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THE MDS NEWS

The Newsletter of The Myelodysplastic Syndromes Foundation

# From the Guest Editor's Desk

***Amit Verma, MD***
**Albert Einstein College of Medicine**
**Cancer Center**
**Bronx, New York, USA**

## Why Do Blood Counts Go Down in MDS?

**Growth Factors Control the Formation of Blood Cells From Bone Marrow Stem Cells**

MDS leads to decreases in red blood cells (anemia), white blood cells (neutropenia) and platelets (thrombocytopenia). These different types of blood cells are derived from stem cells that mainly reside in the bone marrow. Stem cells undergo many divisions before transforming into red cells, white cells or platelets. This process is known as ***hematopoiesis*** and is controlled by proteins known as growth factors or ***cytokines*** (Figure 1). Cytokines can either promote or inhibit hematopoiesis. Growth factors such as erythropoietin (Epo), granulocyte-colony stimulating factor (G-CSF), granulocyte macrophage-colony stimulating factor (GM-CSF), stem cell factor (SCF) and interleukin-3 (IL-3) stimulate the growth and transformation of stem cells into different types of blood cells. In contrast, inhibitory cytokines such as tumor necrosis factor alpha (TNFα), transforming growth factor beta (TGFβ), interleukin-1 beta (IL-1β) and interferons counter balance or attenuate the actions of stimulatory cytokines. These inhibitory cytokines can induce cell death and stop cell division. Maintenance of a fine balance between the actions of stimulatory growth factors and suppressive growth factors is required for optimal production of blood cells. A disturbance in the regulation of these growth factors can upset this balance and lead to blood diseases such as myelodysplasia.

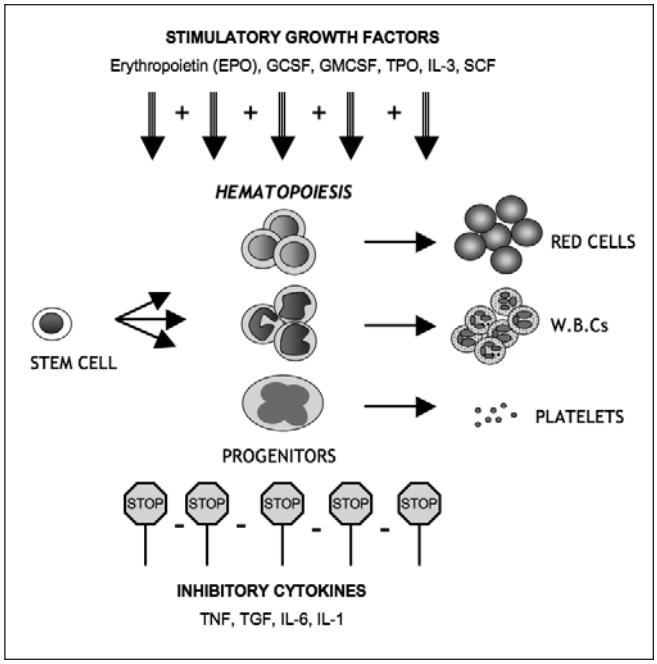


*Figure 1. Hematopoiesis*

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## Contents

### Increased Inhibitory Growth Factors Lead to Death of Stem Cells in MDS

The bone marrow in MDS shows a high percentage of dying cells. Even though the exact molecular mechanisms of why this occurs is unclear, there is considerable evidence to implicate inhibitory cytokines in this process. It appears that the bone marrow stem cells in MDS are exposed to excessive amounts of TNFα, TGFβ, IL-1β and other similarly suppressive cytokines.[1] Since we know that MDS is caused by a genetic mutation in the stem cells, it is hypothesized that the cells with the genetic abnormality trigger this phenomenon of increased cytokines in the bone marrow. Interestingly, the cells responsible for the production of these harmful proteins/cytokines are mainly the cells that line the bone marrow cavity (***stromal cells***) and not the stem cells themselves. We believe that the mutated stem cells interact with the stromal cells and immune cells to cause this inflammation in the bone marrow. The normal stem cells are caught in this "cytokine storm" as bystanders and get killed. On the other hand the mutated stem cells are harder to kill and expand preferentially in the bone marrow. With a passage of time the normal cells all die and the bone marrow is only left with the abnormal mutated stem cells. These cells finally transform into leukemia.

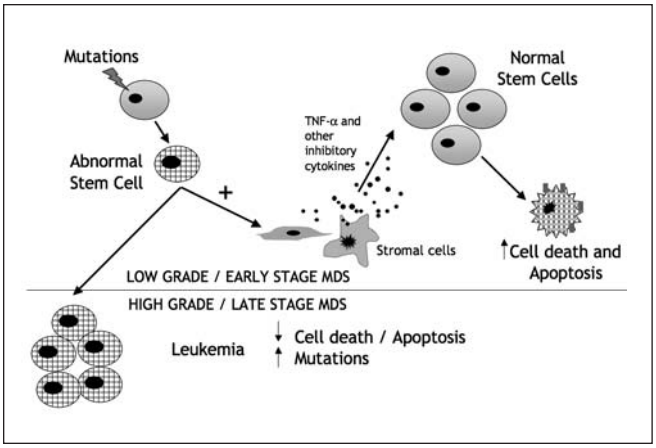



*Figure 2. Stem cell death in MDS*

### Drugs That Can Prevent Normal Stem Cells From Dying Can Be Helpful in MDS

Drugs designed to counter the effects of inhibitory cytokines can help preserve normal stem cells in MDS and potentially raise the blood counts. Thalidomide and lenalidomide (Revlimid®) a recently FDA approved drug for MDS have been shown to interfere in the formation of TNFα, the most prominent inhibitory cytokine.[2] It is possible that increase in the number of normal stem cells and blood cells after treatment with Revlimid are in part due to these actions of the drug. Antibodies against the TNF protein (Infliximab, Remicade®) and a decoy soluble receptor Etanercept (Enbrel®), have also led to improvement in blood counts in some patients with MDS.[3,4]

High doses of growth factors or stimulatory cytokines such as Erythropoietin (Epo) are also being used in the treatment of MDS. Epo is a hormone, functioning like a growth factor, that stimulates stem cells to make more red cells. Giving large doses of Epo can reverse the blockade of hematopoiesis in about a third of patients with MDS. Unfortunately, the beneficial effects of Epo therapy do not last in all patients as the inhibitory cytokines eventually make the cells unresponsive to Epo. It is possible that a combination of Revlimid and Epo and may help overcome this block and will be tested in an upcoming large clinical trial.

Cytokines exert their effect by binding to receptors on the surface of cells and then activating various proteins in the cells. These activated proteins then accomplish the various inhibitory functions of the cytokine on the cell. Thus, another way to prevent stem cells from dying is to stop these intracellular proteins from being activated. Various small molecule chemical compounds that do this are being tested in MDS. PTK-787, an inhibitor of the vascular endothelial growth factor (VEGF, another cytokine)[5] and SCIO-469, an inhibitor of a protein known as p38 MAPK are presently being tested in clinical trials in MDS. The activation of p38 protein has been found to be important for the actions of many cytokines and has been shown to be a potential drug target in lab studies.[6]

## *Conclusions*

MDS is a very complex disease and has many different etiologies and subtypes. Due to the heterogonous nature of this disease, no single drug will be effective for all patients. As we gain more knowledge into the molecular mechanisms that cause anemia in this disease, we have started identifying mutations and protein disorders in individual cases. Advances in genomics and molecular biology are leading to new discoveries that are being brought to the clinic. The near future does hold a lot of promise and it is our hope that we will eventually have combinations of drugs that will help raise blood counts of a majority of patients with this disease.

### References


1. Verma A and List A, Cytokine Targets in Myelodysplastic syndromes. *Current Hematology Reports*. 2005; 4(6):429–35.
2. Moreira AL, Sampaio EP, Zmuidzinas A, Frindt P, Smith KA, and Kaplan G. Thalidomide exerts its inhibitory action on tumor necrosis factor alpha by enhancing mRNA degradation. *J Exp Med*. 1993;177:1675–1680.
3. Deeg HJ, Gotlib J, Beckham C, Dugan K, Holmberg L, Schubert M, Appelbaum F, and Greenberg P. Soluble TNF receptor fusion protein (etanercept) for the treatment of myelodysplastic syndrome: a pilot study. Leukemia 2002;16:162–164.
4. Raza A, Candoni A, Khan U, Lisak L, Tahir S, Silvestri F, Billmeier J, Alvi MI, Mumtaz M, Gezer S, et al. Remicade as TNF suppressor in patients with myelodysplastic syndromes. *Leuk Lymphoma*. 2004;45:2099–2104.
5. Bellamy WT, Richter L, Sirjani D, et al. Vascular endothelial cell growth factor (VEGF) is an autocrine promoter of abnormal localized immature myeloid precursors (ALIP) and leukemia progenitor formation in myelodysplastic syndromes. *Blood*. 2001;97: 1427–1434.
6. Verma A, Sassano A, Deb D, Wickrema A, VanBesien K, and Platanias L. "Blockade of p38 MAP kinase reverses cytokine mediated inhibition in aplastic anemia." *J Immunol*. 2002;12:168.


# Purchase MDS Awareness Pins

The MDS Foundation has enameled lapel pins for you to wear with pride and to increase public awareness about MDS. The pins are available with a $3.99 donation to The MDS Foundation.

To order your pins, call The MDS Foundation at 1-800-MDS-0839.

This item was created especially for The MDS Foundation to contribute to the effort to help people worldwide living with myelodysplastic syndromes. Your donation will help increase awareness of this little known disease, which is the most common of the hematologic malignancies.

Please ask your family and friends to wear these pins in support of our mission!

# MDS Young Investigator Grants Program for 2006

The MDS Young Investigators Grant Fund for Fellows in Hematology includes two awards this year. These awards will provide $40,000 over a 24-month period from January 1, 2007 to December 31, 2008. A formal awards ceremony will be held at a special reception during the ASH Annual meeting in Orlando, Florida.

### Eligibility

The Foundation is dedicated to furthering the research into MDS and invites young investigators (under 40 years of age) from institutions that form our MDS Centers of Excellence to submit their proposals for either basic research or clinical management into the causation, epidemiology, molecular biology, cytogenetics, morphology, prognosis and management of the Myelodysplastic Syndromes.

### Submission

All MDS Centers of Excellence are invited to nominate one candidate from their institution. A mandatory brief letter of intent (L.O.I.) is to be submitted no later than June 15, 2006. The L.O.I. should contain a brief paragraph describing the background of the candidate and 1–2 paragraphs describing the proposed project and the name of the mentor. If approved, a formal application will be sent to you shortly after receipt of the L.O.I.

### Deadline

The application deadline for 2006 is August 15, 2006. Notification of the awards will occur by October 2, 2006 with activation on January 1, 2007.

# FDA Approves New Drugs for MDS, Iron Overload

The first MDS drug approved by the U.S. Food and Drug Administration (FDA) was Vidaza® (generic name, azacitidine), which came on the market in May 2004. Now, there are a total of three MDS drugs approved.

In late 2005, the FDA approved Revlimid® (generic name, lenalidomide) for the treatment of MDS and another new drug for the treatment of iron overload – Exjade® (generic name, deferasirox). On May 3, 2006 it was announced that the FDA approved Dacogen™ (generic name, decitabine) for Injection.

## Revlimid®

Revlimid, an oral medication taken once daily, was approved by the FDA in December 2005 for the treatment of anemic MDS patients with 5q– syndrome (5q "minus" refers to a deletion in the short arm of chromosome #5).

Revlimid has been shown to increase red blood cell production, thereby eliminating or reducing the need for red blood cell transfusions. In a landmark clinical trial in MDS patients, reported in early in 2005, Alan List, M.D., and colleagues found that 63% of patients requiring regular transfusions gained transfusion independence. The median duration of transfusion independence had not been reached after follow-up of more than 48 weeks. The study results also showed that among patients with the 5q syndrome, 75% had a complete cytogenetic (i.e., chromosomal) response, meaning that chromosome #5, in all the cells examined, did not have the deletion.



Currently, Revlimid is approved in the U.S. specifically for use in Low-risk and Intermediate-1 risk MDS patients. (According to the widely used International Prognostic Scoring System, or IPSS for estimating disease progression, Low risk and Intermediate-1 risk categories have the best prognosis.) The complete prescribing information states that Revlimid is for MDS patients with anemia and 5q– syndrome, with or without other cytogenetic abnormalities.

In the European Union, Revlimid is currently under review as a treatment for MDS by the European Agency for the Evaluation of Medicinal Products (EMEA).

Treatment with Revlimid is associated with side effects that include neutropenia (low white blood cell count) and thrombocytopenia (low platelet count). Additionally, because it is chemically related to thalidomide, a drug known to cause severe birth defects, Revlimid cannot be administered to women who are pregnant. To prevent fetal exposure, Celgene Corporation (Summit, New Jersey), the distributor of Revlimid, is making the drug available in the U.S. under a risk management program called RevAssist SM. Under RevAssist, the drug is available only through physicians and pharmacists registered with the program; physicians are required to obtain informed consent, administer pregnancy tests, limit prescriptions to a one-month mail supply, and report any pregnancies to the FDA. Information about the RevAssist program can be obtained by calling the Celgene Customer Care Center at 1-888-423-5436, or via the internet at http://www.revlimid.com/revassist.aspx.

## Exjade®

Approved by the FDA in November, 2005, Exjade is the first orally administered iron chelator, a drug that removes excess iron in transfusion-dependent patients. In the European Union, Switzerland, and Australia, Exjade has been granted Orphan Drug status (reserved for drugs that treat serious or life-threatening diseases that affect a small number of people).

Traditionally, Desferal® (generic name, deferoxamine) has been the first-line therapy for transfusion-related iron overload. However, Desferal has a short half-life (the time required for half the dose to be removed from the body) and must be administered through subcutaneous or intravenous infusions that can last from 8 to 12 hours a day, for each day of transfusion therapy. For years, research efforts were focused on developing an effective oral therapy.

Exjade is given once daily as a drink – tablets dissolved in orange juice, apple juice, or water. This orally administered drug works by combining

with iron in the blood and facilitating its excretion in the feces. In clinical trials, Exjade was found to be comparable to Desferal in effectiveness and was generally well tolerated, with common side effects of transient nausea, vomiting, abdominal pain, diarrhea, and skin rash. Disturbances in hearing and sight and skin irritation are other known side effects.

Because approximately 8% of the administered dose is removed by the kidneys, Exjade should not be used in patients with compromised kidney function. In clinical trials, a small number of patients discontinued use of the drug due to liver abnormalities, and therefore, monitoring of liver function during treatment is recommended.

Exjade is distributed by Novartis, Inc., through a program called EpassÍ (Exjade Patient Assistance and Support Services), which requires completion of a consent form detailing information with regard to the patient and prescribing physician. Both the form and prescribing information for U.S. citizens are available via the internet at http://www.us.exjade.com, or by calling 1-888-903-7277.

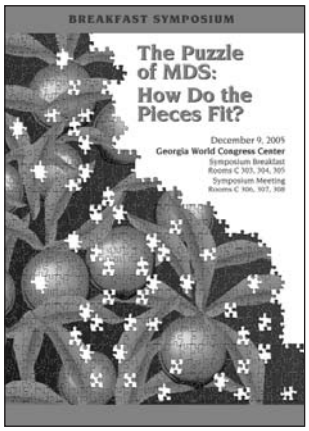
### Dacogen™

Dacogen is an intravenously administered anticancer agent that acts by inhibiting a chemical process called methylation, which causes tumor suppressor genes to be silenced. Preventing these "good cancer genes" from being hypermethylated prevents cancer cells from multiplying. Dacogen is therefore considered a hypomethylating agent, like Vidaza.

Dacogen was approved by the FDA as an MDS treatment and the commercial launch is planned for late May. In the European Union, Dacogen is under review for authorization by EMEA, the European drug regulatory agency.

Encouraging final results of a randomized clinical trial in 170 MDS patients were recently reported in the journal Cancer. Patients who received Dacogen (intravenous infusion over 3 hours, every 8 hours, for 3 days and repeated every 6 weeks) had a significantly higher overall response rate than patients who received supportive care (e.g., red blood cell or platelet transfusions when needed). A total of 9% of Dacogen-treated patients had a complete response versus 0% of patients in the supportive care group. All patients who responded to Dacogen treatment became or remained transfusion-independent. The best response rate was seen in patients with Intermediate-2 risk and High Risk (IPSS risk categories). The most common side effects of Dacogen were low red blood cell counts, white blood cell counts, and platelet counts.

# 47th ASH Annual Meeting Highlights




**Atlanta, Georgia, December 10–13, 2005:** The MDS Foundation held its 8th annual satellite symposium entitled "The Puzzle of MDS: How Do the Pieces Fit?", chaired by Dr. Alan List. This year's program provided physicians with information on the accurate diagnosis and classification of MDS patients.

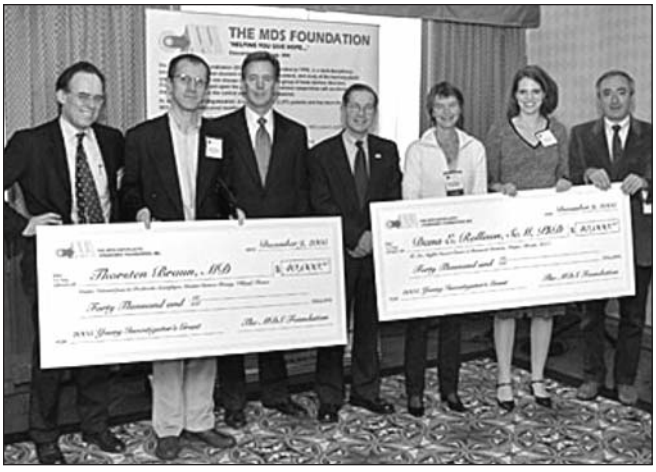
We are experiencing an emergence of novel therapies that may offer significant benefit for one of the most common groups of bone marrow disorders, i.e., the myelodysplastic syndromes (MDS). MDS displays a continuum of biologic features with loss of transcriptional controls of gene expression, accelerated proliferation and apoptosis, and ineffective hematopoiesis. Numerous biological events appear to drive or amplify what we recognize as the MDS phenotype, emphasizing the importance of understanding the molecular and genetic basis of disease for therapeutic development. Acquisition of genetic or epigenetic changes in selected patients may promote gain of function and evolution of the neoplastic clone to acute myeloid leukemia (AML). Investigations of molecular and biochemical targets, in combination with comprehensive molecular analyses (e.g., genomic studies), are providing new insights into the DNA damage and genetic changes that occur in myelodysplastic bone marrow progenitors and AML. Equally important, these investigations are already giving rise to promising targeted therapies and expectations for more effective therapies in the near future.

The meeting was extremely well attended and the focus of more than 1,000 ASH participants. We would like to thank Drs. John M. Bennett, Mario Cazzola, Torsten Haferlach, Alan F. List, Ghulam J. Mufti, and Mary L. Thomas, RN for participating on the Faculty of this symposium.

*For a copy of the CD ROM, which contains all of the slide presentations from this session, please contact the MDS Foundation at 1-800-MDS-0839.*

# Young Investigator's Grant Award Reception

The MDS Foundation presented its inaugural Young Investigator Grants for MDS research at a lunch reception during the 2005 meeting of the American Society of Hematology in Atlanta, Georgia. The Grant Review Committee headed by Stephen Nimer, MD, Foundation Board of Directors member, selected Dana E. Rollison's (H. Lee Moffitt Cancer Center, Tampa, Florida) study entitled "Case-control Study of Telomerase Reverse Transcriptase and Telomere Length in Myelodysplastic Syndromes" and Thorsten Braun's (CNRS Institut Gustave Roussy, Villejuif, France) study entitled "NF-kappaB as a Therapeutic Target in Myelodysplastic Syndromes." Each of these recipients was awarded a $40,000 grant for continued research. Two awards will be granted annually.




*(Pictured left to right) Drs. Theo de Witte, Pierre Fenaux (accepting the award on behalf of Thorsten Braun), Alan List, John Bennett, Eva Hellström-Lindberg (members of the Foundation's Board of Directors), Dana Rollison (award recipient), and Mario Cazzola (Chairman, 9th International Symposium on MDS).*



# From the Director's Desk

***Kathy Heptinstall, Operating Director***

**The MDS Foundation**

Through this column, I will try to keep you up-to-date on the Foundation, its programs and progress, throughout the year! I also welcome questions and suggestions from our members and others.

2006 has seen the third drug for MDS approved by the US Food and Drug Administration, Dacogen (decitabine). This is wonderful news for MDS patients as it offers an additional treatment option for patients with MDS.

The Foundation has conducted a total of five Quality-of-Life forums for MDS patients in the United States and the fifth of our European series on May 12 in Leeds, England, UK with Dr. David Bowen. Forums are scheduled for Germany and Sweden (September 26, 2006) and on Friday, May 19th the Foundation will be represented during the Groupe Français des Myélodysplasies meeting in Marseille, France by a presentation on the Foundation's efforts to work with patient groups within Europe. There will also be a presentation by the Liaison of the first formal MDS Patient Support Group in Europe. This permanent group was developed around the Patient Forum that was held in Paris earlier this year and is currently headed by Sarah Jenny. The second French Patient Forum and Support Group will be held on May 19th following the conclusion meeting of the French society and will feature Professor Pierre Fenaux and Norbert Vey, MD.

The 9th International Symposium will be held May 16–19, 2007 in Florence, Italy. We will update you on the plans for this important symposium in our next issue of the MDS News.

As noted in our last addition, an expansive MDS Awareness Program was initiated in September 2005 and will continue, in a multi-segment format, throughout 2006. If you are interested in participating in this state-of-the-art continuing education program, please join us through the Foundation's website (www.mds-foundation.org) or call 1-800-MDS-0839. New segments will be available bi-monthly and can be completed via our educational website, CD-ROM, or in writing.

The Foundation has participated in the American Society of Hematology (ASH) Annual Meeting for eight consecutive years by hosting our booth for physician attendees and conducting adjunct symposia on the Friday immediately preceding the meeting. Our symposium for this year has been

submitted and we anticipate being accepted by ASH to present our 9th symposium Paradigms in MDS Prognosis and Treatment. Dr. Alan List of Moffitt Cancer Center, and a member of the Foundation's Board of Directors, will once again serve as Chairman for this important program. Dr. List will present the Program Overview and Objectives and discuss Emerging Treatment Strategies in MDS, Dr. John M. Bennett, Foundation Chairman, from the University of Rochester Cancer Center will speak on the Evolution of MDS Morphologic and Response Assessment Criteria, Detlef Haase of George-August-Universität, Göttingen, Germany will provide new insight into Interrogating Less Common Genetic Abnormalities in MDS, Professor Michael Lübbert of Freiberg University, Freiberg, Germany will discuss Therapeutic Targeting of the Epigenome in MDS, and Dr. Luca Malcovati of the University of Pavia Medical School, Pavia, Italy will present information on Integrating Transfusion-Dependence and Iron Chelation into Prognostic and Management Models in MDS

During 2006 the Foundation will, for the third year in a row, participate in the European Society of Hematology's (EHA) Annual Meeting. For the first time the Foundation is presenting a 2-hour symposium (June 15 from 8am to 10 am) on MDS to this prestigious international body. Our co-Chairmen are Ghulam J. Mufti, MD and Pierre Fenaux, MD of King's College, London and Hôpital Avicenne, Paris, respectively. Topics and speakers include: Problems in the Morphological Diagnosis of MDS presented by Barbara J. Bain, MB of St. Mary's College, London, UK; Correlation and Differentiation of New Therapeutic Agents through Uniform Response Criteria in MDS, John M. Bennett, MD of the University of Rochester Cancer Center, Rochester, NY; The Relationship of Quality-of-Life to Hgb Levels in MDS by Eva Hellström-Lindberg, MD, PhD of the Karolinska Institute in Stockholm, Sweden; The Inter-Relationship of Ineffective Hematopoiesis and Cellular Biology in MDS presented by Guido Kroemer, MD, PhD of the Institut Gustave Roussy, Villejuif, France; Clarifying MDS–A Progress Report on Research in Molecular Biology by Claudia Schoch, MD of Ludwig-Maximilians-University, München, Germany. This will hopefully be the first of many educational initiatives in conjunction with EHA.

On April 25–27, 2006 the Foundation participated for the first time in the meeting of the European Working Oncology Group (EWOG) focused on pediatric patients. Chaired by Dr. Charlotte Niemeyer of Freiberg University this important program is currently held once every three years. The Foundation has committed to assisting the JMML Foundation in developing assistance and information for JMML patients and their families as well as developing information to further the knowledge base for this related disease.

We also participated for the third year in the Biotechnology Conference (BIO 2006) that was held last month in Chicago, Illinois.

The International Working Group on MDS Morphology continues its statistical analysis of the work that has been conducted over the past year. This information will soon be presented for publication by this prestigious international group of morphology experts.

The Foundation will conduct its 3rd Annual Jack Keating Memorial Golf Tournament for MDS that supports our Young Investigator Grant program. PGA Golf Professional on the Champion's Tour, Bruce Fleischer, has graciously agreed to put his name and his influence behind this tournament. In 2007 a second tournament will be held in Tampa, Florida and will supply the Foundation with additional funding for this important program. The Moffitt Cancer Center will participate with us in this important event and lend its prestige to this initiative. The Foundation and Moffitt will share the proceeds from this tournament. Hopefully, this is the beginning of significant research funding for the Foundation benefiting the MDS community. The deadline for grant applications for 2006 is June 15th. Interested applicants can request information from the Foundation.

