



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.

AA&MDSIF 1983 - 2003 CELEBRATING 20 YEARS OF DEDICATED SERVICE!

In 1983, a group of bereaved parents teamed up with our first president, Dr. Lyle Sensenbrenner; and our first affiliate, the Earl J. Goldberg Foundation, to form a national organization helping stricken families obtain medical information and support. In the early days our Foundation was run by our first executive director, Lynn Rauch, who created many of the programs that we still offer today. Imagine how hard Lynn's job was with no computer, no internet and no staff! Then in 1990, Marilyn Baker assumed the directorship to manage a new era of communication technology and global services.

Today, as the AA&MDSIF proudly celebrates two decades of life-saving support and service to thousands of patients and their families around the world, we give thanks to those founding spirits whose hard work and vision of saving lives created this vital Foundation.

We also give thanks to the many donors who have given generous financial gifts to fund our patient support services and medical research. Without these abundant donations from families and friends, we could not have grown to become the International organization that we are today. Their investment in our Foundation has paid off multifold...the return on their investment has been to help create one of the premier nonprofit organizations in the country.

Aplastic anemia can be traced as far back as 1888 when German pathologist, Dr. Paul Ehrlich, studied the case of a pregnant woman who died of bone marrow failure. It wasn't until 1904 that this disorder was termed aplastic anemia.

Myelodysplastic syndromes (MDS) was first described as a pre-leukemic condition in the early 1930's and was treated as a separate group of disorders until 1976.

PNH was first described in 1866 as "intermittent haematuria" diagnosed in a man working with chemicals. It wasn't until 1928 that the term paroxysmal nocturnal hemoglobinuria was used.

When the AA&MDSIF was first created, aplastic anemia patients were told they had almost no chance of surviving. Now, after just 20 years of focused research and clinical trials, the current success rate is around 70% to 90%. We hope and pray that with the same concentrated effort we will be able to report a similar success story with MDS and PNH patients.

FROM THE DIRECTOR...

This is a moment of great significance for our Foundation...what started out as a small grassroots effort has developed into two decades of international scientific collaboration and patient services creating the vital international organization that we are today. Our foundation provides proud testimony to the fact that great changes can come from small beginnings.



The AA&MDSIF has helped thousands of people throughout the world and will help thousands more who are not yet born. Thanks to the vision of our founding fathers and mothers, these families are not alone in their battle. As we continue to advance in our fight to improve the quality and quantity of patient's lives, we are acutely aware of our responsibility to lead this charge. Because the soul of our fight is in the family — the patient, the parent, the spouse, the child — whose lives have been forever changed by bone marrow failure diseases, we have an unrelenting commitment to continue our progress.

New in 2003 is the launch of our nationwide awareness campaign (look for us in the March issue of Redbook Magazine!) and advocacy (see page 5 of this newsletter!) The goal of these efforts is to help even more patients and to educate even more people about the ever increasing need for research, platelet-blood-bone marrow donations, and support of our efforts.

As we look to our future we see even more ambitious goals: greater diversity of research funding such as our Established Researcher Awards; more innovative support such as our Patient Travel Fund; a broader scope of assistance such as our "Ask the Expert" service; and a global collaboration of knowledge such as our distinguished international medical advisory board.

And the only way we can arrive at our future is with your help. No one else cares about these rare little diseases but you and our Foundation; we are the only ones who will do the hard work necessary to put an end to bone marrow disease. The challenge is completely on our shoulders ...our generosity, participation and support of the Foundation will determine if we can continue our proud heritage of accomplishments.

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

PATIENT TRAVEL FUND... We are now assisting patients traveling to Clinical Trials by reimbursing each family up to \$500 for their travel costs. This is for clinical trial participants only. Forms are available through our website or by calling our office. Our sincere thanks to Carol Stewart of Redmond, Washington for sponsoring this Fund in loving memory of her father, Raymond.

