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mds news
newsletter of the myelodysplastic syndromes foundation

MDS Join the Journey to Hope

Contents

From the Guest Editor's Desk

Flow Cytometry: Providing Additional Information in Diagnosis, Prognosis and Monitoring Treatment of MDS

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Flow cytometry is only beginning to be used to study patients with MDS. We would like to provide background and an overview of technology, and its basis for assessing patients with MDS which will have increasing importance in the near future in being able to separate MDS from other causes of decreased blood counts.

Flow Cytometry: A 30 Second Primer

The technology of flow cytometry discriminates between different types of blood cells based on the quantitative amounts of unique proteins (and some sugars) found primarily on the cell surface. These proteins are recognized by specific antibodies, each labeled with a different colored fluorescent dye. By incubating the cells with the specific monoclonal antibodies, only the cells which exhibit the target protein become tagged with the fluorescent dyes. The amount of dye is directly related to the amount of the specific protein on that cell which can be detected by the flow cytometer as the cells pass single file through a laser beam. Multiple dyes of different colors can be detected simultaneously along with light scattered by the cells as they traverse the laser light at rates of 500–1000 per second.

The data generated by the flow cytometer can be analyzed by correlating the intensity of each dye along with cell size and cell granularity on each individual cell, resulting in an identifying *phenotype* for that cell. The cell surface proteins or antigens detected by monoclonal antibodies are the final translated products of genes which are highly regulated during maturation from hematopoietic stem cells found in the bone marrow to fully functional mature cells observed in peripheral blood. With proper selection of antibodies, and a careful *multi-dimensional* analysis, it is possible to identify every cell in a marrow aspirate specimen, classifying it to a lineage and a maturational stage within that lineage, and assessing whether or not it displays a normal or an abnormal phenotype.[1,2]

Hematopoiesis (the production of blood cells) can be described as a series of steps with progression from one stage to the next characterized by multiple "intensity" changes in antigenic expression identified by different antibody/dye combinations. In normal developing bone marrow cells, the constellation of antigens and their relative intensities are highly regulated. The changes observed in antigen intensities represent stepwise changes in gene product expression that mark developing cells progress to the next stage. These stages of normal hematopoietic cells are established in fetal life, are invariant with age and remain intact in stressed or regenerating bone marrow, following chemotherapy and even after stem cell transplantation.

Phenotypic Changes in MDS Bone Marrows

Once the patterns of gene product expression during the development of normal blood cells were elucidated, a comparison to the patterns on leukemia cells showed that these neoplastic cells did not match the normal relationships. Every leukemia analyzed by flow cytometry was found to be different from normal and different from other similar leukemias, i.e., the intensities and relationships between antigens (the leukemic phenotype) were unique to individual patients. The *differences* in intensities of antigens on the leukemia as compared to normal cells provided a "tumor specific marker" that can be used to monitor response to chemotherapy and to detect residual disease following treatment.

The flow cytometric assessment of acute (and chronic) leukemias consists of evaluating the major, usually homogenous, neoplastic cell population. When used in a diagnostic role for unexplained cytopenias in suspected MDS, the manner in which the technology is applied changes. Instead of detecting a major abnormal immature cell population (found in leukemia), the approach becomes a search for a more subtle abnormality causing, or related to, the inadequate production of hematopoietic cells resulting in the cytopenia. This requires evaluation of subsets of abnormal cells such as monocytes, maturing myeloid cells, and myeloblasts present in the bone marrow as the abnormalities in protein expression are found not only on the immature cells (blasts) but also on the more mature cells. In this manner, flow cytometric data for MDS must be used in the same way as a morphologic review of an aspirate smear, comparing the features of normal (non-neoplastic) bone marrow elements to their neoplastic counterparts. In a morphologic analysis, each lineage is examined to determine the frequency of cells, the degree of maturation, and suspected abnormalities observed relative to previous knowledge of cytologic appearance. Likewise, a flow cytometric approach requires an intimate knowledge of which antigens are present on each lineage, at each maturational stage, and how their expression is related to other cellular antigenic markers. Multiple studies have shown that the multiple antigenic profiles, or "phenotypes," of bone marrow cells in patients with MDS exhibit differences from the patterns identified in normal bone marrow, not only among the blast cells, but also on the maturing myeloid cells and monocytes.[3-12] The variability in published reports on flow cytometry in studying MDS is due, in part, to the uniqueness of each patient and which antibodies are used to distinguish between the normal presentation of antigens and those observed on each unique patient.

Because of the extensive variability from patient to patient as well as the changes that occur over time for an individual patient, single specific antigenic changes are not sufficient to fully capture the abnormalities present.[13,14] The abnormalities observed are not just in the expression of single antigens but affect the relationships between multiple antigens. Hence, a multidimensional approach is required to relate all cell proteins to each other. This analysis must distinguish between a stressed normal marrow (with an increase in more immature forms called a shift-to-the-left) from a true uncoupling of the co-regulation of gene products as evidenced by abnormal antigens present in neoplastic processes that may occur at any of the developmental steps.[5,15]

In addition to abnormal increase or decrease in intensity of antigens, the types of abnormalities observed in MDS include inappropriate lineage expression (lymphoid antigens on myeloid cells), asynchronous expression where antigens normally identified on immature cells appear on mature cells, and complete absence of antigen expression (possibly due to complete loss of the gene, regulators, or over-inhibition).[16] Other abnormalities detected by flow cytometry can be observed. Physical changes of cell size and decreased cellular granularity are often observed in MDS marrows.

Flow cytometric analysis (focusing on normal/abnormal blasts, myeloid and monocyte development) can be a complimentary addition to a morphologic analysis of bone marrow in facilitating an accurate diagnosis. Dyspoietic features in the erythroid and megakaryocytic lineages are often prominent by morphology, whereas the assessment of abnormal myeloblasts, maturing myeloid cells and especially monocytes, is more difficult by morphology.[17] Flow cytometry, however, focuses on these maturing leukocytes. Together the two technologies can provide a better total picture of the bone marrow in MDS patients. At present, technical considerations limit the analysis of erythroid and megakaryocytic cells by flow cytometry.

Identifying, Enumerating and Classifying Blasts

Flow cytometry has a distinct advantage over morphology for blast cell enumeration because of the ability to count many more cells (10,000–100,000 or more as opposed to 300–500 cell analyzed by microscope) and a definable set of cellular characteristics that can be used to identify the cells, and is potentially less subjective than morphologic criteria of defining what constitutes a blast. Since several different combinations of antibodies can be used to discriminate the myeloblasts, it has been recommended that a phenotypic blast count should be obtained using multiple combinations of antigenic markers, comparing the results for consistency and as an internal quality control check of the data.[5] When applied to MDS, the identification and enumeration of blasts must incorporate the multiple antibody combination approach since the process of neoplastic transformation may involve the loss of one or more of the antigens used to classify the cells as immature. The use of 3 or more combinations of antibodies to define a flow cytometric blast provides a redundant system with internal controls for the loss or inappropriate expression of any one of the markers. Flow cytometric blast

counts are expressed as per non-erythroid cell, i.e. per CD45 positive cell, because of the requirement to remove erythrocytes from the analysis.

In addition to being able to count blasts, a precise phenotypic analysis distinguishes normal from abnormal blasts not only for higher blast counts but also for blasts less than 5%. A study of low grade MDS comparing the phenotype of only the CD34 positive cells (progenitor cells) showed that over half of the patients with morphologic blasts less than 5% showed phenotypic abnormalities.[8] Similar results were obtained in separate studies in which abnormalities on the blast population (defined in multidimensional space) were also found on a majority if not all of cases, independent of the maturing myeloid cells.[17,18] The detection of abnormalities on the myeloblast population, even at low levels, is clear sign of some transformation or genetic dysregulation and may identify patients with unexplained cytopenias as having MDS.

Measuring Phenotypic Dyspoiesis

Since no single antigenic abnormality has been correlated to an accurate diagnosis or prognosis of MDS, counting the number of abnormalities observed for each patient provides a means of measuring how far the marrow has evolved from normal, providing additional prognostic information for that patient. The assumption is that a patient with multiple phenotypic abnormalities, reflecting more extensive loss of gene product regulation, has progressed further than a patient with fewer abnormalities. One scoring system was devised based on experience of comparing the patterns of antigen expression for MDS patients to stressed non-neoplastic marrows assessed early post stem cell transplant (SCT) or for patients with previously treated Hodgkin lymphoma, aplastic anemia or bone marrows following chemotherapy for non-hematologic diseases.[12] The flow score generated was inversely correlated to absolute neutrophil count, and was directly related to the International Prognostic Scoring System (IPSS)[19] score indicating the number of abnormalities was related to decreased neutrophil production and to other, well documented clinical findings (i.e., karyotype, number of cytopenias, and blast count). The scoring system was useful in distinguishing normal/stressed marrow control patients from MDS patients. The flow score was also highly correlated to the relapse rate and survival post allogeneic SCT. Moreover, patients with an Intermediate 1 category by IPSS were further stratified by the flow score with significantly worse prognosis post transplant than those observed with the higher flow scores. This study suggests that the amount of dysregulation in gene product expression (number of antigenic abnormalities) correlates with more severe disease and that the extent of dysregulation may be an entirely independent parameter apart from the features included in the IPSS.

The notion of accumulated dysregulation has been extended in a multicenter study of recently diagnosed patients with MDS using similar panels and based on the above scoring system.[17] A significant number of patients with a morphologic classification of refractory anemia (RA) in the World Health Organization (WHO) classification[20] were identified as having aberrancies on the maturing myeloid cells or monocytes; therefore more appropriately classified as refractory cytopenias with multilineage dysplasia (RCMD). This suggests that flow cytometric analysis may be more sensitive to dysplastic features on the myeloid cells or monocytes as compared to morphology. A significant correlation was observed between the flow cytometric score and the WHO classification. The flow cytometric score was not related to specific cytogenetic risk groups but was related to the overall IPSS and to the WHO classification-based prognostic scoring system (WPSS).[21] The flow cytometric score correlated with transfusion dependency and disease progression to RAEB-1 within 18 months. The expression of lymphoid antigens on the myeloblasts was also related to transfusion dependency.

These quite different studies suggest that accumulation of expressed phenotypic abnormalities is a distinct, independent parameter for assessing patients with MDS that may further subdivide the heterogeneous group of patients with respect to clinical outcomes.

Monitoring Treatment

A bone marrow analysis in MDS is an observation at any given time point and reflects the kinetics of what is happening to maintain the status of the cells in the periphery. In MDS, there may be neoplastic populations that are surviving, or cells that are undergoing programmed cell death or apoptosis. A neoplastic clone may be able to suppress normal cells either by increasing their numbers or by becoming over or under sensitive to growth factors or cytokines expressed by lymphocytes and macrophages present in the marrow. In addition, neoplastic cells may achieve immortality by escaping immune surveillance.

