherooff, Ph.D.  
Perry Hall Middle School  
Cheryl & Joe Polk  
Buford & Mary Price  
Daniel & Mary Reeves Foundation  
Robin & Steven Reifinger  
Mack & Sandy Roark  
Elsa Roberts  
Diane & Robert Rosenfeld  
Roxanne Ruggles & Steve Morgan  
Bruce & Sandra Rule  
Jack & Judith Ryder  
SAIC Frederick Inc  
Maria Salvi  
Judith & Cedric Sampson  
John & Vincentia Schwartz  
Daryl & Kathleen Scott  
Nancy Sells  
Susan & Steven Sepe  
Col. James & Sandra Sharp  
William Shulevitz  
Edgar & Ann Silver  
Eaton & Lucy Smith  
James Sommers  
John & Gina Steiner  
Margaret Steiner  
Robert Stempel  
Charles Stewart Mott Foundation  
Joni Sweetwood & Howard Gralla  
Symmetry Corp  
Kent & Allison Taylor Family Fund  
Linda Temple  
Williams & Jane Theroux  
Julie Triessl  
Mary Elaine Valenzuela  
Scott Van Dyke  
Sherrie Van Vliet  
John & Frances Varden  
Wallenparpack Area Class of 2004  
Walton Electric  
Allen & Susan Weaver  
Robert & Maria Salvi Weinger  
Nicole Williams  
Lois & Jerry Wilson  
Max Wiviott

---

*Our Sincere Gratitude to the Herman Goldman Foundation of New York City for sponsoring this newsletter.  
Their generous donation has made it possible for us to distribute this newsletter to thousands of patients and their families.*



## ANNUAL PATIENT & FAMILY CONFERENCE

Join us for our 19<sup>th</sup> patient meeting!

This year we will be gathering at the newly renovated  
Denver Airport Marriott at Gateway Park  
during the week of July 25<sup>th</sup>

*Registration Forms will be enclosed in our Spring Newsletter and on our website*

## BONE MARROW FAILURE SCIENTIFIC SYMPOSIUM

Sponsored by the NIH Office of Rare Disease and National Cancer Institute  
Co-Chaired by Dr. Jarek Maciejewski of Cleveland Cancer Institute

*and*

Dr. Neal Young of National Heart, Lung & Blood Institute

October 17, 18, 19, 2005

Loews L'Enfant Plaza Hotel in Washington, D.C.

*More than 200 physicians will be in attendance with interests in immunosuppressive therapy,  
stem cell transplantation and basic scientists in cell biology, immunology education are expected to attend.*

Registration Form for researchers is available on AA&MDSIF website



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](http://www.aamds.org)

Nonprofit Org. U.S. Postage <b>Paid</b> Annapolis, MD. Permit No. 310
---

**RETURN SERVICE REQUESTED**

**PRESIDENT:**

Robert Carroll, Ed.D.

**VICE PRESIDENT:**

Vince Wessling

**SECRETARY & CONTRIBUTING EDITOR:**

Ruth Cuadra

**TREASURER:**

Tony Sanfilippo

**CHAIRPERSON, MEDICAL ADVISORY BOARD:**

Richard Stone, M.D.

**EXECUTIVE DIRECTOR & EDITOR:**

Marilyn Baker, M.S.

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!

---