

mds news

newsletter of the myelodysplastic syndromes foundation

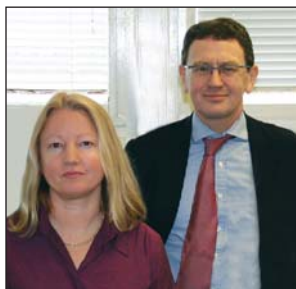


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From the Guest Editor's Desk

The Molecular Basis of the 5q- syndrome



**Dr. Jacqueline Boulwood and
Professor James S. Wainscoat**

**Leukaemia Research Fund
Molecular Haematology Unit
Nuffield Department of
Clinical Laboratory Sciences
John Radcliffe Hospital
Oxford, United Kingdom**

The 5q- Syndrome

The 5q- syndrome was first described in 1974 by Van den Berghe who reported the consistent association of the deletion of the long arm of chromosome 5 [del(5q)] with the following hematological features: macrocytosis, anemia, normal or high platelet count and hypolobulated megakaryocytes in the bone marrow.¹ From the earliest studies a good prognosis and a marked female preponderance have also been reported.^{2,3} The 5q- syndrome is the most distinct of all the myelodysplastic syndromes. However, the strong genotype-phenotype relationship present in the 5q- syndrome is not observed in other MDS or acute myeloid leukemia (AML) characterized by chromosomal deletions. The 5q- syndrome is now recognized as a distinct clinical entity according to the WHO classification and is defined by a medullary blast count of <5% and the

presence of the del(5q) as the sole karyotypic abnormality.⁴ The 5q- syndrome now joins the list of other leukemias in having both a postulated cause and a good therapy. Curiously perhaps the "therapy" (lenalidomide) arrived before the "postulated cause" (the *RPS14* gene) was published but the relationship between lenalidomide and *RPS14* is not clear and so there remains much to be learned about all aspects of this prototypic MDS.

Mapping the Commonly Deleted Region and Identifying Candidate Genes

The del(5q) in the 5q- syndrome is considered to mark the location for a gene(s) the loss of which may affect important processes such as growth control and normal hematopoiesis.² The basis for research on deletions such as the del(5q) in the 5q- syndrome is well known. The first step is to characterize the deletions and to identify the commonly deleted region (CDR) i.e. the region of deletion shared by all patients as this localizes the gene(s) for further study. Over the years several genes and genomic regions have been put forward as significant in the 5q- syndrome or related leukemias characterized by the del(5q). Our group in Oxford identified the CDR of the 5q- syndrome^{5,6} and have since narrowed the CDR to the approximately 1.5 Mb interval at 5q32 flanked by D5S413 and the *GLRA1* gene.⁷ We subsequently generated a transcription map of the CDR and noted several promising candidate genes map within this region, including the tumor suppressor gene *SPARC*, and *RPS14*, a component of the 40S ribosomal subunit.^{5,7,8}

The next step in our research was the sequencing of all the 44 genes that map within the CRD in a group of patients with the 5q- syndrome. The gene sequencing is critical to understanding the pathogenesis of the 5q- syndrome—if Knudsen's two hit model applied to this disorder there would be loss of one allele of a gene and a mutation of the remaining copy of the same gene.⁹ We have sequenced all the genes in the CDR and no mutations have been identified. This is a key step in determining the molecular basis of the 5q- syndrome since it brings forward the consideration of haploinsufficiency (a gene dosage effect resulting from the loss of one allele of a gene) as the basis of the 5q- syndrome. There has been growing recognition of haploinsufficiency as a cancer model over the last decade.¹⁰ Our research indicates that this is the correct model for the 5q- syndrome.