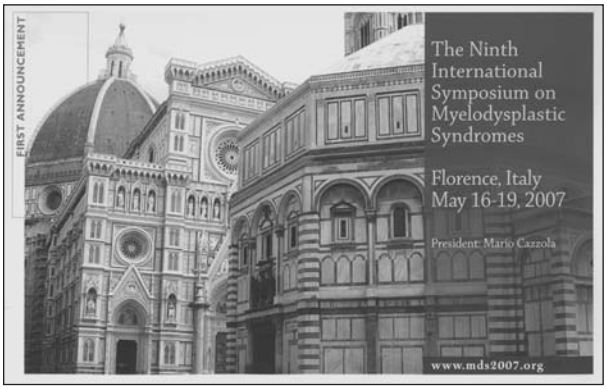
During the remainder of 2006 and into 2007 the Foundation will work to develop satellite offices within the EU. This expansion will assist MDS patients and their families on a more local level and provide influence and a voice within the EU for these patients.

I would like to thank our supporters on behalf of the Foundation and its Board of Directors. These supporters, first and foremost, are the MDS patients, their families and friends, who form the core of this Foundation. You are our center and the reason that the Foundation exists. We work for you!

The second group that we would like to thank are the pharmaceutical companies that provide us with so much support and assistance. This assistance is given in the form of grants that fund programs that are non-product related but, rather, are geared toward improved disease knowledge and patient support. We could not do the work we do without this type of support. I look forward to continuing our relationship with you!

# Foundation Plans International Symposia Through 2011

The MDS Foundation has approved applications for the next three International Symposia. These symposia are scheduled for 2007 in Florence, Italy; 2009 in Patras, Greece; and 2011 in the United Kingdom.




**Ninth International Symposium–www.mds2007.org**
**May 16–19, 2007, *Florence, Italy***

***Organizing Committee:***
*Mario Cazzola (Chairman)*
*Albert Bosi, Cristina Mecucci, Valeria Santina*

***Scientific Secretariat:***
*Matteo G. Della Porta, Luca Malcovati*
*Email: mds2007@haematologica.org*

***Local Organizing Secretariat:***
Studio E.R. Congressi–Gruppo Triumph
Via Marconi, 36 – 40122 Bologna
Phone: +39 051.4210559, Fax: +39 051.4210174
EMail: ercongressi@gruppotriumph.it
www.ercongressi.it

*Sponsorship proposals should be addressed to the local organizing secretariat.*

**Tenth International Symposium – Spring 2009**
***Patras, Greece***
*Sponsor: Nicholas C. Zoumbos, MD*

**Eleventh International Symposium – Spring 2011**
***United Kingdom***
*Sponsor: David T. Bowen, MD*

# Save the Date: July 31, 2006

***The MDS Foundation***
***Third Annual Charity Golf Tournament***

Please plan to be a participant or part of the Gallery for this important charity event.


We have renamed this tournament in honor of Jack Keating who helped start our annual golf tournament. This tournament supports The MDS Foundation's Young Investigator Grant Program. Jack passed away last year but he will not be forgotten.

This year the event takes place at the Tournament Players Club at Jasna Polana in Princeton, New Jersey. This award-winning course was designed by Gary Player and is a Certified Audubon Cooperative Sanctuary, an honor bestowed on the Club for its commitment to environmental excellence.

***Featuring Golf Pro–Guest of Honor:***

Bruce Fleisher, PGA Champions' Tour Professional and Winner of the 2001 U.S. Senior Open Championship

Bruce Fleisher will be joined with other PGA Professionals and Celebrity Guests.

**Special Events include:**

- A golf clinic with small group instruction given by the PGA Professionals on all aspects of the game
- Full access to watch all the PGA Pros and Celebrity Guests play golf or to play golf with these great champions!
- Lunch at the Jasna Polana Clubhouse
- Putting contest

- Golf Tournament Dinner with the Pros and Celebrity Guests, and Silent Auction

As demonstrated during last year's tournament, the Senior PGA players and the other celebrity participants contributed to everyone's enjoyment of the event through their unique personalities, willingness to sign autographs, and general openness to each individual they met. This meant a great deal to every one who participated. We are looking forward to another outstanding golf tournament this year.

Look for future announcements and invitations with more specific information as the time nears. And don't forget to practice!

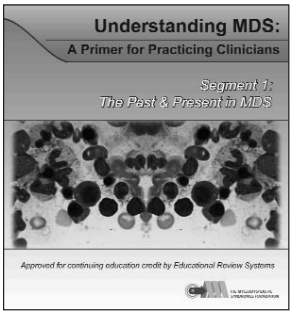
# The Foundation Resource Center is Now Online!

This educational center is designed to provide clinicians, researchers, and other healthcare professionals with a comprehensive source for the latest information and educational programming on the myelodysplastic syndromes.

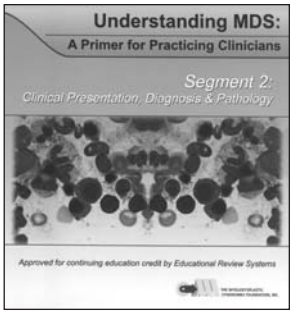
In the Conference section of our website you can view materials presented at MDS conferences or register for upcoming MDS-related symposia.

## *Understanding MDS: A Primer for Practicing Clinicians*

Visit www.mds-foundation.org and click on The MDS Foundation Resource Center to take advantage of this comprehensive program, and other informative programs coming soon, designed to provide you with tools and information that will assist you in administering the best care to your patients.




**Segment 1, *The Past & Present in MDS*.**
Segment 1 provides insight into the history of MDS, development of the MDS classification and prognostic systems, and a glimpse into the future of MDS diagnosis, research and treatment.



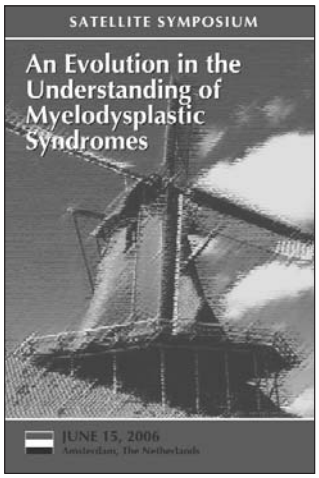

**Segment 2, *Clinical Presentation, Diagnosis & Pathology*.**
Segment 2 provides insight into the clinical picture of adult and pediatric MDS, primary and secondary MDS, FAB and WHO Classification system, and rationale for the proposed MDS pediatric classification system.

This multi-segment program will allow participants to choose the segments that interest them and to learn at their own pace. Segments may be completed via a written program, on-line in our technologically advanced MDS Foundation Educational Center, or via CD-ROM on their personal computer.

The program is approved for 1 hour of CME credit upon completion. There is no charge for this educational activity.

The Myelodysplastic Syndromes Foundation strives to serve as an effective conduit for information regarding the most updated treatment options, clinical studies, referrals to Centers of Excellence, and other information concerning MDS. Please bookmark our site, www.mds-foundation.org, and check back frequently for new, informative programs.

# 11th Congress of the European Hematology Association




**June 15–18, 2006**
***Amsterdam, The Netherlands***

**Please make sure to visit the MDS Foundation Booth #300.**

# Cancer's Molecular Targeted Therapies Disrupt the Inner Workings of Cancer

***Rabiya S. Tuma, PhD***

Gina Nati was diagnosed with metastatic colon cancer in February of 2003. Given the extent of the tumors in her colon and liver, the doctors told her it was unlikely they could operate, so they put her on a combination of 5-fluorouracil, Camptosar® (irinotecan), leucovorin and later Eloxatin® (oxaliplatin). Her tumors remained more or less under control while on these chemotherapy regimens, even shrinking a bit. A week after the Food and Drug Administration approved Avastin® (bevacizumab) in February 2004 for first-line treatment of metastatic colorectal cancer, Nati's doctors changed her chemotherapy regimen to include the new agent. After about six months her tumors had decreased in size enough that the doctors opted for surgery to try to completely remove the remaining tumors. Such responses to Avastin-based combinations are what doctors anticipated when developing targeted therapies. Nati has had two surgeries to remove tumors and has one more to go. "I hope I'm close to going into remission," she says. "I have high hopes now."

Although the concept of using agents that target particular pathways or molecules has been around for more than 40 years, doctors are witnessing a new era in cancer therapeutics. The increasing knowledge of cancer biology combined with an improved ability to develop agents that inhibit these molecular targets have resulted in an influx of novel targeted agents.

The new agents aren't perfect, stress the experts, but they offer some advantages, including better disease control, especially when paired with traditional chemotherapies or other targeted drugs. And while the new drugs can potentially cause serious adverse reactions, they are not typically associated with familiar chemotherapy side effects, such as hair loss, nausea and fatigue.

## *The Advent of Targeted Drugs*

In the 1970s, cancer therapy changed dramatically as researchers found they could slow and sometimes halt cancers using chemotherapies that kill rapidly dividing cells, a hallmark of most cancers. Unfortunately such "cytotoxic" drugs do not discriminate between healthy cells and cancerous ones. Targeted therapies, by comparison, are designed primarily to interact with only tumor cells. Over the years, scientists have uncovered specific molecular changes that turn healthy cells into cancerous ones. Targeted agents block or reverse the negative effects of those changes.

Because different types of mutations or cell changes cause different cancers, a targeted therapy must inhibit a specific mutation or pathway. For example, some of the drugs block signals that tell the cell to proliferate and grow, while others work by inducing cell death.

The new drugs also come in various forms. Some are small molecules that can fit into the pocket of an enzyme and prohibit its activation much like a broken-off key in a lock prevents an intact key from opening a door. Others are monoclonal antibodies that bind to cell surface receptors and either prevent growth signals from reaching the cancer cells or recruit immune cells to target and kill the cancer cell.

## *Approved Agents: Hope for New Indications*

Avastin—the drug that helped shrink Nati's tumors to an operable size—and Erbitux® (cetuximab) are monoclonal antibodies that bind to the vascular endothelial growth factor (VEGF) receptor and the epidermal growth factor receptor (EGFR), respectively. They have both been approved for colorectal cancer, but now researchers are looking at other cancers that may respond to the drugs.

When activated, VEGF induces the formation of blood vessels, a process called angiogenesis. As tumors grow, they require additional blood vessels to supply oxygen and nutrients. By blocking angiogenesis, Avastin "starves" the tumor. In spring 2005, two large studies reported that the addition of Avastin to standard chemotherapy improves survival in metastatic breast cancer and advanced nonsmall cell lung cancer.

"We have been talking about anti-angiogenesis for years, but now it is a clinical reality for treating a number of major cancers," says Roy Herbst, MD, PhD, chief of thoracic oncology at M.D. Anderson Cancer Center. This new trend is so important that Dr. Herbst describes antiangiogenesis as the "fourth modality" of cancer therapy, fitting in with surgery, radiation and chemotherapy.

Unlike Avastin, Erbitux works directly on tumor cells by binding to EGFR and preventing the tumor cells from turning on the growth pathways. Researchers liken the drug to lifting up a stuck accelerator pedal in a car. Without the extra gas (or oxygen and nutrients), the car (or tumor) coasts to a halt.

As a supplement to the current indication for advanced colorectal cancer, the FDA is currently reviewing approval of Erbitux for head and neck cancer. In clinical testing, the drug improved two- and three-year survival when combined with radiation for the treatment of locally advanced disease, compared with radiation alone. The drug also improved response rates in metastatic or relapsed head and neck cancer that did not respond to platinum therapy.

The next question for Erbitux will be if it is active in the front-line setting of previously untreated colorectal cancer patients. "A 22 percent response rate as a third- or fourth-line therapy is a pretty high percentage and suggests this could be an active drug in the front line." says Leonard Saltz, MD, a colorectal cancer specialist at Memorial Sloan-Kettering Cancer Center. "Studies are being done to answer the question, but it will take time."

In the same receptor family as EGFR is HER2, the target of Herceptin® (trastuzumab). Kristie Naines was 35 when she was diagnosed with stage 3 breast cancer. Her cancer was HER2 positive, which is often associated with a particularly aggressive form of the disease, but one that responds to Herceptin.

The FDA approved Herceptin in 1998 for treatment of metastatic breast cancer in the approximately 20 percent of patients whose tumors overexpress HER2. Edith Perez, MD, a breast cancer specialist at the Mayo Clinic in Jacksonville, Florida, and colleagues immediately designed a three-arm trial to test whether the addition of Herceptin to traditional chemotherapy would prolong disease-free survival in patients with local disease following surgery.

Naines joined that trial in early 2003 following a double mastectomy. In one arm, patients received adjuvant chemotherapy with Taxol® (paclitaxel). In the other two arms, patients received adjuvant chemotherapy with Taxol plus Herceptin, which was given either with Taxol or following four cycles of Taxol. When researchers unveiled a joint analysis of the trial and a similar one in the *New England Journal of Medicine* in late 2005, both showed overwhelmingly positive results in women who received Herceptin with surgery and standard chemotherapy. The combined study results showed that among patients taking Herceptin, 85.3 percent were alive and free of disease at four years compared with 67.1 percent in the control group. "The results completely exceeded my expectations," says Dr. Perez.

Naines says she prayed every day that she wouldn't be in the Taxol-alone arm. "But I also thought that if the study wasn't in existence I would be getting the traditional chemotherapy anyway," she says. "And at that time, people really didn't know if Herceptin made a difference or not."

Luck was with her, and she was randomized to an arm that had Herceptin. She continues to be disease free and is participating in the follow-up study with Dr. Perez. Because Herceptin has been associated with increased risk of heart problems, patients with a history of heart disease must be carefully monitored while taking the drug.

Reports indicate Herceptin will be filed for the additional indication in the adjuvant breast cancer setting in early 2006.

## *Investigational Agents*

### Affecting the Immune System

It took Kaete Angel, a realtor from Redding, Connecticut, three years and ultimately a bone marrow biopsy to be properly diagnosed with myelodysplastic syndrome (MDS), a rare cancer of the blood that requires frequent blood transfusions. After an initial diagnosis from her primary care physician in 2002, Angel learned how serious the disease was and scheduled an appointment for a second opinion at Memorial Sloan-Kettering Cancer Center. Angel began receiving blood transfusions almost immediately followed by monthly transfusions for one year. In between transfusions, Angel says life was difficult because of frequent fatigue and shortness of breath.

During the time of Angel's diagnosis, a French trial of Revlimid® (lenalidomide) for MDS showed favorable results. "My doctor called me and she was so excited," says Angel, who credits her doctors for getting her on the Revlimid trial. "For over two years, I have been taking this drug and have not had a blood transfusion since October 2003." With Revlimid, Angel has her energy back and she's started exercising again. "I can now walk 2 miles a day if I want to and I don't have to stop and gasp for air."

Angel is not alone in her positive response to Revlimid. In a single-arm phase II trial involving nearly 150 MDS patients, 64 percent achieved transfusion independence, and more than half of those are still responding to treatment after 58 weeks.

Because Angel participated in the Revlimid trial, she was asked to speak to the FDA's Oncologic Drugs Advisory Committee in September 2005 about her response to Revlimid. "Before this miracle drug, my life was ruled by how long I could last between needing a transfusion," Angel told ODAC. In addition to encouraging clinical trial results, the committee ultimately recommended the drug to the FDA, which is currently evaluating Revlimid for treatment of patients like Angel who have low to intermediate-1 risk MDS with a partial deletion of chromosome 5q and who are dependent on blood transfusions to stave off serious anemia. A final approval decision is due by January 2006.

Revlimid also has activity in patients with refractory or relapsed multiple myeloma. According to data from two phase III studies, response rates more than doubled in the Revlimid-dexamethasone arm compared with patients treated with dexamethasone alone. Disease progression also appeared to be delayed in patients in the combination therapy arm.

"I don't want to overstate the case, but in myeloma patients who do respond to Revlimid, which is about one-third of patients, they can enjoy very durable disease control on the agent," says Paul Richardson, MD, clinical director of the Jerome Lipper Multiple Myeloma Center at the Dana-Farber Cancer Institute.

Revlimid directly attacks myeloma by modulating the patient's immune response to the tumor. Myeloma is a notoriously adaptive disease because it has multiple mechanisms of resistance, says Dr. Richardson, so Revlimid targets not only the tumor but also its environment, making it less hospitable to the cancer cells. The treatment gains of Revlimid do come at a cost, with thrombocytopenia and neutropenia occurring in about half of patients.

Researchers are now testing Revlimid with Velcade® (bortezomib), and "the combination has a manageable side effect profile and the response rate is very promising," says Dr. Richardson, who has worked extensively with both drugs and leads the phase I combination trial.

### Hitting Multiple Targets Nexavar®

Nexavar® (sorafenib) and Sutent® (sunitinib) are tyrosine kinase inhibitors designed to block one or more pathways that promote cell growth. Although similar in a general sense, they each inhibit a different profile of tyrosine kinases, which are enzymes the cell uses to pass on signals. The differences will likely make tyrosine kinase inhibitors more useful in different disease settings or drug combinations.

In early 2005, Ronald Bukowski, MD, director of the Experimental Therapeutics Program at the Cleveland Clinic Taussig Cancer Center, and colleagues reported interim results from a large phase III trial comparing Nexavar to a placebo and best supportive care in patients with relapsed or refractory metastatic kidney cancer. Patients taking Nexavar remained disease free for an average of 12 weeks longer than those on a placebo, doubling the time to disease progression. Updated data released in late 2005 showed a 39 percent improvement in survival for patients receiving Nexavar compared with placebo. Side effects included fatigue, diarrhea, skin rash and hand-foot syndrome.

"This is really the first time in renal cell cancer that we have had a drug that can produce this kind of benefit for patients, especially one that is very easy to take and has a reasonable toxicity profile," says Dr. Bukowski. FDA approval for Nexavar in kidney cancer is expected by early 2006. Meanwhile, the drug is being tested in previously untreated kidney cancer patients, although it is too early to know the results.

Phase II trials using Sutent to treat relapsed metastatic kidney cancer showed activity. Researchers are also testing Sutent in breast cancer, non-small cell lung cancer and neuroendocrine tumors. It has already shown benefit in patients with gastrointestinal stromal tumors (GIST) who have relapsed or are refractory to Gleevec® (imatinib). The FDA is currently reviewing Sutent for approval in GIST and kidney cancer. The agency will make a decision by early 2006.

Numerous combinations are being developed using Sutent or Nexavar with standard chemotherapy or other targeted agents, such as Avastin, which itself has shown activity in kidney cancer.

### A Dual Inhibitor

HER2, one of many growth factors on cancer cells, is part of the same receptor family as EGFR. One of the normal functions of HER2 is to bind to other cancer cell receptors. "It's thought that the normal function of HER2 is to bind proteins like EGFR and control the normal growth and differentiation of the cell,"says Harold Burstein, MD, PhD, an assistant professor of medicine at Harvard Medical School. "In HER2-positive breast cancers, these proteins are deranged, or abnormal. The thinking is that by going after two pieces of this abnormal growth pathway, you might accomplish more than by just going after one half of it."

A new oral drug called Tykerb® (lapatinib) inhibits both HER2 and EGFR. While it is being tested in a

variety of tumor types, Dr. Burstein says the new agent has shown the most promise in HER2-positive breast cancer. Researchers still don't know if the drug is going to be a clinical improvement over Herceptin therapy, but trials testing Tykerb alone and in combination with Herceptin offer an early hint at the answer.

A phase I trial of heavily pretreated HER2-positive metastatic breast cancer patients given Tykerb plus Herceptin resulted in six of 27 patients having their tumors shrink by at least 30 percent, while an additional 10 patients had stable disease. A phase II study with a planned enrollment of 130 patients will test Tykerb alone as first-line therapy in HER2-positive locally advanced or metastatic breast cancer. Early results presented at the 2005 San Antonio Breast Cancer Symposium reported that of the first 40 patients to receive treatment, 14 had their tumors shrink by at least 30 percent and another 14 had stable disease. "These results argue that the drug has substantial activity," says Dr. Burstein. "It doesn't say it's better than Herceptin, but it definitely has activity."

Given the important role of EGFR in a variety of solid tumors, Dr. Burstein says, "Where it's going to shake out for lapatinib is whether there's activity just in breast cancer or whether it will have a wider spectrum of activity in tumors like colon or lung."

Side effects of Tykerb include itching, rash and diarrhea. Early estimates indicate Tykerb will be filed for FDA approval in breast cancer in late 2006 or early 2007.

**Obstructing the mTOR Pathway**

Several signaling pathways are at work within a cell—both normal and abnormal—that regulate its growth and division. Most of these pathways begin at the cell surface with the binding of a growth factor to the receptor. "mTOR (mammalian target of rapamycin) is a protein that is involved several layers down in the cascade in regulating how the cell responds to treatment," says Dr. Burstein. "This deeper step invites the possibility for a broadly useful target in cancer treatment."

Rapamycin was found more than 30 years ago in soil bacteria on Easter Island in the South Pacific. Several rapamycin derivatives that inhibit the mTOR protein are undergoing testing in solid tumors and hematological malignancies.

Temsirolimus (CCI-779) showed benefit in phase II trials for breast cancer, kidney cancer, mantle cell lymphoma and glioblastoma multiforme, and it is now in phase III testing. The FDA granted fast-track status to temsirolimus in late 2004 for the potential indication of first-line kidney cancer therapy. The drug's developer plans to file for approval in kidney cancer in late 2006.

The FDA fast-tracked another mTOR inhibitor called AP23573 for treatment of soft-tissue and bone sarcomas. The intravenous agent is also being studied in breast cancer, prostate cancer and lymphoma. Early data from an ongoing phase II trial in sarcoma patients showed 51 of 188 patients responded to the drug. In addition, the six-month progression-free survival in patients receiving the drug in the first stage of the trial was 22 percent. Early results of a phase I trial using an oral formulation of AP23573 show the drug can be administered safely and has anti-tumor activity.

Everolimus (RAD001) is an oral mTOR inhibitor undergoing testing in endometrial cancer, lung cancer, breast cancer and leukemia. Everolimus had a good safety profile in phase I studies, and phase II trials are now testing the drug's effectiveness.

Dr. Burstein says testing targeted therapies like mTOR inhibitors requires time to locate the molecular pathways critical for the tumor cell's survival. "We check that the biology is relevant to the particular tumor and then find anti-tumor therapies that are likely to be helpful. That's ultimately a higher yield than trying to go after all tumors with relatively focused drugs." Side effects of mTOR inhibitors can include fatigue, rash and mucositis.

## *When and How to Use Targeted Therapies*

Identifying active agents is only part of the task in front of cancer researchers. The other part is deciphering when and how best to use the drugs. An important illustration of that comes from the use of Avastin in metastatic breast cancer. The first phase III trial testing the drug was in women whose disease had already progressed on several chemotherapy regimens. In that trial, the addition of Avastin did not prolong disease-free survival or overall survival. By contrast, more recent results in newly diagnosed metastatic breast cancer patients demonstrate significant benefit from the drug.

Experts emphasize that finding such limitations is just part of the process of using targeted therapies. As cancers progress, they tend to accumulate more and more mutations. That means a therapy that induced a

response or regression at one time may not later, which is the crux of the problem with drug resistance. Dr. Richardson points out, however, that although drug resistance can be a problem with targeted therapies, just like it is with traditional therapies, the dilemma seems to be a bit different. For one thing, doctors are finding that a patient who no longer responds to a drug in one combination might respond to it in another one.

"This is a new way of thinking in tumor biology," says Dr. Richardson. "Traditionally we have always been taught that if a patient has received a drug and progressed on it, under no circumstances should you revisit the drug." That dogma is changing with the advent of targeted therapies.

The list of targeted agents is impressive, and more are in various stages of development from early laboratory studies to clinical trials. The catch, however, is that while many improve patient outcomes, most of them haven't lived up to the original promise of targeted therapies: standard chemotherapy replacements with less toxicity. " 'Targeted therapies' is a popular buzzword and it sounds so great," says Dr. Saltz. Patients are better off with the targeted agents than without them, but he emphasizes, "We really need to keep our efforts going to come up with something better."

*[Editor's note: At the time of publication, numerous drugs discussed in this article are pending approval by the FDA. For the latest updates, visit www.curetoday.com.]*





# 4th International Symposium on MDS in Childhood

## April 24–26, 2006
## Freiburg, Germany

Since the first symposium, held in 1997, the European Working Group on MDS (EWOG-MDS) has increased focus on malignant neoplasias of childhood.

The meeting covered diagnostic, pathogenetic, clinical, and therapy related problems and it is the hope that the results generated by this symposium may lead to a better understanding of the biology of MDS in children and improve long-term survival of those afflicted.

A further purpose of this symposium was to share experiences within the various fields of research and further strengthen the scientific communication that has gradually been built up during the past years. An international panel of leading experts presented keynote lectures within their fields.