At later time points, there can be any permutation of the cell populations previously observed, particularly with treatment. With the development of new treatment strategies in MDS, the response to chemotherapy may be monitored by flow cytometric scoring, quantitatively evaluating the proportion of abnormal myeloblasts and determining the number of abnormalities in the maturing myeloid cells and monocytes. New drugs such as lenalidomide, bevacizumab, drugs interfering with signal transduction pathways, e.g. farnesyl transferase inhibitors, demethylating agents such as 5-azacitidine and decitabine for treatment of low and intermediate-1 risk MDS require advanced flow cytometric methods to identify patients who may benefit from these therapeutic strategies.[13] Recent data has shown that flow cytometry scores decreased during treatment with erythropoietin and antithymocyte globulin.[22,23]

Future Endeavors

In order for flow cytometric data to be routinely used in the management of MDS patients, consensus must be obtained for

counting myeloblasts using standard antibody panels and protocols that also extend to the enumeration of abnormal blasts. It will be necessary to define reproducible criteria to discriminate normal from abnormal myeloblasts to aid in diagnosis of early stage MDS. The assessment of antigen expression on maturing myeloid cells must also be standardized defining what constitutes an abnormal feature. Therefore, large clinical studies must be completed to better define weighting factors that can be used for each abnormality that can be used to generate a flow score that is easy to obtain, is highly reproducible, consistent from laboratory to laboratory and is useful in both diagnosis and prognosis of MDS patients.

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From the Operating Director's Desk

Kathy Heptinstall
Operating Director
The MDS Foundation

There has been an emergence of new and expanding groups working in MDS and meetings have been held or are scheduled in many of the nations outside Asia and Western Europe. This is a welcome addition to the landscape of MDS knowledge and research.

During 2007 the initial Latin American Symposium on Myelodysplastic Syndromes was held in Fortaleza, northeastern Brazil from September 28th–29th. This meeting was chaired by Silvia M. M. Magalhães, MD and Fernando Barroso Duarte, MD of the Federal University of Ceará–Brazil. Approximately 240 participants attended this long anticipated program. The 2nd Symposium on Myelodysplastic Syndromes will be held in Buenos Aires on November 20–21, 2008. The MDS Foundation is very pleased to support the work of this important group and looks forward to participating in this meeting.

In October 2007, the Foundation participated in the 1st Symposium on MDS Romania. The symposium was held by the Association of MDS Physicians in Romania and was co-Chaired by Radu Gologan, MD of the Fundeni Clinical Institute of Bucharest. The meeting was extremely well attended by many Romanian physicians and nurses. The need for information about MDS and for patient support materials was evident in the activity at the MDS booth. In conjunction with this meeting an MDS Patient Forum was held and more than 30 patients and caregivers attended. The Commission of Oncology Patients in Romania assisted the Foundation in recruiting patients to attend this meeting. The issues that MDS patients in Romania face are very much the same as those that patients living with MDS worldwide face.

The Foundation was privileged to participate in a meeting of Russian physicians that was held in Moscow in May 2007. This important meeting was held to educate physicians regarding MDS and the emerging treatment options in MDS. We would like to thank the organizers including Professor Valeriy Savchenko and Assistant Professor Elena Parovichnikova for the opportunity to connect with these physicians and provide information to both the physician attendees and their patients.

In 2008 the Foundation will also participate in the meeting of the Czech and Slovak Hematology in Spindleruv Mlyn on September 5–9, 2008. There will be concurrent sessions for physicians, nurses, and pharmacists. The anticipated attendance is more than 2,000. We look forward to the opportunity to reach this important group and the patients that they serve.

Many of the physicians who worked to develop these meetings are participants with the Foundation as both members of the Foundation and as part of our Centers of Excellence in MDS from their respective countries. Many of them have worked with the Foundation since our inception in 1994 or before the formalization of the Foundation (as is the case with our Brazilian physician friends) and we value their participation and support of our work.

The Foundation looks forward to continuing our collaboration with these groups and partnering with and supporting other emerging MDS organizations in order to expand the reach of the Foundation to all corners of the world.

Practice and Treatment Survey

The Myelodysplastic Syndromes Foundation would like to know more about your approach to the diagnosis and treatment of patients with MDS. Please assist us by completing a brief online survey.

Go to www.mds-foundation.org and click on Practice & Treatment Survey.

MDS Young Investigator Grants Program

MDS Young Investigator Grants Award Reception

In December 2005 the Myelodysplastic Syndromes Foundation, Inc. initiated a series of grants for The Young Investigator's Grant Fund for Fellows in Hematology from institutions that form the Myelodysplastic Syndromes (MDS) Centers of Excellence. Two awards will be granted annually.

This year's recipients were honored at a reception on December 7th in conjunction with the American Society of Hematology's annual meeting. The Grant Review Committee selected Klas Raaschou-Jensen of Copenhagen University Hospital in Denmark for his grant submission entitled "Identification and Characterization of the Genetic Background in a Unique Danish Family with Several Cases of Hypoplastic Myelodysplastic Syndrome" and Azim Mohamedali of Kings College London in the United Kingdom for his submission entitled "Prevalence and Pathogenetic Significance of Uniparental Disomy on Chromosome 4q in RARS." As this year's recipients, each was awarded a $40,000 grant for continued research.

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.

All MDS Centers of Excellence are invited to nominate one candidate from their institution. A mandatory brief letter of intent (LOI) is to be submitted no later than June 16, 2008. The LOI 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. A formal application will be sent to you shortly after receipt of the LOI and will be due no later than August 15, 2008. Notification of the awards will occur by October 1, 2008 with activation on January 1, 2009. These awards will provide $40,000 over a 24-month period from January 1, 2009 to December 31, 2010.

(Pictured L to R) Robert J. Weinberg; Stephen Nimer; Eva Hellström-Lindberg; Klas Raaschou-Jensen; Azim Mohamedali; John Bennett; Ghulam Mufti; Kathy Heptinstall

THIS YEAR'S TIMELINE

Letters of Intent Due: June 16, 2008 ***Proposals Due:*** August 15, 2008

Notification of Awards: October 1, 2008

MDS Foundation-Moffitt Cancer Center Celebrity Gala Party and Pro-Am for MDS

February 17–18, 2008

Innisbrook Resort & Golf Club
Copperhead Course
Tampa Bay, Florida

We are grateful to all of our old friends and our new ones who helped make our annual golf tournament partnership with H. Lee Moffitt Cancer Center such a huge success. We would also like to thank our co-hosts, PGA Champions Tour Professional Bruce Fleisher and NFL Hall of Fame Quarterback Bob Griese who were joined by PGA/LPGA Tour Professionals and many other pro and celebrity guests. We sincerely appreciate the donation of their time and knowledge by our celebrity guests.

On Sunday night, guests attended the VIP Gala where they got to swing into action for MDS by dancing to the sounds of the legendary Hall of Fame Vocal Group, *The Memories* as well as bid on spectacular auction items including golf packages, and rare autographed memorabilia. The $10,000 putting contest was a hit with the golf enthusiasts and the food was scrumptious.

On Monday participants enjoyed the golf clinic, and rounds of golf where they got a chance to play along with professional athletes such as Fred "Crime Dog" McGriff, Mitch Adcock, Dale Eggeling, and P.T. Willis, to just name a few. This was followed by the awards luncheon where guests were

treated to a video montage highlighting the plays of the day.

Participation in this worthwhile event helps fund the Foundation's Young Investigator Grants program. Moffitt Cancer Center serves one of the nation's largest state populations of patients with MDS. Our partnership with H. Lee Moffitt Cancer Center will not only foster regional awareness and understanding of MDS but also raise funds for basic research that will fuel new therapeutic developments. These grants are awarded on an international level to encourage young hematologists to specialize in MDS. After four years, the proceeds from this tournament have funded 6 two-year Young Investigator Grants totaling $240,000.

We thank all the participants who joined "The Journey to Hope" for MDS patients around the world and we look forward to seeing you next year!

MDS Essentials E-Newsletter

The Foundation has created a new electronic E-Newsletter to provide healthcare professionals and patients from around the world with timely information, in a cost-effective manner. The MDS Essentials E-Newsletter is the electronic version of our quarterly newsletter. Receive up-to-date information on clinical trials, research and news by simply subscribing online at:

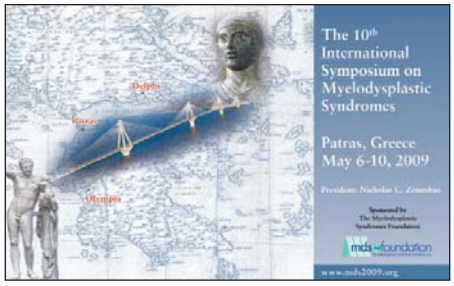
www.mds-foundation.org.

Foundation Initiatives for 2008 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:

- **ADOPT REGISTRY**

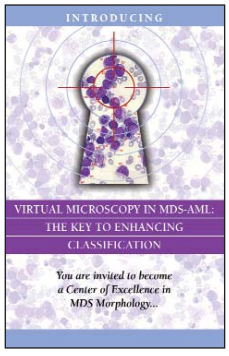
- **PATIENT QUALITY-OF-LIFE FORUMS**
- **WORLDWIDE PATIENT SUPPORT GROUPS**
- **10TH INTERNATIONAL MDS SYMPOSIUM, PATRAS, GREECE: May 6–10, 2009**



BECOME A CENTER OF EXCELLENCE IN MDS MORPHOLOGY

VIRTUAL MICROSCOPY IN MDS-AML: THE KEY TO ENHANCING CLASSIFICATION

A CME Series



http://www.mds-foundation.org/virtualmicroscopy/home.html

- **ADDITIONAL PROGRAMS**
  - – Keys to Identifying Patients at High Risk for Bone Marrow Failure Syndromes: Is it MDS?
  - – MDS Practice and Treatment Survey
  - – The International Working Group on MDS Morphology
  - – The International Working Group on MDS Cytogenetics
  - – The International Working Group on Quality of Life in MDS

CME PROGRAMS

Understanding MDS – A Primer for Practicing Clinicians: An 8-Part Series

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.

The first four segments of this eight segment series are currently available:

Segment 1: The Past & Present in MDS

Segment 2: Clinical Presentation, Diagnosis & Pathology

Segment 3: Ineffective Hematopoiesis: Considerations in Diagnosis and Treatment

Segment 4: Anemia in MDS: Survival, QoL, and Treatment Options

Written programs are available in English, Spanish, French, Italian, German, Japanese.

- CE Awareness Program for Nurses
- CE Awareness Program for Pharmacists

MDS FOUNDATION SPONSORS

The MDS Foundation acknowledges support from:

Celgene · NOVARTIS · Eisai · JANSSEN-CILAG · genzyme · AMGEN · OVATION Pharmaceuticals, Inc.

Meeting Highlights and Announcements

Changing the Characterization of MDS: Diagnosis to Therapy

December 7, 2007
Atlanta, Georgia

MDS Satellite Symposium held at The American Society of Hematology 49th Annual Meeting and Exposition

Georgia World Congress Center

The MDS Foundation held its 10th consecutive satellite symposium on Friday preceding the American Society of Hematology's annual meeting. This symposium entitled "*Changing the Characterization of MDS: Diagnosis to Therapy*," was chaired by Dr. Stephen D. Nimer of Memorial Sloan-Kettering Cancer Center in New York and a member of the Foundation's Board of Directors. The accurate categorization of MDS patients and the predictive course of their disease as well as the appropriate selection of their individual therapy rely on the treating physician's knowledge of the pathogenesis of MDS, as characterized by clinical parameters, laboratory studies, bone marrow morphology, and chromosomal status. This symposium focused on the ever unfolding morphologic and response assessment criteria, the impact of karyotypic abnormalities and acquisition of new abnormal karyotypes as they relate to disease progression, current molecular genetic research on therapeutic targeting of the epigenome, the need for targeted therapies and combination therapies, and the evaluation of therapeutic interventions based upon disease stability or progression. More than 1500 people attended this symposium.