Candidate Gene *RPS14*

We recently demonstrated haploinsufficiency of the ribosomal gene *RPS14* in the CD34+ cells of patients with the 5q- syndrome and commented upon its relevance to the 5q- syndrome from an analogy with Diamond-Blackfan Anaemia (DBA) which is caused in around a quarter of cases by haploinsufficiency for the related ribosomal gene *RPS19*.¹¹ Most recently the genes in the 5q- syndrome CDR were studied by an RNA-mediated interference (RNAi)- based approach: partial loss of function (haploinsufficiency) of *RPS14* in normal hematopoietic stem cells resulted in a block in erythroid differentiation with relative preservation of megakaryocyte differentiation, closely mirroring the defects observed in the 5q- syndrome.¹² Moreover, forced expression of an *RPS14* cDNA in primary bone marrow cells from patients with the 5q- syndrome rescued the phenotype, suggesting that *RPS14* is a 5q- syndrome gene. A block in the processing of pre-ribosomal in *RPS14*-deficient cells was found thus linking the pathogenesis of the 5q- syndrome to DBA.¹²

The anemia in DBA and the 5q- syndrome is due to a failure of erythropoiesis and intriguingly both disorders show haploinsufficiency for ribosomal proteins, *RPS19* and *RPS14* respectively, required for the maturation of 40S ribosomal subunits.^{11,13} These abnormalities may lead to impairment of ribosome biogenesis and subsequent reduction of protein translation capacity, a defect which may be of particular importance for developing erythroid cells, whose survival and division require large amounts of protein synthesis. Indeed, we have recently shown that CD34+ cells from patients with the 5q- syndrome have a defect in the expression of many genes involved in ribosome biogenesis and in the control of translation, suggesting that the 5q- syndrome represents a disorder of aberrant ribosome biogenesis.¹⁴

The data of Ebert et al data strongly suggest that the *RPS14* gene is an important gene in relation to the erythroid differentiation defect of the 5q- syndrome.¹² However, whether it is a causal gene in relation to producing a clonal hematopoietic disorder, and whether haploinsufficiency of an additional gene or genes is involved remain important questions. Haploinsufficiency of other genes localized within the CDR such as the tumor suppressor gene *SPARC* could play a role in establishing clonal dominance.¹⁵ Clearly mouse knockout models might prove very informative in relation to all these questions.

The del(5q) is the most commonly reported deletion in *de novo* MDS and is found in 10–15% of all patients. The relationship between the 5q- syndrome and the other myeloid malignancies with the del(5q) is a complex question. The del(5q) in the 5q- syndrome is cytogenetically indistinguishable from the del(5q) found in other MDS and AML and it should be recognized that in the majority of patients with the del(5q) and a myeloid malignancy, one allele of *RPS14* will be deleted. An exciting possibility is that MDS and AML patients with the del(5q) and the

5q- syndrome share a related molecular basis in that they are all disorders of defective ribosomal biogenesis.

Several of the bone marrow failure syndromes are associated with defects in factors associated with ribosome synthesis¹⁶ and the demonstration of *RPS14* as a 5q- syndrome gene adds to the body of evidence suggesting that defective ribosomal biogenesis may have a more general relevance in leukemogenesis.

Lenalidomide

The good prognosis of patients with the 5q- syndrome is well known, and the rate of leukemic transformation is low. Nevertheless most patients become transfusion dependent and do not respond well to erythropoietin. The introduction of lenalidomide (a derivative of thalidomide) for the treatment of the 5q- syndrome has had a major impact. A majority of patients treated with lenalidomide for the 5q- syndrome become transfusion independent and enter into a cytogenetic remission. This remarkable result is all the more surprising in view of the fact that lenalidomide was not developed for this purpose. The results of lenalidomide in the 5q- syndrome and related MDS are described in a series of seminal papers by List et al.^{17,18}

The US Food and Drug Administration (FDA) approved the use of lenalidomide “for the treatment of patients with transfusion-dependent anemia due to low- or intermediate-1-risk myelodysplastic syndromes associated with a deletion 5q cytogenetic abnormality with or without additional cytogenetic abnormalities”. In contrast the European Medicines Agency (EMA) has refused marketing authorization for lenalidomide intended for the treatment of anemia due to MDS. The EMA wishes to have further evidence pertaining to whether treatment with lenalidomide increases the risk of progression to AML.