**Topics:**

- Childhood MDS - diagnostic challenges
- Morphology and classification
- Cytogenetics
- Oncogenes and tumor suppression genes
- Stem cell biology
- Leukemogenesis in congenital bone marrow failure disorders
- Therapy-related secondary myeloid neoplasia
- Risk assessment and therapeutic decisions
- Novel therapeutics and immunotherapy
- Stem cell transplantation
- Juvenile myelomonocytic leukemia
- Signaling and potential targets
- Biological studies

**Organizing Committee:**

Charlotte Niemeyer, MD, Chairwoman
Peter Bader, MD
Irith Baumann, MD

Alexandra Fischer, MD
Christian Kratz, MD
Direk Reinhardt, MD
Brigitte Schlegelberger, MD

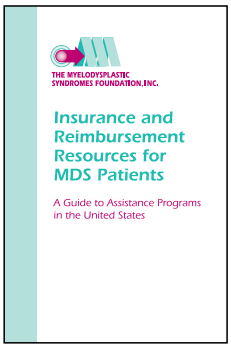
**For EWOG-MDS:**
Jan Stary, MD, Chairman

***Organizing members of the European Working Group on MDS (EWOG-MDS)***

*(Back row from left to right) Axel Karow, Christian Flotho, Marcu von Hornung, Johannes Korn, Eva Odenthal, Sabine Linser-Haar*

*(Front row from left to right) Gaby Prinz, Beate Batz, Cornelia Klein, Charlotte Niemeyer, Alexandra Fischer*

# Now Available From The Foundation

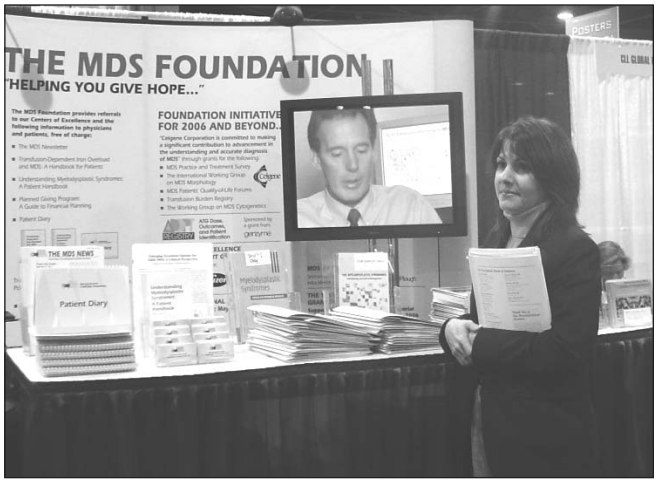



We have assembled a listing of insurance and drug reimbursement resources for MDS patients. It is important to know that there is support for those who cannot afford medicine or other healthcare costs. We hope this new resource will be beneficial in helping you with your medical needs. This guide to assistance programs in the United States is available for download from the Foundation's website or can be ordered in booklet form upon request.

# ICD9 Coding Changes

Changes have been made to the ICD9 codes for MDS. The following sequence reflects the WHO plus the now extinct but still classifiable RAEB-T:

| Diagnostic Term | ICD-0-3 | |
|---|---|---|
| Refractory Anemia | C42.1 | M-9980/3 |
| Refractory Anemia with Ringed Sideroblasts | C42.1 | M-9982/3 |
| Refractory Anemia with Excess Blasts | C42.1 | M-9983/3 |
| Refractory Anemia with Excess Blasts in Transformation | C42.1 | M-9984/3 |
| Refractory Cytopenia with Multilineage Dysplasia | C42.1 | M-9985/3 |
| Myelodysplastic Syndromes (MDS) with 5q-Syndrome | C42.1 | M-9986/3 |
| Therapy-related Myelodysplastic Syndromes (MDS) | C42.1 | M-9987/3 |
| Myelodysplastic Syndromes, NOS | C42.1 | M-9989/3 |




*The Foundation has participated at ASH for eight consecutive years by hosting its booth for physician attendees.*
*(See ASH Highlights on page 5)*

# Share Your Stories

*The Foundation would like to invite patients and their families to share their stories with others in the MDS community. Living with MDS poses challenges and many of you have stories that provide hope to others. Please contact the Foundation, if you would like us to publish your story.*

## Another Perspective

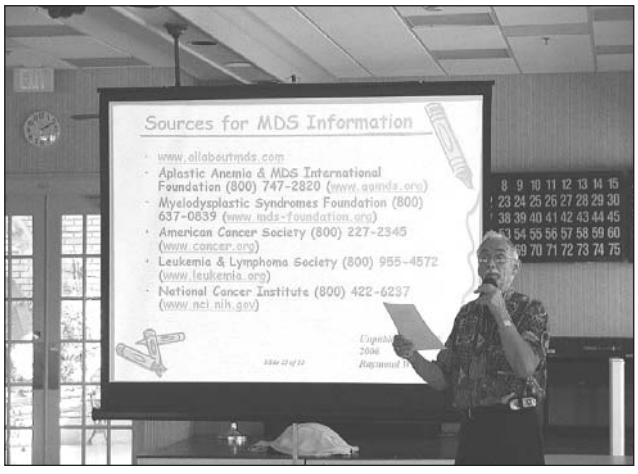
**Raymond W. Malles**
***Doylestown, PA***

Napoleon Bonaparte faced his Waterloo on June 18, 1815. I thought I was facing mine on November 4, 2005. That's the day I learned I had MDS. That life changing revelation launched me and my family on a new path — one never expected in a million years. I and they were determined to learn as much as possible about this insidious disease. We are still on that journey.

Having children who are computer savvy, the internet was the first place they did their data mining. My "middle" daughter was first to uncover the MDS Foundation and she promptly notified me of its existence. I was in Florida for a winter stay but returning to my home in Pennsylvania for Christmas. Someone was looking out for me as I was able to attend their forum in Philadelphia on December 15, 2005, along with my daughter and wife. What a wonderful experience! I learned so much about this disease; met the angels that "are a major part of the Foundation" and found many more affected people who were "weathering the storm" as I was. Not only did I leave this session with a clearer understanding of the disease and its many ramifications, but I also decided to put my teaching talents to work. We discovered many individuals know little about MDS, if anything at all, and we also learned many physicians fail to recognize its symptoms. I am determined to change that reality.

What prompted me to seek a diagnosis of my shortcomings? — Feeling tired and shortness of breath. My wife insisted I undergo a complete physical before departing for Florida last October. I described my symptoms to a new physician in the office where I had been visiting in the past. Looking back, my first inkling of a problem was after the 9-11 tragedy. My wife and I decided to donate blood through the Red Cross. I was shocked when I was turned down for having a low iron level. They suggested I visit my physician and have additional blood work done. This I did. My visit to another physician in the same office resulted in a non-threatening diagnosis of: "Yes, your iron is a little low but don't be concerned and simply live with it." A diet of iron rich foods was part of my treatment. A repeat Red Cross refusal to harvest my blood and the follow-up blood work produced a similar outcome. This latest physical and doctor's visit was different. She ordered an extensive battery of blood tests and I departed for Florida leaving her with my winter telephone number. Her alarming call to me shortly thereafter suggested I see a hematologist. After the shock wore off, I made an appointment with a local specialist. She remarked how my blood work was the most extensive testing she had ever seen ordered by a family practitioner. Only the bone marrow sample was lacking. That day she took the sample and, you guessed it, the combined results and diagnosis became my Waterloo.

The picture you see along with this article is me conducting my first educational presentation, as a layman, on what MDS is all about. I combined my past Adult Education Teaching experience, my familiarity with computers, my personal journey and my newly acquired knowledge of MDS to develop a plain language PowerPoint presentation for our senior Florida community. I had a total of 35 interested seniors sufficiently enticed to be in my audience. When I completed the presentation, I was greeted with a round of applause. It was truly satisfying and well worth the time and effort. I honestly believe my calling is to continue this effort when I return to Pennsylvania. Somehow, if I uncover interested financial backing, I will purchase a projector and screen, marry them to my laptop computer and "hit the road" for MDS education.



# *Illness as More Than Metaphor*

**David Rieff**
***The New York Times***

**December 4, 2005**

My mother, Susan Sontag, lived almost her entire 71 years believing that she was a person who would beat the odds. Even during the last nine months of her life, after she was discovered to have myelodysplastic syndrome, or MDS, a particularly virulent blood cancer, she continued to persevere in the belief that she would be the exception. MDS is technically a precursor to acute myeloid leukemia. On average, its survival rates across the generational cohorts are no better than 20 percent, and far worse for a woman in her early 70's who had had cancer twice before. It wasn't that she didn't know that the biological deck was stacked against her; as someone who prided herself on her ability to grasp medical facts, she knew it only too well. In the immediate aftermath of her diagnosis, she went online to learn all she could about MDS and despaired as the fact of its lethality sank in. But that despair was almost the flip side of a lifelong confidence in her ability to defy the odds. "This time, for the first time," she told me, "I don't feel special."

Remarkably, in only a few weeks she had righted herself psychologically and was gearing up, just as she had done during her successful fights to survive two previous cancers, to find the doctors and the treatments that seemed to offer her some hope of defying those terrifyingly long odds and once more becoming the exception. How she did this, I don't know. Perhaps it was the spirit that had led her, when she recovered from her first cancer, to write a little proudly in her book "AIDS and Its Metaphors" of "confounding my doctors' pessimism." Perhaps she was able, somehow, to confound her own as well. What I do know is that the panic attacks that had overwhelmed her after her diagnosis began to lessen, and in the MDS literature that she found on the Web she began to find reasons for hope rather than despair. She even began to work again, writing a fiery piece on the Abu Ghraib torture photographs for this magazine at the same time she was readying herself to become a patient at the Fred Hutchinson Cancer Research Center in Seattle, where the bone-marrow transplant that was her only realistic hope of cure had been pioneered.

Her "positive denial," as I always thought of it, whether with regard to her health, her work as a writer or her private life, had not been extinguished by the hard facts of MDS after all. On her 70th birthday, 15 months before she found out she was ill again, she talked to me at length and with the characteristic passion she brought to her work about how she was only now starting a new and, she thought, the best phase of her writing life. Leaving for Seattle, she began speaking again of projects she would undertake — above all the novel she had been outlining — after her return to New York and even to speculate about whether she would feel strong enough to write during her treatment.

Was it bravado? Doubtless it was, but not bravado alone. During the two years of chemotherapy she underwent in the mid-1970's to treat her first cancer — Stage 4 breast cancer that had spread into 31 of her lymph nodes — she managed to publish a book on photography and, a year later, her book "Illness as Metaphor." That time, she had beaten the odds. William Cahan, then her principal doctor at Memorial Sloan-Kettering Cancer Center in New York, told me at the time that he saw virtually no hope. (Those were the days when doctors often told patients' relatives things they did not disclose to the patients themselves.) But as her friend Dr. Jerome Groopman, chief of experimental medicine at the Beth Israel Deaconess Medical Center in Boston, told me a few months after her death: "The statistics only get you so far. There are always people at the tail of the curve. They survive, miraculously, like your mother with breast cancer. Her prognosis was horrific. She said: 'No, I'm too young and stubborn. I want to go for it"' — meaning treatment. "Statistically, she should have died. But she didn't. She was at the tail of that curve."

"We tell ourselves stories in order to live." The line is Joan Didion's, and looking back on my mother's life, I've been wondering lately if we don't tell them to ourselves in order to die as well. In retrospect, I realize that death was never something my mother talked about much. But it was the ghost at the banquet of many of her conversations, expressed particularly in her single-minded focus on her own longevity and, as she got older, by her frequent voicing of the hope of living to be 100. She was no more reconciled to extinction at 71 than she had been at 42. After her death, a theme in many of the extremely generous and heartfelt letters of condolence I received from her friends puzzled me: it was surprise — surprise that my mother hadn't beaten MDS as she had beaten both breast cancer and the uterine sarcoma that struck her in her mid-60's.

But then, she, too, was surprised when the doctors in Seattle came in to tell her the bone-marrow transplant had failed and her leukemia was back. She screamed out, "But this means I'm going to die!"

I will never forget that scream, or think of it without wanting to cry out myself. And yet, even that terrible morning, in a pristine room at the University of Washington Medical Center, with its incongruously beautiful view of Lake Union and Mount Rainier in the background, I remember being surprised by her surprise. I suppose I shouldn't have been. There are those who can reconcile themselves to death and those who can't. Increasingly, I've come to think that it is one of the most important ways the world divides up. Anecdotally, after all those hours I spent in doctors' outer offices and in hospital lobbies, cafeterias and family rooms, my sense is that the loved ones of desperately ill people divide the same way.

For doctors, understanding and figuring out how to respond to an individual patient's perspective—continue to fight for life when chances of survival are slim, or acquiesce and try to make the best of whatever time remains?—can be almost as grave a responsibility as the more scientific challenge of treating disease. In trying to come to terms with my mother's death, I wanted to understand the work of the oncologists who treated her and what treating her meant to them, both humanly and scientifically. What chance was there really of translating a patient's hope for survival into the reality of a cure? One common thread in what they told me was that interpreting a patient's wishes is as much art as science. Dr. Stephen Nimer, my mother's principal doctor, heads the division of hematologic oncology at Memorial Sloan-Kettering and is also one of America's foremost researchers in the fundamental biology of leukemia. As he explained it to me: "The fact is that people are never as educated as the doctor. You have to figure out something about the patient"—by which he meant something that takes both patient and physician beyond the profound, frustrating and often infantilizing asymmetry between the patient's ability to comprehend the choices to be made and the doctor's.

Still, the doctor's task here is not impossible. As Nimer put it: "There are risk takers and risk-averse. There are those who say, you know: 'I'm 70 years old. If I get another four or five months, that would be fine.' Others say, 'You do everything you can to save my life.' Then it's easy. You can go straight into a discussion of what a patient wants."

For Nimer, as for Jerome Groopman, the ethical challenge, vital for a doctor to recognize and impossible (and ethically undesirable) to deal with formulaically, comes not with the 30 percent of patients Nimer estimates know for certain whether they want aggressive treatment or not, but with the "undecided" 70 percent in the middle. As Nimer told me somewhat ruefully, the doctor's power to influence these patients, one way or the other, is virtually complete. "There are ways to say things," he said. "'This is your only hope.' Or you could say, 'Some doctors will say it's your only hope, but it has a 20 times better chance of harming you than helping you.' So I'm pretty confident I can persuade people." Groopman, in his clinical practice with patients like my mother, patients for whom, statistically, the prognosis is terrible, at times begins by saying, "There is a very small chance, but it comes with tremendous cost."

In these situations, doctors like Groopman and Nimer see their job as, in effect, parsing the patient's response and trying to determine a treatment plan that is responsive to the patient's wishes but is also not what physicians refer to as "medically futile"—that is, offering no real chance for cure or remission. That is hard enough. What makes the doctor's decision in such situations even more painful is that "medically futile" means different things to different physicians. After my mother's transplant failed and she was medevacked from the University of Washington hospital back to Memorial Sloan-Kettering, Nimer tried one last treatment—an experimental drug called Zarnestra that had induced remission in some 10 percent of the small number of patients to whom it had been administered. I would learn from the nurses' aides who attended my mother in the last weeks of her life that some of the doctors and nurses on the transplant floor were uncomfortable with the decision, precisely because they saw my mother's situation as hopeless, that is, medically futile. As division head, in consultation with Dr. Marcel van den Brink, the hospital's chief of bone-marrow transplantation, Nimer could overrule these objections. But neither man would have denied the difficulty of drawing a clear line between what is and is not medically futile.

My mother was determined to try to live no matter how terrible her suffering. Her choices had been stark from the outset. Unlike some other cancers that can be halted for years through treatment, there are few long-lasting remissions in MDS Her only real chance of survival lay in the possibility of an outright cure offered by an adult-blood-stem-cell transplant.

Otherwise, to quote from one of the medical Web sites my mother visited repeatedly during the first weeks after her diagnosis, treatment offered her only an "alleviation of symptoms, reduction in transfusion requirements and improvement of quality of life." During their second meeting, Nimer offered her the option of treatment with a drug called 5-azacitidine, which gave many MDS patients some months during which they felt relatively well. But the drug did little to prolong life. My mother replied, with tremendous passion, "I am not interested in quality of life!"

What Nimer knew with the horrified intimacy of long clinical practice, but what my mother could not yet know, was just how agonizing the effects of an unsuccessful stem-cell transplant can be: everything from painful skin rashes to inordinately severe diarrhea to hallucinations and delirium. To me, torture is not too strong or hyperbolic a word. After my mother's declaration, Nimer only nodded and began talking about where the best place might be for her to have the stem-cell transplant, going over with her the variations in different medical research centers' approaches to transplantation. After the transplant failed, and my mother returned from Seattle, Nimer obviously knew how long the odds were against an experimental drug like Zarnestra inducing even a brief extension of her life. But he said he felt that he had to try, both because the drug had had some success and because my mother had told him (and me) from the outset that she wanted her doctors to do everything possible, no matter how much of a long shot it was, to save or prolong her life.

"Always assuming it's not medically futile," he told me a few weeks before her death, "if I can carry out my patients' wishes, I want to do that."

My mother could express herself only with the greatest of difficulty in the last weeks of her life. "Protective hibernation" was how one Sloan-Kettering psychiatrist described it. Like most people who have lost someone dear to them, I would say that one of my dominant emotions since my mother's death has been guilt—guilt over what I did and failed to do. But I do not regret trying to get her to swallow those Zarnestra pills even when her death was near, for I haven't the slightest doubt that had she been able to make her wishes known, my mother would have said she wanted to fight for her life to the very end.

But this does nothing to change the fact that it seems almost impossible to develop a satisfactory definition of what is and is not medically futile. What is the cutoff? A 10 percent chance of success? Five percent? One percent? When does the "very small chance" my mother's doctors bought at the "tremendous cost" in suffering that Groopman described for me become so infinitesimal as to make it no longer worth trying?

I have found no consensus among the oncologists I have spoken with in the aftermath of my mother's death, and I don't believe there is one. There are those who take a strong, consistent stance against not just such treatments but also against the general orientation of American medicine, particularly oncology, toward doing everything possible to save individual patients, no matter how poor their chances. These doctors seem inspired by a public-health model based on better health outcomes for communities rather than individuals, viewing it as the most moral and the only cost-effective way of practicing medicine. This view, often associated with the work of the medical ethicist Daniel Callahan, is increasingly influential.

One reason for this is that the current American medical system is breaking down. Several physicians with little sympathy for Callahan's approach pointed out to me that, like it or not, American society either can't afford or no longer chooses to afford to underwrite the kind of heroic care people like my mother, whose prognoses are obviously poor, still receive in the United States. Dr. Diane E. Meier, a palliative-medicine specialist at Mount Sinai Hospital in New York, remarked that if we as a society spent the sort of money on medical care that we spend, say, on the military, the challenge facing physicians would be very different. But neither Meier nor any other doctor I spoke to seemed to believe that there is much chance of that. If anything, medical financing has moved and is likely to continue to move entirely in the opposite direction. As Meier put it to me, "The cost crisis facing Medicare will lead to substantial and real reductions in access to care."

One illustration of Meier's point is that Memorial Sloan-Kettering already treats, through funds received from private philanthropists, many patients whose treatment is not covered by Medicare or who have had their applications for treatment at major cancer centers refused by their insurance companies. But it is one of only a few cancer centers in a position to do so. (Even more sobering is the statistic that only a small percentage of Americans with cancer are treated in a cancer center.) Philanthropy aside—and even the most generous philanthropy can never make up the shortfall the continuing cuts in federal financing are likely to produce—it may well be, as Meier suggests, that we are rapidly moving toward a health care system in which "only the rich will be able to choose the treatment they want."

In a sense, the financial background of my mother's treatment prefigured the world Meier was describing. Once she and Nimer agreed that she would have a bone-marrow transplant at the Hutchinson Center, and she was accepted as a patient there, she applied to Medicare — her primary insurance — for coverage of the treatment. Medicare refused, saying that coverage could begin only once her MDS had "converted" to full-blown leukemia; in other words, when she was far sicker. My mother then applied to her private insurance company. The response was that her coverage did not extend to organ transplants, which was what it considered a bone-marrow transplant to be. Later, my mother's insurance company relented but still refused to allow her to go "out of network" to the Hutchinson Center, even though Nimer was convinced that the doctors there stood the best chance of saving her life. Instead, the insurer proposed four "in network" options — hospitals where it would pay for the transplant to be done. But three out of the four said they would not take a patient like my mother (because of her age and medical history). The fourth did agree to take her but admitted, frankly, that it had little experience with patients of her age.

My mother was determined to get the best treatment possible, and Nimer had told her that treatment was to be found in Seattle. So she persevered. She was admitted to the Hutchinson Center as a so-called self-pay patient and had to put down a deposit of $256,000. Even before that, she had to pay $45,000 for the search for a compatible bone-marrow donor.

The knowledge that she was getting the best treatment available, both at Sloan-Kettering and at Hutchinson, was a tremendous consolation to my mother. It strengthened her will to fight, her will to live. But of course she was getting that treatment only because she had the money to pay for it. To be sure, as she was doing so, her doctors both in Seattle and New York very generously helped with her appeal of her insurance company's decision — calling and writing letters providing documentation and expert opinions explaining why the only viable treatment option was the one they had recommended. But both she and they knew that whatever hope she had of cure depended on moving rapidly toward the bone-marrow transplant. This would have been impossible had she not had the money to in effect defy her insurer's verdict, even as she was appealing it legally.

Let me state the obvious: The number of Americans who can do what she did is a tiny percentage of the population, and while I shall always be thankful beyond words for the treatment she received, and believe that she and her doctors made the right choice, I cannot honestly say that there was anything fair about it.

How or whether the realities of the health care system in America today can be reconciled with the fundamental aspiration of science, which is discovery, and the fundamental aspiration of medicine, which is to cure disease, is impossible for me to say. But if the time I have spent in the company of oncologists and researchers convinces me of anything, it is that these aspirations are almost as fundamental in serious doctors as the will to live is in cancer patients. The possibility of discovery, of research, is like a magnet. Marcel van den Brink, the Sloan-Kettering bone-marrow chief, who is Dutch, told me that one of the main reasons he is in the United States is that here, unlike in the Netherlands or, he thought, in the other major Western European countries, there is money for his research. For his part, Jerome Groopman emphasized the overwhelming number of foreign researchers in his lab. He described it as "the opposite of outsourcing — it's insourcing."

Researchers find inspiration in the example of AIDS research, an almost paradigmatic example of heroic, cost-indifferent medicine. By public-health standards, AIDS has received a big share of the nation's medical resources, in large measure thanks to the tireless campaigning of gay Americans who have had the economic clout and cultural sophistication to make their voices heard by decision-makers in the medical establishment and in government. As Dr. Fred Appelbaum, clinical-research director of the Hutchinson Center, pointed out to me, understanding AIDS and then devising treatments for it at first defied the best efforts of research scientists. And though a cure has not yet been found, effective treatments have been — albeit, extremely expensive ones.

If there is a difference between AIDS research and cancer research, it is that while advances in AIDS came relatively quickly, advances in cancer treatment and, indeed, in the fundamental understanding of how cancer works have come far more slowly than many people expected. Periodically since 1971, when President Nixon declared his war on cancer, the sense that the corner is about to be turned takes hold. We appear to be in such a moment today. The National Cancer Institute has recently put forward ambitious benchmarks for progress in cancer research and treatment. As its director, Dr. Andrew von Eschenbach, a respected surgeon and a cancer survivor himself (he is also acting head of the Food

and Drug Administration), put it recently: "The caterpillar is about to turn into a butterfly. I have never known more enthusiasm among cancer researchers. It's a pivotal moment." The suffering of cancer, he argued, will be well on its way to being alleviated by 2015.

The media have mostly echoed this optimism. It is not unusual to read about the latest "breakthrough" in cancer treatment, both in terms of understanding the basic biological processes involved and with regard to innovative new drug therapies. On the level of research, there is no doubt that significant progress has been made. Dr. Harold Varmus, the Nobel laureate who now heads Memorial Sloan-Kettering, is emphatic on the subject. "Fifty or 60 years ago," he told me, "we didn't know what genes were. Thirty or so years ago we didn't know what cancer genes were. Twenty years ago we didn't know what human cancer genes were. Ten years ago we didn't have any drugs to inhibit any of these guys. It seems to me we've made an awful lot of progress in one person's lifetime."

Other research scientists seemed far more pessimistic when I spoke with them. Dr. Lee Hartwell, also a Nobel laureate, is president and director of the Hutchinson Center. He has urged that the focus in cancer treatment shift from drug development to the new disciplines of genomics and, above all, proteomics, the study of human proteins. Though he acknowledged the profound advances in knowledge made over the past two decades, Hartwell emphasized a different question: "How well are we applying our knowledge to the problem? The therapy side of things has been a pretty weak story. There have been advances: we cure most childhood leukemias with chemotherapy, for one thing. But the progress has been surprisingly weak given the huge expenditures that we've made. We're spending over $25 billion a year improving cancer outcomes, if you include the spending of the pharmaceutical companies. So you've got to ask yourself whether this is the right approach."

The focus needs to be on "diagnostics rather than therapeutics," Hartwell said. "If you catch a cancer at Stage 1 or 2, almost everybody lives. If you catch it at Stage 3 or 4, almost everybody dies. We know from cervical cancer that by screening you can reduce cancer up to 70 percent. We're just not spending enough of our resources working to find markers for early detection."

Some researchers are even more skeptical. Mark Greene, the John Eckman professor of medical science at the University of Pennsylvania and the scientist whose lab did much of the fundamental work on Herceptin, the first important new type of drug specifically designed to target the proteins in the genes that cause cells to become malignant, agrees with Hartwell. The best way to deal with cancer, he told me, is to "treat early, because basic understanding of advanced cancer is almost nonexistent, and people with advanced cancer do little better now than they did 20 years ago."

Varmus, who appears to be somewhere in the middle between the optimists and the pessimists, told me that so far the clinical results are mixed. As he put it: "Many cancers are highly treatable. I am optimistic, but I'm not saying, 'Here's when."'

The irreducible fact is that failure is the clinical oncologist's constant companion. Each of those who treated my mother seemed to have evolved a strategy for coping with this. Stephen Nimer said: "I'd have to be an idiot to think everything I do works. I mean, where have I been the last 20 years? I'm not afraid to fail." Fred Appelbaum put it still more plainly. "You get victories that help balance the losses," he said. "But the losses are very painful."

Appelbaum's almost studied understatement brought home a question that had recurred through the savage months of my mother's illness and also after her death. I kept wondering how the doctors who were treating her with such determination, against all the odds, could possibly stand swimming in this sea of death that they confronted every day, since they did not have the luxury of pretending, at least to themselves, that they didn't know which of their patients were likely to make it and which were not.

The question made sense to some. For Nimer, though, it did not. "I prefer 'swimming in a sea of life,"' he said, adding: "I know I'm not going to save everyone, but I don't think of myself as swimming in a sea of death. People who have congestive heart failure, their outcomes are like the worst cancers. People think of it as a cleaner death and cancer as a dirtier death, but that's not the case. I approach things with the question 'What would it be like if I were on the other side?' The first thing is being dependable. I give people a way to always reach me. They're not going to call me frivolously. There's a peace of mind that comes with knowing you can reach a doctor. I think if you have one of these diseases, you know you can die. Before people get to the time of dying, people want to have some hope, some meaning, that there's a chance things can get better."

