



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

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.

Families Bring New Hope to Patients By Funding Cutting-Edge Research

In an effort to honor the memory of loved ones and advance our understanding of aplastic anemia, myelodysplastic syndromes, PNH, and bone marrow diseases, a growing number of families are creating research funds to foster the work of medical scientists. Now, the AA&MDSIF has announced new opportunities to create these vitally needed Family Named Research Funds.

Already enormously successful (see story on Page 5), the program gives families an opportunity to create a named research fund by raising \$30,000 (one-year sponsor) or \$60,000 (two-year sponsor), in however many years it takes to reach the goal. Some families take many years to raise the funds. Others prefer not to set a goal but rather to donate monies into the general research pool. Either way, every dollar helps to greatly improve our knowledge of bone marrow disorders and bring us closer to finding a cure. Participating families can give their funds any name they choose making this a significant tribute to a loved one.

Today it is accepted etiquette, both personally and professionally, to mark life's occasions by making a meaningful donation to a favorite charity rather than buy useless trinkets. Many families ask for donations to be given in lieu of store bought gifts for birthdays, anniversaries, weddings, graduations, and holidays. It is extremely heartwarming for a family to set this goal of helping others and making the world a better place.

To assist individuals who commit to creating the funds, the AA&MDSIF provides sample appeal letters, reply envelopes, and brochures that can be used to encourage donations by family, friends, and coworkers. All donations are tax-deductible, and *all* of the funds raised go to medical research – not a single penny goes to any type of administrative or management costs.

Under the program, AA&MDSIF invites dedicated medical scientists from throughout the world to apply for research funding. After a rigorous review by AA&MDSIF's medical board, the chosen studies and their family funders are announced in our quarterly newsletter and annual report. Creators of the Family Named Research Funds are kept informed on the work of the scientist they have funded through progress reports and, hopefully, the final research article published in a medical journal.

The AA&MDSIF is now accepting new participants who wish to start their own family research fund. For information, please call Marilyn Baker at (800) 747-2820.

FROM THE DIRECTOR...

"Courage is resistance to fear, mastery of fear – not absence of fear"
-Mark Twain

Very few of us were born Heroes. Most of us have been dragged into the role kicking, screaming and crying like a 2 year old. As patients and caretakers of those who are sick, we know the price we pay for such a label. Being a hero means that we force ourselves to do something that we have no idea how to do while being absolutely terrified every step of the way. Many of us have felt like total cowards while those close to us comment on our bravery. Many of us have fumbled and stumbled while people watched in admiration. Many times being a hero just means just getting out of bed in the morning and facing the new day. Many times we are heroes just by fighting to keep our hearts and spirits from being destroyed by this disease. *Sometimes even to live is an act of courage.*-Seneca



I have been blessed to have known thousands of heroes created by bone marrow failure disease. When I ask them about it most will tell me that they don't like being one and they didn't ask for it but the job was given to them, uninvited, along with the diagnosis and they don't want it – take it back please. Whether we ask for it or not, each of us will be called upon at sometime in our lives to be a hero. Whether it is to help those we love who are sick, or to confront our own health and mortality – all of us will have to face the challenge. I always smile when I remember what one patient told me, "Even though I knew that life has a 100% mortality rate, it still caught me by surprise!"

And then there are times when we are asked, not forced, to be a hero. Like right now...I am asking you to please consider doing something heroic – help us to save lives and to make the world a better place. Have you ever done anything heroic or ever been called a Hero? Try it. You will feel wonderful things in your heart, your mind, your spirit and your soul. *It is one of the most beautiful compensations of this life that no man can seriously help another without helping himself.*-Ralph Waldo Emerson. Please donate your blood, platelets or bone marrow; help organize a drive for donations; call your local hospital's hematology department and volunteer your time or services; fundraise to support AA&MDSIF patient support services and medical research studies; serve on an AA&MDSIF committee; help the AA&MDSIF spread awareness about the disease and need for more research; call the AA&MDSIF and ask what you can do to help.