The mechanism of action of lenalidomide remains uncertain although it is known to have effects on T-cell co-stimulation, angiogenesis inhibition, and modulation of apoptosis.¹⁹ We have provided evidence in favor of the SPARC gene as a candidate target gene for lenalidomide and interestingly similar evidence has emerged from studies of Non Hodgkins Lymphoma cell lines.²⁰ A better understanding of the action of lenalidomide would facilitate the development of further thalidomide derivatives for the treatment of MDS.

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Sign Up for 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

From the Operating Director's Desk



Kathy Heptinstall **Operating Director** **The MDS Foundation**

ASH is here again and we are conducting our 11th consecutive Friday Symposium. The meeting is chaired by Dr. Alan List and the agenda is focused on treatment and new treatment research.

In addition to the Symposium we will again conduct a reception honoring the recipients of the 2008 Young Investigator Awards. These Young Investigators are chosen in a scientific competition from submissions worldwide and scored by our Young Investigator's Grant Committee chaired by Dr. Stephen Nimer of Memorial Sloan-Kettering.

The Foundation has continued to broaden our reach to patients and physicians in 2008. So where have we gone to educate patients and healthcare providers about MDS this year?

We conducted US Patient Forums in Philadelphia, Pennsylvania (February 28, 2008); Rochester, New York (April 24, 2008); Los Angeles, California (May 1, 2008); Scottsdale, Arizona (May 2, 2008); San Antonio, Texas (August 20, 2008); and Atlanta, Georgia (November 13, 2008). Internationally we held meetings in Toulouse, France (May 22, 2008); Copenhagen, Denmark (June 10, 2008); Prague, Czech Republic (September 4, 2008); Lund, Sweden (September 10, 2008); London, England UK (September 26, 2008); and Frankfurt, Germany (October 2–4, 2008). If you would like to host a Patient and Family Forum in your city, please contact the Foundation. We are scheduling our 2009 meetings and hope to conduct more meetings world-wide in conjunction with our Nursing Advisory Boards in the US and Europe.

We participated for the 4th consecutive year in the British Hematology Association meeting and in BIO 2008. In addition we took our booth and materials to the American Society of Clinical Oncology (ASCO) meeting and participated in the Czech and Slovakian meeting in the Czech Republic.

The 10th International Symposium on MDS will be held in Patras, Greece on May 6–9, 2009. Dr. Nicholas Zoumbos is the Chairman for this international meeting and the agenda is inclusive of the newest information on all aspects of MDS. We invite you to visit the website at www.mds2009.org, and to participate in this cutting-edge meeting. The location is also a beautiful and historical site!

We presented our 4th consecutive symposia as well as our booth and information at the European Hematology Association's Annual Meeting. The well attended symposium and influx of visitors to our booth for information in the many languages of Europe make this a busy and extremely worthwhile meeting each year. We look forward to our participation in 2009!

On November 23rd the Foundation participated in the 2nd MDS Symposium to be held in South America. The Foundation brought its booth and materials and conducted a Nursing Forum with Drs. Lewis Silverman, John Bennett, Valeria Santini and nurse practitioners Erin Demakos and Sandra Curtin from the United States. The Forum centered on the drugs that have been recently approved for treatment of MDS in South America and provided information to the nurses who work with MDS patients on therapeutic aspects of these treatments, administration, and side effects.

The MDS Foundation's International Working Groups on Cytogenetics, Morphology, Quality of Life, and IPSS continue to add to our knowledge of MDS and improvement of patient care.

The Foundation is eagerly anticipating 2009 and our participation in our first meetings in Israel for physicians, nurses and patients in early January as well as our 10th International Symposium in Patras, continuation of our participation in country-wide meetings outside the US as well as ASH, ASCO, and EHA.

We will initiate a new partnership with the European Bone Marrow Transplant Nursing Group when we present a luncheon symposium at the EBMT meeting on March 30, 2009. This will significantly expand our work with nurses worldwide that includes additional educational programs with EONS and ONS.

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

The second group that we are very grateful to for their support are the pharmaceutical companies that provide us with so much assistance. The grants that these companies provide to the Foundation fund programs that are non-product related and support our work and educational programs. We could not do the work we do without this type of support. The acquisition of MGI by Eisai and of Pharmion by Celgene made it a very interesting year for all of us. We are grateful to both Celgene and Eisai for their assistance in maintaining our working relationship in a very positive way despite the obvious challenges inherent in these acquisitions.