The topics and international faculty for this symposium included:

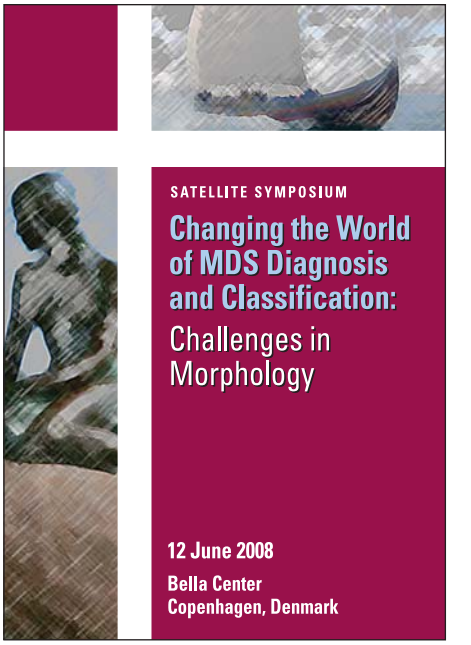
- **Issues in Prognostic Stratification**
  Ulrich Germing, MD
  Heinrich-Heine Universität
  Düsseldorf, Germany
- **What's Beyond Morphology?**
  Denise Wells, MD
  Hematologics, Inc.
  Seattle, Washington
- **Issues in Combination Therapies In MDS**
  Allen Yang, MD, PhD
  University of Southern California
  Los Angeles, California
- **Immunologic Abnormalities in MDS**
  Jaroslaw Maciejewski, MD
  Cleveland Clinic Foundation
  Cleveland, Ohio
- **MDS Molecular and Cytogenetic Characterization**
  Stephen D. Nimer, MD
  Memorial Sloan-Kettering
  New York, New York
- **Highlighting the Newest Trends in MDS Research**
  John M. Bennett, MD
  University of Rochester
  Rochester, New York

If you would like a copy of the CD-ROM containing the video and slide presentations from this symposium you can contact The MDS Foundation, 36 Front Street, P.O. Box 353, Crosswicks, NJ 08515, Tel. 800-MDS-0839 or visit our website www.mds-foundation.org.

PLAN TO ATTEND

Changing the World of MDS Diagnosis and Classification: Challenges in Morphology

June 12, 2008
Bella Center
Copenhagen, Denmark



MDS Satellite Symposium to be held at the 13th Congress of the European Hematology Association (EHA)

Topics for the symposium and faculty speakers will include:

- **MDS Morphology: An Evolution in Criteria**
  Ghulam J. Mufti, MD
- **New Morphologic Definitions in MDS and Virtual Microscopy**
  John M. Bennett, MD
  Jean E. Goasguen, MD
- **Interactive Participation in Morphologic Diagnosis**
  Faculty/Participants

PLEASE MAKE SURE TO VISIT THE MDS FOUNDATION BOOTH #2.013

Evolving Diagnostic Tools and Treatments in MDS

May 16, 2008
Philadelphia Marriott Downtown
Philadelphia, Pennsylvania

MDS Satellite Symposium held at the 33rd Annual Congress of the Oncology Nursing Society (ONS)

The MDS Foundation recently presented an adjunct symposium held in conjunction with the 33rd Annual Congress of the Oncology Nursing Society (ONS) in Philadelphia, Pennsylvania.

Topics for the symposium and faculty speakers included:

- **Welcome and Introduction**
  John M. Bennett, MD
  University of Rochester
  Rochester, New York

- **The MDS Foundation and Quality of Life**
  Kathy Heptinstall, BSN, RN
  The MDS Foundation, Inc.
  Crosswicks, New Jersey

- **Improving the Classification and Prognostic Stratification of MDS Patients**
  John M. Bennett, MD

- **Evolution in MDS Research and Treatment**
  Lewis Silverman, MD
  Myelodysplastic Disease Center and the International Myeloproliferative Disease Clinical Consortium
  Mount Sinai Medical Center
  New York, NY

- **Expanding Your Impact on Patient Outcomes: Tracking Treatment**
  Erin Demakos, RN, CCRC
  Mount Sinai Medical Center
  New York, NY

If you would like a copy of the CD-ROM containing the video and slide presentations from this symposium you can contact The MDS Foundation, 36 Front Street, P.O. Box 353, Crosswicks, NJ 08515, Tel. 800-MDS-0839 or visit our website www.mds-foundation.org.

International and Country Congresses and Emerging MDS Societies

International Congresses

In order to promote awareness and education for patients and healthcare professionals, the MDS Foundation booth will be at the following country society and international meetings to distribute information:

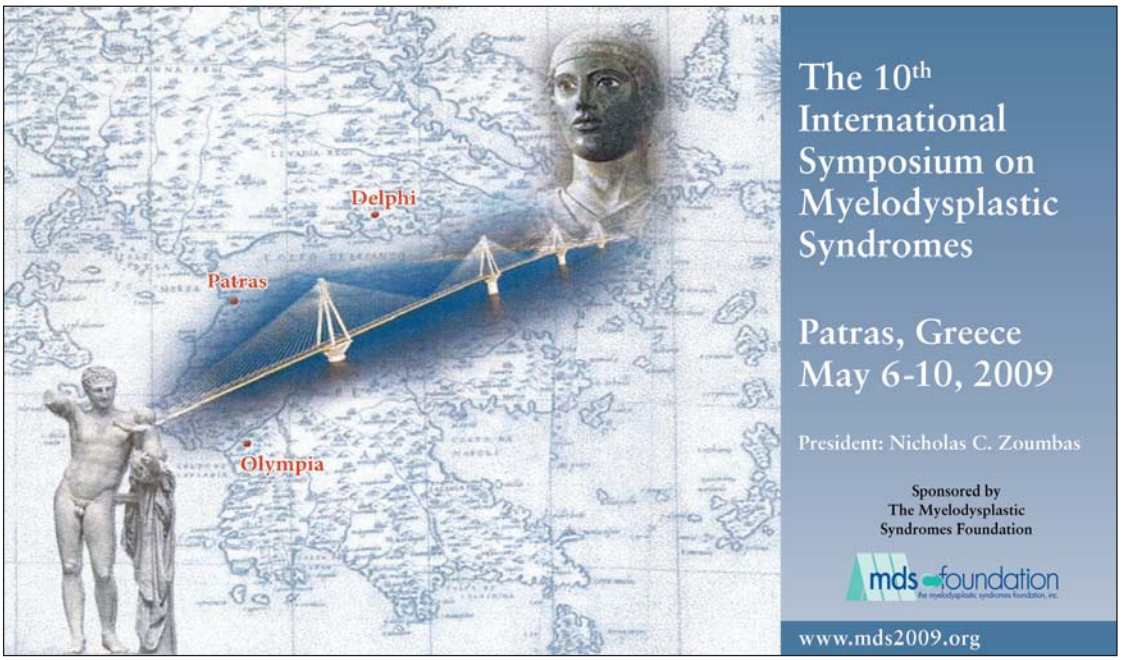
- American Psychosocial Oncology Society
- Oncology Nursing Society
- American Society of Clinical Oncology
- BIO International Convention
- International Society of Experimental Hematology
- American Society of Clinical Pathology
- American Society of Hematology
- European Oncology Nursing Society
- European Group for Blood and Marrow Transplantation
- British Society for Hematology
- European Hematology Association
- International Society of Hematology

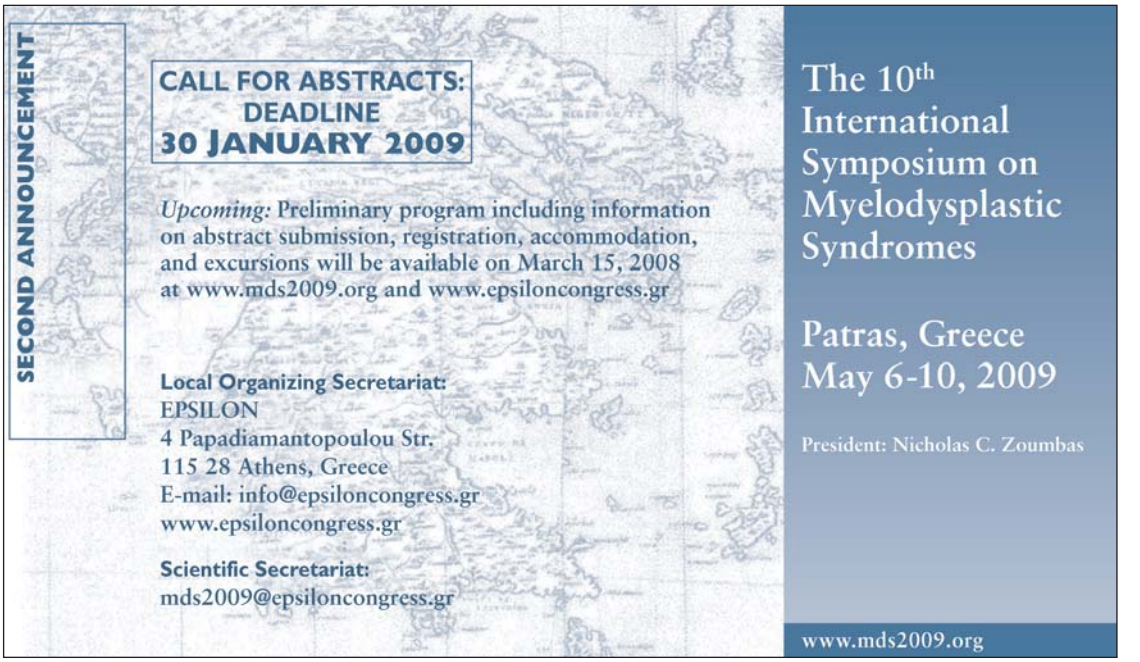
European MDS Societies

- Belgian Hematology Society
- Budapest MDS Group
- Dutch Haemato-Oncology Association
- German Society for Hematology
- Slovenian Hematology Congress
- Nordic Society of Hematology
- Baltic Congress on Hematology
- Groupe Français des Myélodysplasies
- Czech & Slovak Congress in Hematology
- Romanian Society of Hematology
- Society of Portuguese Hematology
- Turkish Society of Hematology
- LOSEV – Ankara Türkiye Losemili Cocuklar Vakfi

Foundation Plans International Symposia Through 2013

The MDS Foundation has approved applications for the next three International Symposia. These symposia are scheduled for 2009 in Patras, Greece; 2011 in Edinburgh, Scotland, and 2013 in Berlin, Germany.





Tenth International Symposium: Spring 2009

Patras, Greece

Sponsor:
Nicholas C. Zoumbos, MD

Eleventh International Symposium: Spring 2011

Edinburgh, Scotland

Sponsor:
David T. Bowen, MD

Twelfth International Symposium: Spring 2013

Berlin, Germany

Sponsor:
Wolf-Karsten Hofmann, MD, PhD

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, DC.

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.

Contact Angel Flight

Mailing Address:

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

E-mail: info@angelflight.org

Phone:

Main: 310-390-2958

Toll-Free: 888-4-AN-ANGEL

Automated Voice Mail:
310-398-6123

24-Hour Emergency Response:
310-317-1000

Fax: 310-397-9636

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.

Services Provided:

Angel Flight coordinates the following services:

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.
2. Passengers must be medically stable and able to fly in an unpressurized aircraft.
3. Passengers must demonstrate financial need.

Application Method:

To request a free flight, just call toll-free 888-4-AN-ANGEL. In urgent situations, a coordinator can be paged after normal business hours. Just call 888-4-AN-ANGEL and follow the paging instructions on the voice mail message.

You may also request a flight by visiting www.angelflight.org.

Additional Information:

Service Area: All U.S. states, parts of Canada and Mexico

Cost/Fees: None, but donations accepted.