Why should you care about being a hero? Aside from making you feel all warm and fuzzy inside, being a hero will gain you membership into the most exclusive club that humanity can offer – a club that includes mankind's most distinguished membership list. Please join our club - become a hero and help the AA&MDSIF help humanity.

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

The National Patient Travel Center

(800) 296-1217 — www.PatientTravel.org
Provides information about all forms of free long-distance medical air transportation and provides referrals to appropriate sources of help available through the Angel Flight America Network. Includes airline ticket assistance, private aviation resources, and corporate aviation resources.

National Assoc.Hospital Hospitality Houses

(800) 542-9730 — www.nahhh.org
The NAHHH is an association of over 150 nonprofit organizations located throughout the U.S. that provides family-centered lodging and support services to families who are receiving medical treatment far from home.

AA&MDSIF Patient Travel Fund

(800) 747-2820 — www.aamds.org
The AA&MDSIF pays \$500 per family to pay for travel costs to participate in a clinical trial.

Recommended Readings:

- ◆ Survivor's Guide for Bone Marrow/Stem Cell Transplant: What To Expect and How To Get Through it by Keren Stronach.
Available from the National Bone Marrow Transplant Link (800) 546-5268.
- ◆ The Miracle of Change by Dennis Wholey.
- ◆ Wisdom of the Ages by Wayne Dyer.
- ◆ When Life is Changed Forever by Rick Taylor.
- ◆ Living Through Personal Crisis by Ann Steams.
- ◆ The Right Words at the Right Time by Marlo Thomas.
- ◆ The Courage to Grieve by Judy Tattelbaum.
- ◆ How to Survive the Loss of a Love by Bloomfield, Colgrove & Williams.

Readings For Children:

- ◆ The Fall of Freddie the Leaf by Leo Buscaglia.
- ◆ Dog Heaven by Cynthia Rylant.



Additional Friends:

In our 2002 End-Of-Year Thanks listing we regretfully misnamed a valued donor. Here is a very special *Thank You* to Bruce and Sandy Rule of Clarkston, Michigan for their generous donations!

THE ART OF MDS

In 1996 at age 44, Bill Wofford was a happy Florida artist who had been experiencing unusual fatigue and went in for routine bloodwork. He was immediately hospitalized and diagnosed with MDS...no, another doctor said it was AA...no wait, another doc said it was MDS again...hold on, the first doctor had said a couple of shots would clear it right up...oh no, the second doc said he only had less than a year to live...and suddenly Bill became a not so happy artist.



"I knew nothing of this disease, and the doctors I went to knew very little about the disease, so of course I freaked out and was in shock," Bill remembers. "Fear of the unknown is incredibly stressful, especially when it comes to life and death, and I couldn't find any answers to my questions. Those I did find in lab books that were 5 years old weren't very positive to say the least. Finally I was lucky enough to be referred to a well-known research center and was seen by recognized experts who gave me accurate information and cutting edge treatment options. While I was there, I saw some AA&MDSIF brochures and was shocked to discover that there was an actual foundation created just to help patients like me!" Bill credits the knowledge and care that the researchers gave him, along with the support from the AA&MDSIF, as being what has helped him the most. "I encourage every patient to make sure they are being seen by an expert, make sure they learn all they can about their treatment options, and make sure they talk to as many other patients as possible. Knowledge is a powerful tool in regaining, as well as keeping, a sense of control in these situations.