TALKING TO KIDS... Deep gratitude to the KNIGHT TRADING GROUP of New Jersey for their generous corporate sponsorship which will enable the AA&MDSIF to create a special brochure just for children explaining bone marrow illness, medical procedures, emotions and death. Children and parents around the world will benefit greatly from this valuable manual.

CHILDREN DESERVE A MEDAL... Imagine the courage it takes for a child to undergo complicated medical procedures...they truly deserve a medal. And now we're giving them one! Our 1½" gold "BRAVERY" pin tells the hospital staff, family and friends how brave they are. Pin it on a child's hat, bandana, pendant or hospital bed. To order a medal, visit our website or call our office. Thank you to Barb, Rob and Lauren Kaplan of Williamsburg, Virginia for sponsoring this medal in loving memory of their daughter and sister, Alison.

FAMILIES NEEDED... The National Heart, Lung and Blood Institute in Bethesda, Maryland are interested in aplastic anemia patients who have one or more family members with blood abnormalities or a blood disease. Dr. Neal Young is investigating the relationship of mutations in genes related to the inherited bone marrow syndrome, dyskeratosis congenita, to seemingly acquired aplastic anemia. Interested individuals may contact Olga Nunez (301) 402-0764 to arrange for a free evaluation. Testing may also have implications for choice of therapies and other members of an affected person's family. Results will assist science in learning more about the causes of aplastic anemia and bone marrow failure diseases.

TWINS NEEDED... Cleveland Clinic Taussig Cancer Center are seeking aplastic anemia or MDS patients who have identical twins to participate in a research study of disease mechanisms. By comparing the recognition spectrum of lymphocytes from identical twins, disease-specific changes may be better studied. Please contact Jaroslaw P. Maciejewski, M.D. Ph.D. (216) 445-5962.

GIFTS FROM SHANE... Shane was a special needs child stricken with aplastic anemia. His mother, Marie, wrote a book of their inspiring struggle called "Gifts From Shane" available at Amazon.com or your local bookstore. Winston Groom, author of *Forrest Gump* wrote about Marie's book: "A tale of triumph and tragedy that at times elates, at times gives one chills. The reader comes away at each turn of the page sharing the hope, feeling the let-downs, and getting to know Shane, a remarkable member of the human race." A percentage of proceeds from this book benefit the AA&MDSIF.

AA&MDSIF PATIENT ADVOCATE

Because aplastic anemia, MDS and PNH are such rare diseases, it is hard to compete for resources against larger diseases. The needs of our patients will only be met if we speak up as an organization and a united community.

Recognizing this, we retained the services of Steven Grossman, president of HPS Group, LLC. Steven was formerly Health Staff Director to a Senate committee and a Deputy Assistant Secretary for Health in the US Department of Health and Human Services.

The Board of Directors and I were impressed with Steven's political and communications background, as well as his extensive knowledge of public health. His column below—the first of many—will guide us in achieving the Foundation's three advocacy goals: increased research, improved treatments and broader access to care.

— Marilyn Baker, M.S.
Executive Director

Thank you for the honor of serving the Aplastic Anemia and MDS International Foundation.... and especially of serving you, the patients and their families who are most in need. My government service taught me—and my subsequent work as an advocate has reinforced—that government works best when it knows what people want.

My job is to make sure that your voices are heard on the issues of most concern to patients with aplastic anemia, MDS, PNH and other acquired bone marrow failure diseases (ABMFD). The opportunities are many because government is so much a part of our lives. Some of this is well-known:



- ◆ The National Institutes of Health (NIH) spends millions of dollars each year researching acquired bone marrow failure diseases, both on its campus in Bethesda, Maryland and in academic hospitals throughout the nation.
- ◆ The Centers for Medicare and Medicaid Services (CMS...formerly the Health Care Financing Administration) pays for health care for the elderly and helps the states to pay for health care for the poor.
- ◆ The Food and Drug Administration (FDA) reviews and approves (or not) the medications and medical devices that hold promise to delay or cure disease.

Both the NIH and the FDA have offices specifically devoted to encouraging research and product development on rare diseases, such as aplastic anemia, MDS and PNH.