From all of us at the Foundation, I wish you a wonderful Holiday Season and a Happy New Year!

Foundation Initiatives for 2009 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:

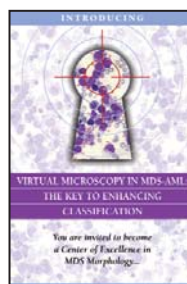
- **ADOPT REGISTRY**
- **PATIENT-CAREGIVER QUALITY-OF-LIFE FORUMS**
- **WORLDWIDE PATIENT SUPPORT GROUPS**
- **PATIENT QUALITY-OF-LIFE FORUMS**
- **EU-WIDE PATIENT & FAMILY FORUM FRANKFURT, GERMANY: March 6–7, 2009**
- **MDS SUMMIT, US-WIDE PATIENT AND FAMILY FORUM, ATLANTA, GEORGIA: February 23–24, 2009**
- **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
- CME Program on Differentiating Anemia
- CME Educational Program on Accurate Morphologic Diagnosis: a 6-part Series

MDS FOUNDATION SPONSORS

The MDS Foundation acknowledges support from:



MDS Young Investigator Grants Program

THANKS TO ALL WHO SUPPORTED

MDS Foundation—
H. Lee Moffitt Cancer Center

Our Annual Charity Golf Tournament

***Celebrity Gala Party and
Pro-Am for MDS presented by
Bruce Fleisher and Bob Griesse***

Our annual golf tournament partnership with H. Lee Moffitt Cancer Center was held February 17–18, 2008 at the Innisbrook Resort & Golf Club in Palm Harbor, Florida.

With the success of this tournament we are able to provide additional Young Investigator Grants for Fellows in Hematology working in MDS. 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.

It is essential to develop the new generation of researchers so that the causes of these syndromes and new therapies are identified as soon as possible. With that goal in mind we invite you to “Join the Journey to Hope for MDS” for the more than 30,000 new MDS patients diagnosed each year in the United States and to help us encourage the next generation of experts in MDS!



(Left to right) Bob Griesse, John Bennett, Tom Tracy, Matt Kutner, H. Lee Moffitt



Our entryway to the Celebrity Gala at the Innisbrook Resort & Golf Club in Palm Harbor.



(Left to right) Kathy Heptinstall, John Bennett, H. Lee Moffitt, and Alan List



(Left to right) Bob Griesse, NFL Hall of Fame Quarterback and Bruce Fleisher, Host of MDS Tournament since 2004

***THE JOURNEY IS NOT OVER!
Are you ready to join us?***

***“Your participation in the 2008
Moffitt/MDS Golf Tournament
will help Moffitt Cancer Center
continue to fight this terrible
disease and make a difference
in the lives of millions.
Join The Momentum!”***

– Bob Griesse



Mr. and Mrs. Moffitt



Dancing the night away to The Memories



(Left to right) Bob Griesse with fan, Art Rosengarten

Foundation Awards Grants



THE YOUNG INVESTIGATOR GRANT PROGRAM FOR FELLOWS IN HEMATOLOGY

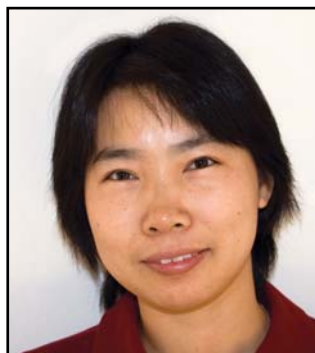
In December 2005 The Myelodysplastic Syndromes Foundation, Inc., initiated a series of grants "The Young Investigator's Grant Program for Fellows in Hematology". These awards are granted annually.

The Grant Review Committee selected Li Zhou's grant submission entitled "SMAD Dysregulation in Myelodysplasia" and Matthew J. Walter's submission entitled "Role of DNA Repair Genes in Therapy-Related MDS/AML" as the two Young Investigator Grant winners.