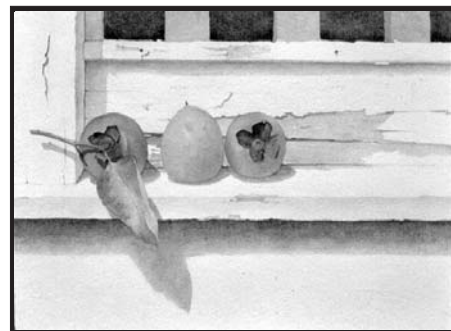
"I think this disease has made me nuttier than I already am though. You know, I've got that temperamental artist thing going on! I find that the thought of the disease sometimes drives me to distraction and then I have to back away from all things medical and give myself a good talking to. It's a challenge not to let this disease control me. When I do feel down, I just tell my friends and family that I'm not in a very good mood and they leave me alone for

a while. Then I settle down with my 2 cats and dog and talk myself out of whatever blues I'm feeling. Or, should I say, talk myself out of feeling sorry for myself, and find a way to be productive again. The

fatigue alone is hard enough to deal with, so feeling sorry for myself for long isn't really a luxury I can afford. Besides, I have a very caring family, and they do anything and everything they can to help. I just prefer to be as independent as I can. That isn't something I ever want to let go of.

"Thank God I can paint. I've been painting since I was a kid and art has been the one constant passion that has kept me going through my various

trials and tribulations. Being sick has affected the depth of my art. I have always been someone who paints for the love and depth of painting, but now I look at certain subjects and they have that much more meaning to me which inspires me even moreso to paint them. And because I am constantly challenged to live, my work has much more emotion. Some of my paintings mean so much to me that I am very reluctant to sell them! In fact, some just aren't for sale and others get sold down-the-line a bit. I have to let go of them slowly. I'm not someone who paints to suit anyone else's tastes. I paint for my own love of art and expression of that love."



Currently Bill isn't on any medications for his MDS, or for the PNH that he has also been diagnosed with. He was treated with ATG in March 1996 and had 5 years of transfusion independence. In the past two years he has required only several transfusions. Bill keeps up on current medical literature and continues to research all available treatment options.

To see Bill's work, and to talk to him further: www.wofford-art.com or call the AA&MDSIF.

PNH

Jaroslav Maciejewski, M.D., Ph.D., Taussig Cancer Center – Cleveland Clinic



The general principles of the management of paroxysmal nocturnal hemoglobinuria (PNH) have not significantly changed over many years. It is a fate of many “orphan” diseases that the progress in their understanding is slow. Only recently, we have learned the complicated mechanisms and pathologic relationships leading to the

development of PNH. Despite progress in the basic knowledge in this disease, no specific therapy exists. Due to the rarity of PNH, even for many traditional treatments such as steroids, no rigorous studies have been performed to assess their efficacy, risks and long-term effects.

However, advances have been made in many other fields of medicine. In many instances, therapies developed for specific diseases have proven effective in other conditions. PNH has benefited from improvements in general supportive care and through progress in the treatment of other diseases such as aplastic anemia.

While we still do not understand why PNH evolves and by which mechanisms it is related to aplastic anemia, we can explain why the red cells in PNH are fragile. Lack of certain proteins on the surface of red cells (produced by the mutated bone marrow stem cell) makes the cells susceptible to being more easily destroyed (hemolysis). This process is mediated by a complicated system of serum proteins called “complement.”

Under normal circumstances, complement serves as an antimicrobial defense factor and kills microorganisms. Healthy red cells are equipped with surface proteins that make them resistant to the action of complement. However, in PNH red cells lack these proteins and are susceptible to the destruction by complement. When PNH red cells are destroyed, they release hemoglobin, which is the red pigment of blood. Hemoglobin is excreted in the urine causing its red or coca-like discoloration, which is a characteristic sign of PNH. More importantly, this destruction of red cells can result in anemia. Usually, destruction of PNH red cells continues at a certain individual rate, and the bone marrow can compensate for it with increased production.

Unfortunately, the bone marrow of some PNH patients may not be able to produce enough red cells so patients experience more severe anemia and may even require transfusions. In addition to the ongoing hemolysis, several unknown factors may cause a dramatic increase in destruction of PNH cells, often referred as to a hemolytic crisis.

