



## 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. We are proud to spend only 6% on administrative and 2% on fundraising costs. Please compare our performance with other charities when making your tax-deductible contributions.

## FDA APPROVES FIRST DRUG FOR TREATING MDS

On May 19, 2004, the U.S. Food and Drug Administration (FDA) announced the approval of Vidaza (azacitidine) injection for patients with Myelodysplastic Syndrome (MDS). Vidaza is the first drug therapy approved for treating MDS. The FDA approved Vidaza for treatment of all five MDS subtypes, including refractory anemia (RA) or refractory anemia with ringed sideroblasts (RARS), refractory anemia with excess blasts (RAEB), refractory anemia with excess blasts in transformation (RAEB-T), and chronic myelomonocytic leukemia (CMML).

"The approval of Vidaza by the FDA is a landmark decision which will bring to physicians our first treatment with an FDA-approved indication in MDS," Dr. Alan List, Program Leader, Hematologic Malignancies of H. Lee Moffitt Cancer Center comments. "For the first time, treatment for patients with MDS will transition from an exclusive focus on supportive care to a treatment that may impact the natural history of the disease."

Vidaza is thought to work by restoring normal growth and differentiation of bone marrow cells. It is believed to exert its effects by causing demethylation (changes in the structure) of DNA in abnormal blood-forming cells in the bone marrow. Vidaza is the first in a new class of compounds called demethylation agents to be approved.

The product was given Fast Track Status and a priority review. The safety and effectiveness of Vidaza, in the treatment of all subtypes of MDS, were established in a randomized, controlled trial and in two non-randomized studies in a total of 268 patients. About 15% of patients in the three trials had complete or partial responses to Vidaza. Responses consisted of complete or partial normalization of blood counts and of immature cell percentages in the bone marrow. In responders the need for transfusions was eliminated.

The most common adverse events reported in clinical trials included nausea, anemia, thrombocytopenia (low platelets in blood), diarrhea, fatigue, irritation at the injection site, and constipation. Because Vidaza is associated with neutropenia and thrombocytopenia, complete blood counts should be performed as needed to monitor response and toxicity. Liver chemistries and serum creatinine should be obtained before beginning therapy.

Vidaza is manufactured by Pharmion Corporation, [www.pharmion.com](http://www.pharmion.com) and is classified as an orphan product. Orphan products are developed to treat rare diseases, or conditions that affect fewer than 200,000 people in the U.S.

## FROM THE DIRECTOR...

*"This is our purpose: to make as meaningful as possible this life that has been bestowed upon us, ...to live in such a way that we may be proud of ourselves, to act in such a way that some part of us lives on."*

—Oswald Spengler  
German Philosopher



Time. We all thought we would have so much more time in our lives. And the fact that many of us might be closer to the end, rather than the beginning, can account for some of our grumpiness. But possibly our irritation comes from the nagging suspicion that we might have wasted much of our time, and we are just now realizing how precious it really is.

We know we can't take our possessions with us; all of the pretty objects we gather are merely to provide entertaining diversions while on earth. The real value of our lives is not in what we have accumulated, but in what we have done during the time we have been given. This is the real measure of a life. And this is a good way to ensure that we will live on long after our time is gone.

There are a variety of ways to act in such a way that some part of us lives on - we can raise children, bring knowledge to others, improve the lives of others, preserve the earth and wildlife, accomplish much in our jobs and hobbies, bring joy to those we love, donate our blood, platelets, bone marrow, and organs. Here at the AA&MDSIF I know thousands of people whose spirits will live on in the generous work that they do through our Foundation.

Carol Stewart will live on in the dozens of patients she has helped by paying for their travel to clinical trials. Aaron Donahue lives on in hundreds of patients through his fathers' monthly platelet donation. Oliver Wyss will live on in hundreds of children whom he teaches winning strategies for soccer and beating bone marrow disease. Ivan Fisher lives on in his father's "Give a Life" effort motivating thousands to donate organs and tissue. And many loved ones live on in the patients who are benefiting from the medical research study funded by the PNH Support Group.