The 2009 Recipients Are:



Matthew J. Walter, MD
Washington University School of Medicine
St. Louis, Missouri USA



Li Zhou, PhD
Albert Einstein College of Medicine
Bronx, New York USA

The Foundation is dedicated to furthering the research into MDS and invites Young Investigators (under the age of 40) to submit either basic or clinical research proposals into the causation, epidemiology, molecular biology, cytogenetics, morphology, prognosis, or management of the Myelodysplastic Syndromes.

THE YOUNG INVESTIGATOR GRANT PROGRAM

is supported by this year's

MDS Foundation-H. Lee Moffitt Cancer Center Golf Tournament for MDS

Platinum Sponsors:



Silver Sponsor:



Bronze Sponsor:



TIMELINE FOR 2010 AWARDS

Proposals Due: August 17, 2009 • **Award Notification:** October 1, 2009 • **Award Ceremony:** December 2009

Meeting Highlights and Announcements

*On behalf of the MDS Foundation and our Board of Directors,
thank you for joining us for our Satellite Symposium:*

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

**June 12, 2008
Copenhagen, Denmark**



The Foundation has participated for four consecutive years in this meeting via our booth presence. 2006 marked the first Foundation symposium conducted in conjunction with EHA. The symposium was greeted by standing room only. 1000 copies (on CD-ROM) were distributed on Friday and Saturday of the EHA meeting. This educational video and the accompanying slides will be provided to audiences via both our Educational website and on CD for continued use throughout 2008. Our second symposium was conducted in June 2007 and distribution of that meeting continues as well.

Our symposium was accepted for presentation on June 12, 2008 with a focus on the "Stratification of Patients for Treatment in MDS via Virtual Microscopy".

■ **MDS Morphology:
An Evolution in Criteria**
Ghulam Mufti, MD

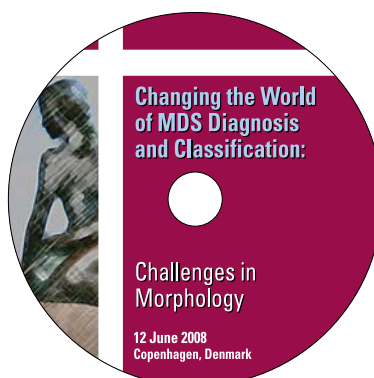
■ **New Morphologic Definitions in
MDS and Virtual Microscopy**
John Bennett, MD/Jean Goasguen, MD

■ **Interactive Participation in Morphologic Diagnosis** *Faculty/Participants*

The accurate differential diagnosis of the subtypes of myelodysplastic syndromes (MDS) depends in great measure on the morphologic assessment of the disease coupled with cytogenetic findings. Since the original French-American-British (FAB) Classification System was established multiple refinements have been made, and new proposals are pending, to enhance the existing classification and prognostic scoring systems.

As drugs have become available to treat MDS the stratification of MDS patients is essential to therapeutic choice and good therapeutic choices will, hopefully, optimize positive outcomes for patients.

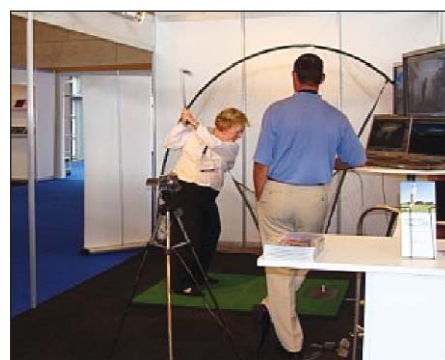
This program provided participants with background information on the historical use of MDS morphology as part of differential diagnosis and classification of patients, current standards for stratification of MDS patients, and the development of new morphologic criteria in MDS. The program highlighted the opportunity for participants to actively participate via a unique, interactive, educational tool developed specifically designed to educate hematologists, hematopathologists, and pathologists in recognizing key morphological criteria of specific cell lines in the diagnosis of MDS.



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



Translations of educational materials in English, key European languages and Japanese, as well as many other resource materials, were also provided free of charge at our booth.



EHA attendees participated in our "Drive Out the Iron" challenge.