Recently, many researchers began to realize that complement may play a role in many other diseases. Because some diseases in which complement is involved are by far more frequent than PNH, commercial interest arose to use complement as a target for new drugs. Consequently, several companies initiated development of medicines that could block complement in a variety of conditions such as arthritis, certain kidney diseases or rejection of transplanted organs. In all of these conditions complement appears to be an important disease factor. Specifically, two companies have developed drugs that have potential to control complement-mediated destruction of red cells in PNH. One of these new drugs, Eculizumab, is developed in the US by Alexion. Recently, Dr. Hillmen reported the results of an initial trial conducted with this drug in the UK.

Eculizumab is a monoclonal antibody that binds to complement and inhibits its action. Patients who were transfusion dependent were enrolled in the trial. The results were very encouraging and demonstrated a remarkable decrease in hemolysis so that patients did not require transfusions. Although it is administered intravenously, it showed relatively few side effects. While there was no effect on cell production, the results of this pilot study suggest that Eculizumab may be an effective drug to prevent hemolysis and improve care of PNH patients. Of course, additional studies with more patients will need to be conducted to learn about the potential benefits the long-term effects of Eculizumab. Alexion plans a larger study of this drug in the US, but the starting date of this study is still not known.

A second promising agent has been developed in the UK by Adprotech and is referred to as APT070. The mode of action for this drug is similar as it has also been designed to block complement. As with Eculizumab, APT070 has been developed to treat other conditions, and trials in humans have been already conducted with promising results. Currently, PNH trials of this drug are in a planning stage in Europe.

2003 AA&MDSIF RESEARCH AWARDS

DAVID HOMZA RESEARCH STUDY AWARDED TO DR. MACIEJEWSKI

Dr. Jaroslaw Maciejewski of the Taussig Cancer Center at the Cleveland Clinic

Foundation has been awarded two year funding for his study, "Immune Pathophysiology of AA & MDS – Lessons

Molecular Analysis of T-Cell

Receptor Repertoire A A." Dr. Maciejewski comments on receiving this award. "I want to thank all those who have given their support to our research. I consider this award a great honor and assure you that we will work extremely hard to make significant contributions towards improving the medical care of patients with AA and MDS. While it is obvious that these diseases change the lives of patients and their loved ones, for the last 13 years my life has been shaped by each of the patients histories and my continuous research work in this area. When I came to the United States after completion of studies at the Medical School in Berlin, I did not know that my research in bone marrow failure diseases would compel my future clinical training as an internist, hematologist and scientist. Now I have dedicated my career to trying to cure sick people and am amazed daily by the path my life has taken."



The funding for this study was raised by Wendi Homza in loving memory of her husband, David. "My only wish when David died was to do something extraordinary to honor his life in a manner that would impact the world! I chose to fund medical research because I believe with all my heart that it will provide hope to patients, inspiration to the medical community and sustain David's memory. The biggest fear for me is that the world will forget my David. I believe his memory will live on forever through medical research and touch more people than I could ever imagine. I was truly blessed to have David in my life for 12 years and now it is my turn to bless the world through funding medical research that will have a lasting impact. It is only through efforts such as this that a cure will be found. I would like to thank my family and friends for showering me with compassion, love, and their generous financial donations to help make my wish a reality."

HAROLD SPIELBERG RESEARCH STUDY AWARDED TO DR. PERKINS

Dr. Archibald Perkins of Yale University School of Medicine has been awarded two year funding for his study, "Role of the Mds/Evi1 locus in MDS." Dr. Perkins comments on receiving this award. "With funds from the AA&MDSIF we will be studying this model with the



hope of discovering the origins of myelodysplastic syndrome, and, with this, come closer to devising a remedy. We are greatly honored to have been chosen to receive this research grant. The funds we receive will be put to the best possible use to achieve our goals and provide real benefit to the patients and families with myelodysplastic syndrome."

The funding for this study came from Shizue Spielberg in loving memory of her husband, Harold. "Harold started this Research Study before he passed away because he was grateful to the work that the AA&MDSIF was doing and wanted to support their efforts in helping other patients. Now that he is gone I am continuing to fund his study because I want to help find a cure, I don't want other families to lose their husband and father the way that my family has lost Harold."