Take a moment to reflect upon your time here on earth. Regardless of whether you think you still have a lot of time, or just a little, mull over your meaningful accomplishments and consider ways that you want to be remembered. The AA&MDSIF offers you many opportunities to help those affected by bone marrow disease making it possible for you to live on in the hearts and lives of future generations. Please call us today to get started!

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

## **GREAT NEW BROCHURE...**

"Talking To A Child with Bone Marrow Disease" is a great new tool to help you talk to a child about their illness and their feelings. This booklet is dedicated to board member, Tony Sanfilippo and his family. We are extremely grateful to the Knight Trading Group, Inc. of Jersey City for funding this vital brochure. Call us to get your free copy.

## **GREAT SITE...**

[www.myphr.com](http://www.myphr.com) "My Personal Health Record" A guide to help you become an active partner in managing your personal health information ensuring complete documentation of your treatment and care.

## **GREAT READ...**

"Blindsided – Lifting a Life Above Illness" by Richard Cohen. Must reading for absolutely everyone. This short book was written by veteran television news producer and multiple sclerosis patient who will make you think twice about your own life and struggles.

## **GREAT IMAGERY...**

Look into the power of imagery by Belleruth Naparstek. CD: "Health Journeys Guided Imagery" Books: "Unlocking the Power of your Intuition," "Staying Well With Guided Imagery."

## **GREAT COMBINED FEDERAL CAMPAIGN...**

Please encourage your government coworkers to donate to the AA&MDSIF – Agency #0816 – through your federal place of employment. Remind them of our extremely low administrative and fundraising costs and ask them to compare our efficiency to other charities. Every dollar helps!

## **GREAT EDUCATION...**

[www.mybloodyourblood.org/hs\\_biology.htm](http://www.mybloodyourblood.org/hs_biology.htm). This is an outstanding site that provides an excellent education on our basic hematology.

## **GREAT ORGANS...**

Please consider giving the ultimate gift, the gift of life through organ donation. All you need to do is say YES to organ and tissue donation on your donor card and/or driver's license, sign up on your state's donor registry (if there is one), and discuss your decision with your family. Each day about 70 people receive an organ transplant, but another 16 people on the waiting list die because not enough organs are available. For more information:

[www.organdonor.gov](http://www.organdonor.gov)  
[www.donatelife.net](http://www.donatelife.net)

---

---

# Tool Kit for Families Living with Bone Marrow Disease

Before bone marrow illness moved into your world, how did your family deal with crisis? Typically one member goes into Fix It Mode, and others take roles that feel most comfortable to them. The ideal, yet least common approach to problems is honest problem solving that includes talking about emotions and feelings. Families that have worked through the more difficult aspects of having an ill member may schedule regular family meetings to help “clear the air” and make sure that there are as few misunderstandings as possible. The more coping techniques the better.

There are several common areas that are challenges for families with chronic illness: Comfort, trust, and respect are other ingredients that strengthen connections. Other relationship issues that must be negotiated are: dealing with emotions: denial, depression and disappointments; planning, preparation, concerns and fears about the future; teamwork, fighting for your rights, dealing with doctors and medical systems; care and support for care-partner, sharing of information about the illness when “protecting” the ill person and others; what amounts of information are most helpful and when; and reducing the burden on the children and family members.

At the core of any strong relationship is good communication. Communication is one of the biggest challenges for families with chronic illness. The big question is how to find ways to let your partner, family or friends know how you feel without feeling like you are being a burden. (Yes, this goes both ways – the ill person AND the care partners.) Healthy communication depends on several factors:

1. Your comfort knowing and sharing your emotions and needs with others
2. Your comfort level dealing with conflict, can you agree to disagree?
3. The severity of the disease and
4. How well you worked as a team before the diagnosis.

If you can work out disagreements about where to eat when you go out, you are likely to have fewer problems talking about more difficult topics, such as changes in levels of independence. Being able to talk openly about loss, changes in what each of you are able to do, are all skills. These are skills that most people never learned. Knowing how to discuss and make your needs known can make it easier to cope with the ups and downs of chronic illness. These same tools will enrich other aspects of your relationships.