Patients with acquired bone marrow failure diseases are touched by many other parts of the government, such as the Veteran's Health Administration (VHA), the Centers for Disease Control, and the medical and radiation research activities of the Department of Energy and the Department of Defense. NIH is very important, but it is not the only place where biomedical research occurs.

Congress is central to our efforts to increase research, promote awareness and assure patients of access to the best treatments for their condition. To get Congress' attention and support, as well as to get help from government agencies, we are focusing on the opportunities for research. We must convince them that the time is ripe for more resources to improve care for patients with acquired bone marrow failure diseases. Also, we are working with the Foundation's Medical Advisory Board to develop guidelines on the best ways to treat MDS and other bone marrow diseases.

You might ask: what's in it for me? I admit that advocacy will probably not make an immediate change in your daily routine...whether as patient, family member, or survivor.

We hope you will find comfort in knowing that we are out there fighting on your behalf to raise as much money as possible for medical research. Many of those dollars support clinical trials, where patients have the best possibility for effective treatment and cure. Because research is the best hope for cures, no clinical trial on acquired bone marrow failure diseases should be underfunded.

And very directly for you, after lots of hard work, we will find effective treatments and cures in your lifetime. This is a journey...and our advocacy is an important part of reaching our most important goals.

You can help with our advocacy effort. Over the next few months we will be developing a grassroots network of patients and families. In addition to information on the website and in this column, we will keep you informed on issues that affect patients. In turn, at appropriate times, we will ask you to participate by writing or visiting your elected officials.

To join the Foundation's grassroots advocacy network: send me your name, address, phone, and e-mail address (very important). Also, let me know if you have specific interests and whether you have written or met with elected officials before. Please keep your note short because I hope there will be a lot of them to read. My e-mail address is: grossman@aamds.org.

Join us. Together, we can make a difference.

— Steven Grossman

COMMUNICATION BETWEEN ADULT CHILDREN & PARENTS

By Renee Hoffman Sussman of Fairlawn, New Jersey, an adult child of a parent with MDS

When communication issues surface during a serious illness, generational differences may complicate matters. Adult children today may approach medical care much more interactively than their parents. They may be more apt to question doctors' opinions, research the internet, and debate various treatment options. Conversely, their ill parent may have been brought up to keep quiet about personal crises, not acknowledge accompanying emotions, and to never question a medical professional.

These different attitudes about medical care can complicate power and communication issues that may already exist within a family. So how far should children try to involve themselves in their parents' care? In Donna Deleno's case, her family's influence with her father only went so far. "My brother and I found lots of studies on the internet, but when we tried to discuss these with my dad, he refused to get a second opinion or go to a different hospital. He trusted his doctor and didn't want to leave. When we insisted, he got mad and said we were interfering."

Marilyn Baker, Executive Director of AA&MDSIF, deals with communication issues when family members call her for help. "This can be a very difficult situation. Sometimes parents need their children to manage their medical care, sometimes not. What is hard for some children to understand is that our parents want to handle their illness differently than we do, just like when we were teenagers and wanted to do things differently than our parents - life comes full circle. Sometimes children have to just let go and let their parents control the situation because in the long run, it may be worse to have angry confrontations during the precious last month's of a parent's life than to get our own way."

Dr. Aratan of Memorial Sloan Kettering Cancer Center also feels the parent should have the final say, "Usually the reason why a parent is reluctant to come in for definitive treatment, while the child wants the parent to undertake aggressive therapy, is that the patient is looking at quality of life and the child is looking at quantity," he explains. "The children can and should state their point of view, but the trade off between quality and quantity is a decision only a patient can make for him or herself."

Many family members have differing opinions on how much the patient should know. "The hardest cases I've seen in terms of intergenerational conflicts is when a patient comes to you willingly for an opinion, there's a serious diagnosis of bone marrow failure, and the children don't want the parent to know," says Dr. Aratan "They want to spare him or her because they're worried that the patient will have a bad reaction to the news. There's serious difficulties in treating a patient who doesn't know their diagnosis at all. Nowadays, we tell the patient the whole truth in as positive a way as possible and they decide how they want to tell their children. It is much more anxiety producing to feel sick and not to know why, versus being given a diagnosis that's serious but has options."