Waiting List: None, but 1–2 weeks advance notice is preferred.

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

Patient Forums and Support Groups

Spreading the Word Worldwide – Patient Quality-of-Life Forums

Patient forums have been held to date in:

UNITED STATES

- New York City, New York
- Tampa, Florida
- Palo Alto, California
- Scottsdale, Arizona
- Chicago, Illinois
- Philadelphia, Pennsylvania
- Pittsburgh, Pennsylvania
- Oak Brook, Illinois
- Dallas, Texas
- Seattle, Washington
- Covina, California
- Rochester, Minnesota
- Baltimore, Maryland
- Rochester, New York
- Los Angeles, California

EUROPE

- Edinburgh, Scotland UK
- Paris, France
- Bournemouth, England UK
- London, England UK
- Leeds, England UK
- Marseille, France
- Vienna, Austria
- Prague, Czech Republic
- Stockholm, Sweden
- Freiburg, Germany
- London, United Kingdom
- Florence, Italy
- Dubrovnik, Croatia
- Sinaia, Romania
- Toulouse, France

Future forums are scheduled in:

- Lund, Sweden – June 9, 2008
- Copenhagen, Denmark – June 10, 2008
- Boston, Massachusetts (TBD)

On October 26th, 2004 we held our first MDS Patient Forum in New York City. Since then we have held 34 worldwide. Patients participate in a study group and share their experiences living with MDS and the quality-of-life issues that they face. They are also given the opportunity to participate in a question and answer session with an MDS specialist. The information we develop is used to educate healthcare professionals about MDS from the patient's perspective.

Established MDS Patient Support Groups

UNITED STATES

- Chicago Illinois Support Group meets on the fourth Tuesday of the month from 1:30–3:00 pm at Northwest Community Hospital's Cancer Service department (lower level), 800 W. Central Road, Arlington Heights, Illinois. Contact Kim Jensen at kjensen@nch.org or call 847-618-6914.
- Puget Sound, Washington Support Group meets on the third Tuesday of the month at 6:30 pm at the Puget Sound Blood Center, 921 Terry Avenue, Seattle, Washington. Contact Steve Kessler at steve@ Qamonline.com or call 800-877-0168.
- San Francisco Bay Area Support Group meets on the second Sunday of the month at 2 pm at the Park Blvd. Presbyterian Church, 4101 Park Blvd., Oakland, California. Contact 800-MDS-0839 for more information.

EUROPE *(Countryside Groups)*

- France: Association Connaître et Combattre les Myélodysplasies
- United Kingdom: UK MDS Patient Forum
- Croatia: Croatian Association of Leukemia and Lymphoma Patients
- European Cancer Patient Coalition (ECPC)

GIVE A GIFT OF HOPE...

Journey to Hope Bracelet

Lovin' Kisses Beading
Promoting MDS Awareness

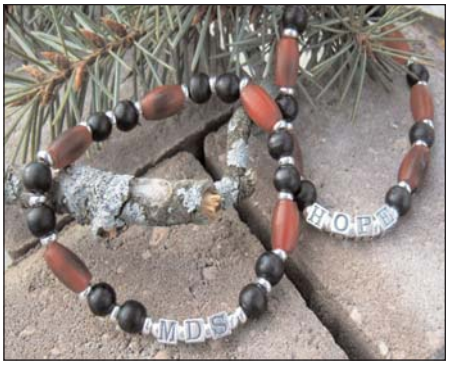
Sandy Madrigal, Designer/Creator
P.O. Box 2541
Davenport, Iowa 52809-2541

Visit www.lovinkissesbeading.com.

This handcrafted bracelet was created to draw attention to Myelodysplastic Syndromes. My design is dedicated to the loving memories of my mother, Betty and my sister, Linda. They were diagnosed with MDS, just eight weeks apart. Both fought the disease bravely and with great dignity.

Now, I'm doing what I can to continue their fight. Each bracelet is only $20.00 (plus S&H). Visit my website for details. A portion of the proceeds from the sale of my bracelets will be donated to The MDS Foundation, to help further their research and create awareness.

Women's Journey to Hope Bracelet



Men's Journey to Hope Bracelet

Living with MDS...

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!!!

My Story...

Eugene "Gene" Temple

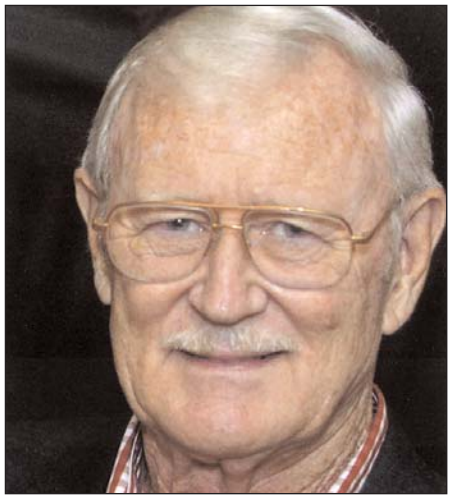
My name is Eugene Temple and I am an eighty year old retiree, formally engaged in a pest control business for thirty-five years. Unfortunately, years ago, safety standards were not practiced as much as they are today. I handled benzene petroleum products on a daily basis. I was diagnosed with MDS approximately three or four years ago.

I have been treated with Procrit, Aranesp, Leukine, and Neupogen administered to me in the early MDS stages. I have had eight blood transfusions over a period of several months, each of two units at approximately three week intervals. Unfortunately, these transfusions brought on side effects of iron overload. A chelate drug called Exjade was prescribed and took approximately four months to expel the iron overload in my system.

During this difficult time, I kept in touch with Audrey at the MDS Foundation and found her most helpful and reassuring. I later offered to discuss my treatment (going on seventeen months now) with any new patients about to start treatment with Vidaza — considering it was a relatively new chemo drug.

I have since taking Vidaza received several phone calls from people living in Florida, to as far away as Anchorage, Alaska. I answered their questions to the best of my ability, hoping to relieve any feelings of anxiety they may have, as I had experienced in the beginning of my treatment. I wish them all the best! Just to stand in the shower for five minutes without fear of collapsing, how great is that!!!

I wish to thank the Foundation for allowing me to express my gratitude. I also wish to continue to offer possible comfort to any new patients (with expectations of improving their present condition) by sharing my personal experience.



MDS patient Gene Temple shares his story

I wish to thank the Foundation for allowing me to express my gratitude. I also wish to continue to offer possible comfort to any new patients (with expectations of improving their present condition) by sharing my personal experience.

While understanding MDS is at present a disease with no quick cure in sight, Vidaza has improved the quality of my life by tenfold. Vidaza has been my salvation! Kudos to all the researchers that put the quality of life first and foremost, and to the MDS Foundation for giving out the latest updated treatment information available to the public.

In closing, I wish to announce that my blood counts are presently up and life is sweet. I am eternally grateful to my Heavenly Father for giving me "one day at a time".

Respectfully,

Eugene "Gene" Temple

MDS Fundraiser Original One-Act Musical a Success

Canton, Michigan

On January 12th and 13th, an original one-act musical, *Behind the Curtain*, opened to a full house in the Biltmore Studio at The Village Theater at Cherry Hill in Canton, Michigan. The show, a lighthearted musical about two people that meet working props at a community theater show rehearsal, was written by Linda Pohl with Tim Chanko as the composer of the music and lyrics. The actors in the play were Tim Chanko, Stefanie Mallasch, Christopher Tremblay and Joe Cone. The crew consisted of Linda Pohl, director, Betty Berryman, assistant director, Kelvin Elvidge handled the lighting and Janet Carson was the pianist.

The show was free to attend, although donations were accepted. The money collected, over $600, was then divided between the American Cancer Society and the MDS Foundation.

Linda and Tim wrote the show over a period of two years. It took almost another year to find a place to perform. They wanted to do the show as a fundraiser and picked the two organizations because Linda's son, Mike Nelley, is afflicted with both conditions. They also received informational brochures to display at the table that held the donation jar to help raise awareness of MDS.

Mike Nelley, Linda's 21-year old son, has MDS

Miracle Workers

David Rieff

Even today, in our high-tech, accountability-obsessed and, supposedly at least, patient-empowered times, the oldest of all relations between patient and physician—that of supplicant to shaman—continues to exert its authority. This may not seem sensible if the only valid criterion for judging the doctor-patient relationship is the use that is made of scientific data and clinical findings. But good doctors want to treat their patients, not just their patients' diseases, and certainly most patients want to be treated as human beings, not cases. Viewed from that perspective, the elevated expectations patients bring to the consulting room may be for the best.

When my mother found out she had myelodysplastic syndrome, the terrible blood cancer that eventually took her life, she oscillated between numb despair and acute panic. When she was panicked, nothing those who loved her did or said could calm her down, let alone console her. And yet we soon learned that if we could reach Stephen Nimer, her principal physician at the Memorial Sloan-Kettering Cancer Center, by telephone, or if, better still, Dr. Nimer could make time to see my mother, however briefly, her awful distress would abate—at least for a while.

Observing my mother's exchanges with Dr. Nimer, I could not help wondering why what he said consoled her. For he never played down the lethality of her disease, nor did he hold out false hope. Doubtless, Dr. Nimer's long experience with gravely ill people, the hard-won human skills he acquired over decades of practice, played a central role. But it was my sense at the time, and it is my sense now, more than three years after my mother's death, that the comfort my mother derived from speaking with him was also due to her own conception—her very traditional conception—of their relationship.

She was a person who had no time for so-called alternative medicine, nor did she believe that her will would somehow be strong enough to counter the scientific realities. And yet, when all was said and done, I think that my mother's relationship with her principal doctors can only be fully understood—and was only fully effective—because it was in some ways as shamanistic as the relations our ancestors knew before the advent of modern scientific medicine.

Of course, she wanted the science as well as the magic. But the fact that someone so untempted by mystical inclinations could in an important sense be sustained by what was in part a mystical relationship is emblematic of the extraordinary demands that, in extremis, patients cannot help making—demands that are as impossible for doctors to fulfill as they are impossible for patients to forgo.

Ultimately, it is no doubt simply irrational to expect physicians to simultaneously be great clinicians, great scientists and great psychologists and humanists (as well as great accountants). Some are; but a medical system built on the assumption that such mastery can be normative would be an exercise in folly. Perhaps this is why in recent years, the doctrine of "evidence-based medicine" has become so influential in American medicine.

By pushing medical providers to make their decisions almost exclusively on the basis of statistics, this doctrine implies that what is good for a group can be assumed to be good for every individual despite the fact that this is often not the case. Evidence-based medicine may help the physician avoid the subjective and take a harder line on what is medically useful and what is medically futile, but what Dr. Jerome Groopman has called its "strict binary framework" is hardly likely to help a doctor treat a person, as opposed to that person's disease.

What my mother wanted—which was to undergo any treatment, no matter how terrible, that promised a cure for her disease—would probably have been viewed skeptically by a physician schooled in what Groopman calls the "bean counting" of evidence-based medicine. But doctors like Nimer and Groopman hold that their mission is to try to treat their patients as their patients want to be treated until doing so can be called with assurance (rather than in terms of probability alone) medically futile.

Obviously, there is a cost to this. In opting for treatment—in her case, a bone-marrow transplant—my mother suffered far more physically than she would have had she opted for palliative care alone. But in honoring her wishes, without for a moment understating the risks, her doctors opted for treating her in the full, human sense of the word.