What is most important in your relationships and life in general? Most of us want to feel close to those we love, to be heard, valued and understood, to be able to communicate, work as a team, be able to be friends, and

handle the ups and downs that come with illness. A tall order for any couple, and even taller when illness is stirred into the mix. One exercise you might want to try is having each person jot down their thoughts about what is most important in their relationships and life in general and then read them aloud to each other. You may be surprised what you learn about your priorities and your loved ones. (Who knows, you might learn that your loved one has a secret desire to go to Disneyland.)

How you cope as a family depends on many factors. Tension, unresolved anger, financial stresses and being stuck in “survival mode” can aggravate or cause problems. For example, when was the last time you planned something **Fun**? Is there room for playfulness in your relationship? When was the last time you spent time doing something just for relaxation or pleasure? If your answer is “Too long ago!” talk with your family or close friends about scheduling a short get-away within the next month. Or at least schedule a time to do something outside of your normal routine that you can enjoy, like going out to see a movie or making a picnic in the living room.

During times of crisis or exacerbations, your focus may be on survival. This is normal. Nevertheless, it is important to find ways to inject comfort and joy, even in small doses. These are times when each Team Member needs an extra dose of compassion, for everyone, especially themselves. The challenge is to balance the arts of Patience, Creativity and Flexibility.

In short, making room for support from others is a gift that helps everyone. One of the many gifts that the AAMDS foundation gives is the variety of ways it connects members to each other throughout the year. The richness of the support you offer each other is one of the greatest gifts I have seen.

## About the Author:

*Ann Steiner, Ph.D., M.F.T., CGP, is a licensed marriage family therapist, professional speaker and author who specializes in work with the medically ill and relationship issues. She is in private practice in Lafayette, CA, is an Associate Clinical Professor, Department of Psychiatry, University of California Medical School, San Francisco, and has been leading psychotherapy groups for 24 years. Her Medical Information Form, a free downloadable way to keep a current list of your medications and emergency contact information is available at [www.DrSteiner.com](http://www.DrSteiner.com)*

## Note:

This article is based on sections of her upcoming self-help book. Please do not use this material without the author's written consent. Dr. Steiner can be contacted at [email@DrSteiner.com](mailto:email@DrSteiner.com) or (925) 962-0060.

---

---

# FDA'S ROLE IN THE APPROVAL OF DRUG PRODUCTS

*Marlene E. Haffner, M.D., MP.H.*

*Director, Office of Orphan Products Development  
Rear Admiral, U.S. Public Health Service*



Patients with rare diseases encounter unique challenges, often beginning with the issue of diagnosis. As many of you are aware, it may take many months, if not years to receive an accurate diagnosis, only to be told that there are few, if any, drugs available to treat the disease. If

a disease is an orphan disease – that is, it affects fewer than 200,000 patients in the U.S., pharmaceutical firms may be reluctant to invest in developing therapies for disease, since the return on investment may not be realized. What, then, is the role of the FDA and the Office of Orphan Products Development (OPD) in helping patients receive therapy for their specific disease?

As a result of the obvious need to serve patients with rare diseases, the U.S. Congress, in 1982 passed the Orphan Drug Act (ODA), amending the Federal Food, Drug and Cosmetic Act. This law, which was signed by then President Reagan in 1983, created incentives for companies and academic researchers to develop products to treat rare diseases.

It is estimated that there are more than 6 000 rare diseases in the U.S., and the number of these diseases is constantly growing. In addition to aplastic anemia and myelodysplastic syndrome (MDS), other rare diseases include the childhood and adult leukemias, the inherited and inborn errors of metabolism like phenylketonuria (PKU), Lou Gehrig's Disease (Amyotrophic Lateral Sclerosis or ALS), Gaucher Disease, Severe Combined Immunodeficiency Syndrome and many, many more.

People with rare diseases are entitled to treatment for their disease that is safe and effective, just like patients with more common diseases. So, the ODA did not in any way change the standards for

development, review and approval of a new drug. What the ODA did do is establish incentives that would create sufficient reward for pharmaceutical companies to be willing to invest in drugs for rare diseases.