And when they don't, Nimer continued, "whatever happens is going to happen. But how about the ride? How rough will it be? If I were dying, the thing I'd worry about most is how much I'm going to suffer. I've had a lot of people die over the years. One thing is to reassure people, 'Look, I'm going to do whatever is humanly possible so that you don't suffer.' We're all going to die, but I'm going to spend just as much time paying attention to your last days as I do at the beginning."

And with my mother, that is exactly what he did in the moment of her death — one of the many, too many, Nimer has seen. With all due respect to him, if that's not swimming in a sea of death... .

If my mother had imagined herself special, her last illness cruelly exposed the frailty of that conceit. It was merciless in the toll of pain and fear that it exacted. My mother, who feared extinction above all else, was in anguish over its imminence. Shortly before she died, she turned to one of the nurses' aides — a superb woman who cared for her as she would have her own mother — and said, "I'm going to die," and then began to weep. And yet, if her illness was merciless, her death was merciful. About 48 hours before the end, she began to fail, complaining of generalized low-grade pain (possibly indicating that the leukemia was in her bloodstream). Shortly after, she came down with an infection. Given the compromised state of her immune system, the doctors said, there was little chance that her body could stave it off. She remained intermittently lucid for about another day, though her throat was so abraded that she could barely speak audibly and she was confused. I feel she knew I was there, but I am not at all sure. She said she was dying. She asked if she was crazy.

By Monday afternoon, she had left us, though she was still alive. Pre-terminal, the doctors call it. It was not that she wasn't there or was unconscious. But she had gone to a place deep within herself, to some last redoubt of her being, at least as I imagine it. What she took in I will never know, but she could no longer make much contact, if, indeed, she even wanted to. I and the others who were at her side left around 11 p.m. and went home to get a few hours' sleep. At 3:30 a.m. on Tuesday, a nurse called. My mother was failing. When we arrived in her room, we found her hooked up to an oxygen machine. Her blood pressure had already dropped into a perilous zone and was dropping steadily, her pulse was weakening and the oxygen level in her blood was dropping.

For an hour and a half, my mother seemed to hold her own. Then she began the last step. At 6 a.m., I called Nimer, who came over immediately. He stayed with her throughout her death.

And her death was easy, as deaths go, in the sense that she was in little pain and little visible anguish. She simply went. First, she took a deep breath; there was a pause of 40 seconds, such an agonizing, open-ended time if you are watching a human being end; then another deep breath. This went on for no more than a few minutes. Then the pause became permanence, the person ceased to be and Nimer said, "She's gone."

A few days after my mother died, Nimer sent me an e-mail message. "I think about Susan all the time," he wrote. And then he added, "We have to do better."

*David Rieff is a contributing writer for The New York Times.*

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# New MDS Publications

Listed below are citations of some new publications relevant to MDS (pathogenesis, clinical characterization, management, etc.). To access the complete article log on to www.pubmed.gov.

## *Classification*

**Malcovati L, Porta MG, Pascutto C, et al.** Prognostic factors and life expectancy in myelodysplastic syndromes classified according to WHO criteria: a basis for clinical decision making. *J Clin Oncol*. 2005;23:7594–7603.

## *Treatment*

### GENERAL

**Greenberg PL, Bennett JM, Bloomfield C, et al.** NCCN Practice Guidelines for Myelodysplastic Syndromes, Version 2. *J Nat Comp Canc Network*. 2006;4:58–77. (Also on web @ www.nccn.org)

### BIOLOGIC AGENTS

**Naing A, Sokol L, List AF.** Developmental Therapeutics for Myelodysplastic Syndromes. *J Natl Compr Cancer Netw*. 2006;4:78–82.

**Gore SD.** Six (or More) Drugs in Search of a Mechanism: DNA Methyltransferase and Histone Deacetylase Inhibitors in the Treatment of Myelodysplastic Syndromes. *J Natl Compr Cancer Netw*. 2006;4:83–90.

**Deeg HJ, Jiang PYZ, Holmberg LA, et al.** Hematologic responses of patients with MDS to antithymocyte globulin plus etanercept correlate with improved flow scores of marrow cells. *Leuk Res*. 2004;28:1177–1180.

### IRON CHELATION

**Greenberg PL.** Myelodysplastic Syndromes: Iron Overload Consequences and Current Chelating Therapies. *J Natl Compr Cancer Netw*. 2006;4:91–96.

### HEMATOPOIETIC STEM CELL TRANSPLANTATION

**Fukumoto J, Greenberg PL.** Management of patients with higher risk myelodysplastic syndromes. *Critical Reviews in Oncology/Hematology*. 2005;56:179–192.

**de Lima M, Anagnostopoulos A, Munsell M, et al.** Nonablative versus reduced-intensity conditioning regimens in the treatment of acute myeloid leukemia and high-risk myelodysplastic syndrome: dose is relevant for long-term disease control after allogeneic hematopoietic stem cell transplantation. *Blood*. 2004;104:865–872.

**Wallen H, Gooley TA, Deeg HJ, et al.** Ablative allogeneic hematopoietic cell transplantation in adults 60 years of age and older. *J Clin Oncol*. 2005;23:3439–3446.

**Scott BL, Sandmaier BM, Storer B, et al.** Myeloablative vs nonmyeloablative allogeneic transplantation for patients with myelodysplastic syndrome or acute myelogenous leukemia with multilineage dysplasia: a retrospective analysis. *Leukemia*. 2006;20:128–135.

**Kerbauy DMB, Chyou F, Gooley T, et al.** Allogeneic hematopoietic cell transplantation for chronic myelomonocytic leukemia. *Biol Blood Marrow Transplant*. 2005;11:713–720.

**Scott BL, Sandmaier BM, Storer B, et al.** Myeloablative vs nonmyeloablative allogeneic transplantation for patients with myelodysplastic syndrome or acute myelogenous leukemia with multilineage dysplasia: a retrospective analysis. L*eukemia*. 2006;20:128–135.

### *Books*

**Greenberg PL, Editor.** *Myelodysplastic Syndromes: Clinical and Biological Advances*. Cambridge University Press, Cambridge, England, 2006.

### *Symposia*

**ASH Education Session: Myelodysplastic Syndromes**

**A.T. Look.** Molecular Pathogenesis of MDS.

**E. Hellström-Lindberg.** Update on Supportive Care and New Therapies.

**H.J. Deeg**. Optimization of transplant regimens for patients with myelodysplastic syndromes.

In: *Hematology 2005: American Society of Hematology Education Program Book*. Washington, DC: American Society of Hematology;156–173.

## Act of Kindness

Recently we received a wonderful letter from Chris Jenkins detailing the events of Tuesday, January 17, 2006 when Dr. Paul Nemiroff saved the life of his father, Jim Jenkins at the Pittsburgh International Airport.

As his father lay dying from a heart attack, Dr. Nemiroff sprang into action and kept him alive until the paramedics arrived. Without his gallant efforts, Chris feels his father would not be here today. Furthermore, when his family expressed a desire to repay him in some way, he graciously suggested that they make a donation to our Foundation.

The MDS Foundation would like to acknowledge Paul Nemiroff's heroism and we feel he should be recognized for his courageous act of kindness and commitment to helping the Foundation.

*Dr. Nemiroff is a nationally recognized surgeon, television medical correspondent, winner of the prestigious 2003 C. Everett Koop Media Award presented by the American Heart Association, and author of over 100 articles and research papers in the medical sciences.*

# News About the MDS Foundation's Support Groups

The first MDS Foundation Patient Support Group Chapter is being established in Philadelphia, Pennsylvania. Plans are also underway for Pittsburgh, Pennsylvania and Scottsdale, Arizona. The firmed up details for all meetings will be available shortly and we hope you join us.

The MDS Foundation would like to provide ongoing support in any way that we can in helping your group to become self-sustaining and enable newly diagnosed patients to meet and obtain support from other patients.

We will work with you to make this group a success including ongoing support for refreshments, meeting space, printing, or other needs.

To date we have held patient support groups in Philadelphia and in Pittsburgh, PA. The groups were very well attended and we were fortunate to have had Drs. Emmanuel Besa, Selina Luger, and Richard Shadduck as our guest speakers.

*Dr. Richard K. Shadduck presenting "New Therapies and Patient Treatment Options"*

Any member of the Foundation, patients, family members, friends, and caregivers are invited to join. If you are interested in joining an existing group or starting a new group in your area, please contact, Audrey Hassan, Patient Liaison at patientliaison@mds-foundation.org or call her at 800-637-0839.

An alternative source of information and support for patients is our MDS Foundation Forums, an excellent place to receive support by meeting and talking with people who have MDS. To post messages on this very active message board you must log on to our website at www.mds-foundation.org, which will lead you to the web page where you can register to join.

*Patient Support Group Meeting held at The Western Pennsylvania Cancer Institute in Pittsburgh, PA*

# Suzanne Fleischman Memorial Fund for Patient Advocacy

A fund has been established by the MDS Foundation in memory of Suzanne Fleischman. Contributions may be sent to the Foundation with a notation designating the Suzanne Fleischman Memorial Fund for Patient Advocacy.

New donations have been made by:

**Edward Fleischman, *Prescott, AZ***
**Eloise B. Fox, *Kensington, CA***
**Fay Wanetick, *Pittsburgh, PA***
**Roslyn Raney, *Menlo Park, CA***

# MDS Foundation Initiatives for 2006 and Beyond

The MDS Foundation is committed to making a significant contribution to the advancement in understanding and of accurately diagnosing the myelodysplastic syndromes. We will be focusing our efforts in the following initiatives:

- **MDS Practice and Treatment Survey**
- **The International Working Group on MDS Morphology**
- **MDS Patients' Quality-of-Life Forums**
- **Transfusion Burden Registry**
- **The Working Group on MDS Cytogenetics**
- **ADOPT Registry: ATG Dose, Outcomes, and Patient Identification**
- **Centers of Excellence Patient Support Groups**
- **CME Awareness Program for 2006**
  *Translations available in Spanish, French, Italian, German and Japanese.*
- ***The MDS News 2006***
- **The Young Investigator Grant Program**
  ***Supported by the Jack Keating Memorial Golf Tournament***
- **Jack Keating Memorial Golf Tournament for MDS**
  **July 31, 2006**
- **9th International MDS Symposium, Florence, Italy: May 16–19, 2007**

*Supported by educational grants from:*

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# Patient Referrals

Myelodysplastic syndromes can be difficult to diagnose and treat. It is important for both patients and their families to know that optimal treatment is available and that quality-of-life can be enhanced.

If you would like information about treatment options, research, or quality-of-life, we would be glad to help. The Foundation offers a variety of patient services, including preferential referrals to the Foundation's MDS Centers of Excellence. We can also help identify physicians and centers to support you if you are travelling and need assistance.

Please contact us at:
1-800-MDS-0839 (phone) or 609-298-0590 (fax).
Outside the US please call: 609-298-1035.

You can visit our website at
http://www.mds-foundation.org.

# Blood & Marrow Transplant Newsletter

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# MDS Centers of Excellence

Would you like your treatment center to become part of the referral system for MDS patients and be designated as a Center of Excellence? To be recognized as a Center of Excellence, an institution must have the following:

- An established university (or equivalent) program
- Recognized morphologic expertise in MDS
- Available cytogenetics and/or molecular genetics
- Ongoing research, including Institutional Review
- Board–approved clinical trials
- Documentation of peer-reviewed publications in the field
- The ability and intention to register patients in the MDS International Registry database

*Please contact the Foundation for further information and an application form for your center.*

**The following centers have qualified as MDS Centers of Excellence:**

## UNITED STATES

### ALABAMA

**University of Alabama at Birmingham Comprehensive Cancer Center**
Birmingham, Alabama
*Peter Emanuel, MD*

### ARIZONA

**Mayo Clinic Hospital**
Phoenix, Arizona
*James L. Slack, MD*

**University of Arizona Arizona Cancer Center**
Tucson, Arizona
*Daruka Mahadevan, MD, PhD*

### CALIFORNIA

**Cedars-Sinai Medical Center UCLA School of Medicine**
Los Angeles, California
*H. Phillip Koeffler, MD*

**City of Hope National Medical Center**
Duarte, California
*Stephen J. Forman, MD*

**Stanford University Medical Center**
Stanford, California
*Peter L. Greenberg, MD*

**University of Southern California Keck School of Medicine**
Los Angeles, California
*Allen S. Yang, MD, PhD*

### FLORIDA

**Mayo Clinic**
Jacksonville, Florida
*Alvaro Moreno-Aspitia, MD*

**University of South Florida H. Lee Moffitt Cancer Center and Research Institute**
Tampa, Florida
*Alan F. List, MD*

### ILLINOIS

**Loyola University Chicago Cardinal Bernardin Cancer Center**
Maywood, Illinois
*Scott E. Smith, MD, PhD*

**Rush University Medical Center**
Chicago, Illinois
*Stephanie A. Gregory, MD*
*Jamile Shammo, MD*

**University of Chicago Medical Center**
Chicago, Illinois
*Richard A. Larson, MD*

### INDIANA

**Indiana University Medical Center**
Indianapolis, Indiana
*Larry Cripe, MD*

### MARYLAND

**Johns Hopkins Oncology Center**
Baltimore, Maryland
*Steven D. Gore, MD*

**National Heart, Lung, and Blood Institute**
Bethesda, Maryland
*Elaine Sloand, MD*

### MASSACHUSETTS

**Dana-Farber Cancer Institute**
Boston, Massachusetts
*Richard M. Stone, MD*

**Tufts University School of Medicine New England Medical Center**
Boston, Massachusetts
*Geoffrey Chan, MD*

**University of Massachusetts Medical Center**
Worcester, Massachusetts
*Azra Raza, MD*

### MICHIGAN

**Barbara Ann Karmanos Cancer Institute Wayne State University**
Detroit, Michigan
*Charles A.Schiffer, MD*

**William Beaumont Hospital Cancer Center**
Royal Oak, Michigan
*Ishmael Jaiyesimi, MD*

### MINNESOTA

**Mayo Clinic**
Rochester, Minnesota
*David P. Steensma, MD*

### MISSOURI

**Washington University School of Medicine Siteman Cancer Center**
St. Louis, Missouri
*John F. DiPersio, MD, PhD*

### NEBRASKA

**University of Nebraska Medical Center**
Omaha, Nebraska
*Lori Maness, MD*

### NEW JERSEY

**The Cancer Center of Hackensack University Medical Center**
Hackensack, New Jersey
*Stuart Goldberg, MD*
*Charles S. Hesdorffer, MD*

### NEW MEXICO

**University of New Mexico Health Sciences Center**
Albuquerque, New Mexico
*Robert Hromas, MD*

### NEW YORK

**Albert Einstein College of Medicine Cancer Center**
Bronx, New York
*Amit Verma, MD*

**Memorial Sloan-Kettering Cancer Center**
New York, New York
*Stephen D. Nimer, MD*

**Mount Sinai School of Medicine**
New York, New York
*Lewis R. Silverman, MD*

**New York Medical College/ Westchester Medical Center Zalmen A. Arlin Cancer Center**
Valhalla, New York
*Karen Seiter, MD*

**North Shore University Hospital**
Manhasset, New York
*Steven L. Allen, MD*

**Roswell Park Cancer Center**
Buffalo, New York
*Maria R. Baer, MD*

**University of Rochester Cancer Center**
Rochester, New York
*John M. Bennett, MD*

**Weill Medical College of Cornell University New York Presbyterian Hospital**
New York, New York
*Eric J. Feldman, MD*

### NORTH CAROLINA

**Duke University Medical Center**
Durham, North Carolina
*Carlos M. deCastro, MD*

**Wake Forest University School of Medicine Comprehensive Cancer Center**
Winston-Salem, North Carolina
*Istvan Molnar, MD*

### OHIO

**Cleveland Clinic Foundation Taussig Cancer Center**
Cleveland, Ohio
*Jaroslaw Maciejewski, MD, PhD*

### OREGON

**Oregon Cancer Center at Oregon Health and Science University**
Portland, Oregon
*Peter T. Curtin, MD*

### PENNSYLVANIA

**The Western Pennsylvania Cancer Institute**
Pittsburgh, Pennsylvania
*Richard K. Shadduck, MD*
*James M. Rossetti, DO*

**Thomas Jefferson University Kimmel Cancer Center**
Philadelphia, Pennsylvania
*Emmanuel C. Besa, MD*

**University of Pennsylvania Cancer Center**
Philadelphia, Pennsylvania
*Selina Luger, MD*

### TENNESSEE

**St. Jude Children's Research Hospital**
Memphis, Tennessee
*Gregory Hale, MD*

### TEXAS

**Southwest Regional Cancer Center**
Austin, Texas
*Richard Helmer, III, MD*

**University of Texas MD Anderson Cancer Center**
Houston, Texas
*Elihu H. Estey, MD*

**University of Texas Southwestern Medical School**
Dallas, Texas
*Simrit Parmar, MD*

### WASHINGTON

**Fred Hutchinson Cancer Research Center**
Seattle, Washington
*Joachim Deeg, MD*

**Seattle Cancer Care Alliance University of Washington**
Seattle, Washington
*John A. Thompson, MD*

### WASHINGTON, DC

**Georgetown University Hospital**
**Lombardi Comprehensive Cancer Center**
Washington, D.C.
*Ekatherine Asatiani, MD*

### WISCONSIN

**Medical College of Wisconsin**
**Bone Marrow Transplant Program**
Milwaukee, Wisconsin
*David H. Vesole, MD, PhD, FACP*

**University of Wisconsin**
**Madison Medical School**
Madison, Wisconsin
*Mark B. Juckett, MD*

## OUTSIDE THE UNITED STATES

### AUSTRALIA

**Peter MacCallum Cancer Institute**
**University of Melbourne**
East Melbourne, Australia
*John F. Seymour, MD*

**University of Tasmania**
**Royal Hobart Hospital**
Hobart, Tasmania, Australia
*Raymond M. Lowenthal, MD*

### AUSTRIA

**University Hospital of Innsbruck**
Innsbruck, Austria

**University of Vienna**
Vienna, Austria
*Peter Valent, MD*

### BELGIUM

**AZ Sint-Jan AV**
Brugge, Belgium
*Dominik Selleslag, MD*

**University Hospital Leuven**
Leuven, Belgium
*Michel Delforge, MD, PhD*

### BRAZIL

**AC Camargo Hospital–**
**Cancer Center**
São Paulo, Brazil
*Luiz Fernando Lopes, MD, PhD*

**Universidade Federal de Ceará**
Ceará, Brazil
*Fernando Barroso Duarte, MD*

### CANADA

**University of Toronto**
**Hospital for Sick Children**
Toronto, Ontario, Canada
*Yigal Dror, MD*

### CZECH REPUBLIC

**Institute of Hematology**
**and Blood Transfusion**
Prague, Czech Republic
*Jaroslav Cermák, MD, PhD*

### DENMARK

**Odense University Hospital**
**The University of Southern Denmark**
Odense, Denmark
*Gitte Birk Kerndrup, MD*

**Rigshospitalet**
**National University Hospital**
Copenhagen, Denmark
*Lars Kjeldsen, MD, PhD*

**University of Århus**
**The University Hospital**
Århus, Denmark
*Johan Lanng Nielsen, MD, PhD*

### FRANCE

**Hôpital Avicenne/**
**University Paris XIII**
Bobigny, France
*Pierre Fenaux, MD*

**Hôpital Claude Huriez, CHU Lille**
**Service des Maladies du Sang**
Lille, France
*Bruno Quesnel, MD*

**Hôpital Cochin/University Paris V**
Paris, France
*Francois Dreyfus, MD*

**Hôpital Saint Louis/**
**University Paris VII**
Paris, France
*Christine Chomienne, MD, PhD*

### GERMANY

**Hannover Medical School**
**Medizinische Hochschule Hannover**
Hannover, Germany
*Arnold Ganser, MD*

**Heinrich-Heine University**
**Düsseldorf**
**University Hospital**
Düsseldorf, Germany
*Ulrich Germing, MD*

**Johann Wolfgang Goethe University**
Frankfurt Main, Germany
*Johannes Atta, MD*

**MLL Munich Leukemia Laboratory**
**Ludwig Maximilians Universität**
Munich, Germany
*Torsten Haferlach, MD*

**St. Johannes Hospital**
**Heinrich-Heine University**
Duisburg, Germany
*Carlo Aul, MD, PhD*

**University of Freiburg**
**Medical Center**
Freiburg, Germany
*Michael Lüebbert, MD*

**Universität Hamburg**
Hamburg, Germany
*Nicolaus Kröger, MD, PhD*

**Universitätsklinikum**
**Carl Gustav Carus**
Dresden, Germany
*Uwe Platzbecker, MD*

**University Children's Hospital**
Freiburg, Germany
*Charlotte Niemeyer, MD*

**University Hospital**
**Benjamin Franklin**
Berlin, Germany
*Wolf-Karsten Hofmann, MD, PhD*

**University of Heidelberg**
**Medical Center**
Heidelberg, Germany
*Ulrich Mahlknecht, MD PhD*

### GREECE

**Patras University Hospital**
Patras, Greece
*Nicholas C. Zoumbos, MD*

**University General Hospital Attikon**
Athens, Greece
*Theofanis Economopoulos, MD*

**University of Athens**
**Laikon Hospital**
Athens, Greece
*Nora Viniou, MD*

### ISRAEL

**Tel-Aviv Sourasky Medical Center**
Tel-Aviv, Israel
*Moshe Mittelman, MD*

### ITALY

**Centro di Riferimento Oncologico**
**di Basilicata (CROB)**
Rionero in Vulture (PZ), Italy
*Pellegrino Musto, MD*

**University of Florence**
**Azienda OSP Careggi**
Florence, Italy
*Valeria Santini, MD*

**University of Pavia Medical School**
Pavia, Italy
*Mario Cazzola, MD*

**University Tor Vergata**
**Ospedale S. Eugenio**
Roma, Italy
*Sergio Amadori, MD*

### JAPAN

**Kyoto University Hospital**
Kyoto, Japan
*Takashi Uchiyama, MD*

**Nagasaki University Hospital**
**School of Medicine**
**Atomic Bomb Disease Institute**
Nagasaki City, Japan
*Masao Tomonaga, MD*

**Nippon Medical School**
Tokyo, Japan
*Kiyoyuki Ogata, MD, PhD*

**Saitama Medical School Hospital**
Morohongo, Iruma, Japan
*Akira Matsuda, MD*

**Tokyo Medical College**
Tokyo, Japan
*Kazuma Ohyashiki, MD*

### POLAND

**Jagiellonian University**
**Collegium Medicum**
Kraków, Poland
*Aleksander Skotnicki, MD, PhD*

### PORTUGAL

**Hospital de Santa Maria**
Lisbon, Portugal
*Joao F. Lacerda, MD*

### ROMANIA

**Fundeni Clinical Institute**
Bucharest, Romania
*Radu Gologan, MD, PhD*

### SAUDI ARABIA

**King Faisal Specialist Hospital**
**& Research Centre**
Riyadh, Saudi Arabia
*Mahmoud Deeb Aljurf, MD*

### SOUTH AFRICA

**University of Cape Town**
**Groote Schuur Hospital**
Cape Town, Cape South Africa
*Nicolas Novitzky, MD, PhD*

### SPAIN

**Hospital Universitario**
**de Salamanca**
Salmanca, Spain
*Jesus F. San Miguel, MD*

**Hospital Universitario La Fe**
Valencia, Spain
*Miguel A. Sanz, MD, PhD*

**Hospital Universitario**
**Vall d'Hebron Laboratorio del**
**Citologia-Citogénetica**
Barcelona, Spain
*Maria Teresa Vallespi-Sole, MD, PhD*

### SWEDEN

**Karolinska Institutet**
**Huddinge University Hospital**
Stockholm, Sweden
*Eva Hellström-Lindberg, MD, PhD*

### THAILAND

**King Chulalongkorn**
**Memorial Hospital**
Pathumwan, Bangkok, Thailand
*Tanin Intragumtornchai, MD*

### THE NETHERLANDS

**Academic Hospital**
**Free University Amsterdam**
Amsterdam, The Netherlands
*G.J. Ossenkoppele, MD, PhD*

**University Medical Center**
**Nijmegen St. Radboud**
Nijmegen, The Netherlands
*Theo J.M. de Witte, MD, PhD*

### TURKEY

**Ankara University**
**School of Medicine Hospital**
Ankara, Turkey
*Osman Ilhan, MD*

### UNITED KINGDOM

**King's College Hospital**
**University of London**
London, United Kingdom
*Ghulam J. Mufti, MD*

**Leeds General Infirmary**
**The Leeds Teaching Hospitals**
Leeds, United Kingdom
*David T. Bowen, MD*

**Royal Bournemouth Hospital**
Bournemouth, United Kingdom
*Sally Killick, MD*

# International Clinical Trials: An Update

The following trials are current as of the date of this newsletter. We will update the list in The MDS News each quarter. If you are a treating physician who would benefit from any such study, you may want to contact the appropriate institution. If you are an MDS patient, you may wish to discuss a trial with your primary treating physician to see if you qualify as a candidate.

Clinical trials study new interventions (drugs or procedures) to evaluate their safety and effectiveness in humans. Trials follow a careful set of steps, allowing for the systematic gathering of information to answer questions and confirm hypotheses that were formed earlier, in either laboratory experiments or preliminary trials.

A clinical trial falls into one of four phases:

*Phase I.* This is the first time a drug is used in humans. The trial is designed to determine dosage, route of administration (oral, intravenous, or by injection), and schedule of administration (how many times a day or week). In this phase researchers also begin to determine the drug's safety. The phase I trial is normally conducted in healthy adults and enrolls only a small number of people.