DINNER SYMPOSIUM

Integrating New Developments in MDS into Clinical Practice

Friday, December 5, 2008
6 pm to 10 pm

Moscone Center South
San Francisco, California

Symposium and Dinner:
Esplanade Level, Room 307/309

*Seating will be on a first-come,
first-served basis.*

Dinner will be served.

**VISIT THE MDS FOUNDATION
BOOTH: #705-711**

This symposium will be available on CD-ROM
on December 7th at The MDS Foundation booth.

PLEASE PLAN TO ATTEND!

Agenda

6:00–6:30 pm

Dinner

6:30–6:40 pm

Introduction/Educational Objectives

Alan F. List, MD

6:40–7:10 pm

What and “WHO” Is New in MDS?

John M. Bennett, MD, Chair

7:10–7:40 pm

Changing the Landscape of Cytogenetics

Marilyn L. Slovak, PhD

7:40–8:10 pm

Adapting the Role of Prognostic Scoring in the Treatment of MDS

Detlef Haase, MD, PhD

8:10–8:40 pm

Understanding the Immunopathogenesis in MDS

P.K. Epling-Burnette, PhD

8:40–9:10 pm

Understanding the “Novel” in MDS Therapy

Alan F. List, MD

9:10–9:40 pm

Making Combination Therapy a Reality

Guillermo Garcia-Manero, MD

9:40–10:00 pm

Discussion of the Program

Audience/Faculty Interaction

Program Overview


The MDS Foundation will hold its 11th consecutive satellite symposium on Friday preceding the American Society of Hematology’s annual meeting. There has been an upsurge in new information in MDS research, diagnosis, and treatment during the past year that

continues to mold our understanding of the disease and its treatment in 2008 and beyond. This symposium has been designed to comprehensively integrate and evaluate this information that will impact diagnosis, stratification, biology, treatment and “tracking” of MDS patients. A thorough overview of the upsurge in unique therapies under investigation will be presented; cutting-edge information on the role of immunopathology in MDS will be explored; improvements in the morphologic classification and diagnosis of MDS will be explained (International Working Group on MDS Morphology); innovative new research designed to broaden knowledge and improve techniques in testing for and analysis of MDS cytogenetics will be presented by the International Working Group on MDS Cytogenetics; the evolution of the prognostic scoring systems for MDS (IPSS and WPSS) aimed at improving patient stratification will be presented, a new state-of-the-art methodology to “track” MDS patients that is designed to provide real-time alerts to the

The MDS Foundation presents

Integrating New Developments in MDS into Clinical Practice

Dinner Symposium



Friday, December 5, 2008
6 pm to 10 pm
Moscone Center South
San Francisco, California

THIS IS A FRIDAY SATELLITE SYMPOSIUM
PRECEDING THE 50TH ASH ANNUAL MEETING

clinician regarding disease progression and/or response to MDS therapy, and, finally, an exploration of the path(s) that will make combination therapy a reality for MDS patients.

Faculty

John M. Bennett, MD Chairman

University of Rochester
James P. Wilmot Cancer Center
Rochester, New York

P.K. Epling-Burnette, PhD

Moffitt Cancer Center
Tampa, Florida

Guillermo Garcia-Manero, MD

M.D. Anderson Cancer Center
Houston, Texas

Detlef Haase, MD, PhD

University of Göttingen
Göttingen, Germany

Alan F. List, MD

University of South Florida
H. Lee Moffitt Cancer Center
and Research Institute
Tampa, Florida