Dr. William Meyerson, of Del Ray Beach Community Hospital sees the reverse happening. "Sometimes the parents try to downplay the problem to protect the children. They know, and are trying to protect the family, and the family is trying to protect them. All communications are blocked." Some resolve this dilemma very simply. "We go with whatever the parent wants us to do, not the child," advises Cheryl Breed, nurse practitioner at the University of California S.F. Medical Center. "However, I've seen elderly patients in some cultures with very extensive families who are very aggressive in pursuing other options. Even if patients say no, families say yes until the patients say yes."

"I try to contact all family members if big decisions need to be made so that disagreements can be discussed together," recommends Dr. Pamela Becker, from the University of Massachusetts Medical Center. "The key is to keep having discussions to be able to make decisions." When her mother was diagnosed with MDS, Susan Steiger did just that. "My mom and I would talk about her illness and even though she would say what she wanted and I would say something different, we were able to come to a decision between the two of us and present a united front to the doctor. And even though the doctor disagreed with us, he accepted it because we were united in our decision."

In an ideal world, doctors and families should work together to do what's best for the patient. Communication is the key to making this happen.

THANK YOU 2002 DONORS!

The following wonderful people have made an investment in the fight against bone marrow disease by generously supporting our efforts. Unfortunately, because of limited space, we were not able to acknowledge every donor. Please know that every dollar fills the pot that provides patient support and research. We are truly grateful to these donors for helping us to assist thousands of patients and their families around the world who are so desperately asking for our help. On behalf of these families who are battling aplastic anemia, MDS & PNH, thank you.

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QUESTIONS & ANSWERS

Will Medicare cover Desferal therapy to treat iron overload in transfusion-dependent patients?

Desferal (desferrioxamine), an iron chelating agent manufactured by Novartis, is used to remove excess iron from the tissues of patients with aplastic anemia and myelodysplastic syndromes who are experiencing iron overload due to multiple transfusions. Typically, Desferal is administered as an 8–10 hour subcutaneous infusion over six nights per week. Once Desferal treatment begins it may be continued for as long as the patient requires transfusions or until the serum ferritin decreases to an acceptable level. Most patients prefer to self-administer the drug through a pump while they sleep rather than having to go to the hospital.

Medicare will cover self-administered Desferal when a physician deems it medically necessary. *However, your physician must specify that the drug will be administered as a continuous subcutaneous infusion via a pump for more than 8 hours at a time.* According to Medicare officials the pump will be covered under the durable medical equipment category and the Desferal will be covered as a necessary element of the pump. If your doctor specifies administration by IV therapy, though, the treatment will fall into the injectable drug category and will not be covered unless it is administered in a hospital or clinic setting. So if you are on Medicare and require this therapy, talk with your physician, before he or she officially orders the treatment, about the Medicare coverage requirements.

Medically necessary Desferal therapy is covered under most secondary insurances. In some cases, though, a secondary insurer may not cover it if it is administered via a pump. As with any treatment you receive, therefore, it is advisable to check with your secondary insurer in advance to clarify their coverage rules and what you will need to do to ensure coverage. In some cases you may need to submit the secondary claim yourself, in which case you will need a copy of the Medicare explanation of benefits (EOB). All primary and secondary insurers have an appeals process for challenging denied claims. If your claim is denied, review your company's appeals process to determine how to proceed. Supplemental insurance usually covers 20 percent of the cost of medically necessary Desferal.

If you are transfusion dependent you need to talk with your doctor as to when you need to begin chelating. Iron overload initially causes no symptoms. Although in most patients it takes many years to develop symptoms from iron overload, some patients may develop problems more rapidly. Doctors measure iron accumulation by checking serum ferritin levels. Most hematologist recommend treatment when ferritin level has reached 1000 ng/ml (normal is 40-160) or if problems with heart function, sugar balance, liver function or joints develop with lower levels of iron accumulation. Desferal treatment may cause side effects in some patients, namely hearing loss or loss of vision. Usually adjusting the dosage can stop these side effects

Currently, Desferal is the only approved iron chelating agent in the U.S. An oral iron chelator is currently being evaluated for patients suffering from thalassemia and other diseases.