*Phase II.* Patients with the disease receive the drug at dose levels determined in the earlier phase. The phase II trial begins to determine the effectiveness of the drug and provides more information about its safety.

*Phase III.* The drug is tested alone or against an approved standard drug. The typical phase III trial enrolls a large number of patients. If it is a comparison trial, patients may be randomly assigned to receive either the new drug or the standard intervention.

*Phase IV.* In phase IV the drug, already approved by the FDA and available to the public, undergoes continued evaluation. The phase IV designation is rare.

Some trials—screening studies evaluating supportive care or prevention—are not conducted in phases. In these trials a group following a certain disease combating strategy, such as a detection method, is compared to a control group.

## *U.S. Trials*

### NATIONAL CANCER INSTITUTE TRIALS*

As we go to press the National Cancer Institute (NCI) has listed more than 100 clinical trials that focus on Myelodysplastic syndromes. Full study information on these trials is available at www.nci.nih.gov. This information includes basic study information, study lead organizations, study sites, and contact information. To access the information:

- Log on to www.nci.nih.gov
- Click on "Finding Clinical Trials"
- on the next screen look for "Ways to Find Clinical Trials" and
- Click on "Search for Clinical Trials"
- Click on "Type of Cancer" and type in 'myelodysplastic syndromes'
- Hit search

This search will provide you with all the trials currently underway in MDS. You may also sort by trials that only focus on treatment or trials that only focus on supportive care. You can also contact 1-800-4-CANCER for more information.

### MDS CLINICAL TRIALS ANNOUNCEMENT

***Advanced Cancers: A New Transplant Method***
Researchers at the National Institutes of Health (NIH/DHHS) are investigating a new method of improving transplant results in individuals with advanced cancers. If you or someone you know are between the ages of 10 to 50 years old and have one of the following cancers: Myelodysplastic Syndromes, Leukemia, or Myeloproliferative Disorder, you may be able to participate in this clinical trial. To find out if you qualify, please call 1-800-411-1222 or visit www.cc.nih.gov.

***MethylGene Inc.***, of Montreal, initiated the first of two dose-escalating Phase I trials for MGCD0103 in hematological cancers. MGCD0103 is a rationally designed isotypic selective small-molecule inhibitor of histone deacetylase. The second hematologic cancer trial is scheduled to be initiated in early 2005. Both trials will evaluate the safety, pharmacokinetics, pharmacodynamics and tolerability of MGCD0103 in patients with leukemias or myelodysplastic syndromes.

***Novartis.*** EXJADE Trial CICL670AUS02. An open label, safety and tolerability study of deferasirox for treatment of transfusional iron overload in low-risk and INT-1 myelodysplastic patients. Thirty patients will be enrolled into this open-label, single-arm trial designed to assess the safety and tolerability of oral deferasirox in adult transfusion dependent myelodysplastic syndromes (MDS) patients with iron overload. Patients enrolled in this study will have low or intermediate (INT-1) risk MDS per International Prognostic Scoring System (IPSS) criteria. All patients will initiate treatment with 20 mg/kg/day deferasirox. Deferasirox will be administered orally once per day for 12 months.

***Novartis.*** Phase I, open-label, dose escalating study to evaluate the safety, biologic activity and pharmacokinetic profile of LAQ824 in patients with relapsed or refractory AML, CLL, or CML in blast crisis, or advanced MDS. The primary objective of this study is to determine the Maximum Tolerated Dose (MTD) and Dose Limiting Toxicity (DLT) of LAQ824 as a single agent when administered by intravenous infusion as outlined in the protocol.

***Novartis.*** An Open-label Phase II Trial of PKC412 Monotherapy in Patients with Acute Myeloid Leukemia and Patients with Myelodysplastic Syndromes PKC4122104. Patients who agree to participate in this trial will be screened for the FLT3 mutation. If positive, they will have a physical exam, blood test, EKG, chest x-ray, bone marrow aspirate and a pregnancy test.

***Pharmion.*** AZA PH GL 2003 CL 001. A Survival Study in Patients with High Risk Myelodysplastic Syndromes

Comparing Azacitidine versus Conventional Care. The purpose of this study is to determine whether patients with high-risk myelodysplastic syndromes (MDS) treated with azacitidine have improved survival compared to conventional care treatments. The study will also assess the effect of treatments on response, duration of response, and transformation to acute myeloid leukemia (AML).

***Schering-Plough Research Institute.*** P02978. A Pivotal Randomized Study of Lonafarnib (SCH 66336) Versus Placebo in the Treatment of Subjects With Myelodysplastic Syndromes (MDS) or Chronic Myelomonocytic Leukemia (CMML) Who Are Platelet Transfusion Dependent With or Without Anemia. The purpose of this study is to determine clinical benefit of Lonafarnib plus best supportive care versus Placebo plus best supportive care, measured as achievement of platelet transfusion independence. This Phase III trial will be conducted at approximately 60 sites in US, Canada, Europe, Latin America, Far East. Contact: Sabine Loechner, e-mail: sabine.loechner@spcorp.com; or Mary Sugrue, MD, e-mail: mary.sugrue@spcorp.com.

***Telik, Inc.*** Phase I-IIa trial to evaluate the safety and efficacy of TLK199 in patients with myelodysplastic syndromes (MDS). Eligible patients must have a diagnosis of MDS, be at least 18 years old and ineligible or refusing bone marrow transplant.

*Contact www.clinicaltrials.gov to learn more about other trials for Myelodysplastic Syndromes. Type in "myelodysplastic syndromes" in "Search Clinical Trials" then click on the "Search" button to obtain a listing.*

## Other U.S. Trials

***Barbara Ann Karmanos Cancer Institute, Detroit, MI.*** D-696. Allogeneic and syngeneic marrow transplantation in patients with acute non-lymphocytic leukemia. Contact: Jared Klein, MD. Phone: 313-963-2533.

***Barbara Ann Karmanos Cancer Institute, Detroit, MI.*** POG A2971: Treatment Of Children with Down Syndromes and Acute Myeloid Leukemia, Myelodysplastic Syndromes, or Transient Myeloproliferative Disorder. Contact: Jeffrey Taub, MD. Phone: 313-963-2533.

***Cancer and Blood Institute of the Desert, Rancho Mirage, CA.*** Phase I/II study of arsenic trioxide in combination with cytosine arabinoside in patients with MDS. Contact: R. Lemon. Phone: 760-568-4461.

***Cancer Institute Medical Group, Los Angeles, CA.*** Phase I/IIa Study of TLK199 HCl Liposomes for injection in Myelodysplastic Syndromes. Contact: Lawrence D. Piro, MD. Phone: 310-231-2182.

***Case Western Reserve University, Cleveland, OH.*** CWRU-5Y97. Phase II trial using umbilical cord blood to evaluate the efficacy of transplantation to treat aplastic anemia and myelodysplastic syndromes patients. Eligible patients must have disease not responsive to medical therapy. Contact: Mary J. Laughlin, MD. Phone: 216-368-5693.

***Case Western Reserve University, Cleveland, OH.*** CWRU-6Y01. This is a phase I trial using Umbilical Cord Blood to evaluate the efficacy of Allogeneic Transplantation to treat myelodysplastic syndromes or severe aplastic anemia. The rationale for this study is to investigate whether transplantation of more than one UCB unit is safe and whether this approach may overcome the current problems of primary graft failure and delayed engraftment with single unit UCB. This concept will be evaluated in the setting of non-myeloablative conditioning in attempt to decrease the risk of mortality in the event of primary graft failure. Eligible patients must have hematologic cancer including MDS or severe aplastic anemia requiring allogeneic transplantation. Contact Mary J. Laughlin, MD. Phone: 216-368-5693.

***Cedars-Sinai Medical Center, Los Angeles, CA.*** 02287. Phase II Trial of Paricalcitol in Myelodysplastic Syndromes to determine if an oral, relatively non-toxic, novel vitamin D3 compound, paricalcitol, (Zemplar) can improve red, white and platelet counts as well as decrease the risk of development of leukemia, without causing undue toxicity in patients with myelodysplastic syndromes (MDS). Patients will receive oral administration of paricalcitol in increasing doses. Contact: H. Phillip Koeffler, MD. Phone: 310-423-4609.

***Children's Hospital of New York Presbyterian, New York, NY.*** 01-504. Phase II trial using fludarabine, busulfan, and anti-thymocyte globulin (ATG) to evaluate the efficacy of reduced intensity allogeneic stem cell transplantation to treat MDS. Eligible patients must have 1) MDS and <5% bone marrow myeloblasts at diagnosis; 2) minimum of >10% CD33 positivity; 3) adequate organ function (renal, hepatic, cardiac and pulmonary); 4) age <65 years; 5) matched family donor (5/6 or 6/6),unrelated donor (5/6 or 6/6), or cord blood donor (3/6, 4/6, 5/6, 6/6). Contact: Mitchel S. Cairo, MD. Phone: 212-305-8316.

***Cleveland Clinic Foundation, Cleveland, OH.*** IRB6818. Phase II trial of combination therapy with arsenic trioxide (Trisenox) and gemtuzumab ozogamicin (Mylotarg) for the treatment of adult patients with advanced myelodysplastic syndromes. Contact: Liz Kuczkowski. Phone: 216-445-3795.

***Cleveland Clinic Foundation, Cleveland, OH.*** IRB8135. Randomized, multicenter, open-label, modified dose-ascension, parallel study of the safety tolerability, and efficacy of oral SCIO-469 in patients with myelodysplastic syndromes. Contact: Liz Kuczkowski. Phone: 216-445-3795.

***Cleveland Clinic Foundation, Cleveland, OH.*** IRB7671. Phase II trial of combination therapy with thalidomide, arsenic trioxide, dexamethasone, and ascorbic acid (TADA) in patients with chronic idiopathic myelofibrosis or overlap myelodysplastic syndromes. Contact: Liz Kuczkowski. Phone: 216-445-3795.

***Comprehensive Cancer Center of Wake Forest University, Winston-Salem, NC.*** Phase II Study of Arsenic Trioxide and Dose-Escalated Cholecalciferol in Myelodysplastic Syndromes (CCCWFU 29304). Contact: Istvan Molnar, MD. Phone: 336-716-5847.

***Comprehensive Cancer Center of Wake Forest University, Winston-Salem, NC.***CCCWFU-29203. Orthomolecular Vitamin D in Low-Risk Myelodysplastic Syndromes: Phase II trial using cholecalciferol (Vitamin $D_3$) to evaluate the efficacy of 2000 IU Vitamin $D_3$ daily for 6 months to treat MDS. Eligible patients must have MDS; IPSS score 0–1.0; life expectancy >1 year; no other concurrent therapy for MDS; no history of hypercalcemia. Contact: Istvan Molnar, MD. Phone: 336-716-5847.

***Comprehensive Cancer Institute. Huntsville, AL.*** Phase II study of arsenic trioxide (Trisenox) in patients with MDS. Contact: J.M. Waples, MD. Phone: 256-551-6546.

***Dana-Farber Cancer Institute, Boston, MA.*** Phase I Study of Vaccination with Lethally Irradicated, Autologous Acute Myeloblastic Leukemia Cells Engineered by Adeonviral Mediated Gene Transfer to Secrete Human Granulocyte-Macrophage Colony Stimulating Factor in Patients with Advanced Myelodysplasia or acute Myelogenous Leukemia. This is a study to determine the feasibility of preparing lethally irradiated autologous myeloblastic leukemia cells engineered by adenoviral mediated gene transfer to secrete GM-CSF in patients with myelodysplasia or acute myelogenous leukemia. The study will also investigate the safety and biologic activity of vaccination with lethally irradiated, autologous myeloblastic leukemia cells engineered by adenoviral mediated gene transfer to secrete GM-CSF in patients with advanced myelodysplasia or acute myelogenous leukemia. Contact: Ilene Galinsky. Phone: 617-632-3902.

***Duke University Medical Center, Durham, NC.*** 2875. Phase II trial to assess the value of non-myeloablative allogeneic therapy (mini bone marrow transplant) for patients with aplastic anemia or myelodysplastic syndromes. Patients must have severe disease to be eligible and may have either a matched sibling, mismatched family member, or large cord blood unit found for use on our trial. Contact: David A. Rizzieri, MD at Rizzi003@mc.duke.edu.

***Fallon Clinic. Worcester, MA.*** PR01-09-010. Phase II study on the effectiveness of low dose Thalidomide combined with Erythropoietin in the treatment of anemia in patients with low and intermediate risk-1 myelodysplastic syndromes. Contact: Laszlo Leb, MD. Phone: 508-368-3168.

***Fox Chase, BMT Program, Philadelphia, PA. 3297.*** Phase II trials using fludarabine-based regimen to evaluate the efficacy of mini-allogeneic blood stem cell transplantation to treat myelodysplastic syndromes. Eligible patients must have HLA identical donor available, be under age 70 and platelet or red cell transfusion dependent. Patients with matched related donors will be considered up to age 70 with Karnofsky Performance Scale >80%. Patients with matched unrelated donor will be considered to age 65 only. Contact: Marge Bellergeau, RN. Phone: 215-214-3122.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1297. Radiolabeled BC8 (anti-CD-45) Antibody Combined with Cyclophosphamide and Total Body Irradiation Followed by HLA-Matched Related or Unrelated Stem Cell Transplantation as Treatment for Advanced Acute Myeloid Leukemia and Myelodysplastic Syndromes. Phase II trial to determine the efficacy (as measured by survival and disease-free survival) and toxicity of a regimen of cyclophosphamide, TBI, plus the maximum tolerated dose of I labeled BC8 (anti-CD45) antibody in patients with AML beyond first remission receiving HLA matched related hematopoietic stem cell transplants. Contact: J. Pagel, MD. Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1432. Phase I trial to determine the maximum tolerated dose of radiation delivered via BC8 antibody when combined with the non-myeloablative regimen of fludarabine, TBI + CSP/MMF in elderly patients (>50 and <70 years) with advanced AML or high risk MDS. Contact: J. Pagel, MD. Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1809. Phase I trial to determine the maximum tolerated dose of radiation delivered via BC8 antibody when combined with the non-myeloablative regimen of fludarabine, TBI + CSP/MMF in patients (<50 years) with advanced AML or high risk MDS. Contact: J. Pagel, MD. Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1591. Phase I trial to determine whether stable allogeneic engraftment from related and unrelated HLA-mismatched stem cell donors can be safely established using a non-myeloablative conditioning regimen plus escalating doses of the anti-CD52mAb Campath® in patients with hematologic malignancies. Contact: B. Sandmaier, MD. Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1732. Phase II trial to evaluate the efficacy of non-myeloablative allogeneic HCT from related and unrelated donors for the treatment of patients with MDS and MPD, who are not candidates for conventional allogeneic HCTG due to advanced age or serious comorbid conditions. Contact: B. Sandmaier, MD. Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1813. Phase III trial to compare the non-relapse mortality at 1-year after conditioning with TBI alone vs. fludarabine/TBI in heavily pretreated patients with hematologic malignancies at low/moderate risk for graft rejection who have HLA-matched related donors. Contact: B. Sandmaier, MD. Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1536. Transplantation of peripheral blood stem cells from related or unrelated volunteer donors in patients with "less advanced" MDS. Conditioning therapy includes busulfan (targeted to a pre-determined plasma level) and cytoxan (targeted BUCY); patients up to 65 years of age. Contact: H.J. Deeg, MD. Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1596. Transplantation from related donors for high-risk patients with MDS. Conditioning includes a "non-myeloblative" regimen of fludarabine and 200 cGy of total body irradiation. Patients are evaluated individually for eligibility. Contact: David Maloney, MD, PhD. Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1478. Non-transplant therapy for "less advanced" MDS with ATG plus Enbrel. No age restrictions. Contact: H.J. Deeg, MD. Phone: 206-667-4324.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #117. Uses a combination of ATG and cyclophosphamide (CY) for the conditioning of patients with AA who are transplanted from HLA-identical family members. Contact: R. Storb, MD. Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #800. Uses a combination of ATG, CY and low dose (200 cGy) TBI for conditioning of patients with AA (up to 55 years of age) to be transplanted from unrelated donors. Contact: H.J. Deeg, MD. Phone 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1641. Transplantation from unrelated donors for high-risk patients with MDS. Conditioning will be with a "non-myeloablative" approach using 200 cGy of TB1 and

fludarabine. No age restriction (other exclusion criteria exist). Contact: M. Maris, MD. Phone 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1723. Transplantation from related or unreleased donors for patients with advanced MDS or myeloproliferative disorders. Conditioning includes busulfan (targeted to a predetermined plasma level) and Cytoxan (targeted BUCY) with the addition of thymoglobulin; patients up to 65 years of age. Contact: H.J. Deeg, MD. Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1781. Non-transplant therapy for "less advanced" transfusion-dependent MDS with DN-101 (Calcitriol). No age restrictions. Contact: H.J. Deeg, MD. Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1628. Uses a targeted busulfan plus cyclophosphamide approach for conditioning. G-CSF-mobilized peripheral blood cells will be partially T-cell depleted with the intent of reducing the GVHD frequency and severity. Eligible are patients with MDS or high-risk AML who have an HLA-identical sibling donor. Contact: A. Woolfrey. Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1913. Combines targeted busulfan with fludarabine plus Thymoglobulin. This protocol enrolls patients with MDS, myeloproliferative disorders, and other myeloid diseases. The objective is to further reduce non-relapse mortality. Patients with related and unrelated donors will be eligible. Contact: P. O'Donnell Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1668. Uses combinations of fludarabine and low-dose TBI for the conditioning of "older" patients or patients with clinically significant co-morbid conditions to be transplanted from related or unrelated donors. Contacts: M. Maris, B. Sandmaier. Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1872. Uses a combination of ATG given for 4 days, followed by intermittent injection of Enbrel for patients with low or intermediate-1 risk disease by IPSS. Generally these are patients with <10% marrow blasts. The ATG is administered at the Center; the administration of Enbrel can be done by the patients themselves at home or in your office. Contact: B. Scott. Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1888. Uses a combination of Enbrel plus arsenic trioxide (Trisenox) in patients with more advanced MDS (generally IPSS intermediate-2 or high risk) or patients who have failed to respond in Protocol #1872. Contact: B. Scott. Phone: 206-288-1024.

***Fred Hutchinson Cancer Research Center, Seattle, WA.*** FHCRC #1926. Uses a combination of Enbrel plus 5-azacitidine (Vidaza) for patients with advanced MDS or patients who fail to respond to treatment in Protocol #1872. The Protocol is currently being reviewed by the IRB. Contact: B. Scott. Phone: 206-288-1024.

***Froedtert Memorial Lutheran Hospital, Milwaukee, WI.*** AZA PH GL 2003 CL 001. Multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: David Vesole, MD. Phone: 414-805-4629.

***Georgetown University, Washington, DC.*** Clinical and biologic effects of arsenic trioxide in MDS. Contact: B. Mavromatis, MD. Phone: 202-784-0124.

***Georgetown University Medical Center, Lombardi Cancer Center, Washington, DC.*** 05-064. CALGB: Phase II oral VegF receptor/TKI for MDS high-risk disease. Contact: Jenny Crawford. Phone: 202-687-0893.

***Georgetown University Medical Center, Lombardi Cancer Center, Washington, DC.*** 02053. Gene expression profiling in myelodysplastic syndromes (collection of bone marrow aspirate is needed). Contact: Ekatherine Asatiani, MD. Phone: 202-444-3958.

***H. Lee Moffitt Cancer Center, Tampa, FL.*** MCC# 14634. Phase I study of MGCD0103 given as a twice weekly oral dose in patients with Leukemia or myelodysplastic syndromes. Contact: Michelle Burton, RN. Phone: 813-745-3965.

***H. Lee Moffitt Cancer Center, Tampa, FL.*** MCC# 14454. An open-label, safety and tolerability study of deferasirox for treatment of transfusional iron overload in low risk and intermediate-1 MDS patients using serum ferritin monitoring. Pending. Contact: Lisa Nardelli. Phone: 813-745-4731.

***H. Lee Moffitt Cancer Center, Tampa, FL.*** MCC# 13937. A Pharmacokinetic and Pharmacodynamic Study of Oral Lenalidomide (Revlimid) in Subjects with Low or Intermediate-1 Risk Myelodysplastic Syndromes. Open. Contact: Kelly Bretz. Phone: 813-745-2071.

***H. Lee Moffitt Cancer Center, Tampa, FL.*** MCC# 14154. SCIOS–A randomized, multicenter, open-label, modified dose ascension. Parallel study of the safety, tolerability, and efficacy of oral SCIO-469 in low to intermediate-1 risk patients with MDS. Contact: Stacy Moss. Phone: 813-745-8391.

***H. Lee Moffitt Cancer Center, Tampa, FL.*** MCC# 13346. A randomized, placebo-controlled, double-blind trial of the administration of the MDR Modulator, Zosuquidar Trihydrochloride, during conventional induction and post-remission therapy in patients >60 years with newly diagnosed AML, Refractory Anemia with Excess Blasts in Transformation, or High-Risk Refractory Anemia with Excess Blasts. Contact: Stacy Moss. Phone: 813-745-8391.

***Indiana University Medical Center, Indianapolis, IN.*** AZA PH GL 2003 CL 001. Multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Larry Cripe, MD. Phone: 317-274-0901.

***Johns Hopkins Oncology Center, Baltimore, MD.*** J0252. Phase II study of the farnesyl transferase inhibitor Zarnestra in complete remissiom following induction and/or consolidation chemotherapy in adults with poor-risk acute myelogenous leukemia (AML) and high-risk myelodysplasias. Contact: Pamela Powell, RN. Phone: 410-614-1329.

***Johns Hopkins Oncology Center, Baltimore, MD.*** J0443. A dose-Finding Trial of the Histone Deacetylase Inhibitor MS-275 in Combination with 5-Azacytidine (5AC, NSC 102816) in patients with Myelodysplastic Syndromes (MDS), Chronic Myelomonocytic Leukemia, and Acute Myeloid Leukemia (AML). Contact: Tianna Dauses, RN. Phone: 410-502-7110.

***Johns Hopkins Oncology Center, Baltimore, MD.*** J0254. Phase I study of Flavopiridol in timed sequential combination with Cytosine Arbinoside and Mitoxantrone for adults with poor-risk Acute Leukemias and Myelo-dysplasias. Contact: Jackie Greer. Phone: 410-614-1329.

***Los Angeles Hematology and Oncology Assoc., Los Angeles, CA.*** Phase I/II study of arsenic trioxide in combination with cytosine arabinoside in patients with MDS. Contact: C. Gota, MD. Phone: 818-409-0105.

***MD Anderson Cancer Center, Houston, TX.*** Phase II study of combination of Thymoglobulin and cyclosporine in patients with newly diagnosed aplastic anemia or with hypoplastic myelodysplastic syndromes. The purpose of this study is to determine the efficacy of the combination of thymoglobulin, methylprednisone, cyclosporine and G-CSF in achieving response and to assess the effect of treatment on transfusion requirements and overall survival. Eligible patients must have a diagnosis of severe aplastic anemia or MDS with bone marrow cellularity less than 30%, two of three peripheral counts low with ANC less than 500/mL, Plt less than 20,000/mL or reticulocyte count less than 40,000/mL. Patients with MDS who have received prior biological therapy (not chemotherapy), age 15 or greater, adequate renal and hepatic function, no other investigational therapy in the past 14 days, able to comply with the need for contraception during the entire study period. Exclusion criteria include active and uncontrolled pulmonary, cardiac, neurological or other medical illness that would interfere with study treatment, pregnant or breast-feeding, HIV positive or active and uncontrolled infection. Contact: Farhad Ravandi, MD. Phone: 713-745-0394.

***MD Anderson Cancer Center, Houston, TX.*** Phase I/IIa Study of TLK199 HCl Liposomes for injection in Myelodysplastic Syndromes. Contact: Stefan Faderl, MD. Phone: 713-563-4613.

***MD Anderson Cancer Center, Houston, TX.*** Open-Label, Phase II Study to Evaluate The Efficiency and Safety of the Farnesyltransferase Inhibitor Zarnestra (R115777) in Subjects with High-Risk Myelodysplastic Syndromes (MDS). Contact: Razelle Kurzrock, MD.

***MD Anderson Cancer Center, Houston, TX.*** ID02-266. Therapy of inversion (16) and T (8:21) AML/MDS with fludarabine and Ara-C. Contact Elihu H. Estey, MD. Phone: 713-792-7544.

***MD Anderson Cancer Center, Houston, TX.*** Phase I/II Study of PR1 (NSC698102) Human Leukemia Peptide Vaccine with Incomplete Freund's Adjuvant (NSC 675756). Contact: Jeffrey Molldrem, MD. Phone: 713-745-4820.

***MD Anderson Cancer Center, Houston, TX.*** Phase II Open-Label Study of the Intravenous Administration of Homoharringtonine (CGX-635) in the Treatment of Myelodysplastic Syndromes (MDS). Contact: Jorge Cortes, MD. Phone: 713-794-5783.

***MD Anderson Cancer Center, Houston, TX.*** Phase II Study of Arsenic Trioxide in the Treatment of Myelodysplastic Syndromes. Contact: Miloslav Beran, MD. Phone: 713-792-2248.

***MD Anderson Cancer Center, Houston, TX.*** Phase II, Multicenter, Open-Label Study of the Safety and Efficacy of High-Dose Pulse Administration DN-101 (Calcitriol) in Patients with Myelodysplastic Syndromes. Contact: Guillermo Garcia-Manero, MD. Phone: 713-745-3428.

***MD Anderson Cancer Center, Houston, TX.*** Randomized, Open-Label, Phase III Trial of Decitabine (5-AZA-2'Deoxycytidine) Versus Supportive Care in Adults with Advanced-Stage Myelodysplastic Syndromes. Contact: Jean-Pierre Issa, MD. Phone: 713-745-2260.