Doctors abandon such commitments at their peril. To generalize, after all, is to deny the complexity of each human being. To be sure, these are complicated questions—complicated still further by the democratization of medical information that the Internet has brought us and by the less hierarchical and priestly approach to patients on the part of doctors. Forty years ago, for example, doctors did not typically advise their patients to seek second opinions; today, most good physicians actively encourage it.

But information is not knowledge, and there is a real question as to whether a person without medical training can navigate the thickets of information on the Web and distinguish good information from bad. This is not to say that this democratization is a bad thing; only that it poses problems and that, in any case, there are limits to what it can offer us.

In the end, whether or not we welcome the continuation of the old shamanistic relation between the gravely ill and their doctors, it is probably humanly inevitable. Without it, everyone becomes their own physician, and, attractive as that fantasy may be, it is still a fantasy. Of course, this should not be allowed to occlude the fundamental truth that the physician-patient relationship has become murky and even contradictory. What, if anything, we can do about this is another question. In all likelihood, we will all have to live with it and, of course, die with it as well.

David Rieff, a contributing writer, is the author most recently of "Swimming in a Sea of Death: A Son's Memoir."

First published in The New York Times Magazine, February 17, 2008.

Once-Daily Exjade® Shown to Remove Iron From the Heart, According to Data Presented at ASH

- ***Approximately 78% of beta-thalassemia patients had decreases in cardiac iron and 90% had decreases in liver iron after six months, interim data show***
- ***Study in sickle cell disease (SCD) patients with iron overload showed continued safety and efficacy over two years***
- ***Safety and efficacy demonstrated in lower-risk myelodysplastic syndromes (MDS) patients***

On December 10, 2007, Novartis Pharmaceuticals Corporation announced in their press release that new data show once-daily Exjade® (deferasirox) reduces iron levels in the heart and liver in beta-thalassemia patients. These interim results from an ongoing trial show that at six months, approximately 78 percent of participants had decreases in cardiac iron and 90 percent of patients had decreases in hepatic iron. These results were reported at the 49th Annual Meeting of the American Society of Hematology (ASH) in Atlanta.

"These preliminary data are encouraging. At a dose of 30 mg/kg, Exjade lowered both heart and liver iron levels in most patients," said John C. Wood, MD, PhD, Children's Hospital of Los Angeles. "Removal of heart iron is particularly important because iron cardiotoxicity remains the leading cause of death in thalassemia major patients."

Chronic iron overload is a potentially life-threatening condition that results from frequent blood transfusions required to treat certain types of chronic blood disorders, including sickle cell disease (SCD), thalassemia, and myelodysplastic syndromes (MDS) and other anemias. If left undiagnosed or untreated, excess iron in the body can become toxic. The body has no inherent mechanism to remove excess iron, so iron chelation is used as an effective treatment for transfusion-related iron overload.

Prior to Exjade, patients in the United States relied on chelation therapy that had to be administered by continuous infusion. Once-daily Exjade oral monotherapy offers patients effective iron reduction without the need for any infused chelation therapy.

Long-Term Efficacy and Safety Demonstrated in SCD Patients

A separate four-year extension study demonstrates the long-term, dose-dependent efficacy and safety of treatment with Exjade for chronically transfused patients with SCD. Patients treated in the core study with doses of 20 and 30 mg/kg/day showed continued decline in serum ferritin (SF), an indication of iron buildup in the body. For patients initially treated with 5 and 10 mg/kg/day doses in the core study, SF levels gradually declined following a dose increase to approximately 20 mg/kg/day. There were no significant changes in markers of liver or renal function and no cases of progressive increases in serum creatinine (SCr). Additionally, no new adverse events or safety concerns have been reported thus far in the extension study.

Exjade Demonstrates Safety and Efficacy in Lower-risk MDS Patients

Additional research demonstrates that treatment with Exjade decreased mean SF levels over one year in patients with low- or intermediate-1 IPSS risk MDS. Additionally, 100 percent of patients experienced a stabilized labile plasma iron (LPI), the reactive species of non-transferrin-bound iron, over 12 months, indicating 24-hour sustained suppression of toxic iron with Exjade. Exjade was shown to have a manageable safety profile in this population. Ongoing assessments of this trial, evaluating cardiac, hepatic and endocrine function, will determine the impact of iron reduction with Exjade on morbidity and mortality in MDS.

These data provide further context to a separate study presented at this year's meeting, which demonstrates that chelation therapy provides a significant survival benefit for heavily-transfused patients with low and intermediate MDS. A prospective study of MDS patients found that the median overall survival from diagnosis was 115 months in chelated patients versus 51 months in non-chelated patients ($P < 0.0001$).

Study Details

[Abstract #2781]

The first study is a prospective, single-arm, phase II trial of 18 chronically transfused beta-thalassemia patients. During this trial, SF levels are tested monthly and liver and cardiac iron concentration levels are tested every six months. This study will enroll 30 patients at four U.S. centers, with Exjade administered at 30–40 mg/kg/day for the next 12 to 18 months. The ongoing assessments will determine whether Exjade continues to improve cardiac iron burden and maintain or improve cardiac function in severely iron-overloaded patients. Data from other larger studies measuring the effects of Exjade on cardiac iron reduction and cardiac function will be available next year. This study will be presented in a poster session on Sunday, December 9 from 6:00–8:00 PM.

[Abstract # 3395]

The SCD study, an extension phase of an ongoing phase II study comparing Exjade with deferoxamine, evaluated the safety and efficacy of Exjade at 20–30 mg/kg/day in 159 patients over a 2.7-year period. Patients in the deferoxamine arm of the extension trial were allowed to cross over to Exjade for the extension trial. This study will be presented in a poster session on Monday, December 10 at 5:00 PM.

[Abstract #1470]

The third study, US03, is a phase II, open-label, three-year trial in 176 patients with low- or intermediate-1 IPSS risk MDS and transfusional iron overload (SF 1000 g/L and >20 units red blood cell (RBC) transfusions), with SCr within two-fold the upper limit of normal (ULN). Initial Exjade dose was 20 mg/kg/day and could be increased to 40 mg/kg/day based on tolerability and response. SF was monitored monthly and LPI was assessed quarterly. This abstract will be presented during a poster session on Saturday, December 8 at 5:30 PM.

[Abstract #249]

The MDS survival results are from a prospective survey of hematological data in 170 MDS patients from 18 Groupe Francophone des Myelodysplasies Centers who were referred for blood transfusions during a one-month period (May 15–June 15, 2005). Survival was analyzed two years later, at the reference date of May 15, 2007. This study will be presented on Monday, December 10 at 8:00 AM.

University of Pennsylvania Health System

Penn Program for Stress Management

Stressed? Want to learn how to manage your symptoms of stress more effectively? The Penn Program for Stress Management is a mindfulness-based stress management program that uses powerful meditation-based techniques as the primary tool for long-term stress management. Mindfulness is taught as a scientific, systematic approach in which participants learn to rest attention in the moment-to-moment awareness of their experience of physical sensations, thoughts and feelings. Participants of the program thoroughly explore mindfulness and its uses in reducing the symptoms of stress that are experienced in the body and mind. 7 class locations in the Philadelphia region.

To learn more about this program go to www.pennhealth.com/stress or contact:

PENN Program for Stress Management
3930 Chestnut Street, 6th floor
Philadelphia, PA 19104

Phone: 215-615-2774
Fax: 215-615-2729

E-mail: stress.management@ uphs.upenn.edu
www.pennhealth.com/stress

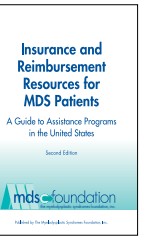
MDS White Paper Available Through MDS Foundation

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.

Insurance and Drug Reimbursement Resource Guide

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.



Patient Registries and Referrals

MDS Patient Registry

The patient registry form has been revised and a patient authorization form has been developed to meet 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.

Slone Patient Registry

The Slone Epidemiology Center at Boston University is enrolling patients who have recently been diagnosed with myelodysplastic syndromes in a voluntary research project called the Patient Registries at Slone: MDS. The registry gathers important information about the impact of MDS and its treatments on patients' physical, emotional, social, and economic well-being. Participation in the Registry does not affect the care or treatments that patients receive.

You are eligible to join if:

- You have been diagnosed with MDS within the past 3 months
- You live in the US

You do not need to have received any medicines or other treatments for your MDS to be eligible.

For more information or to enroll:

Visit http://www.bu.edu/prs/mds,
e-mail mdsinfo@slone.bu.edu or
call the registry at 800-231-3769.

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.

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.

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
James M. Foran, 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

UCLA Center for Health Science UCLA School of Medicine
Los Angeles, California
Gary J. Schiller, 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

Robert H. Lurie Comprehensive Cancer Center of Northwestern University Feinberg School of Medicine
Chicago, Illinois
Olga Frankfurt, MD

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 University School of Medicine
Baltimore, Maryland
Steven D. Gore, MD
Charles S. Hesdorffer, MD

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

University of Maryland Greenebaum Cancer Center
Baltimore, Maryland
Maria R. Baer, MD
Ivana Gojo, MD

MASSACHUSETTS

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

Tufts University School of Medicine New England Medical Center
Boston, Massachusetts
Kellie Sprague, 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

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
Lake Success New York
Steven L. Allen, MD

Roswell Park Cancer Center
Buffalo, New York
Minoo Battiwala, MD

St. Vincent's Comprehensive Cancer Center
New York, New York
Azra Raza, 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
Bayard L. Powell, MD

OHIO

Cleveland Clinic Foundation Taussig Cancer Center
Cleveland, Ohio
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Portland, Oregon

PENNSYLVANIA

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Gregory Hale, MD

TEXAS

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San Antonio, Texas
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Southwest Regional Cancer Center
Austin, Texas
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University of Texas MD Anderson Cancer Center
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Simrit Parmar, MD

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Fred Hutchinson Cancer Research Center
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Joachim Deeg, MD

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Leeds, United Kingdom
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Queen Elizabeth Hospital University Hospital Birmingham NHS Trust
Charles Craddock, MD

Royal Bournemouth Hospital
Bournemouth, United Kingdom
Sally Killick, MD

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, Arizona

Daniel and Sandra Linn
La Jolla, CA

Roslyn Raney
Melo Park, CA

Information on Clinical Trials

International Clinical Trials: An Update

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.

To view listings of additional studies you can log onto www.clinicaltrials.gov. You can also contact 1-800-4-CANCER for more information.

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.

New Research Protocol Listings

The MDS Foundation wants you to know about clinical trials of investigational treatment options for patients with MDS and has updated its International Clinical Trials list on our website and for distribution.

For a detailed listing featuring new protocols visit http://www.mds-foundation.org, email patientliaison@mds-foundation.org or call 800-MDS-0839 and the current clinical trials will be sent to you under separate cover.

Clinical trials often have very specific eligibility requirements. Please talk with your doctor to help decide which, if any, trials might be right for you.

Please note that the information is provided strictly as a resource and is not an endorsement of any physician, institution or treatment.

New Clinical Study

Johnson & Johnson Pharmaceutical Research & Development is currently recruiting US sites for a new clinical research study for the investigational use of Epoetin alfa in patients with IPSS low or intermediate-1 risk Myelodysplastic Syndromes. If you see newly diagnosed MDS patients and would like additional information regarding this clinical research study, please contact The MDS Foundation at 800-MDS-0839.