DEB VALCHIK PNH RESEARCH STUDY AWARDED TO DR. WARE

Dr. Russell Ware of Duke University Medical Center has been awarded two year funding for his study, "Genetic Analysis of Growth Advantage and Thrombosis in PNH." Dr. Ware comments on receiving this award. "I first became interested in PNH 20 years ago while I was in Medical School and began working with Dr. Rosse. After completing my medical training I continued my interest in bone marrow research, specifically PNH. I sincerely thank the AA&MDSIF for awarding me the means to continue this important research."



The funding for this study came from 4 families and their friends who joined forces to honor their loved ones with PNH: Mandy Foreman; Amy Glick; Katrin Schultz; and Deb Valchik. Our sincere thanks to Rebecca Gaskin who began this study and spearheaded the fundraising efforts for her dear friend, Deb. Deb's husband, Steven Valchik comments on this research award. "We are grateful beyond words, and happy to see that the research will get started. It is a beginning that we all have been waiting for in happy expectation. Almost all PNH patients convey a feeling of being alone because there is nothing new going on that can offer them help and peace. Often a feeling of despair occurs. With this research we have a great feeling of hope. It is a feeling that unites all PNH-ers and their families, and gives us the strength to hang in there and not give up. I know that Debbie would be grateful, as her family is, to all who have participated in raising the money needed to begin this research. We look forward to seeing a positive change in the treatment of those that have PNH. We pray that this is a new beginning to find a cure."

RECENT MEDICAL LITERATURE

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

APLASTIC ANEMIA

Bessho M, Hotta T, Ohyashiki K, et al. Multicenter prospective study of clonal complications in adult aplastic anemia patients following recombinant human granulocyte colony-stimulating factor (lenograstim) administration. *International Journal of Hematology*, Feb 2003; vol 77(2):152-8.

Frickhofen N, Heimpel H, Kaltwasser JP, Schrezenmeier H. Eleven years follow-up of a randomized trial comparing antithymocyte globulin with or without cyclosporine A for treatment of aplastic anemia. *Blood*, Feb 15, 2003; vol 101(4):1236-1242.

Kim HJ, Park CY, Park YH, et al. Successful allogeneic hematopoietic stem cell transplantation using triple agent immunosuppression in severe aplastic anemia patients. *Bone Marrow Transplantation*, Jan 2003; vol 31(2):79-86.

Rosenfeld S, Follmann D, Nunez O, Young NS. Antithymocyte globulin and cyclosporine for severe aplastic anemia: association between hematologic response and long-term outcome. *JAMA*, Mar 5, 2003; vol 289(9):1130-5.

MDS

Bowen D, Culligan D, Jowitt S, et al. Guidelines for the diagnosis and therapy of adult myelodysplastic syndromes. *British Journal of Haematology*, Jan 2003; vol 120(2):187-200.

Cermak J, Michalova K, Brezinova J, Zemanova Z. A prognostic impact of separation of refractory cytopenia with multilineage dysplasia and 5q-syndrome from refractory anemia in primary myelodysplastic syndrome. *Leukemia Research*, Mar 2003; vol 27(3):221-9.

Erba HP. Recent progress in the treatment of myelodysplastic syndrome in adult patients. *Current Opinion Oncology*, Jan 2003; vol 15(1):1-9.

Hasle H, Niemeyer CM, Chessells JM, et al. A pediatric approach to the WHO classification of myelodysplastic and myeloproliferative diseases. *Leukemia*, Feb 2003; vol 17(2):277-82.

Ooi J, Iseki T, Takahashi S, et al. Unrelated cord blood transplantation for adult patients with advanced myelodysplastic syndrome. *Blood*, prepublished online Feb 2003, www.bloodjournal.org.

Ribrag V, Suzan F, Ravoet C, et al. Phase II trial of CPT-11 in myelodysplastic syndromes with excess of marrow blasts. *Leukemia*, Feb 2003; vol 17(2):319-22.