***MD Anderson Cancer Center, Houston, TX.*** Safety And Efficacy Trial of Bevacizumab: Anti-VEGF Humanized Monoclonal Antibody (NSD 704865) Therapy for Myelodysplastic Syndromes (MDS). Contact: Jorge Cortes, MD. Phone: 713-794-5783.

***MD Anderson Cancer Center, Houston, TX.*** Phase II Study of Neumega (Oprelvekin)(Interleukin-11) in Patients with Myelodysplastic Syndromes. Contact: Razelle Kurzrock, MD. Phone: 713-794-1226.

***MD Anderson Cancer Center, Houston, TX.*** Multicenter Phase I/II Study of Continuous Oral Administration of SCH 66336 in Patients with Advanced Myelodysplastic Syndromes, Acute Myelogenous Leukemia, Chronic Myelogenous Leukemia in Blast Crisis, Acute Lymphoblastic Leukemia. Contact: Jorge Cortes MD. Phone: 713-794-5783.

***MD Anderson Cancer Center, Houston, TX.*** Phase II Study of Intravenous Homoharringtonine in Chronic Myelogenous Leukemia (CML). Contact: Jorge Cortes, MD. Phone: 713-794-5783.

***MD Anderson Cancer Center, Houston, TX.*** Therapy of Hypereosinophilic Syndromes, Polycythemia Vera, Atypical CML or CMML with PDGF-R Fusion Genes, or Mastocytosis with Gleevec (STI571). Contact: Jorge Cortes, MD. Phone: 713-794-5783.

***MD Anderson Cancer Center, Houston, TX.*** DCTER. Chemotherapy in Patients Ages 1 through 49 with Untreated AML or High-Risk Myelodysplasia. Contact: Elihu Estey, MD. Phone: 713-792-7544.

***MD Anderson Cancer Center, Houston, TX.*** Phase II study of clofarabine in combination with cytarabine (Ara-C) in pts ≥50 yrs with newly diagnosed and previously untreated acute myeloid leukemia (AML) and high-risk myelodysplastic syndromes (MDS) (≥10% bone marrow blasts). Contact: Stefan Faderl, MD. Phone: 713-745-4613.

***MD Anderson Cancer Center, Houston, TX.*** ID03-0181. Phase I/II trial using clofarabine, idarubicin, and/or clofarabine to evaluate the efficacy and safety of clofarabine combinations to treat high-risk myelodysplastic syndrome. Eligible patients must have (as defined in the study title): AML or high-risk MDS. Contact: Stefan Faderl, MD. Phone: 713-745-4613.

***MD Anderson Cancer Center, Houston, TX.*** DM02-203. Phase Ia, Open-Label, 3-Arm, Dose Escalation Study of PTK787/ZK 222584. Contact: Francis Giles, MD. Phone: 713-792-8217.

***MD Anderson Cancer Center, Houston, TX.*** ID03-0044. Phase I Clinical Trial of Oral Suberoylanilide Hydroxamic Acid (SAHA) in Patients with Advanced Leukemias. Contact: Guillermo Garcia-Manero, MD. Phone: 713-745-3428.

***MD Anderson Cancer Center, Houston, TX.*** DM01-646. Phase I Study of ABT-751 in Patients with Refractory Hematologic Malignancies. Contact: Francis Giles, MD. Phone: 713-792-8217.

***MD Anderson Cancer Center, Houston, TX.*** ID99-059. Phase II trial using ATG and Fludarabine or Cyclosporine to evaluate the efficacy of immunosuppression to treat aplastic anemia and myelodysplastic syndromes patients. Eligible patients must have RA or RARS and low blood counts. Contact: Jeffrey Molldrem, MD. Phone: 713-792-7346.

***Mayo Clinic, Phoenix, AZ.*** PO2978. Study of Lonafarnib versus placebo in treatment of subjects with myelodysplastic syndromes or chronic myelomonocytic leukemia who are platelet transfusion-dependent with or without anemia. Contact: James Slack, MD. Phone: 480-342-2088.

***Mayo Clinic, Phoenix, AZ.*** CICL670AUS03. Phase II study of Exjade (deferasirox) for treatment of transfusional iron overload in low-risk and intermediate-1 transfusion-dependent MDS patients using ferritin monitoring. Contact: James Slack, MD. Phone: 480-342-2088.

***Mayo Clinic, Rochester, MN***. DACO-020. A phase II study of decitabine administered daily for 5 days every 4 weeks to adults with advanced stage myelodysplastic syndromes. Contact: David P. Steensma, MD. Phone: 507-538-0107.

***Mayo Clinic, Rochester, MN.*** MC0313. Phase I multicenter trial using high dose cytarabine and 17-allylamino-17-demethoxygeldanamycin (a new signal transduction inhibitor) to identify the maximum tolerated dose of the combination and secondarily to evaluate the efficacy of the combination to treat myelodysplastic syndromes. Eligible patients must have: High grade MDS (RAEB-2) or IPSS MDS prognostic score of >1.5, chronic myelomonocytic leukemia or relapsed/refractory acute leukemia. Contact: Scott H. Kaufmann, MD, PhD. Phone: 507-284-8383.

***Memorial Sloan-Kettering Cancer Center, New York, NY.*** 99-057. Phase I study of salicylate for adult patients with advanced myelodysplastic disorders, acute myelogenous leukemia or chronic lymphocytic leukemia. Contact: Virginia Klimek, MD. Phone: 212-639-6519.

***Memorial Sloan-Kettering Cancer Center, New York, NY.*** 00-116. Pilot study of FR901228 or Depsipeptide (NSC#630176) for adult patients with advanced hematologic disorders. Contact: Virginia Klimek, MD. Phone: 212-639-6519.

***Memorial Sloan-Kettering Cancer Center, New York, NY.*** 02-063. Tolerability and PK/PD of multiple oral doses of CT53518 in patients with acute myelogenous leukemia. Contact: Mark Heaney, MD, PhD. Phone: 212-639-2275.

***Mount Sinai Medical Center, New York, NY.*** Phase I-II Pilot Study of Divalproex Sodium and All-Trans-Retinoic Acid (ATRA) in Relapsed or Refractory Acute Myeloid Leukemia (except M3, FAB Classification). Contact: Lewis Silverman, MD. Phone: 212-241-5520.

***Mount Sinai Medical Center, New York, NY.*** AZA PH GL 2003 CL 001. Multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Lewis Silverman, MD. Phone: 212-241-5520.

***National Heart, Lung, and Blood Institute, Bethesda, MD.*** 05-H-0201. Metoclopramide to Treat Anemia in Patients with Myelodysplastic Syndromes (MDS). The study drug, metoclopramide, may help increase blood red blood cell counts, reduce anemia symptoms, and/or reduce dependence on transfusions. If eligible to participate, consenting subjects will take metoclopramide by mouth 3 times a day for 20 weeks. Subjects will be followed for safety and effectiveness monitoring at either the NIH or through their home physician. If you have been diagnosed with MDS and are age 18 to 72, you may be able to participate in this clinical trial. Contact: Carol Webb, MSRN. Phone: 301-402-0797.

***National Heart, Lung, and Blood Institute, Bethesda, MD.*** 01-H-0162. Stem Cell Transplantation for Older Patients with Myelodysplastic Syndromes. If you are 55 to 75 years of age and have been diagnosed with MDS, you may be eligible for a transplant procedure designed to decrease a major transplant complication, graft-versus-host disease (GVHD). Under evaluation is a novel method of treating your donor's cells prior to transplant. You must have an HLA-matched brother or sister to participate. We will do the blood testing free of charge to see if your sibling is a match upon request. Contact: Laura Wisch, RN. Phone: 301-402-3595.

MDS

# Membership Information

The MDS Foundation would like to have you as a member. Membership is US$35 a year for physicians and other professionals. Patients, their families, and others interested in MDS may join at the reduced rate of $20.

Membership benefits include quarterly issues of the *MDS News*, a special subscription rate of $109 for *Leukemia Research* (a substantial discount from the current institutional subscription rate of $2,373), and the worldwide Centers of Excellence patient referral service.

If you would like additional information, please contact us at:

The MDS Foundation
36 Front Street
P.O. Box 353
Crosswicks, NJ 08515

Phone: 1-800-MDS-0839
Fax: 609-298-0590

Outside the US only:
609-298-1035

***National Heart, Lung, and Blood Institute, Bethesda, MD.*** 04-H-0112. Stem Cell Transplantation and T-Cell Add Back to Treat Myelodysplastic Syndromes. Clinical trial designed to decrease graft versus host disease, promote engraftment, and improve immune system recovery following a bone marrow stem cell transplant. You must have an HLA matched brother or sister donor to participate in this trial. Contact: Laura Wisch, RN. Phone: 301-402-3595.

***National Heart, Lung, and Blood Institute, Bethesda, MD.*** 03-H-0209. Stem Cell Transplant for MDS from a partially HLA-matched family member. Many patients are not considered for a stem cell transplant because an HLA-matched sibling or unrelated donor is unavailable. For such patients, the only curative option is a transplant from a partially HLA-matched family member. If you are 10–50 years of age and have been diagnosed with advanced myelodysplastic syndromes, you may be eligible for a clinical trial of a transplant procedure that evaluates using peripheral blood stem cells from an HLA-mismatched family donor. Eligible patients are not asked to pay for their medical treatment and hospital costs. Contact: Laura Musse, MSRN. Phone: 301-496-3841.

***National Heart, Lung, and Blood Institute, Bethesda, MD.*** 05-H-0206. A Pilot Study of Alemtuzumab (Campath®) in Patients with Myelodysplastic Syndromes (MDS). The study drug, a monoclonal antibody, may help increase blood counts, reduce anemia symptoms, and/or reduce dependence on transfusions. If eligible to participate, consenting subjects will receive an intravenous infusion of study medication alemtuzumab (Campath®) once a day for 10 days. Subjects will be admitted to the NIH Clinical Center hospital for study drug initiation. If the study drug infusion is tolerated well, the subject may be discharged and receive the remainder of the treatment course as an outpatient. Contact: Carol Webb, MSRN. Phone: 301-402-0797.

***National Heart, Lung, and Blood Institute, Bethesda, MD.*** 06-H-0062. If you or someone you know is 18 years old or older and has been diagnosed with MDS, you may be able to participate in a clinical trial evaluating a new therapy. We believe your immune system might be able to control the abnormal growth of cells that is causing your MDS. This study will test the safety of a vaccine that may increase the number of immune cells responding to the MDS and thereby slow progression of the illness, improve blood counts, reduce the need for transfusions of blood and platelets, or even achieve a remission (but not a complete cure) of the MDS. To find out if you qualify or for more information please call our coordinator at 301-402-0797 or email us at Bloodstudy@nhlbi.nih.gov.

***National Heart, Lung, and Blood Institute, Bethesda, MD.*** 99-H-0050. Non-Myeloablative Allogeneic Peripheral Blood Mobilized Hematopoietic Precursor Cell Transplan-tation for Hematologic Malignancies in High Risk Patients and in Patients with Debilitating Hematologic Diseases. If you have been diagnosed with MDS, you may be able to participate in a stem cell transplant clinical trial designed to evaluate methods to decrease graft versus host disease, promote engraftment, and improve immune system recovery following a bone marrow stem cell transplant procedure.

You must have an HLA-matched family member to participate. You will be given chemotherapy followed by a transfusion of stem cells and lymphocytes from your donor, which will replace your immune system with the immune system of your healthy donor. Post transplant therapy is designed to reduce the risk of graft versus host disease. We do the blood testing free of charge to see if your family member is a match. We pay for all medical costs related to the transplant procedure. You must be available to live near NIH for approximately 3 months. We also provide a daily allowance to help with living expenses while you are on the study and living away from home. Contact: Rose Goodwin. Phone: 301-594-8013.

***New York Medical College/Westchester Medical Center, Valhalla, NY.*** Log 8350. Pivotal randomized study of Lonafarnib Versus Placebo in the treatment of subjects with MDS or CMML who are platelet transfusion dependent with or without anemia. Contact: Dr. Karen Seiter. Phone: 914-493-7514.

***New York Medical College/Westchester Medical Center, Valhalla, NY.*** CLI-033. Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Contact: Dr. Karen Seiter. Phone: 914-493-7514.

***New York Medical College/Westchester Medical Center, Valhalla, NY.*** Log 6252. Phase I/II study of a non-myeloablative regimen of pentostatin, mitoxantrone and cytarabine for engraftment of allogeneic hematopoetic progenitor cells in patients with acute leukemia, chronic myelogenous leukemia and myelodysplasia: The mini allo protocol. Contact: Dr. Delong Liu. Phone: 914-493-7514.

***New York Presbyterian Hospital, New York, NY.*** Phase I/II trial of Trisenox in combination with low dose Ara-C for the treatment of high-risk MDS and poor prognosis AML in patients >60 years. Contact: Gail Roboz, MD. Phone: 212-746-3126.

***North Shore University Hospital, Manhasset, NY.*** 10105. Phase II study of an oral VEGF agent in myelodysplastic syndromes. Contact: Colleen DeGaetano, RN. Phone: 516-562-8976.

***Oregon Health & Science University, Portland, OR.*** 8346. Phase 1-2a Study of TLK199 HCl Liposomes for Injection in Myelodysplastic Syndromes (MDS). Contact: Peter Curtin, MD. Phone: 503-494-5058.

***Oregon Health & Science University, Portland, OR.*** 7944. A Randomized, Double-blind Trial of Fluconazole vs. Voriconazole for the Prevention of Invasive Fungal Infections in Allogeneic Blood and Marrow Transplant Patients. Contact: Peter Curtin, MD. Phone: 503-494-5058.

***Oregon Health & Science University, Portland, OR.*** 8186. A Phase III Randomzied, Multicenter Trial Comparing G-CSF Mobilized Peripheral Blood Stem Cell with Marrow Transplantation from HLA Compatible Unrelated Donors. Contact: Peter Curtin, MD. Phone: 503-494-5058.

***Oregon Health & Science University, Portland, OR.*** 8343. Prolonged Mycophenolate Mofetil and Truncated Cyclosporine Postgrafting Immunosuppression to Reduce Life-Threatening GvHD after Unrelated Donor Peripheral Blood Cell Transplantation using Nonmyeloablative Conditioning for Patients with Hematologic Malignancies and Renal Cell Carcinoma — A Multicenter Trial. Contact: Peter Curtin, MD. Phone: 503-494-5058.

***Oregon Health & Science University, Portland, OR.*** 7881. Donor Lymphocyte Infusion for the Treatment of Malignancy After Hematopoietic Cell Transplantation Using Non-Myeloablative Conditioning — A Multicenter Trial. Contact: Peter Curtin, MD. Phone: 503-494-5058.

***Oregon Health & Science University, Portland, OR.*** 7039. Randomized Controlled Trial of Posaconazole (SCH56592) vs. Standard Azole Therapy for the Prevention of Invasive Fungal Infections Among High-Risk Neutropenic Patients. Contact: Peter Curtin, MD. Phone: 503-494-5058.

***Oregon Health & Science University, Portland, OR.*** 4352. Transplantation of Unrelated Donor Marrow or Placental Blood Hematopoietic Stem Cells for the Treatment of Hematological Malignancies. Contact: Peter Curtin, MD. Phone: 503-494-5058.

***Oregon Health & Science University, Portland, OR.*** 8119. Phase III trial to compare the non-relapse mortality at 1-year after conditioning with TBI alone vs. fludarabine/TBI in heavily pretreated patients with hematologic malignancies at low/moderate risk for graft rejection who have HLA-matched related donors. Contact: Peter Curtin, MD. Phone: 503-494-5058.

***Roswell Park Cancer Institute, Buffalo, NY.*** I35904. A trial of Campath-1H (Alemtuzumab) for Myelodysplastic Syndromes. This is an open label trial of a single course of subcutaneous Campath-1H monotherapy to improve the cytopenias of MDS patients with a Low to Intermediate-2 IPSS score. The study is designed as a two-stage Phase II trial with a total of 20 subjects and stopping rules for both safety and futility. Contact: Minoo Battiwalla, MD. Phone: 716-845-1145.

***Roswell Park Cancer Institute, Buffalo, NY.*** PTK787. Phase II study of an oral VEGF agent in myelodysplastic syndromes. Contact: Maria Baer, MD. Phone: 716-845-8840.

***Roswell Park Cancer Institute, Buffalo, NY.*** RPC-02-03. Treatment of anemia in patients with low-and intermediate-risk MDS with darbepoetin alfa. Multicenter, phase II trial also open at the University of Alabama (Birmingham), Loyola University Medical Center (Chicago), and Rochester General Hospital (Rochester, NY). Contact: Maria Baer, MD. Phone: 716-845-8840.

***Stanford University Medical Center, Stanford, CA.*** Phase I/II trial: Decitabine treatment of MDS. Eligibility: IPSS High, Intermediate-2. Contact: Kathy Dugan, RN. Phone: 650-723-8594.

***Stanford University, Stanford, CA.*** Study of DARBEPOETIN ALFA in Patients with MDS. Primary objectives are 1) to assess erythroid response to DARBEPOETIN ALFA, as determined by changes in hemoglobin and /or red blood cell (RBC) transfusion-dependence. 2) to describe the safety profile of DARBEPOEITN ALFA in patients with MDS. Phase II trial. Eligibility: IPSS Low, Intermediate-1. Contact: Sylvia Quesada, R.N. Phone: 650-725-4041.

***Stanford University, Stanford, CA.*** Phase II trial: Exjade (ICL670) oral iron chelator treatment of MDS patients with iron overload. Contact: Kathy Dugan, RN. Phone: 650-723-8594.

***St. Francis Hospital, Hartford, CT.*** CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years old and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior cytotoxic chemotherapy for the purpose of this study. Prior treatment with Mylotarg is excluded. Contact: Dr. Bilgrami. Phone: 860-714-4680.

***St. Jude Children's Research Hospital, Memphis, TN.*** INFT2. Allogeneic stem cell and natural killer cell transplantation for children less than 2 years of age with hematologic malignancies. Contact: Wing Leung, MD. Phone: 901-495-3300.

***St. Jude Children's Research Hospital, Memphis, TN.*** AML02. Collaborative trial for the treatment of patients with newly diagnosed acute myeloid leukemia or myelodysplasia. Contact: Jeffrey Rubnitz, MD, PhD. Phone: 901-495-3300.

***St. Jude Children's Research Hospital, Memphis, TN.*** REFSCT. Pilot study to evaluate haploidentical stem cell transplantation utilizing T-Cell depletion as therapy for patients with refractory hematological malignancies. Contact: Ely Benaim, MD. Phone: 901-495-3300.

***Texas Oncology Medical City Dallas Hospital, Dallas, TX.*** D-0007. Randomized, open-label, Phase III trial of decitabine (5-aza-2'-deooxycytidine) versus supportive care in adults with advanced-stage myelodysplastic syndromes. This Phase III trial evaluates the efficacy of decitabine to treat MDS. Eligible patients may have de novo or secondary MDS. Growth factors (G-CSF, erythropoietin), steroids, hormones or chemotherapy for treatment of MDS are not allowed for 2 weeks prior to enrollment. Contact: Ronda Waldrop. Phone: 972-566-7790.

***Texas Oncology Medical City Dallas Hospital, Dallas, TX.*** SMC-101-1020. Open-label, prospective, stratified, randomized, controlled, multicenter, phase IIB study of the impact of Thymoglobulin therapy on transfusion needs of patients with early myelodysplastic syndromes. This protocol evaluates Thymoglobulin therapy for 4 days. Eligibility includes low risk MDS (RA, RAEB <10%), IPSS <1.0, transfusion dependence, No prior chemotherapy allowed. Contact: Ronda Waldrop. Phone: 972-566-7790.

***Texas Oncology Medical City Dallas Hospital, Dallas, TX.*** T-MDS-001. Multicenter, randomized, double-blind, placebo-controlled trial comparing best supportive care and thalidomide for the treatment of anemia in patients with myelodysplastic syndromes followed by an open-label treatment with thalidomide. Recently, treatment with thalidomide has been reported to improve the anemia in some patients with MDS. The purpose of this study is to further evaluate the effect of thalidomide or placebo pills (50:50 chance) for 24 weeks. Thereafter, all subjects can receive thalidomide for an additional 24 weeks. The effect of treatment on transfusions and quality of life will be evaluated. Contact: Ronda Waldrop. Phone: 972-566-7790.

***Thomas Jefferson University, Philadelphia, PA.*** A multicenter, single-arm, open-label study of the efficacy and safety of CC-5013 Monotherapy in RBC transfusion-dependent subjects with Myelodysplastic Syndromes. Contact: Emmanuel C. Besa, MD. Phone: 215-955-0356.

***Tufts-New England Medical Center, Boston, MA.*** E1902. Phase II study of reduced intensity allogeneic stem cell transplant for the treatment of myelodysplastic syndromes. This is a trial by the Eastern Cooperative Oncology Group using a reduced intensity preparative regimen pioneered here at Tufts-NEMC to cure patients with MDS and a genetically compatible related or unrelated donor. Contact: Regina Thornton. Phone: 617-636-7651.

***Tufts-New England Medical Center, Boston, MA.*** RAISCT001. A randomized trial of extracorporeal photophoresis, pentostatin, and total body irradiation versus pentostatin, and total body irradiation in patients undergoing reduced intensity allogeneic stem cell transplantation for the treatment of malignancies. Contact: Carrie Grodman, RN. Phone: 617-636-2682.

***Tufts-New England Medical Center, Boston, MA.*** B008. A randomized, multicenter, open-label, modified dose-ascension, parallel study of the safety, tolerability, and efficacy of oral SCIO-469 in patients with myelodysplastic syndromes. Contact: Carrie Grodman, RN. Phone: 617-636-2682.

***University of Alabama at Birmingham Comprehensive Cancer Center, Birmingham, AL.*** Phase I/IIa Study of TLK199 HCl Liposomes for injection in Myelodysplastic Syndromes. Contact: Peter Emanuel, MD. Phone: 205-975-2944.

***University of Arizona Cancer Center, Tucson, AZ.*** 04154. Phase I/II trial of subcutaneous decitabine optimizing genomic methylation in patients with myelodysplastic syndromes. Contact: Daruka Mahedevan, MD. Phone: 520-626-0191.

***University of Arizona Cancer Center, Tucson, AZ.*** HSC #02-11. Safety and efficacy trial of bevacizumab: anti-vegf humanized monoclonal antibody therapy for MDS. Contact: Daruka Mahedevan, MD. Phone: 520-626-0191.

***University of California at Los Angeles (UCLA) Medical Center, Los Angeles, CA.*** Randomized, multicenter, double-blind, placebo controlled trial assessing the safety and efficacy of thalidomide (Thalidomid) for the treatment of anemia in patients with myelodysplastic syndromes. Recently, treatment with thalidomide has been reported to improve the anemia in some patients with MDS. The purpose of this study is to further evaluate the effect of thalidomide or placebo pills (50:50 chance) for 24 weeks. Thereafter, all subjects can receive thalidomide for an additional 24 weeks. The effect of treatment on transfusions and quality of life will be evaluated. The most common side effects of thalidomide include severe birth defects, drowsiness, weakness, rash, shortness of breath, fluid retention, constipation, low blood pressure, decreased white blood counts, slow heart beats and nerve damage. Contact: Ron Paquette, MD. Phone: 310-825-5608.

***University of Chicago, Chicago, IL***. AMG531. An open label sequential cohort, dose escalation study to evaluate the safety and efficacy of AMG 531 in thrombocytopenic subjects with low or intermediate 1 risk MDS. Contact: Margaret Green, RN. Phone: 773-702-0267.

***University of Chicago, Chicago, IL***. 11884A. High-dose cytarabine/mitoxantrone followed by autotransplantation for therapy-related MDS. Contact: Margaret Green, RN. Phone: 773-702-0267.

***University of Chicago, Chicago, IL*** 2978. A pivotal randomized study of Lonafarnib (SCH 66336) vs. placebo in the treatment of subjects with Myelodysplastic Syndromes (MDS) or Chronic Myelomonocytic Leukemia (CMML) who are platelet transfusion dependent with or without anemia. Contact: Margaret Green, RN. Phone: 773-702-0267.

***University of Chicago, Chicago, IL*** 13172B. Phase 1-2a of TLK199 HCl Liposomes for Injection in Myelodysplastic Syndromes. Contact: Margaret Green, RN. Phone: 773-702-0267.

***University of Chicago, Chicago, IL*** 12981A. A Phase II study of an oral VegF receptor tyrosine kinase inhibitor (PTK787/2K222584) (IND #66370, NSC #719335) in Myelodysplastic Syndromes. Contact: Margaret Green, RN. Phone: 773-702-0267.

***University of Louisville, Louisville, KY.*** #541.02. Pilot study of arsenic trioxide and amifostine for the treatment of myelodysplastic syndromes. Eligible patients must have a confirmed diagnosis of MDS. For patients with lower-risk only: documented red blood cell dependence, defined as the inability to maintain a hematocrit of >25% without transfusion support and patients with serum erythropoietin less than 200 IU/mL at screening should have failed to respond to a trial of recombinant erythropoietin (EPO) administered in accordance with institutional guidelines. Patients must have an ECOG PS 0-2 and adequate hepatic and renal function as evidenced by specific laboratory criteria. Contact: R. Herzig, MD. Phone: 800-234-2689.

***University of Massachusetts Medical Center, Worcester, MA.*** Pilot Study to Test the Efficacy of the Anti-CD52 Antibody Campath-1H in Combination with the Growth Factor GM-CSF in Improving the Cytopenias of Patients with Myelodysplastic Syndromes. The purpose of this study is to evaluate the effects of Campath-1H and GM-CSF, in combination, on the low counts seen in MDS. What happens in MDS is a cell in your bone marrow becomes abnormal and starts to grow and multiply. However, the abnormal cells that this bone marrow cell makes die via cell suicide on the way to the blood, resulting in the low blood counts seen in MDS. We hope that Campath-1H will target these abnormal bone marrow cells and cause them to die, while GM-CSF will cause the normal cells to grow and multiply more. If true, these drugs would improve the low blood counts. Both of these drugs must be given by injection (PI: Dr. Raza). Contact: Murtaza Mehdi. Phone: 508-856-3509.