Before talking about the incentives, I would first like to address, briefly, the process of drug development. How are new drugs developed? When a promising compound is described for a particular disease, the first step is to determine whether it is safe for people. The literature is replete with stories of disasters occurring when products were given to people without first establishing safety. The first step in safety is to look at the product in animals – both from a general safety/toxicity standpoint as well as from the standpoint of long-term use which might affect the offspring of the patient, or which might result in organ damage or cancer causation. When the product passes the safety threshold, it is time for the company to request an IND (Investigational New Drug Exemption) from the FDA Center for Drug Evaluation and Research (CDER), or the FDA Center for Biologic Evaluation and Review (CBER). Once the IND is approved, the company is then able to test the product in patients.

The first step in giving a previously untested product to patients is to give it to a small group of individuals – either normal volunteers or actual patients – to further evaluate safety parameters. If no problematic side effects appear during Stage I, we are ready to further evaluate the product as a treatment for the disease. Ideally, the next step would be Stage II: determining the best dosage of the product to be given. With rare diseases, this may or may not be easy to do. Often with very rare diseases – such as aplastic anemia and MDS, we do the best we can to ascertain proper dosage, but exact dosage establishment may not occur. And, finally, the Stage III trial(s). This is the stage at which the efficacy of the product in this type of disease is actually evaluated. Ideally, this trial is conducted in a double-blinded fashion, where some of the patients get the drug and some get a placebo. Neither the patients nor their physicians know what they are taking.

*(continued on next page)*

(continued from previous page)

Hence the term, “double blinded.” After a pre-determined period of time, the results are reviewed to determine if the individuals taking the product did significantly better than the individuals who received a placebo. Side effects are also reviewed. Usually two double-blinded trials are performed to be certain that the effects seen are real.

If the results of the trials are positive – that is to say, the patients on the real drug did better than the patients on the placebo – then the product data is ready to be presented to the FDA who will review the data and determine if significant efficacy and safety standards have been met. Needless to say, the above description is an over- simplification of the entire clinical trial process which actually takes a tremendous amount of time, and costs a significant amount of money.

How can the ODA assist in the process of development of treatments for rare diseases? As I previously mentioned, the ODA provides incentives to induce companies to develop products for rare diseases. The most important incentive is seven years exclusive marketing rights for that drug for that disease upon FDA market approval. No like product may be approved by the FDA to treat that disease for seven years. Marketing exclusivity provides assurance to the firm that their investment is safe from competition and erosion of their share of the market. There are also tax incentives which may be applied forward for 20 years and have a one year “fall back” provision as well. This incentive is particularly valuable for small and medium sized firms. The incentive is administered by the Internal Revenue Service (IRS) and not by the FDA. Once the product is designated as an orphan product, the company may seek advice and counsel from the OPD concerning the drug and its development. Staff from the OPD attend meetings with the company and the review divisions of the Center for Drug Evaluation and Research (CDER) and the Center for Biologic Evaluation and Research (CBER). At these meetings, the best way to study the drug is determined. The OPD serves as the ombudsman for the company and for the patients with the disease.

Another significant incentive of the ODA is the waiver of the PDUFA fee. PDUFA stands for Prescription Drug User Fee Act. That law permits FDA to charge a company for the review of the data leading up to the approval of a new drug. In 2004, the user fee for a

new drug approval application is \$573,000. For small and medium sized firms, this is a significant cost. The waiver of this expenditure is very helpful in promoting the development of a product to treat a rare disease.

Grant dollars are also available to assist, mainly academic researchers, in the development of treatments for rare diseases. Often the awarding of an OPD grant will be the first time a particular product can be used in a patient. If the drug shows promise, a pharmaceutical firm will be more likely to be interested in the product.

Over the past 21 years, the ODA has proven to be VERY successful. There are 252 drugs and biological products that have been FDA approved to treat rare/orphan diseases. In the aggregate these products treat more than 13 million patients in the U.S. In addition, there are more than 1300 drugs and biological products that have been designated as orphan drugs by the OPD. Many of them will become FDA approved products to treat orphan diseases.