Find out more about iron overload and its treatment in our booklet "Iron Chelation Therapy in Aplastic Anemia, MDS & PNH". Call (800) 747-2820 or email help@aamds.org to request a copy and to be put in touch with others coping with iron overload.

What is Medicare's policy regarding coverage of EPO shots?

EPO (erythropoietin), which is also known by the brand names Procrit or Epogen, is a growth factor used to stimulate production of red blood cells in patients with anemia. Generally speaking EPO is covered by Medicare for the treatment of anemia caused by MDS and other chronic diseases. Injections typically will be covered for up to three times per week as long as the average hematocrit level is below 36. However, if there is no significant increase in HGB/HCT levels or a significant decrease in transfusion requirements after two months, coverage may be terminated. Your physician is required to include your hematocrit level on each claim that is submitted related to the EPO injections. If your doctor believes that the treatment should be continued and the carrier disagrees, you may appeal the decision to the carrier's medical director. Your physician will need to write a letter indicating his or her belief that the treatment is medically necessary and why.

Self-injection of EPO is not covered unless a patient is undergoing home dialysis for treatment of kidney failure, according to Medicare officials. In all other cases, including the treatment of anemia related to MDS, injections of EPO are only covered if they are given by your physician in his or her office. Self-injection or injections administered by a home health aide are not covered by Medicare in these instances, regardless of circumstances.

Coverage requirements for EPO do vary somewhat by state and carrier. We recommend that you visit www.lmrp.net/download.asp. Click on "Carriers" and then select your state and Medicare insurance carrier. This will bring up the coverage policies for that carrier. Select "erythropoietin" for details on specific coverage of this drug under your plan. If your plan is not listed, contact Medicare directly at (800) MEDICARE to request information on coverage.

FURTHER INFORMATION:

Centers for Medicare and Medicaid Services
<http://www.medicare.gov/>
(800) MEDICARE — (800) 633-4227

Patient Advocate Foundation
(800) 532-5274 — patient@pinn.net
Provides resources for patients in need of insurance and financial assistance.

Local information and resources for financial assistance can be found through your hospital's social worker or financial counselor.

RECENT MEDICAL LITERATURE

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

APLASTIC ANEMIA

Kojima S, Matsuyama T, Kato S, et al. Outcome of 154 patients with severe aplastic anemia who received transplants from unrelated donors: the Japan Marrow Donor Program. *Blood*, 2002 Aug 1;100(3):799-803.

Kojima S, Ohara A, Tsuchida M, et al. Risk factors for evolution of acquired aplastic anemia into myelodysplastic syndrome and acute myeloid leukemia after immunosuppressive therapy in children. *Blood*, 2002 Aug 1;100(3):786-90.

Maciejewski JP, Risitano A, Kook H, et al. Immune pathophysiology of aplastic anemia. *International Journal of Hematology*, 2002 Aug; 76 Suppl 1:207-14.

Ohga S, Ohara A, Hibi S, et al. Treatment responses of childhood aplastic anaemia with chromosomal aberrations at diagnosis. *Br Journal of Haematology*, 2002 Jul;118(1):313-9.

Paquette RL. Diagnosis and management of aplastic anemia and myelodysplastic syndrome. *Oncology (Huntingt)*, 2002 Sep;16(9 Suppl 10):153-61.

Park J, Jun J, Kim Y, et al. Osteonecrosis of the hip in patients with aplastic anemia. *J Korean Med Sci*, 2002 Dec;17(6):806-10.

Tisdale JF, Maciejewski JP, Nunez O, et al. Late complications following treatment for severe aplastic anemia (SAA) with high-dose cyclophosphamide (Cy): follow-up of a randomized trial. *Blood*, 2002 Dec 15;100(13):4668-70.