***University of Massachusetts Medical Center, Worcester, MA.*** Pilot study to test the efficacy of coenzyme Q10 in patients with low to intermediate-1 risk myelodysplastic syndromes. The purpose of this study is to test the efficacy of coenzyme Q10 in improving abnormalities seen in bone marrow cells of patients with MDS. One of the abnormalities that tend to occur in the bone marrow cells involves part of the cell called the mitochondria. The mitochondria are like energy producing factories in your cells. Coenzyme Q10 is used by the mitochondria to do their job. Coenzyme Q10 may potentially correct the abnormalities seen in the cells of the bone marrow in MDS. Coenzyme Q10 is a natural, non-toxic substance that can be taken by mouth (PI: Dr. Raza). Contact: Murtaza Mehdi. Phone: 508-856-3509.

***University of Massachusetts Medical Center, Worcester, MA.*** Pilot study to test the efficacy of curcumin and gingerol in patients with myelodysplastic syndromes. The purpose of this study is to test the efficacy of the natural compounds curcumin and gingerol in improving the low blood counts seen in patients with MDS. In MDS, a patient's bone marrow makes more cells than usual that eventually turn into blood cells. However, the increased number of blood cells made die by suicide on the way to the blood. A chemical substance called TNF-α causes the increased cell suicide. Curcumin and ginerol inhibit TNF-α. They are also non-toxic substances, making them ideal for the generally older patient population of MDS, especially since two thirds of the population will not go on to develop acute leukemia. These compounds can be taken at home by mouth (PI: Dr. Raza). Contact: Murtaza Mehdi. Phone: 508-856-3509.

***University of Massachusetts Medical Center, Worcester, MA.*** Oral iron chelation (ICL670) in patients with low to intermediate-1 risk myelodysplastic syndromes. Some patients with MDS are dependent on transfusions to treat their low blood counts. When a patient receives a transfusion, they also get iron that is contained in the blood. This becomes a problem because the body cannot rid itself of iron and a buildup of iron can be toxic and even lethal for the patient. ICL670, also called deferasirox, can get rid of some of this extra iron accumulating in the blood and can thus reduce the morbidity associated with frequent transfusions sometimes required for MDS. Deferasirox can be taken by mouth (PI: Dr. Raza). Contact: Murtaza Mehdi. Phone: 508-856-3509.

***University of Massachusetts Medical Center, Worcester, MA.*** Pivotal Randomized Study of Lonafarnib versus Placebo in the Treatment of Subjects with Myelodysplastic Syndromes or Chronic Myelomonocytic Leukemia who are Platelet Transfusion Dependent with or without Anemia. This study is attempting to test the efficacy of Lonafarnib against the abnormal cells found in the bone marrow of patients with MDS. Lonafarnib inhibits a certain protein in your cells that causes the cell to grow and multiply. We believe that Lonafarnib will stop the abnormal cells in the bone marrow from multiplying so that more normal cells can get to the blood. Lonafarnib can be taken by mouth (PI: Dr. Raza). Contact: Murtaza Mehdi. Phone: 508-856-3509.

***University of Massachusetts Medical Center, Worcester, MA.*** Phase II Trial of Combination Therapy with Thalidomide, Arsenic Trioxide, Dexamethasone, and Ascorbic Acid (TADA) in Patients with Chronis Idiopathic Myelofibrosis or Overlap Myelodysplastic/Myeloproliferative Disorders. The purpose of this study is to see if Thalidomide in combination with arsenic trioxide can improve the low blood counts seen in MDS. In MDS, the cells in the bone marrow are increased, but the blood cells die in greater numbers via cell suicide, resulting in the low blood counts. Thalidomide works to decrease this cell suicide and raise blood counts, while arsenic trioxide works to cause cell suicide of some of the abnormal cells in the bone marrow. We believe the result will be more normal blood cells getting to the blood. The Dexamethasone and Ascorbic Acid are used to improve the function of the Thalidomide and arsenic trioxide. Thalidomide can be taken by mouth, but arsenic must be administered through an IV (PI: Dr. Raza). Contact: Murtaza Mehdi. Phone: 508-856-3509.

***University of Massachusetts Medical Center, Worcester, MA.*** Phase 1-2a Study of TLK199HCl Liposomes for Injection in Myelodysplastic Syndromes. The purpose of this study is to test the efficacy of TLK in improving the low blood counts seen in MDS. One of the main causes of death seen from MDS is infection. This occurs because the white blood cells that fight infections are lowered in number due to the disease. TLK increases the white blood cell count, making it easier for a patient's body to fight infection and thus lowering their chance of dying from infection. This drug is administered through an IV, so patients must come into the hospital to receive this treatment (PI: Dr. Raza). Contact: Murtaza Mehdi. Phone: 508-856-3509.

***University of Massachusetts Medical Center, Worcester, MA.*** Pilot study to determine efficacy of combining Vidaza and arsenic trioxide for the treatment of patients with intermediate and high risk myelodysplastic syndromes. The purpose of this study is to determine the efficacy of Vidaza and arsenic trioxide, in combination, at improving the low blood counts seen in MDS. As stated in a description above, Vidaza prevents the silencing of good genes in your cell that prevent the cell from growing out of control. This means that Vidaza will hopefully prevent abnormal cells from growing out of control. Arsenic, as described above, works in a different way to do the same thing. Arsenic prevents abnormal cells from growing by causing them to commit suicide. It is hoped that in combination these drugs will increase the blood counts in patients with MDS. Arsenic trioxide must be given via an IV, while Vidaza must be given through an injection (PI: Dr. Raza). Contact: Murtaza Mehdi. Phone: 508-856-3509.

***University of Massachusetts Medical Center, Worcester, MA.*** Pilot Study to Determine the Efficacy of Combining Vidaza and Thalidomide for the Treatment of Myelodysplastic Syndromes and Acute Myeloid Leukemia. This study is assessing the efficacy of Vidaza and Thalidomide, in combination. We hope that these drugs will increase the low blood counts seen in patients with MDS. There are certain genes in your cell that keep it from growing out of control. These genes get what we call 'silenced' in MDS and the now abnormal cell grows out of control. However, the cells that it makes die via cell suicide before they reach the blood, resulting in the low blood count. Vidaza prevents the silencing of the good genes so that the cell does not grow out of control and die on the way to the blood. Thalidomide works to decrease the cell suicide of normal cells and raise blood counts. In combination, we hope that these drugs will raise the blood counts in MDS. Thalidomide can be taken by mouth, while Vidaza must be given via an injection (PI: Dr. Raza). Contact: Murtaza Mehdi. Phone: 508-856-3509.

***University of Massachusetts Medical Center, Worcester, MA.*** Phase I, multi-dose study of SGN-33 (anti-huCD33mAb; HuM195; lintuzumab) in patients with acute myeloid leukemia and myelodysplastic syndromes (PI: Dr. Raza). Contact: Murtaza Mehdi. Phone: 508-856-3509.

***University of Massachusetts Medical Center, Worcester, MA.*** Phase II study of Tandutinib (MLN518) in patients with newly diagnosed acute myelogenous leukemia who are considered ineligible for or who decline treatment with standard induction therapy (PI: Dr. Raza). Contact: Murtaza Mehdi. Phone: 508-856-3509.

***University of Massachusetts Medical Center, Worcester, MA.*** Phase I/II study to evaluate the safety and preliminary activity of ZARNESTRA® (R115777, tipifarnib) in combination with low dose ara-C (LDAC) in patients with myelodysplastic syndrome (MDS) and AML (PI: Dr. Raza). Contact: Murtaza Mehdi. Phone: 508-856-3509.

***University of Massachusetts Medical Center, Worcester, MA.*** Phase III randomized controlled study of Clofarabine versus low dose Cytarabine (LDAC) in previously untreated older adult patients with acute myeloid leukemia (AML) for whom standard induction chemotherapy is not an appropriate option (PI: Dr. Raza). Contact: Murtaza Mehdi. Phone: 508-856-3509.

***University of Massachusetts Medical Center, Worcester, MA.*** Phase III randomized controlled study comparing Clofarabine and Cytarabine versus Cytarabine alone in adult patients ≥60 years old with acute myeloid leukemia (AML) who have relapsed or are refractory after receiving up to two prior induction regimes (PI: Dr. Raza). Contact: Murtaza Mehdi. Phone: 508-856-3509.

***University of Michigan Comprehensive Cancer Center, Ann Arbor, MI.*** Phase II trial of combination therapy with arsenic trioxide (Trisenox) and gemtuzumab ozogamicin (Mylotarg) for the treatment of adult patients with advanced myelodysplastic syndromes. Contact: Harry P. Erba, MD, PhD.

***University of Pennsylvania Cancer Center, Philadelphia, PA.*** A pilot study of valproic acid in patients with MDS. Contact: Selina Luger, MD. Phone: 215-662-6348.

***University of Pennsylvania Cancer Center, Philadelphia, PA.*** Pilot study of arsenic trioxide in patients with MDS. Contact: Selina Luger, MD. Phone: 215-662-6348.

***University of Pennsylvania Cancer Center, Philadelphia, PA.*** IRB# 801752. Establishment of a Myelodysplastic Syndromes Tissue Bank. The protocol is intended to expand the availability of MDS patient samples for research into the etiology of these disorders. Contact: James Thompson, MD. Phone: 215-573-7617.

***University of Texas Health Science Center at San Antonio, San Antonio, TX.*** Phase I/IIa Study of TLK199 HCl Liposomes for injection in Myelodysplastic Syndromes. Contact: Natalie Callander, MD. Phone: 210-617-5300 Ext. 4720.

***University of Texas Health Science Center at San Antonio, San Antonio, TX.*** Randomized, double-blind, phase II study of the matrix metalloproteases inhibitor Prinomastat in patients having myelodysplastic syndromes. Eligible patients must be over 18 years of age and have a diagnosis of MDS of at least 8 weeks duration, hemoglobin <9.0 g/dL (or be transfusion dependent) with adequate renal/hepatic function of serum creatinine less than or equal to 1.5 mg/dL and serum total bilirubin less than or equal to 2.0 mg/dL. Contact: Natalie Callander, MD. Phone: 210-567-4848.

***University of Washington, Seattle, WA.*** UW-26-245-B. Phase I trial using subcutaneous, outpatient injection to evaluate the efficacy of Interleukin-2 to treat MDS. Eligible patients must have either refractory anemia, refractory anemia with ringed sideroblasts, refractory anemia with excess blasts, or chronic myelomonocytic leukemia; more than 30 days since any prior treatment for MDS; Karnofsky performance status >70; serum creatinine <2.0 mg/dL; bilirubin <1.6 mg/dL or SGOT <150. Contact: John A. Thompson, MD. Phone: 206-288-2015.

***UPMC Hillman Cancer Center, Pittsburgh, PA.*** 01-020. Phase II multicenter trial of Calcitrol and Dexamethasone for Adult Myelodysplastic Syndromes to evaluate the efficacy of the combination of the two drugs, will cause apoptosis to treat MDS. Contact: Hillman Cancer Center. Phone: 412-641-8073.

***Vanderbilt University Medical Center, Nashville, TN.*** Phase II study of arsenic trioxide in myelodysplasia. Contact: Shubhada M. Jagasia, MD. Phone: 615-322-4752.

***Wake Forest University School of Medicine, Winston-Salem, NC.*** CCCWFU-29203. Orthomolecular Vitamin D in Low-Risk Myelodysplastic Syndromes: Phase II trial using cholecalciferol (Vitamin D3) to evaluate the efficacy of 2000 IU Vitamin D3 daily for 6 months to treat MDS. Eligible patients must have MDS; IPSS score 0–1.0; life expectancy >1 year; no other concurrent therapy for MDS; no history of hypercalcemia. Contact: Istvan Molnar, MD. Phone: 336-716-5847.

***Wake Forest University School of Medicine, Winston-Salem, NC.*** CCCWFU-29304. Phase II Study of Arsenic Trioxide and Dose-Escalated Cholecalciferol in Myelodysplastic Syndromes: The purpose of this study is to determine how many patients with myelodysplastic syndromes (MDS) respond to the combination treatment with arsenic trioxide and cholecalciferol (vitamin $D_3$). All MDS patients are eligible if they have a life expectancy of at least six months. Arsenic trioxide is administered daily for 5 days intravenously (as a "loading" dose) followed by twice a week administration. Vitamin $D_3$ is given at 100 microgram/day by mouth and the dose is increased by 50 microgram/d every three months up to a year in patients who have no toxicity and did not achieve complete remission. Bone marrow samples are obtained before and during treatment to look at response with morphological and biological parameters. Patients may remain on the study for up to one year. Contact: Istvan Molnar, MD. Phone: 336-716-5847.

***Washington University School of Medicine, St. Louis, MO.*** 03-1277. A phase III randomized, multicenter trial comparing G-CSF mobilized peripheral blood stem cell with marrow transplantation from HLA compatible unrelated donors. Contact: Nick Fisher. Phone: 314-454-5090.

***Washington University School of Medicine, St. Louis, MO.*** 01-1014. Tissue acquisition for analysis of genetic progression factors in hematologic diseases for AML and MDS. Contact: Nick Fisher. Phone: 314-454-5090.

***Washington University School of Medicine, St. Louis, MO.*** 03-0187. CALGB 100002: Non-myeloablative allogeneic hematopoietic cell transplantation for patients with disease relapse or myelodysplasia after prior autologous transplantation. Contact: Nick Fisher. Phone: 314-454-5090.

***Washington University School of Medicine, St. Louis, MO.*** 03-0349. A pilot study evaluating the safety and efficacy of AMD3100 for the mobilization and transplantation of HLA-matched sibling donor hematopoietic stem cells in patients with advanced hematologic malignancies. Contact: Nick Fisher. Phone: 314-454-5090.

***Washington University School of Medicine, St. Louis, MO.*** 05-0141. A phase I pharmacokinetic trial of decitabine administered as a 3-hour infusion to patients with acute myelogenous leukemia or myelodysplastic syndromes. Contact: Nick Fisher. Phone: 314-454-5090.

***Washington University School of Medicine, St. Louis, MO.*** 04-0337. CALGB10105: A phase II study of an oral VegF receptor tyrosine kinase inhibitor (PTK78/ZK222584) in myelodysplastic syndromes (MDS). Contact: Nick Fisher. Phone: 314-454-5090.

***Western Pennsylvania Cancer Institute, Pittsburgh, PA.*** WPCI2004-17. Arsenic trioxide, ascorbic acid, filgrastim and erythropoietin for the treatment of myelodysplastic syndromes. Contact: Richard K. Shadduck, MD. Phone: 412-578-1034.

***Western Pennsylvania Cancer Institute, Pittsburgh, PA.*** WPCI2004-37/AZA PH US 2004 CL003. A multicenter, randomized, open-label study comparing three alternative dosing regimens of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Richard K. Shadduck, MD. Phone: 412-578-1034.

***Western Pennsylvania Cancer Institute, Pittsburgh, PA.*** WPCI2004-08/CALGB 10105. A phase II study of an oral VegF receptor tyrosine kinase inhibitor (PTK787/ZK222584) in the treatment of myelodysplastic syndromes. Contact: Richard K. Shadduck, MD. Phone: 412-578-1034.

***Western Pennsylvania Cancer Institute, Pittsburgh, PA.*** WPCI2005-19. Azacitidine in the Treatment of Elderly Patients with Acute Myelogenous Leukemia. Contact: James M. Rossetti, D.O. Phone: 412-578-3407.

## *International Trials*

### AUSTRALIA

***Peter MacCallum Cancer Centre, Victoria.*** A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: John F. Seymour, MD. Phone: +613 9656 1697.

***The Newcastle Mater Miseriecordiae Hospital, New South Wales.*** A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Arno Enno. Phone: +61 2 4921 1215.

***Princess Alexandra Hospital, Queensland.*** A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Anthony Mills. Phone: +61 7 3240 2086.

***Royal Adelaide Hospital, South Australia.*** A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Noemi Horvath. Phone: +61 8 8222 3550.

***The Alfred Hospital, Victoria.*** A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Andrew Spencer. Phone: +61 3 9276 3392.

***The Royal Perth Hospital, Western Australia.*** A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Richard Herrman, MD. Phone: +61 8 9224 2405.

### BELGIUM

***AZ Sint-Jan AV, Brugge.*** Idarubicin and AraC in combination with Gemtuzumab Ozogamicin (IAGO) for young untreated patients without an HLA identical sibling with high risk MDS or AML developing after a preceding period with MDS of 6 months duration. A phase II study. EORTC study 06013. Study coordinator: Theo de Witte. Contact person in Belgium: D.Selleslag 3250452321.

***AZ Sint-Jan AV, Brugge.*** Intravenous low dose decitabine versus supportive care in elderly patients with primary myelodysplastic syndrome (>10 % blasts or high risk cytogenetics), secondary MDS or CMML who are not eligible for intensive therapy. An EORTC-German MDS Study Group randomised phase III study. EORTC study 06011. Study coordinator: Pierre Wijermans. Contact person in Belgium: D.Selleslag 3250452321

***AZ Sint-Jan AV, Brugge.*** Randomized phase II trial with Infliximab (Remicade) in patients with a myelodysplastic syndrome and a relatively low risk of developing acute leukemia. EORTC protocol 06023. Study coordinator: Heinz Zwierzina. Contact person in Belgium: D.Selleslag 3250452321

***Cliniques Universitaires Saint-Luc, Bruessel.*** CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years old and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior cytotoxic chemotherapy for the purpose of this study. Prior treatment with Mylotarg is excluded. Contact: Dr. Ferrant. Phone: 32 2 764 1810 (1880).

### FRANCE

***Groupe Français des Myelodysplasies.*** CC5013-MDS-004. A phase III trial, three arms, randomized multi-center in double blind to evaluate the efficacy and toxicity of two doses of Lenalidomide versus placebo in subjects with IPSS low or Intermediate-1 risk MDS associated with deletion 5q and red blood cell transfusion-dependent anemia defined as having received >4 transfusions within 56 days of randomization of symptomatic anemia. Contact: Pierre Fenaux, MD. Phone: +33 1 48 95 70 50/70 51 pierre.fenaux@avc.ap-hp.fr.

***Groupe Français des Myelodysplasies.*** THAL-MDS-200. A phase II multi-center study of Thalidomide at low dose for the treatment of patients with IPSS low or Intermediate-1 risk MDS. Contact: Didier Bouscary, MD. Phone: +33 1 40 51 65 43 bouscary@cochin.inserm.fr.

***Groupe Français des Myelodysplasies.*** ICL670. A multi-center study to evaluate the efficacy and tolerance of treatment by ICL670 (20 mg/kg/d) during 1 year in RBC transfusion-dependent subjects with hemosiderosis. Contact: Christian Rose. Phone: +33 3 20 87 45 32 rose.christian@ghicl.net.

***Groupe Français des Myelodysplasies.*** MAQ2005. A phase II study of intensive chemotherapy combined to quinine in high risk MDS with PGP expression. Contact: Pierre Fenaux, MD. Phone: +33 1 48 95 70 50/70 51 pierre.fenaux@avc.ap-hp.fr. or Stephane de Botton s.de-botton@voila.fr.

***Groupe Français des Myelodysplasies.*** A multicenter randomized open-label parallel group phase III trial of subcutaneous azacytidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Pierre Fenaux, MD. Phone: +33 1 48 95 70 50/70 51 pierre.fenaux@avc.ap-hp.fr.

***Groupe Français des Myelodysplasies.*** GFMaza05. Phase II study on maintenance treatment with azacytidine in high risk MDS patients in response after intensive chemotherapy. Contact: Claude Gardin, MD. Phone: +33 1 48 95 70 50/70 51 claude.gardin@avc.aphp.fr.

***Institute Paoli Calmettes, Marseilles.*** CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years old and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior cytotoxic chemotherapy for the purpose of this study. Prior treatment with Mylotarg is excluded. Contact: Norbert Vey, MD. Phone: +33 4 91223695 veyn@marseille.fnclcc.fr.

***Chu Purpan, Toulouse.*** A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Guy Laurent, MD. Phone: +33 5 61772078.

***Chu De Nantes, Nantes.*** A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Beatrice Mahe, MD. Phone: +33 2 40083252.

***Chu De Lille, Lille.*** A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Bruno Quesnel, MD. Phone: +33 3 20446640.

***Hôpital Cochin, Paris.*** A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Francois Dreyfus, MD. Phone: +33 1 58412120.

## GERMANY

***Heinrich-Heine University Düsseldorf.*** A multicenter randomized open-label parallel group pPhase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Norbert Gattermann, MD. Phone: +49 211 811 6500.

***Heinrich-Heine University Düsseldorf.*** Phase II Trial of Valproic Acid as a Monotherapy or in Combination with All-trans Retinoic Acid for the treatment of Myelodysplastic Syndromes. Contact: Norbert Gattermann, MD. Phone: +49 211 811 6500.

***University Hospital Freiburg.*** Phase II study of low-dose intravenous decitabine in patients aged >60 years with acute myeloid leukemia who are not eligible for standard induction chemotherapy. Contact: Michael Lübbert, MD, PhD. Phone: +49-761-270-3279.

***University Hospital Freiburg.*** Intravenous low-dose decitabine versus supportive care in elderly patients with primary Myelodysplastic Syndrome (MDS) (>10% blasts or high-risk cytogenetics), secondary MDS or Chronic Myelomonocytic Leukemia (CMML) who are not eligible for intensive therapy: an EORTC-German MDS Study Group randomized Phase III study. Contact: Michael Lübbert, MD, PhD. Phone: +49-761-270-3279.

***University Hospital Hamburg.*** Allo/Treo-Flud/MDSsAML. Allogeneic stem cell transplantation after toxicity-reduced conditioning regimen with treosulfan and fludarabine for patients with MDS or sAML, who were not eligible for a standard conditioning regimen: a phase II study. Contact: Nicolaus Kröger, MD. Phone: +49-40-42803-5864.

***University Hospital Hamburg.*** RICMAC-MDSsAML. EBMT: Dose-reduced versus standard conditioning followed by allogeneic stem cell transplantation in patients with MDS or sAML. A randomized phase III study. Contact: Nicolaus Kröger, MD. Phone: +49-40-42803-5864.

***University Hospital Benjamin Franklin, Berlin.*** SAKK 33/99. Antithymocyte Globulin (ATG) and Cyclosporine (CSA) to treat patients with Myelodysplastic Syndrome (MDS). A randomized trial comparing ATG & CSA with best supportive care. Contact: Prof. Dr. Wolf-K. Hofmann. Phone: +49-30-8445-5903.

***University Hospital Benjamin Franklin, Berlin.*** Phase II clinical trial using vaccination with Wilms-Tumor-Gen 1 (WT1) derived peptide in patients with acute myeloid Leukemia and Myelodysplastic Syndrome. Contact: Prof. D. Wolf-K. Hofmann. Phone: +49-30-8445-5903.

***University Hospital Benjamin Franklin, Berlin.*** AZA PH GL 2003 CL 001. A multicenter, randomized, open-label, parallel-group, Phase 3 trial of subcutaneous Azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Prof. Dr. Wolf-K. Hofmann. Phone: +49-30-8445-5903.

***Universitätsklinikum Carl Gustav Carus, Dresden.*** EVTAC trial. Tacrolimus and everolimus as graft-versus-host disease prophylaxis for patients with MDS or AML receiving hematopoietic stem cells from HLA-compatible siblings or unrelated donors. Contact: Uwe Platzbecker, MD. Phone: +49-351-458-4190.

***Universitätsklinikum Carl Gustav Carus, Dresden.*** AZA PH GL 2003 CL 001. A multicenter, randomized, open-label, parallel-group, Phase 3 trials for subcutaneous Azacitidine plus best supportive care versus conventional care regimens plus best supportive care for treatment of MDS. Contact: Uwe Platzbecker, MD. Phone: +49-351-458-4190.

***Universitätsklinikum Carl Gustav Carus, Dresden.*** 06011 (EORTC). Intravenous low-dose decitabine versus supportive care in elderly patients with primary Myelo-dysplastic Syndrome (MDS) (>10% blasts or high-risk cytogenetics), secondary MDS or Chronic Myelomonocytic Leukemia (CMML) who are not eligible for intensive therapy: an EORTC-German MDS study group randomized Phase III study. Contact: Uwe Platzbecker, MD. Phone: +49-351-458-4190.

***Universitätsklinikum Carl Gustav Carus, Dresden.*** 2003/4. Radioimmunotherapy with Re-188-anti-CD66-antibody for conditioning of AML and MDS patients above the age of 55 prior to stem cell transplantation. Contact: Martin Bornhäuser, MD. Phone: +49-351-458-2321.

***Universitätsklinikum Carl Gustav Carus, Dresden.*** 2003/2. Tacrolimus and Mycophenolate mofetil as Graft-versus-Host disease Prophylaxis for patients with Myelodysplastic Syndrome (MDS) or Acute Myeloid Leukemia (AML) receiving conditioning with Fludarabine and targeted intravenous Busulfan and Hematopoietic stem cells from HLA-compatible siblings or unrelated donors. Contact: Martin Bornhäuser, MD. Phone: +49-351-458-2321.

## HUNGARY

***Semmelweis University School of Medicine, Budapest.*** Investigation of the multifactorial cause of iron overload by testing HFE gene mutations: C282Y and H63D, determination of copper and coeruloplasmin level, analysis of transferring receptor mutation and also TNF-α promoter gene polymorphism in MDS patients. Contact: Judit Varkonyi, MD, PhD. Phone/Fax: 361-355-8251.