Most orphan diseases are serious and life-threatening diseases. FDA has always viewed these diseases as requiring more attention and faster review times. The OPD staff work diligently with the staffs at CDER and CBER to be certain that necessary products to treat serious orphan diseases are approved as quickly as possible.

Clearly, more needs to be done. While 252 is an impressive number of new drug approvals, with more than 6 000 diseases, we have just begun to scratch the surface.

- ◆ U.S. Food and Drug Administration, Center for Drug Evaluation and Research  
<http://www.fda.gov/cder/>
- ◆ From Test Tube to Patient  
[http://www.fda.gov/fdac/special/newdrug/ndd\\_toc.html](http://www.fda.gov/fdac/special/newdrug/ndd_toc.html)
- ◆ Consumer Education: What You Should Know About Buying and Using Drug Products  
<http://www.fda.gov/cder/consumerinfo/DPAdefault.htm>
- ◆ New Drug Approval Process – chart  
<http://www.fda.gov/cder/handbook/develop.htm>
- ◆ Investigational New Drug (IND) Review Process – chart  
<http://www.fda.gov/cder/handbook/ind.htm>
- ◆ New Drug Application (NDA) Review Process - chart  
<http://www.fda.gov/cder/handbook/nda.htm>

---

---

# The Importance of Supplemental Insurance for Medicare Patients

Carol Ware, CPC  
PharmAnalysis Group, Inc.

Under the traditional Medicare fee-for-service insurance plan there is a portion of charges that are not paid for by Medicare and are the patient's responsibility. Medicare will pay 80% of the approved charges while requiring the patient to pay the remaining 20%. Most supplemental insurance plans fill the "gap" for that 20% that is not paid by Medicare.

There are different types of supplemental insurance for Medicare patients. An employer, union, or association can offer supplemental insurance to its employees/members at the time of retirement. For those patients who are low income and meet other criteria for the state in which they live, Medicaid may serve as a supplemental form of insurance for these "dual eligible" beneficiaries. Finally, Medicare beneficiaries have the option to choose a Medi-Gap insurance plan to fulfill the patient co-insurance responsibility.

Supplemental insurance plans are important to seniors for a variety of reasons. During this time in their life they are retired and often living on a fixed income with increasing medical expenses. A typical patient may require several services within one doctor visit. For instance, charges may include: an office visit, administration of chemotherapy, and drug charges. Medicare will only reimburse 80% of the approved Medicare charges for these services. The remaining 20% is the patient's responsibility. In the absence of a supplemental insurance plan, the patient could be left with a bill ranging from \$100 and upward per visit. This situation can represent a significant financial burden to a retired patient with limited financial resources.

Types of services covered under the Medi-Gap plans include:

- ◆ A basic benefit that covers the 20% patient co-insurance,
- ◆ Medicare Part A deductible,
- ◆ Skilled nursing co-insurance,
- ◆ Medicare Part B deductible,
- ◆ Foreign travel emergency,
- ◆ At-home recovery,
- ◆ Preventive care,
- ◆ Medicare Part B excess charge (or a portion of) and;
- ◆ A limited prescription drug benefit.

The cost of a supplemental insurance plan is associated with the level of benefits offered. Services not covered by Medi-Gap supplemental plans include:

- ◆ Long term care,
- ◆ Vision or dental care,
- ◆ Hearing aids,
- ◆ Private duty nursing and;
- ◆ Unlimited prescription drug coverage.

To enroll in employer sponsored supplemental plans, patients should talk to their employer's Benefit Office to determine if these types of plans are available and identify if the employer or employee pays the premium. For low-income Medicare beneficiaries, these patients should contact their state Medicaid office and determine the income level and additional state requirements to qualify for Medicaid supplemental insurance.

In addition, some federal programs offer supplemental insurance to their employers (i.e. the Department of Defense, The Department of Veterans Affairs, and the Federal Employer's Health Benefits Program). Employees of these agencies should contact them directly to identify the types of supplemental insurance available.