Young NS, Maciejewski JP, Sloan E, et al. The relationship of aplastic anemia and PNH. *International Journal of Hematology*, 2002 Aug; 76 Suppl 2:168-72.

Zeng W, Maciejewski JP, Chen G, et al. Selective reduction of natural killer T cells in the bone marrow of aplastic anaemia. *British Journal of Haematology*, 2002 Dec;119(3):803-9.

PNH

Flotho C, Strahm B, Kontny U, et al. Stem cell transplantation for paroxysmal nocturnal haemoglobinuria in childhood. *British Journal of Haematology*, 2002 Jul;118(1):124-7.

Kai T, Shichishima T, Noji H, et al. Phenotypes and phosphatidylinositol glycan-class A gene abnormalities during

cell differentiation and maturation from precursor cells to mature granulocytes in patients with paroxysmal nocturnal hemoglobinuria. *Blood*, 2002 Nov 5;100(10):3812-8.

Murakami Y, Kosaka H, Maeda Y, et al. Inefficient response of T lymphocytes to glycosylphosphatidylinositol anchor-negative cells: implications for paroxysmal nocturnal hemoglobinuria. *Blood*, 2002 Dec 1;100(12):4116-22.

Wang H, Chuhjo T, Yasue S, et al. Clinical significance of a minor population of paroxysmal nocturnal hemoglobinuria-type cells in bone marrow failure syndrome. *Blood*, 2002 Dec 1;100(12):3897-902.

MYELODYSPLASTIC SYNDROMES

Alessandrino EP, Amadori S, Barosi G, et al. Evidence- and consensus-based practice guidelines for the therapy of primary myelodysplastic syndromes. A statement from the Italian Society of Hematology. *Haematologica*, 2002 Dec;87(12):1286-306.

Arboscello E, Botta M, Lerza R, et al. Amifostine promotes hemopoietic progenitor cell mobilization in patients with myelodysplastic syndrome. *Anticancer Research*, 2002 May-Jun;22(3):1819-24.

Cazzola M. Practice guidelines for the therapy of primary myelodysplastic syndromes: a word of caution... *Haematologica*, 2002 Dec;87(12):1240-1.

Chan G, DiVenuti G, Miller K. Danazol for the treatment of thrombocytopenia in patients with myelodysplastic syndrome. *American Journal of Hematology*, 2002 Nov;71(3):166-71.

Deeg HJ, Storer B, Slattery JT, et al. Conditioning with targeted busulfan and cyclophosphamide for hemopoietic stem cell transplantation from related and unrelated donors in patients with myelodysplastic syndrome. *Blood*, 2002 Aug 15;100(4):1201-7.

Estey EH. Current challenges in therapy of myelodysplastic syndromes. *Current Opinion in Hematology*, 2003 Jan;10(1):60-7.

Greenberg PL, Young NS, Gattermann N. Myelodysplastic syndromes. *Hematology (Am Soc Hematol Educ Program)*, 2002;:136-61.

Gryn J, Zeigler Z, Shaddock R, et al. Treatment of myelodysplastic syndromes with 5-azacytidine. *Leukemia Research*, 2002 Oct;26(10):893.

Gupta C, Francis S. Clinical and laboratory characteristics of myelodysplastic syndromes. *American Clinical Laboratory*, 2002 Oct;21(8):26-8.

Kasahara S, Hara T, Itoh H, et al. Hypoplastic myelodysplastic syndromes can be distinguished from acquired aplastic anaemia by bone marrow stem cell expression of the tumour necrosis factor receptor. *Br Journal of Haematology*, 2002 Jul;118(1):181-8.

Leone G, Teofili L, Voso MT, Lubbert M. DNA methylation and demethylating drugs in myelodysplastic syndromes and secondary leukemias. *Haematologica*, 2002 Dec;87(12):1324-41.

Luger S, Sacks N. Bone marrow transplantation for myelodysplastic syndrome - who? when? and which? *Bone Marrow Transplantation*, 2002 Aug;30(4):199-206.

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