Rothstein G. Disordered hematopoiesis and myelodysplasia in the elderly. *Journal of American Gerontology Society*, Mar 2003, vol 51(2 Suppl):22-6.

Steensma DP, Tefferi A. The myelodysplastic syndrome(s): a perspective and review highlighting current controversies. *Leukemia Research*, Feb 2003; vol 27(2):95-120.

Strupp C, Gattermann N, Giagounidis A, et al. Refractory anemia with excess of blasts in transformation: analysis of reclassification according to the WHO proposals. *Leukemia Research*, 2003 May;27(5):397-404.

PNH

Inoue N, Murakami Y, Kinoshita T. Molecular genetics of paroxysmal nocturnal hemoglobinuria. *International Journal of Hematology*, Feb 2003; vol 77(2):107-12.

Meyers G, Parker CJ. Management issues in paroxysmal nocturnal hemoglobinuria. *International Journal of Hematology*, Feb 2003; vol 77(2):125-32.

Nakakuma H, Kawaguchi T. Pathogenesis of selective expansion of PNH clones. *International Journal of Hematology*, Feb 2003; vol 77(2):121-4.

Rosse WF, Nishimura J. Clinical manifestations of paroxysmal nocturnal hemoglobinuria: present state and future problems. *International Journal of Hematology*, Feb 2003; vol 77(2):113-20.

PNH EDUCATIONAL CONFERENCE

Duke University May 16 - 17, 2003

Duke University PNH Clinic is holding an educational conference for researchers and physicians as well as patients and family members. Leading experts will discuss diagnosis and treatment of paroxysmal nocturnal hemoglobinuria (PNH), current understanding of PNH and clinical manifestations, and current and future therapies for PNH. Key speakers include Dr. Taroh Kinoshita, Dr. Lucio Luzzatto, Dr. Wendell Rosse, Dr. Charles Parker. The Symposium will be held in the Searle Center on the Medical Center Campus of Duke University in Durham, NC. Hotel accommodations can be made at the Washington Duke Inn (919) 490-0999 or the Millennium Hotel (919) 383-8575. Be sure to mention you are with the PNH Symposium.

Find out more about this conference through Duke University's web site at www.dukepnh.zansu.com (click on Bulletin Board) or by calling Duke PNH Clinic at (919) 684-8964. A registration form can be downloaded from their web site.

COUNTERFEIT PROCRIT® ALERT

Health care professionals were alerted to counterfeit batches of Procrit® (erythropoietin) in a letter of warning from officials at Ortho Biotech Products. Procrit® is used to treat severe anemia in cancer and other chronic diseases such as aplastic anemia and myelodysplastic syndromes. The company warns that the three batches with lot numbers P007645, P004677 and P004389 contain bacteria that could pose a health risk to patients accidentally taking the drug. Full descriptions and photos of authentic PROCRIT® are compared to the counterfeit recently discovered by FDA inspectors.

Health professionals and patients can read the letter at www.procrit.com. For those who do not have Internet access or have medical questions regarding Ortho Biotech products, please contact Ortho Biotech Medical Information at 1 (800) 325-7504, prompt #2.

QUESTIONS & ANSWERS FROM THE AA&MDSIF EXPERTS

One of the goals of the AA&MDSIF is to provide information about the disease, medical updates, treatment options and research findings for patients with aplastic anemia, MDS and PNH. As part of our web site we offer the AA&MDSIF Ask The Experts forum where you can search a library of questions asked by others and answers from our panel of Experts. Also, you may ask a question by completing a form on the site. All relevant questions receive a personal response and new questions are added to the Q&A Library. If you would like to ask a question but do not have Internet access, please contact Deborah Judy at (800) 747-2820 or by fax (410) 867-0240. Responses from our medical experts are general in terms and should not be considered as medical advice or medical recommendations. If is very important that patients should seek advice from a qualified hematologist before making any changes in treatment.

How does the doctor decide when the patient on iron chelation therapy (Desferal) no longer needs further treatment for transfusional iron overload? What ferritin level needs to be reached?