Medicare beneficiaries should review the 10 Medi-Gap plans (A-J) available to them through their respective State Insurance Department and determine which plans best meet their medical and financial circumstances. In general, most Medicare beneficiaries are eligible for Medi-Gap plans when they reach age 65. There is a one-time enrollment period during which MediGap insurers must allow beneficiaries to enroll into any open plan. If Medicare beneficiaries miss the open enrollment period, they may still contact the State Insurance Department to determine the premium cost and whether an insurer can medically underwrite a supplemental plan for a new applicant.

*(continued on back cover )*

---

---

## AA&MDSIF Progress In Research

Part of our mission is to fund medical research to find effective prevention, treatment, and cure for bone marrow failure. Each year the AA&MDSIF Medical Advisory Board reviews applications from all over the country and recommends funding for those medical research studies judged to be the most promising. Research in any area of bone marrow greatly assists in the understanding of all bone marrow failure diseases. The following are updates from AA&MDSIF awards.

---

### **DR. MONICA BESSLER**

Assistant Professor in Hematology  
at Washington University, Missouri

“Genes, Chromosomes, and Bone Marrow Failure.”

#### ***Study funded by the Florentine Camenisch Fund.***

Initial studies show that bone marrow failure (aplastic anemia & MDS) due to short chromosome ends (telomeres) is much more frequent than anticipated and that the course of the disease and the response to treatment is different from those of individuals with bone marrow failure and normal telomere length. A constantly increasing number of institutions are participating in our study to identify and follow individuals that have bone marrow failure due to short telomeres and to identify the genes responsible for telomere shortening. We are convinced that telomere length should be investigated in all individuals that have bone marrow failure (AA and/or MDS), particularly in those with bone marrow failure before the age of 50 years and should become part of the routine diagnostic work-up at the time of diagnosis – paper published in “Current Opinion Pediatrics” February 2004, Lippincott Williams & Wilkins.

---

### **DR. JAROSLAW MACIEJEWSKI**

Section Head Experimental Hematology  
at Cleveland Clinic, Ohio.

“Immune Pathophysiology of Myelodysplastic Syndromes – Lessons from the Molecular Analysis of T Cell Receptor Repertoire in Aplastic Anemia.”

#### ***Study funded by the friends and family of David Homza.***

Similar immune mechanisms have been suggested to operate in aplastic anemia (AA) and paroxysmal nocturnal hemoglobinuria (PNH), and the presence of

PNH clones in AA may indicate that an immune reaction directed against hematopoietic stem cells may be responsible for the immune selection pressure leading to PNH evolution. In patients with a past history of AA, and when subgrouped by current blood counts as “hypoproliferative” PNH patients (in contrast to purely hemolytic form of PNH), more pronounced skewing of VB family utilization was found, consistent with T-cell responses involving several immunodominant CTL Clones. In the future, the analysis of CDR3 amino acid sequence pattern may be used for structural comparisons of CTL clones in MDS and AA, and may have application in the study of T cells in other diseases, including autoimmune diseases and bone marrow transplant. We are convinced that our experimentation will help to improve our understanding of the immune-mediated inhibition of hematopoiesis as seen in AA and certain forms of MDS and it is likely that the results obtained in these specific diseases will be applicable to other immune-mediated conditions. - paper published in “Experimental Hematology” March 2004, Elsevier Inc.

---

### **DR. ACHIBALD PERKINS**

Associate Professor at Yale University School of  
Medicine, Connecticut

“Role of the Mds/Evi 1 Locus in MDS.”

#### ***Study funded by the Harold Spielberg Research Fund.***

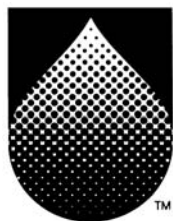
There is a region on human chromosome 3 called “Mds/Evi 1” that rearranges itself when the MDS disease occurs. This study is investigating the involvement of complex genetic locus and how it can be manipulating to determine how it contributes to MDS. Through this research, it has been determined that the loss of gene function does not contribute to MDS. It has also been determined that when the expression of the Evi 1 is suppressed, cell differentiation occurs which indicates that the Evi 1 part of the locus is critically important. When expression is suppressed, the cells become more normal. We are convinced these findings indicates a potential pathway to therapy.