Important Research Study Opportunity

Researchers at the H. Lee Moffitt Cancer Center and Research Institute in Tampa, FL are looking for people who have recently been diagnosed with MDS to participate in a research study designed to better understand why people get myelodysplastic syndrome. Specifically, researchers are studying a part of the chromosome called the telomere to see if telomeres are shorter in people with MDS as compared to people who don't have MDS. A specific gene, called human telomerase reverse transcriptase, or hTERT, will also be studied, to see if hTERT is related to telomere length. People who participate in this study will be asked to complete a questionnaire and provide a blood sample. Participation in this research study will not in any way affect an individual's medical care or MDS treatment options.

To find out more information about this important research study, please contact Kristen Jonathan at 813-745-8395 or email kristen.jonathan@moffitt.org.

Clinical Research Trial For An Oral, At-Home Treatment Option

Learn More About P02978

The MDS Foundation wants you to know about clinical trials of investigational treatment options for patients with MDS. In the current clinical research trial, all patients will receive therapy with Lonafarnib, an investigational drug that is being evaluated for treating patients with MDS or CMML who have been regularly receiving at least 1 and not more than 8 platelet transfusions every 4 weeks. The medicine is taken by mouth at home, and although patients will be monitored closely, routine hospital stays are not required.

About the MDS Foundation: The MDS Foundation is a publicly supported, multidisciplinary, international organization devoted to the prevention, treatment, and study of MDS. The Foundation has conducted international symposia and has established an international information network that provides patients with referrals to the MDS Foundation's Centers of Excellence worldwide, contact names for available programs, and information about new research and treatment options. The Foundation also provides educational support to both physicians and patients.

For more information about clinical trials with Lonafarnib, call the MDS Foundation at 1-888-813-1260 (outside the US 609-298-7741)

Talk to your doctor to decide if this trial is suitable for you.

(Clinical trial site list on next page)

Clinical Research/Trial with Lonafarnib–Now Open for Accrual

A Pivotal Randomized Study of Lonafarnib (SCH66366) versus Placebo in the Treatment of Subjects with Myelodysplastic Syndrome (MDS) or Chronic Myelomonocytic Leukemia (CMML) Who Are Platelet Transfusion Dependent With or Without Anemia (Protocol No. P02978)

Study Background

- Lonafarnib (SCH66336) is a potent, orally bioavailable, specific inhibitor of farnesyl transferase. As a farnesyl transferase inhibitor (FTI), Lonafarnib prevents the farnesylation of specific target proteins, including RAS, which are involved in the regulation of cellular proliferation. Preclinical data have documented activity of Lonafarnib against numerous neoplastic cell lines in vitro, including several derived from subjects with myeloid and lymphoid leukemias. Lonafarnib has also inhibited the growth of primary leukemic cells derived from subjects with CMML. These data suggest that Lonafarnib may have clinical efficacy against a variety of hematologic malignancies and deserves further study
- This trial P02978 is designed to determine whether Lonafarnib can improve patient outcomes in MDS

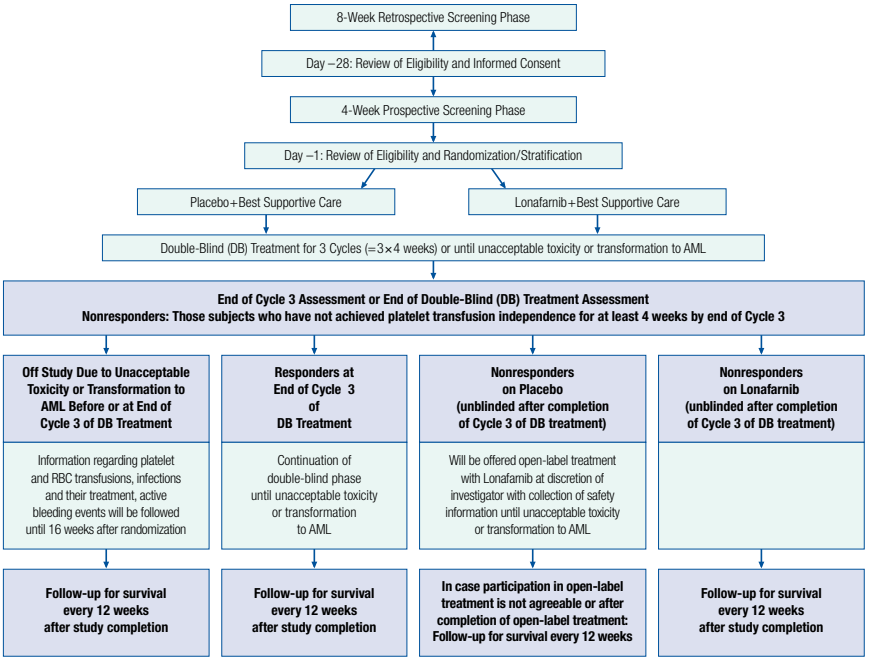
Key Eligibility Criteria

- Platelet transfusion-dependent MDS or CMML patients with or without anemia diagnosed with de novo disease as confirmed by bone marrow aspirate

Additional Eligibility Criteria

- Diagnosed MDS as classified by the French-American-British Classification (FAB) and defined as refractory anemia (RA), refractory anemia with ringed sideroblasts (RARS), refractory anemia with excess blasts (RAEB), and refractory anemia with excess blasts in transformation (RAEB-T), or chronic myelomonocytic leukemia (CMML)
- No prior therapy with farnesyl transferase inhibitors
- No current therapy with any drugs for the treatment of MDS/CMML other than best supportive care within 12 weeks prior to randomization
- ECOG performance status 0 to 2
- Sexually active women of childbearing age will need to use adequate birth control methods while in the study and will be required to maintain this method throughout the study

P02978 Schema



About the MDS Foundation: The MDS Foundation is a publicly supported, multidisciplinary, international organization devoted to the prevention, treatment, and study of MDS. The Foundation has conducted international symposia and has established an international information network that provides patients with referrals to centers of excellence, contact names for available programs, and information about new research and treatment options. The Foundation also provides educational support to both physicians and patients. For more information about the MDS Foundation, visit www.mds-foundation.org.

Patient enrollment needed. For more information please call 1-888-813-1260 (Outside the US: 609-298-7741) or visit *www.mds-foundation.org.*

mds foundation
the myelodysplastic syndromes foundation, inc.

Lonafarnib Clinical Trial Site List *(at date of publication)*

UNITED STATES

Alvin and Luis Lapidus Cancer Institute
Baltimore, MD
Stephen Noga, MD

University of Minnesota
Minneapolis, MN
Mark Reding, MD

Georgia Cancer Specialists
Tucker, GA
Mansoor Saleh, MD

New York Presbyterian Hospital
New York, NY
Eric Feldman, MD

New York Medical College
Valhalla, NY
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University of Massachusetts Medical Center
Worcester, MA
Azra Raza, MD

University of Texas Southwestern Medical Center
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Robert Collins, MD

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Tampa, FL
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University of South California, Norris Cancer Center
Los Angeles, CA
Dan Douer, MD

Mayo Clinic Hospital
Phoenix, AZ
James Slack, MD

Scripps Cancer Center
La Jolla, CA
James Mason, MD

CANADA / LATIN AMERICA

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Cross Cancer Institute
Edmonton, Alberta
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Sunnybrook Regional Cancer Center
Toronto, Ontario
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Thank You to Our Pharmaceutical Supporters

We would like to thank our pharmaceutical supporters for their commitment to the Foundation and its work. They have contributed in the form of educational grants, which maintains not only this newsletter but also the development of the MDS homepage on the World Wide Web, the Center of Excellence program, continuing medical education programs, the Patient Registry, and the dissemination of patient information.

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Spain

Hospital Universitario
Salamanca, Spain
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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 in either a rectangular or circular design with a $3.99 donation to The MDS Foundation. To order your pins, call 1-800-MDS-0839.

The pins were created especially for The MDS Foundation to contribute to the effort to help people worldwide living with MDS. 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!**

Learn More About MDS: Join the Journey to Hope for MDS

- MDS is a puzzling, life-threatening group of diseases of the bone marrow for which there are no easy cures or quick remedies.
- The most common of all the cancers related to the blood system, it is estimated there are more than 30,000 new MDS cases each year in the United States alone. We believe this is vastly underestimated.
- Despite more than three decades of dedicated research, the causes of MDS remain largely unknown.
- MDS is largely unknown to the general public.
- For roughly 30% of the patients diagnosed with MDS, these diseases will progress to acute myeloid leukemia (AML), a type of bone marrow malignancy which does not respond well to chemotherapy.
- Until recently treatment consisted only of supportive care including blood trans-fusions (red blood cells or platelets), and treatment with growth factors like erythropoietin (EPO) with G-CSF or GM-CSF. There are now three drugs approved for the treatment of MDS: Vidaza® (azacitidine), Dacogen® (decitabine), and Revlimid® (lenalidomide). At present, there are two FDA-approved drugs for the treatment of transfusion-dependent iron overload: Exjade® (deferasirox) and Desferal® (deferoxamine). None of these are curative.

How to Help:

- Bone marrow transplantation is often the only chance of survival. Nearly 70% of the patients are without a match. The need is especially critical in racial and ethnic minority groups.
- As a not-for-profit organization, the MDS Foundation depends entirely on public funding in the form of individual gifts, donations from individual and corporate entities, and membership fees to further our work.
- To learn how to support the MDS Foundation, go to the Foundation's website at www.mds-foundation.org.

Educational Resources

The Foundation Resource Center is Now Online!

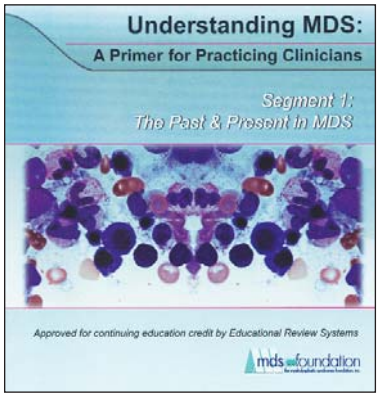
This educational center is designed to provide clinicians, researchers, and other healthcare professionals with a comprehensive source for the latest information and educational programming on the myelodysplastic syndromes.

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.

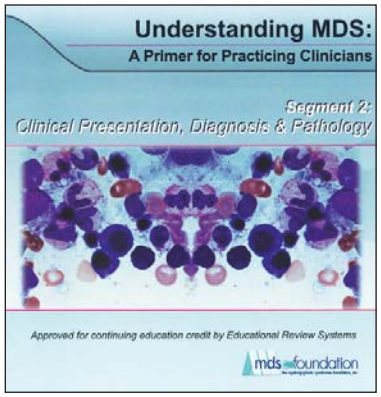
Written programs are available in Spanish, French, Italian, German and Japanese.



Segment 1:

The Past and Present In MDS

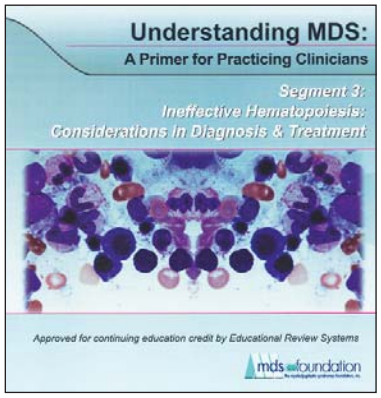
Segment 1 provides insight into the history of MDS, development of the MDS classification and prognostic systems, and a glimpse into the future of MDS diagnosis, research and treatment.