If the patient is continuing to require red cells, one would probably need to continue indefinitely. If the patient responds to therapy and no longer requires red cells, the risk of side effects from Desferal, especially retinal (vision part of the eye) and nerve damage is increased when the ferritin is less than 800. That might be a reasonable time to stop if there are no ongoing transfusion requirements. Patients should discuss their situation with the treating hematologist. Patients on desferal should have their vision and hearing checked every 6 months so they can monitor any side effects.

What kind of experience is there in using darbepoietin (Aranesp) and pegfilgrastim (Neulasta) in patients with MDS?

Aranesp and pegfilgrastim are formulations of EPO and G-CSF with longer half-lives. Darbepoietin

and pegfilgrastim were approved for patients undergoing cancer chemotherapy, and darbepoietin for the chronic anemia associated with renal failure. Both agents are new and experience in treating anemia due to MDS is limited. There is no reason to think that they would be more (or less) effective than the "parent" drugs (epoietin and filgrastim). They can be given less frequently.

How long can a patient stay on cyclosporine?

There is no upper limit on the duration of cyclosporine therapy, as we know from the renal transplant patients. Cyclosporine was originally used in patients receiving solid organ transplants (kidney, liver). These patients have taken cyclosporine for many years to prevent graft rejection. Most hematologists start to taper cyclosporine 6-12 months after achieving a maximal response. Some patients will then relapse and respond to restarting the drug. In some cases the drug must be discontinued if there is kidney toxicity. Generally speaking, patients can remain on cyclosporine indefinitely as long as

there is evidence that the drug is providing some benefit and no evidence of significant side effects. Some patients require prolonged treatment to prevent or minimize the risk of disease relapse.

Is high blood pressure frequently observed in aplastic anemia patients successfully treated with immunosuppressive therapy?

High blood pressure in a patient being treated for aplastic anemia is likely to be due to the treatments, such as high dose steroids being given at the time of ATG therapy or cyclosporine. Treatment depends on the severity of hypertension and the need for continued use of the drug. In the case of the latter, if the diastolic is greater than 90 or the systolic greater than 150, the doctor will review the trough cyclosporine levels to see if it could be decreased. Hypertension due to cyclosporine can be treated with calcium channel blockers, such as diltiazem (Cardizem CD, Cardizem SR, Dilacor XR, Tiazac). These drugs will have the effect of increasing the cyclosporine levels, therefore cyclosporine levels should be monitored closely.

For a child treated with combination ATG and cyclosporine for aplastic anemia, is it necessary to re-immunize or do you continue immunizations from where the patient left off?

Reimmunization is not necessary. Doctors will resume immunization only when the patient is off of immune suppression and has stable blood counts for at least 6 months. Live virus vaccines are not used for immunizing aplastic anemia patients.

AA&MDSIF WISH LIST

- Envelopes 9x12 or larger, preprinted acceptable
- Office Supplies: pens, markers, post-its, clips, paper, files, etc.
- Toner Cartridges for desktop computer printers
- Toner Cartridge for Xerox machine 5328

PRINTERS NEEDED!

We are in need of a commercial printer to print one issue of this newsletter. This tax-deductible contribution will be extremely appreciated and you will get your company's name and web address printed here!

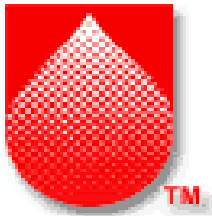
AWARENESS

Looking for volunteers to help spread awareness about the bone marrow failure disease and the need for further research. If you are interested in helping out in your local community, please contact us.

CONFERENCE SILENT AUCTION

We are looking for treasured items to auction off at our Conference. If you, or your company, can contribute small items or services to help offset our Conference costs please call us. Everything legal is welcome! Stationary, quilts, autographed stuff, sports stuff, art stuff, dolls, weekend vacations, gift baskets, pens, pottery, clothing, etc. Please contact Mary Faber for details. You will receive a letter from the AA&MDSIF verifying that your gift is tax-deductible.

Thank You!



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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.