In 2001, the average premium for Plan F, the most common standardized plan option, was \$122 per month; premiums for standardized plans that include outpatient prescription drug coverage ranged from \$119 for plan H to \$196 for plan J. Medi-gap premiums vary considerably by benefits included under the plan and the state in which the beneficiary resides.

Another alternative for Medicare beneficiaries may be to review Medicare+Choice Plans (Medicare Advantage) managed care plans, that will likely minimize or eliminate the need for a supplemental plan. Seniors should review their medical needs and financial resources when determining the appropriate supplemental plan or Medicare+Choice Plan option for them.

Today's rising healthcare cost require that serious consideration be given to supplemental insurance plans. In a study performed by The Commonwealth Fund, it reported that to help fill gaps in coverage, most Medicare beneficiaries rely on some form of supplemental insurance coverage. The majority of beneficiaries enrolled in fee-for-service Medicare have some form of supplemental coverage, whether private insurance, individually purchased Medi-Gap, employer-sponsored retiree health coverage or Medicaid. Including those beneficiaries enrolled in HMOs as well as those with private or public insurance supplements to Medicare, more than eighty-two percent (82%) of Medicare beneficiaries had some form of supplemental coverage.

For additional information on Medicare supplemental plans visit <http://www.medicare.gov/medigap/default> and contact your State Insurance Department.



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:  
Adrian Menapace, R.N.  
TREASURER:  
Tony Sanfilippo  
CHAIRPERSON, MEDICAL ADVISORY BOARD:  
Jarek Maciejewski; M.D., Ph.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!

---



# APLASTIC ANEMIA & MDS INTERNATIONAL FOUNDATION, INC.

P.O. BOX 587 ANNAPOLIS, MARYLAND 21404-0587 U.S.A.  
TEL: 410.867.0242 800.747.2820 FAX: 410.867.0240  
help@aamds.org www.aamds.org

## DONATIONS

Your generous gifts help us to: *fund medical research to find a cure; provide patient support and advocacy; distribute educational materials and updated medical information.*

Print Your Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_

State: \_\_\_\_\_

Zip: \_\_\_\_\_

Daytime Phone: (            ) \_\_\_\_\_

email address: \_\_\_\_\_

Enclosed is my tax-deductible gift of:

(\$35) \_\_\_\_\_ (\$50) \_\_\_\_\_ (\$100) \_\_\_\_\_ (\$500) \_\_\_\_\_ Other \_\_\_\_\_

### PAYMENT OPTIONS:

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

♦ BY CREDIT CARD:  VISA  MASTERCARD  
 AMERICAN EXPRESS

ACCOUNT #: \_\_\_\_\_

EXP. DATE: \_\_\_\_\_

SIGNATURE: \_\_\_\_\_

*All donations received by December 31st will be acknowledged in our Annual Report and End-Of-Year Thanks published in our Winter Newsletter for annual donations over \$500.*

**In Honor of....** If you wish to make your gift in honor of a loved one, print the necessary information in the space below. An acknowledgment of your gift will be sent out to whomever you specify.

**This gift is made in honor of: (Please Print Clearly)**

\_\_\_\_\_

### **Please notify:**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_

State: \_\_\_\_\_

Zip: \_\_\_\_\_

- I have enclosed my company's Matching Gift Form to increase my giving to the AA&MDSIF.
- Please contact me with further information concerning ways of giving by will, trust, life insurance, gifts of stock, real estate or other special opportunities.

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

**For more information, please call the AA&MDSIF at:  
800.747.2820 or 410.867.0242  
or help@aamds.org**

### ***Know Where Your Money Is Going...***

The American Institute of Philanthropy has determined that the reasonable industry standard for administrative and fundraising expenses is a maximum of 40%.

The AA&MDSIF is proud to spend **only 8%**. Please compare our performance with other organizations when making your annual charitable contribution.