Segment 2:

Clinical Presentation, Diagnosis & Pathology

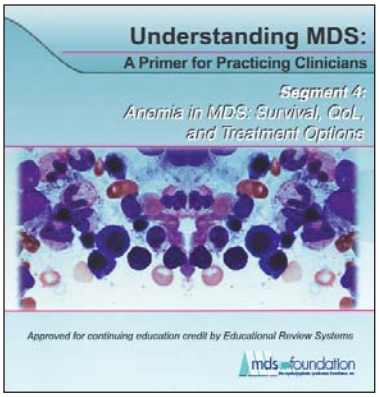
Segment 2 provides insight into the clinical picture of adult and pediatric MDS, primary and secondary MDS, FAB and WHO Classification system, and rationale for the proposed MDS pediatric classification system.



Segment 3:

Ineffective Hematopoiesis: Considerations in Diagnosis and Treatment

Segment 3 provides insight into the pathogenic mechanisms that contribute to the development of MDS, including the altered bone marrow microenvironment of MDS in terms of cells, cytokines, growth factors, receptors, and microvasculature; dyserythropoiesis in MDS, and therapeutic targets and approved drugs for the treatment of MDS.



Segment 4:

Anemia in MDS: Survival, QoL, and Treatment Options

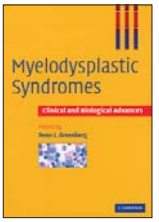
COMING SOON!

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.

Help the Foundation and Buy Your MDS Textbooks From Us!



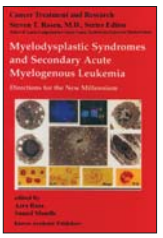
Myelodysplastic Syndromes: Clinical and Biological Advances

Peter L. Greenberg, MD
Stanford University Medical Center

Hardback, Nov. 2005/320 pp., 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.

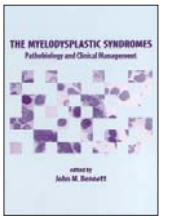
This book will be a valuable resource to clinicians and researchers who wish to learn more about myelodysplastic syndromes.



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

Edited by:
Azra Raza, MD; Suneel D. Mundle, PhD
June 2001/278 pp., 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".

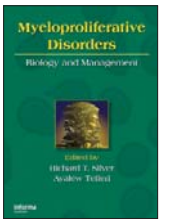


The Myelodysplastic Syndromes Pathobiology and Clinical Management (Basic and Clinical Oncology Series/27)

Edited by:
John M. Bennett, MD
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.



Myeloproliferative Disorders: Biology and Management

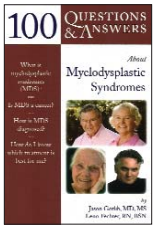
Edited by:
Richard T. Silver, MD; Ayalew Tefferi, MD

October 2007/240 pp., illus.
ISBN: 9781420061628/$161.96**
CRC Press: 800-272-7737

Myeloproliferative disorders, written by international renowned experts in the field, examines:

- New and developing diagnostic protocols and algorithms and supportive care regimens
- The evolution and classification of recent myeloproliferative disorders
- Advancements and the implications arising from clinical care and practice
- The activating JAK2V617F developed in a chapter by top experts
- The overlap between myeloproliferative disorders and myelodysplastic syndromes
- The importance of histopathology and cytogenetics on understanding these diseases

With the recent discovery of JAK2 mutations in myeloproliferative disorders, medical science has taken a revolutionary stride forward toward understanding the pathogenesis of these diseases. This new advancement translates not only to a more rapid and reliable diagnosis, but also allows groundbreaking research into the development of new therapeutics. Written in an easy-to-follow text myeloproliferative disorders gives the practicing clinician a single source answer to classification, diagnosis, management, and recent advances in this disorder.



100 Questions & Answers About Myelodysplastic Syndromes

By:
Jason Gotlib, MD, MS;
Lenn Fechter, RN, BSN

December 2007/172 pp., illus.
ISBN: 9780763753337 /$19.95**

Jones and Bartlett Publishers:
800-832-0034; www.JBpub.com

Whether you're a newly diagnosed patient, a survivor, or loved one of someone suffering from MDS, this book offers help. The only text available to provide both the doctor's and patient's views, *100 Questions & Answers About Myelodysplastic Syndromes*, provides practical, authoritative answers to 100 of the most common questions asked. Written with commentary from actual patients, this is an invaluable resource for anyone struggling with the medical, physical, and emotional turmoil of this disease.

***All prices are in US dollars.*

To order call MDS Foundation at 1-800-MDS-0839. TERMS OF THE OFFER:
All individual orders must be prepaid by check or money order or charged on Visa, Mastercard, or AmEx). Canadian residents, please add 7% GST. Residents of CA and NY, please add local sales tax. Shipping and handling charges 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.

Highlights of Latest Literature in MDS

Suneel D. Mundle, PhD

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.

MDS OVERVIEW AND PERSPECTIVES:

1. Kuendgen A and Lübbert M. Current status of epigenetic treatment in myelodysplastic syndromes. *Ann Hematol.* 2008, Apr 5. *[Epub ahead of print]*

   The article provides perspective on epigenetic treatment modalities highlighting inhibitors of DNA methyl transferase and histone deacetylase.

2. Itzykson R, Gardin C and Fenaux P. Meeting report: myelodyspalstic syndromes at ASH 2007. *Leukemia*. 2008, Mar 6 *[Epub ahead of print]*

   ASH 2007 overview.

3. Giagounidis A et al. Practical recommendations on the use of lenalidomide in the management of myelodysplastic syndromes. *Ann Hematol*. 2008;87: 345–352.

   This comprehensive review provides recommendations on selection of patients for lenalidomide therapy, laboratory monitoring, course of treatment in different situations, maintenance, and management of neutropenia, thrombocytopenia and other adverse events associated with lenalidomide treatment.

4. Jabbour E et al. Red blood cell transfusion and iron overload in the treatment of patients with myelodysplastic syndromes. *Cancer*. 2008; 112:1089-1095.

   A comprehensive review of RBC transfusion burden in MDS, the potential adverse outcomes and compromised survival associated with prolong RBC transfusions, and chelation therapy for the management of resultant iron overload.

5. Valent P et al. Iron Overload in myelodysplastic syndromes (MDS)-diagnosis, management and response criteria: a proposal of the Austrian MDS platform. *Eur J Clin Invest*. 2008; 38:143–149.

DIAGNOSIS AND PROGNOSIS:

1. Garcia-Manero G et al. A prognostic score for patients with lower risk myelodysplastic syndrome. *Leukemia*. 2008; 22:538–543

   A retrospective review of 856 cases with low/int-1 MDS at the MD Anderson Cancer Center, Houston, Tx, USA, showed 10% AML transformation with a mean follow up of 19.6 months. Low platelet count, anemia, older age, higher marrow blast counts, poor-risk cytogenetics, and higher serum ferritin were associated with worse survival outcome. Attempts have been made to group patients in 3 categories with median survival of 80.3, 26.6 and 14.2 months, clearly demonstrating heterogeneity within the low/int-1 IPSS category.

2. van de Loosdrecht AA et al. Identification of distinct prognostic subgroups in low and intermediate-1 risk myelodysplastic syndromes by flow cytometry. *Blood*. 2008;111:1067–1077.

   Of note was the finding that in 60% of transfusion dependent or progressive disease patients, myeloid blasts expressed CD7 or CD56 in contrast to only 9% non-transfusion dependent patients.

TREATMENT:

1. Moyo V et al. Erythropoiesis-stimulating agents in the treatment of anemia in myelodysplastic syndromes. *Ann Hematol*. 2008, Mar 20 *[Epub ahead of print]*

   This literature meta-analysis showed improved erythroid response rates with the institution of standardized response evaluation criteria (IWG 2000) and comparable response with two commonly used ESAs, epoetin alfa and darbepoetin alfa.

2. Park S et al. Predictive factors of response and survival in myelodysplastic syndrome treated with erythropoietin and G-CSF: the GFM experience. *Blood*. 2008;111:574–582.

   This large study evaluated effects of ESAs (Epo alfa, Epo beta and Darbepoetin alfa) with or without GCSF in comparison with historic untreated controls to show that different ESAs were comparable in eliciting erythroid response, did not impact leukemic transformation or survival. In fact, in ESA responders the survival appeared to be superior to the historical controls.

Demethylating Agents:

3. Borthakur G et al. Activity of decitabine in patients with myelodysplastic syndrome previously treated with azacitidie. *Leuk Lymphoma*. 2008;49:690–695.

   The study (N=14) showed activity of decitabine with overall response rate of 28% (CR-3/14 and HI 1/14) and minimal Gr 3–4 toxicities in MDS patients who previously failed treatment with azacitidine.

Allogeneic Transplant:

4. Castro-Malaspina H et al. Transplantation in remission improves the disease-free survival of patients with advanced myelodysplastic syndromes treated with myeloablative T cell-depleted stem cell transplants from HLA-identical siblings. *Biol Blood Marrow Transplant*. 2008;14: 458–468.

   The report describes experience with 49 patients over a period of 20 years, who received hematopoietic stem cell transplant after conditioning that included chemotherapy in some patients. The report demonstrates the potential of achieving long term remission (3 year post-transplant survival rate of 54%) in patients with earlier remission or second refractory cytopenia phase following initial therapy.

5. Warlick ED et al. Myeloablative allogeneic bone marrow transplant using T cell depleted allografts followed by post-transplant GM-CSF in high risk myelodysplastic syndromes. Leuk Res 2008, Feb 6 [Epub ahead of print]

   Post-transplant treatment with GM-CSF showed event free survival rates of 47% and 34% at 1 and 3 years respectively with a median follow up of 22.8 months.

Lenalidomide:

5. Raza A et al. Phase 2 study of lenalidomide in transfusion-dependent low risk and intermediate-2-risk myelodysplastic syndromes with karyotypes other than deletion 5q. *Blood*. 2008;111:86–93.

   Transfusion independence (TI) was seen in 25% of the total of 214 patients with low/int-1 MDS without del 5q abnormality who were treated with 10 mg oral lenalidomide daily or on days 1–21 of a 28-day cycle. Median time to TI was 4.8 weeks and median duration of TI was 41 weeks. The overall rate of Hematologic improvement was seen in 43% patients. Neutropenia and Thrombocytopenia were the major adverse events.

Farnesyl Transferase Inhibitors:

6. Kurzrock R et al. Phase I study of alternate-week administration of tipifarnib in patients with myelodysplastic syndrome. *Clin Cancer Res*. 2008;14: 509–514.

   Oral tipifarnib administered twice daily at escalating dose from 100 mg until MTD for 8 weeks followed by maintenance, showed OR of 26% (16 of 61 evaluable patients) with CR-5% and HI-21%. Most common toxicity was myelosuppression. However, 20% patients did not have any side effects.

PATHOBIOLOGY:

1. Cortelezzi A et al. Bone marrow glycophorin-positive erythroid cells of myelodysplastic patients responding to high dose rHuEPO therapy have a different gene expression pattern from those of nonresponders. *Am J Hematol*. 2008, Feb 13. *[Epub ahead of print]*

   Purified Gly (+) cells from the marrow of MDS patients responding to EPO therapy had normal expression of genes associated with proliferation, differentiation and DNA repair, while these genes were found to be repressed in nonresponders.

2. Volpicelli P et al. Pregnancy in patients with myelodysplastic syndromes (MDS). *Leuk Res*. 2008 Mar 26 *[Epub ahead of print]*

   This observational study over 15 years demonstrated occurrence of full term uneventful pregnancies in 5 cases within 10 yrs from diagnosis of MDS in young women with a median age of 28 yr (range 26–29 yrs).

3. Lin J et al. Methylation status of fragile histidine triad (FHIT) gene and its clinical impact on prognosis of patients with myelodysplastic syndrome. *Leuk Res*. 2008, Mar 14. *[Epub ahead of print]*

   FHIT methylation showed correlation with the advanced disease by IPSS and shorter survival.