## ISRAEL

***Tel-Aviv Sourasky Medical Center.*** OCC5013-MDS-004. Randomized 3-arm controlled trial: 2 doses of Revlimid vs control for transfusion-dependent 5q- MDS patients. Contact: Dr. Moshe Mittelman. Phone: +972 (0) 3-697-3366.

## ITALY

***Unit of Hematology and Stem Cell Transplantation, Centro di Riferimento Oncologico di Basilicata.*** RIV0106. A phase II trial with high dose darbepoetin +/– Peg-Filgrastim in low-intermediate risk myelodysplastic syndromes. Contact: Dr. Pellegrino Musto. Phone: 39 (0) 972 716117.

***Unit of Hematology and Stem Cell Transplantation, Centro di Riferimento Oncologico di Basilicata.*** RIV0206. A phase I/II trial with bortezomib in low-intermediate risk myelodysplastic syndromes. Contact: Dr. Pellegrino Musto. Phone: 39 (0) 972 716117.

***Unit of Hematology and Stem Cell Transplantation, Centro di Riferimento Oncologico di Basilicata.*** PO2978. A pivotal randomized study of Lonafarnib vs placebo in the treatment of myelodysplastic syndromes who are platelet transfusion dependent, with or without anemia. Contact: Dr. Pellegrino Musto. Phone: 39 (0) 972 716117.

***Unit of Hematology and Stem Cell Transplantation, Centro di Riferimento Oncologico di Basilicata.*** AZA PH GL 2003 CL 001. A confirmatory survival randomized trial of azacytidine vs standard of care in patients with high-risk myelodysplastic syndromes. Contact: Dr. Pellegrino Musto. Phone: 39 (0) 972 716117.

***Unit of Hematology and Stem Cell Transplantation, Centro di Riferimento Oncologico di Basilicata.*** GIMEMA MDS 0205. An open-label, phase II trial of 5-azacytidine plus valproic acid +/– ATRA combination in int-2/high risk myelodysplastic syndromes. Contact: Dr. Pellegrino Musto. Phone: 39 (0) 972 716117.

## JAPAN

***Nippon Medical School, Tokyo.*** IRB2002-22. Open-label study of the safety and efficacy of Thalidomide in patients with Myelodysplastic Syndrome. Contact: Dr. Kiyoyuki Ogata. Phone: 81-3-3822-2131 (Ext. 6321).

## THE NETHERLANDS

***Universitaire Ziekenhuis Gasthuiberg, Leuven.*** CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years old and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior cytotoxic chemotherapy for the purpose of this study. Prior treatment with Mylotarg is excluded. Contact: Dr. Verhoeft. Phone: 011-32-16-346880.

***University of Nijmegen, Nijmegen.*** AZA PH GL 2003 CL 001. A multicenter, randomized, open-label, parallel-group, Phase 3 trial of subcutaneous Azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Dr. P. Muus. Phone: +31-24-3614762.

***University of Nijmegen, Nijmegen.*** EBMT200502. A prospective 2×2 randomized muticenter study evaluating the role of remission-induction and consolidation chemotherapy prior to allogeneic transplantation and of G-CSF mobilized peripheral blood progenitor cells versus bone marrow stem cells using HLA-identical siblings in patients with Myelodysplastic Syndromes and between 5% and 20% bone marrow blasts. Contact: Prof. Dr. T. de Witte. Phone: +31-24-3614762.

***University of Nijmegen, Nijmegen.*** EORTC 06011. Intravenous low-dose decitabine versus supportive care in elderly patients with primary MDS (>10% blasts or high-risk cytogenetics), secondary MDS of CMMOL who are not eligible for intensive therapy. Contact: Dr. P. Muus. Phone: +31-24-3614762.

***University of Nijmegen, Nijmegen.*** EPO 2003. A Phase 2 clinical trial to evaluate the feasibility of treatment with Aranesp in patients with Myelodysplastic Syndrome (MDS). Contact: Prof. Dr. T. de Witte. Phone: +31-24-3614762.

***University of Nijmegen, Nijmegen.*** EORTC 06013. Idarubicin and Ara-C in combination with Gemtuzumab-Ozogamicin (IAGO) for young untreated patients, without an HLA identical sibling, with high risk MDS or AML developing after a preceding period with MDS during 6 months duration. Contact: Prof. Dr. T de Witte. Phone: +31-24-3614762.

***University of Nijmegen, Nijmegen.*** EORTC 06023. Randomized Phase II trial with Infliximib (Remicade) in patients with Myelodysplastic Syndrome and a relatively low risk of developing acute leukemia. Contact: Dr. P. Muus. Phone: +31-24-3614762.

***VU University Medical Center, Amsterdam.*** Impact on apoptosis of immature myeloid and erythroid progenitor cells and its relation to immune escape mechanisms of a standardized regimen of epoëtine bèta (NeoRecormon®) and granulocyte colony-stimulating-factor (Neupogen®) in low-risk myelodysplasia. Contact: Prof. Dr. G.J. Ossenkoppele or Dr. A.A. van de Loosdrecht. Phone: +31-20-4442604; +31-20-4442642 (www.hematologie.nl).

***VU University Medical Center, Amsterdam.*** Randomized phase II trial with infliximab (Remicade) in patients with myelodysplastic syndrome and a relatively low risk of developing acute leukemia (EORTC 06023). Contact: Prof. Dr. G.J. Ossenkoppele or Dr. A.A. van de Loosdrecht. Phone: +31-20-4442604; +31-20-4442642 (www.eortc.be).

***VU University Medical Center, Amsterdam.*** Antithymocyte globulin (ATG) and cyclosporine (CsA) to treat patients with MDS. A randomized trial comparing ATG and CsA with best supportive care (HOVON60). Contact: Prof. Dr. G.J. Ossenkoppele or Dr. A.A. van de Loosdrecht. Phone: +31-20-4442604; +31-20-4442642 (www.hovon.nl).

***VU University Medical Center, Amsterdam.*** Randomized induction and post induction therapy in adult patients (d 60 yrs of age) with acute myelocytic leukemia (AML) or refractory anemia with excess of blasts (RAEB, RAEB-t) with IPSS score e1.5 (HOVON 42). Contact: Prof. Dr. G.J. Ossenkoppele or Dr. A.A. van de Loosdrecht. Phone: +31-20-4442604; +31-20-4442642 (www.hovon.nl).

***VU University Medical Center, Amsterdam.*** Randomized induction and post induction therapy in older patients (>61 yrs of age) with acute myelocytic leukemia (AML) and refractory anemia with excess of blasts (RAEB, RAEB-t) with IPSS score e 1.5 (HOVON43). Contact: Prof. Dr. G.J. Ossenkoppele or Dr. A.A. van de Loosdrecht. Phone: +31-20-4442604; +31-20-4442642 (www.hovon.nl).

## THE NORDIC COUNTRIES

***Nordic MDS Group.*** NMDSG02B. Phase II study on maintenance treatment with Azacytidine in patients with advanced MDS and MDS-AML, who have obtained CR with intensive chemotherapy. Contact: Dr. Eva Hellström-Lindberg. Phone: 011-46-85-858-0000.

***Nordic MDS Group.*** NMDSG03A. An open, non-randomized Phase II study on the effects of anemia in MDS quality of life, cardiac function and health care costs. Contact: Herman Nilsson-Ehle. Phone: 011-46-85-858-0000.

***Nordic MDS Group.*** AZA PH GL 2003 CL 001. A multicenter, randomized, open-label, parallel-group, Phase 3 trial of subcutaneous Azacytidine plus best supportive care versus conventional care regimens plus best supportive care for treatment of Myelodysplastic Syndromes. Contact: Dr. Eva Hellström-Lindberg. Phone: 011-46-85-858-0000.

## POLAND

***Jagiellonian University, Cracow.*** A randomized trial comparing Antithymocyte Globulin (ATG) and Cyclosporine (CSA) with best supportive care in patients with MDS. Contact: Prof. Aleksander B. Skotnicki, MD. Phone: +48-12-421-3693.

***Jagiellonian University, Cracow.*** Phase I/II study of Thalidomide in low-risk MDS. Contact: Pawel Sledziowski, MD. Phone: +48-12-424-7600.

***Jagiellonian University, Cracow.*** Phase III clinical trial of Amifostine/pentoxifylline/ciprofloxacin/dexamethasone for low-risk MDS. Contact: Janusz Krawczyk, MD. Phone: +48-12-424-7600.

***Jagiellonian University, Cracow.*** Phase I/II study of Arsenic Trioxide in high-risk MDS. Contact: Marcin Sobocinski, MD. Phone: +48-12-424-7600.

## SPAIN

***Hospital Clinic, Barcelona.*** A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Benet Nomdedeu, MD. Phone: +34 93 227 55 11.

***Hospital Son Llatzer, Palma de Mallorca.*** A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Joan Bargay, MD. Phone: +34 871 20 21 38.

***Hospital Universitario del Salamanca, Salamanca.*** 2001395. A multicenter randomized open-label parallel group phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Maria Consuelo del Cañizo, MD. Phone: +34 923 291384.

***Hospital Universitario del Salamanca, Salamanca.*** 200500045473. Chelation therapy in RBC transfusion-dependent myelodysplastic syndromes (MDS) patients. Contact: Maria Consuelo del Cañizo, MD. Phone: +34 923 291384.

## UNITED KINGDOM

***Kings College Hospital.*** AZA PH GL 2003 CL 001. A randomized trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of myelodysplastic syndromes. Contact: Professor Ghulam J. Mufti. Phone: 00 44 207-346-3080.

***Kings College Hospital.*** Randomized controlled trial of prolonged treatment with darbepoetin alpha and recombinant

human granulocyte colony stimulating factor (GCSF) versus best supportive care in patients with low-risk MDS. Contact: Professor Ghulam J. Mufti. Phone: 00 44 207-346-3080.

***The Leeds Teaching Hospitals.*** Celgene MDS 004: A multi-centre, randomised, double-blind, placebo-controlled, 3-arm study of the efficacy and safety of 2 doses of Lenalidomide versus placebo in red blood cell (RBC) transfusion-dependent subjects with low or intermediate-1-risk myelodysplastic syndromes associated with a deletion of 5q cytogenetic abnormality. Contact: David Bowen, MD. Phone: 44 113 392 2407.

***The Leeds Teaching Hospitals.*** Novartis 2409: A one-year multi-centre clinical trial evaluating the efficacy and safety of ICL670 (20 mg/kg) in patients diagnosed with transfusion-dependent iron overload. Contact: David Bowen, MD. Phone: 44 113 392 2407.

***The Royal Bournemouth Hospital.*** Multi-centre study of the role of 5-Azacytidine in high risk MDS. Contact: Sally Killick, MD. Phone: 44 (0) 11202 704783.

***The Royal Bournemouth Hospital.*** Multi-centre trial of CEP-701 in older patients with AML. Contact: Sally Killick, MD. Phone: 44 (0) 11202 704783.

***To submit information on your clinical trials for publication, you can fax (609-298-0590) us at the Foundation. Please include a contact person, a phone number, and if applicable, the trial number.***

# Gifts to the Foundation

The MDS Foundation relies entirely on gifts and membership fees to further its work. We would like to acknowledge the generosity of the following individuals and organizations that have recently provided gifts to the Foundation:

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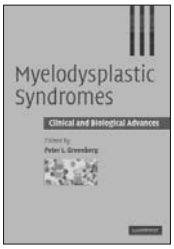
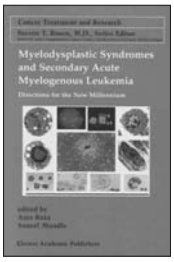



***Myelodysplastic Syndromes: Clinical and Biological Advances***

***Peter L. Greenberg, MD***
**Stanford University Medical Center**
Hardback
Nov. 2005/320pp., illus.
ISBN: 0521496683/$125.00**
Cambridge University press

As the current major comprehensive reference on all aspects of the clinical classification underlying pathogenetic mechanisms and treatment of the myelodysplastic syndromes, Myelodysplastic Syndromes stands out as the definitive text on the genetics, pathophysiology, and clinical management of this wide range of syndromes. Authored by international experts, this book provides a state-of-the-art update of the current status and recent advances in the field. The chapters cover all aspects of the myelodysplastic syndromes, from an in-depth analysis of the multifactorial nature of this disease, including a careful assessment of stromal, immunological and stem cell abnormalities, to a review of recent molecular and cytogenetic discoveries and insights.

This book will be a valuable resource to clinicians and researchers who wish to learn more about myelodysplastic syndromes.

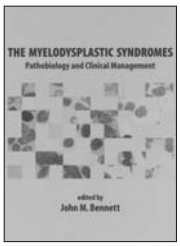



***Myelodysplastic Syndromes & Secondary Acute Myelogenous Leukemia: Directions for the New Millennium* (Cancer Treatment and Research)**

Edited by:
***Azra Raza, MD and***
***Suneel D. Mundle, Ph.D.***

June 2001/278pp., illus.
ISBN: 0792373660/$198.00**
Springer Science + Business Media, Inc.

Myelodysplastic syndromes are to the bone marrow what pneumonia is to the lungs; the response of an organ to a variety of etiologic insults like aging, toxic exposure, infections and auto-immunity. Among infectious causes alone, pneumonia could be the result of a variety of possible pathogens including bacterial, viral, tuberculous or fungal agents. Similarly, MDS cannot be treated as a single disease. Attempts to harness the inherent complexity of MDS by devising "classifications" which group the various syndromes as one disease is as misguided as saying that a pneumonia is not infectious because it did not respond to antibiotics. Progress in the field will occur faster when we re-analyze this premise. Therefore, until a clearer picture of the disease emerges it is best to treat each of the MDS syndromes as a separate entity. Having no classification is better than a misleading one. This book is our attempt to define the most crucial questions related to MDS that need to be addressed immediately through logic, analysis and rigorous experimentation. If the emerging problems appear daunting, then instead of being overwhelmed by them, we should follow the advice of the great 20th century thinker Antonio Gramsci, "pessimism of the intellect must be faced with the optimism of will".




***The Myelodysplastic Syndromes Pathobiology and Clinical Management* (Basic and Clinical Oncology Series/27)**

Edited by:
***John M. Bennett***
**James P. Wilmot Cancer Center of the University of Rochester, Rochester, New York, U.S.A.**

May 2002/528 pp., illus.
ISBN: 0-8247-0782-6/$165.00**
CRC Press. 800-272-7737

This reference provides a comprehensive overview of the latest research detailing the etiology, epidemiology, treatment, and detection of myelodysplastic syndromes (MDS)—identifying effective therapeutic regimens, adverse environmental and genetic factors, and efficient modalities of supportive care that improve patient survival and enhance quality of life.

***To order call MDS Foundation at 1-800-MDS-0839.***

***All prices are in US dollars.*

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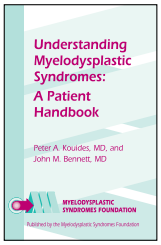
*for North America are $6.00 for the first book and $1.75 for each additional book. Outside North America (only credit card orders accepted) — $9.00 for first book; $5.00 for each additional book.*

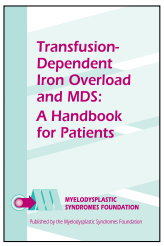
# MDS Educational Resources for Clinicians

## PATIENT INFORMATION AND EDUCATIONAL MATERIALS AVAILABLE FROM THE MDS FOUNDATION




***A. Understanding Myelodysplastic Syndromes: A Patient Handbook***

Peter A. Kouides, MD;
John M. Bennett, MD




***B. Transfusion-Dependent Iron Overload and MDS: A Handbook for Patients***

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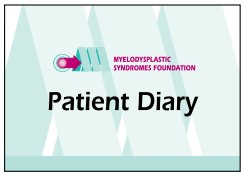


***C. Patient Diary***

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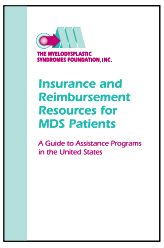


***D. Insurance and Reimbursement Resources for MDS Patients***

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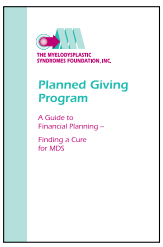


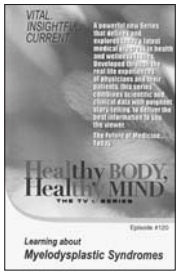

***E. Planned Giving Program***

Published by
The MDS Foundation

*Translations available in Spanish, French, Polish, Czech, Japanese, German and Portuguese.*

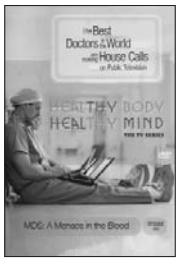

***F. Your Journal: Learning About Myelodysplastic Syndromes (MDS)***

Supported by a grant from
Celgene Corporation.




**G. PBS Program Videotape**

***Healthy Body, Healthy Mind: Learning About Myelodysplastic Syndromes***




**H. PBS Program DVD**

***Healthy Body, Healthy Mind: A Menace in the Blood***

*All of these materials are available free of charge from the Foundation.*

# Now Available through The MDS Foundation

This MDS White Paper discusses comparative data and the potential clinical benefits of treatments that are either approved by the U.S. FDA or the EMEA or are under consideration by these bodies. This paper and a subsequent peer-review manuscript will hopefully assist physicians in matching patients with treatment. Coupled with the Foundation's other endeavors we hope to impact the care that is available to patients around the world.

To download your free pdf copy, visit our website www.mds-foundation.org or, if you prefer, call 800-MDS-0839 to request a hard copy.

# Patient Services

***Angel Flight:*** For nearly 25 years, **Angel Flight** has helped people overcome the obstacle of distance and access to healthcare. Through a nationwide network of 1,500 volunteer pilots, Angel Flight coordinates *free* air transportation for people in need. Angel Flight's generous and compassionate volunteer pilots—men and women from all 50 states with a wide variety of backgrounds—donate flights in their personal general aviation aircraft. Passengers fly *totally free*, as often as necessary and for as long as needed, to reach medical care or for numerous other humanitarian needs. Since 1978, Angel Flight volunteer pilots have flown over 30,000 missions.

In 2002, Angel Flight volunteer pilots provided free air transportation for nearly 9,500 passengers (men, women, and children), saving them over $4 million in commercial travel expenses, helping them reach medical treatment that would otherwise be inaccessible.

Although the vast majority of its passengers fly for medical reasons, Angel Flight pilots also offer free flights for other humanitarian reasons. Each summer, Angel Flight's volunteer pilots distribute the children from Chernobyl to host homes across the U.S. for a two-month summer respite. They also transport hundreds of children to health-related summer camps each year. And, within 48 hours of the terrorist attacks on 9/11/01 and while most aircraft were still grounded, Angel Flight volunteer pilots were in the air transporting emergency service personnel, disaster victims, blood and medical supplies in support of disaster relief efforts in New York City and Washington, D.C.

Angel Flight is a non-profit 501 (c) (3) organization that relies 100% on the generosity of volunteer pilots, as well as individual, corporate, and foundation contributions. Angel Flight is the oldest and largest national volunteer pilot organization in the United States. For more information about Angel Flight, visit www.angelflight.org or call toll-free (888) 4-AN-ANGEL (888-426-2643).

## CONTACT AF:

***Mailing Address***
Angel Flight
3161 Donald Douglas Loop South
Santa Monica, CA 90405

info@angelflight.org

***Phone:***

| | |
|---|---|
| Main number | (310) 390-2958 |
| Toll-Free number | (888) 4-AN-ANGEL |
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***Information***
*General Information*
info@angelflight.org

*Prospective pilot information*
pilotinfo@angelflight.org

*Social worker information*
swinfo@angelflight.org

*Member information*
memberinfo@angelflight.org

***Program Description:***
Since 1978, Angel Flight has helped to ensure equal access to healthcare and improve the quality of life for thousands of people throughout the United States by coordinating free air transportation for those in need.

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1. Transporting people with medical and financial need to reach medical care far from home.
2. Transporting people with time-critical needs associated with a transplant procedure.
3. Transporting precious cargo such as organs, blood, tissue and medical supplies.
4. Providing free air support for disaster relief efforts in times of crisis.
5. Providing flights for numerous other humanitarian needs.

***Funding Source:***
Angel Flight is a national non-profit 501(c)(3), charitable organization funded entirely by tax deductible donations from individuals, foundations and corporations and the generosity of our volunteer pilots who donate the direct costs of every flight. Over 94% of all support and contributions donated to Angel Flight goes directly to program services.

***Volunteer Opportunities:***
Angel Flight is currently seeking volunteer pilots in many areas of the country. For more information, visit www.angelflight.org or call (888) 4-AN-ANGEL.

***Passenger Eligibility:***
Our volunteer pilots fly passengers free of charge and as often as necessary for diagnosis, treatment, and follow-up care, and for other humanitarian reasons.

1. Angel Flight passengers must be ambulatory or need little or no assistance to board and exit the aircraft.
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***Service Area:***
All U.S. states, parts of Canada and Mexico.

***Cost/Fees:***
None, but donations accepted.

***Waiting List:***
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***Target Group:***
Anyone with financial need who needs air transportation.

***Age Range:*** All

***Handicap Access:***
Somewhat, depending on type and size of aircraft.

***Languages:***
English and Spanish



MDS

## About the Foundation

The Myelodysplastic Syndromes Foundation was established by an international group of physicians and researchers to provide an ongoing exchange of information relating to MDS.

Until the Foundation was set up, no formal working group had been devoted to MDS. During the past decade we have conducted eight international symposia—in Austria, England, the United States, Spain, Czech Republic, Sweden, France, and Japan. The Ninth International Symposium is being held in May 2007 in Florence, Italy.

A major Foundation effort is our international information network. This network provides patients with referrals to Centers of Excellence, contact names for available clinical trials, sharing of new research and treatment options between physicians, and extension of educational support to both physicians and patients.

In response to the needs expressed by patients, families, and physicians, we have established patient advocacy groups, research funding, and physician education.

The MDS Foundation is a publicly supported organization, exempt from federal income tax under section 501(C)(3) of the IRS code.

## Our Website

**The MDS Foundation webpage is for healthcare professionals, patients, and other interested people. The Professional Forum and the Patient Forum are integral parts of our website.**

**The website is constantly being updated to better serve the needs of our patients, their families, and the physicians who treat them.**

**We welcome your suggestions.**

**Please visit us at *http://www.mds-foundation.org***

# A Living Endowment

Many families are affected by living with the reality of MDS. There is an extraordinary way to contribute to the MDS Foundation and support our mission of working as a resource for patients, families, and healthcare professionals.

A commitment to donate to the Foundation on occasions of loss, birthdays and anniversary remembrances can be made. Honor your friends or family members on these occasions with a donation, and The MDS Foundation will send an acknowledgment to the recipient, recognizing the occasion.

The MDS Foundation is grateful for community support. Our work as a non-profit organization depends on public funding.

If you would like to contribute in this way, please write to us at:

MDS Foundation
36 Front Street
P.O. Box 353
Crosswicks, NJ 08515

or call us at 1-800-MDS-0839.

**A Living Endowment donation has been made in honor of:**

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# Be a Bone Marrow Donor

For those patients diagnosed with a fatal blood disorder, bone marrow transplantation (BMT) is often the only chance of survival. Related donors provide suitable matches only 33 percent of the time. This leaves nearly 70 percent of patients without a match. The need is especially critical in racial and ethnic minority groups.

Registering as a donor is simple. A blood sample is all you need to enter your tissue type into the National Marrow Donor Program (NMDP) computerized registry. If you are in good health and between the ages of 18 and 55, you can contact NMDP at 1-800-MARROW-2. They will send additional information, including the NMDP center nearest you.

Give the Gift of Life!

**OTHER SITES OF INTEREST:**

**ASBMT™ American Society for Blood and Marrow Transplantation:**
www.asbmt.org

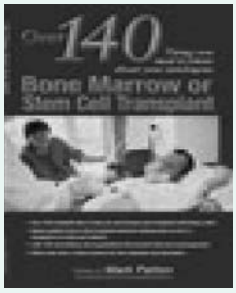
**International Bone Marrow Transplant Registry:**
www.isbmtr.org

**National Marrow Donor Program®:**
www.marrow.org

**Blood & Marrow Transplant Information Network:**
www.bmtinfonet.org

**Blood & Marrow Transplant Resources:**
www.BMTresources.org

*Over 140 Things You Need to Know about Your Autologous Bone Marrow or Stem Cell Transplant* is available online at www.BMTresources.org or call (414) 870-4850, ISBN# 0-9768060-0-2/ Price: $11.95.




Contains over 140 invaluable tips to help transplant patients sail through their procedures.

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# MDS Patient Registry

The patient registry form has been revised and a patient authorization form has been developed to meet the new HIPAA guidelines. The Patient Registry will help further research into the etiology, diagnosis and treatment of MDS. Currently, the MDS Patient Registry is only accepting patients through our designated Centers of Excellence. A two page data sheet will be forwarded to investigators who wish to contribute patient's names to the Registry. The Registry is located at the MDS Foundation's Statistical Center at the University of Rochester Cancer Center. The Foundation looks forward to building the Patient Registry with our Centers of Excellence. If you would like to become a Center of Excellence, please contact The Foundation at the address below.

**The MDS Foundation, Inc.**
36 Front Street
P.O. Box 353
Crosswicks, NJ 08515

Phone: 1-800-MDS-0839 within the US
Outside the US only: 1-609-298-6746
Fax: 1-609-298-0590

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*Bottom (L to R): Dr. Daniela Georgescu, Resident Clinical Hematology; Dr. Radu Gologan, Senior Physician; Dr. Iulia Ungureanu, Medical Representative Schering Company; Gabriela Gavrilescu, Registrar*

*Top (L to R): Dr. Iona Radulescu, Resident Clinical Hematology; Dr. Denisa Bratu, Teaching Assistant in Hematocytology; Dr. Madalina Schmidt, Resident Clinical Hematology; Dr. Didona Vasilache, Researcher in Hematocytology; Dr. Aurelia Tatic, Teaching Assistant Clinical Hematology*

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