4. Khan R et al. Hypomethylation and apoptosis in 5-azacytidine treated myeloid cells. *Exp Hematol*. 2008;36: 149–157.

   5-Azacytidine induced dose-dependent apoptosis and hypomethylation was found in apoptotic fraction (41% reduction in methylation status). No change in methylation was observed in non-apoptotic cells. Apoptosis seemed to involve both intrinsic mitochondrial pathway and extrinsic pathway.

MDS Foundation Publications

MDS Handbooks Now Available in Multiple Languages

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

*Available in the following languages:**

Arabic	*Greek*	*Polish*	*Spanish*
English	*Hungarian*	*Portuguese*	*Turkish*
Czech	*Italian*	*Russian*	
German	*Japanese*		

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

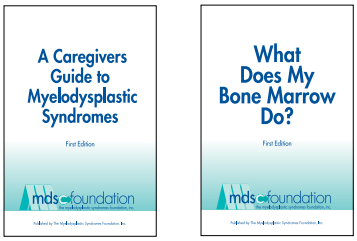
*Available in the following languages:***

Arabic	*French*	*Italian*	*Russian*
English	*German*	*Japanese*	*Spanish*
Czech	*Greek*	*Polish*	*Swedish*
Dutch	*Hungarian*	*Portuguese*	

* The MDS Patient Handbooks will soon be available in the following languages: *Dutch, Swedish.*
** The Iron Overload booklets will soon be available in the following language: *Turkish.*

New MDS Publications Coming Soon...

- A Caregivers Guide to Myelodysplastic Syndromes
- What Does My Bone Marrow Do?



Patient Information & Educational Materials Available from The MDS Foundation

- The MDS News
- MDS Essentials: The Foundation's E-Newsletter
- Patient Diary
- Understanding Myelodysplastic Syndromes: A Patient Handbook
- Transfusion-Dependent Iron Overload and MDS: A Handbook for Patients
- Insurance and Reimbursement Resources for MDS Patients
- Emerging Treatment Options for Adult MDS: A Clinical Perspective
- Planned Giving Program: A Guide to Financial Planning
- PBS Program — (DVD) Healthy Body, Healthy Mind: A Menace in the Blood

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

Contributions to the MDS Foundation

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:

Ed and Susan Johnson, *Clifton, NJ*

United Way of New York City
On behalf of Ms. Lauren M. Hollander

Susan J. Ferber
In memory of Dr. Jerome Ferber
New York, NY

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Dr. Stuart Goldberg, *Hackensack, NJ*

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Ways to Support Us

The MDS Foundation is very grateful for the heartfelt support of its donors. Our work as a non-profit organization depends on public funding and we hope that you include us as one of the worthy charities that you support this year. We have enclosed a pre-addressed contribution envelope to make it easier. You will receive an MDS Foundation enamel lapel pin in appreciation of your donation.

All donations are tax-deductible.

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 health-care 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.

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This donation was submitted by: **Armando Cruz, Jose & Elba Cruz, Jose & Carmen Garcia, John & Dulce Heinz, Hilda A. Irola, Concepcion C. Jorge, Juan & Elva Lopez, Jorge & Oralia Parada, Delia Perez, Alfonso & Benita Rojas**

A Living Endowment donation has been made in honor of:

Dipti Shorey's 15 year anniversary with The Capital Group Companies

This $1,500 donation was submitted by: **The Capital Group Companies Charitable Foundation**

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A memorial fund has been established in the name of

Mr. Wayne Barker

Donations have been made in Mr. Barker's memory by:

Bill & Denise Foor, Wes & Evelyn Foor, Denny & Dee Foor, and Kevin & Dee Blume, *Eureka, IL*

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Donations have been made in Mrs. Bernstein's memory by:

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Ray and Audrey Cowan
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A memorial fund has been established in the name of

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Beverly Crawford, *Spring Park, MN*

A memorial fund has been established in the name of

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Kenneth and Linda Jacobs, *Scandia, MN*

A memorial fund has been established in the name of

Mrs. Nancy Margaret Booker

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Mr. Neb Rennerfeldt

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A memorial fund has been established in the name of

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Charles and Cecile Lemen, *Lakewood, CO*

A memorial fund has been established in the name of

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Denver, CO

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A memorial fund has been established in the name of

Mr. Orlando Sanchez

Donations have been made in Mr. Sanchez' memory by:

Rick and Helen Dahlstrom
Arcadia, CA

Susan Ishikawa (Catalina)
Montclair, CA

Ed and Dianna Lindseth
Norco, CA

Salvatore & Mary Ann Taibi
Hayden, ID

Sue Sonnenberg
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George and Arlene Trumble
Walton, KY

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Annette Rasse
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Eustis, FL

Kathleen McCloskey
Trinity, FL

Rod and Pat Anderson
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Carolyn Sanchez
Garden City, NY

Tillie Hogan
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William Worobe
Oceanside, CA

Kathleen Campion
San Juan Capistrano, CA

Larry Mott
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Ken and Debbie Williams
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Dana Point, CA

Robert and Patrice Finley
Eustis, FL

Gary Shindler
San Juan Capistrano, CA

Paul Redish
Marietta, GA

Al and Gloria Ravera
San Juan Capistrano, CA

A memorial fund has been established in the name of

Mr. Carl Siddall

Donations have been made in Mr. Siddall's memory by:

EMR, INC., *Lawrence, KS*

A memorial fund has been established in the name of

Mr. Agustin Sierra

Donations have been made in Mr. Sierra's memory by:

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A memorial fund has been established in the name of

Mr. James H. Sims

Donations have been made in Mr. Sims' memory by:

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A memorial fund has been established in the name of

Mr. Art Smith

Donations have been made in Mr. Smith's memory by:

Gerry Kroll, *Agoura, CA*

A memorial fund has been established in the name of

Mr. Jay R. Southcombe

Donations have been made in Mr. Southcombe's memory by:

Mary James
Milford, OH

Joseph & Elizabeth Schuch
Batavia, OH

A memorial fund has been established in the name of

Ms. Pam Speth

Donations have been made in Ms. Speth's memory by:

Marroni, Inc., *South Bend, Indiana*

A memorial fund has been established in the name of

Ms. Claudia Elaine Stanton

Donations have been made in Ms. Stanton's memory by:

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Saint Joseph, MO

Short Cressman & Burgess PLLC, *Seattle, WA*

A memorial fund has been established in the name of

Ms. Betty Jean Stevenson

Donations have been made in Ms. Stevenson's memory by:

Jim and Louise Lopeman
Hercules, CA

Dorothy Mittelstaedt
Bloomington, IL

Edward J. Barulich
Rodeo, CA

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A memorial fund has been established in the name of

Ms. Doris Stewart

Donations have been made in Ms. Stewart's memory by:

Joan Scott, *Irving, TX*

A memorial fund has been established in the name of

Mr. Rocky Sullivan

Donations have been made in Mr. Sullivan's memory by:

Robert Mahaffey
San Rafael, CA

Sally DeHart
San Francisco, CA

Mario and Judith Gianetti
San Rafael, CA

Muffin Mania
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Bernard Giorgi
Corte Madera, CA

Bruce and Sue Scott
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Mitchell and Rebecca DeShields
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A memorial fund has been established in the name of

Ms. Madeline Sutera

Donations have been made in Ms. Sutera's memory by:

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John and Matilda Randazzo
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Brooklyn, NY

Andrew and Carol Alesi
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Mr. Robert L. Syre

Donations have been made in Mr. Syre's memory by:

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A memorial fund has been established in the name of

Mr. John P. Tedesco

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A memorial fund has been established in the name of

Mr. Donald Earl Thomas

Donations have been made in Mr. Thomas' memory by:

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Midland, MI

Frederick and Ardythe Grosskopf
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Donald Thomas
Palatine, IL

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Seeley Lake, MT

A memorial fund has been established in the name of

Mr. John D. Tillman

Donations have been made in Mr. Tillman's memory by:

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A memorial fund has been established in the name of

Ms. Caprice Titone

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Upper Saddle River, NJ

Jeffrey and Jo Ann Chaus
Upper Saddle River, NJ

Sandy, Greg and Ayan Kriser
Upper Saddle River, NJ

USR Girl Scout Troop 880
Upper Saddle River, NJ

Ken and Dayne Colameo
Upper Saddle River, NJ

Norman and Alison Axelrod
Upper Saddle River, NJ

A memorial fund has been established in the name of

Mrs. Jeanette Toth

Donations have been made in Mrs. Toth's memory by:

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Jackson, NJ

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Arlington, VA

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Dennis and Toni Winans
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David and Lynne Toth
Westport, MA

The Toth & Koutis Families
Manalapan, NJ

Jim and Liz Coffin
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Austin and Johanna Kingston
Freehold, NJ

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Arlington, VA

Louis & Elizabeth Baumgaertner
Colts Neck, NJ

Joe Toth
Manalapan, NJ

Stacey, Brady & Gabrial Milak-Youngman
Flemington, NJ

A memorial fund has been established in the name of

Mr. Richard Valicenti

Donations have been made in Mr. Valicenti's memory by:

Victoria V. Michelmore, *Port Jefferson, NY*

A memorial fund has been established in the name of

Mr. Erich P. Valstyn

Donations have been made in Mr. Valstyn's memory by:

Carol Fischer Valstyn, *Gig Harbor, WA*

A memorial fund has been established in the name of

Mr. Clifford D. Victorine

Donations have been made in Mr. Victorine's memory by:

Noreen Victorine, *Lakewood, WA*

A memorial fund has been established in the name of

Ms. Eunice Wagneer

Donations have been made in Ms. Wagneer's memory by:

Nuchael and Mary Kay Keenan, *Fairfax Station, VA*

A memorial fund has been established in the name of

Mr. Karl Wagner

Donations have been made in Mr. Wagner's memory by:

Elisabeth Demarest, *Hillsdale, NJ*

A memorial fund has been established in the name of

Ms. Peggy Wanner

Donations have been made in Ms. Wanner's memory by:

Mary Ellen Huetsch, *Waterloo, IL*

A memorial fund has been established in the name of

Mr. Gordon Wascher

Donations have been made in Mr. Wascher's memory by:

Bonnie K. Wascher, *St. James City, FL*

A memorial fund has been established in the name of

Mrs. Jennifer Sharon Gallagher-Welch

Donations have been made in Mrs. Welch's memory by:

Sara Edith Gallagher, *Dayton, OH*

A memorial fund has been established in the name of

Mr. Don Ziegler

Donations have been made in Mr. Ziegler's memory by:

George and Carol Pintelon, *Cologne, MN*

MDS Foundation Information

The Foundation's Board of Directors

Membership Information

The MDS Foundation would like to have you as a member. Membership is US$40 a year for physicians and other professionals. Patients, their families, and others interested in MDS may join at the reduced rate of $25.

Membership benefits include quarterly issues of the MDS News, a special subscription rate of $119.00 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: 800-MDS-0839, Fax: 609-298-0590
Outside the US only: 609-298-1035

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 nine international symposia—in Austria, England, the United States, Spain, Czech Republic, Sweden, France, Japan, and Italy. The Tenth International Symposium is being held May 6–10, 2009 in Patras, Greece.

A major Foundation effort is our international information network. This network provides patients with referrals to our Centers of Excellence, entry into available clinical trials, sharing of new research and treatment options between physicians and researchers, and extension of educational and emotional support to physicians, nurses, patients, caregivers, and others working with MDS 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.

Please visit us at www.mds-foundation.org.