Marilyn L. Slovak, PhD

City of Hope
Duarte, California

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

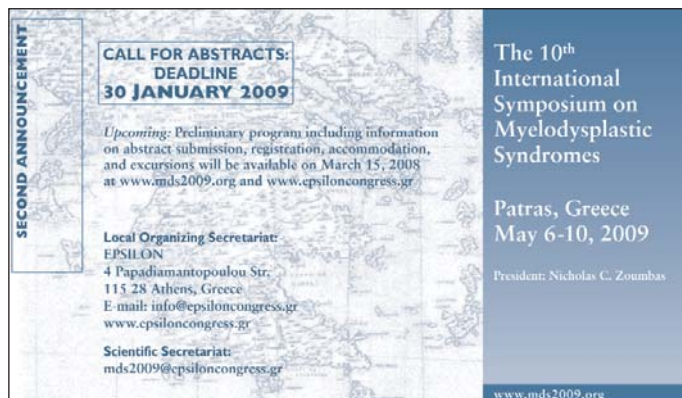
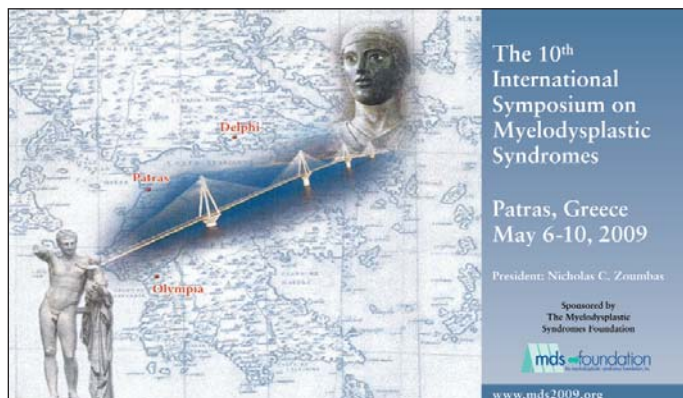
Edinburgh, Scotland

Sponsor: David T. Bowen, MD

Twelfth International Symposium: Spring 2013

Berlin, Germany

Sponsor: Wolf-Karsten Hofmann, MD, PhD



International and Country Congresses & 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 Lösemili Çocuklar Vakfı

We are continuing to participate in countrywide as well as EU-wide meetings that we have previously attended and striving to expand into other major European countries and actively participate in their society meetings. Meetings completed or coordinated:

- British Society of Hematology
April 7–9, 2008
- ESH Conference Albufeira, Portugal
May 15–18, 2008
- Groupe Français des Myélodysplasies
May 22–23, 2008
- Israel Society of Hematology: TBD
- Czech and Slovak Hematology Congress
September 5–9, 2008
- The XXXII World Congress of the International Society of Hematology
Bangkok, Thailand
October 20–23, 2008

Patient Services

Mercy Medical Airlift®

Dedicated to Helping Those in Need of Air Medical Transportation

(a non-profit 501(c) charity)

MMA's mission is to ensure that no needy patient is denied access to distant specialized medical evaluation, diagnosis or treatment for lack of a means of long-distance medical air transportation; further, to ensure the provision of urgent transportation in situations of compelling human need and homeland security emergencies.

The following programs are administered by Mercy Medical Airlift®.

NATIONAL PATIENT TRAVEL CENTER

Tel: 1-800-296-1217

www.PatientTravel.org

Provides information about all forms of charitable, long-distance medical air transportation and provides referrals to all appropriate sources of help available in the national charitable medical air transportation network.

ANGEL FLIGHT MID-ATLANTIC

800-296-3797

www.AngelFlightMidAtlantic.org

Ambulatory outpatients traveling less than 1000 miles departing from District of Columbia, Delaware, Kentucky, Maryland, Michigan, Ohio, Pennsylvania, Virginia and West Virginia.

AIRLIFT HOPE AMERICA

800-325-8908

www.AirliftHope.org

Ambulatory outpatients traveling less than 1000 miles departing from North Carolina, Tennessee.

CHARITABLE PATIENT AIRLINE TICKETS

888-675-1405

www.PatientTravel.org

Patient travel exceeds 1,000 miles or there are reasons a patient cannot fly on light aircraft.

AIR COMPASSION AMERICA

866-270-9198

www.AirCompassionAmerica.org

Patient travel requires air ambulance and medical monitoring en route.

AIR COMPASSION FOR VETERANS

888-662-6794

www.AirCompassionForVeterans.org

Provide medically related air transport services to troops, veterans and their immediate family members.

HOMELAND SECURITY EMERGENCY AIR TRANSPORTATION SYSTEM (HSEATS)

757-318-9174

www.HSEATS.org

HSEATS is the United States civil aviation response to disasters. It is a jointly coordinated program that utilizes aircraft owned and flown by volunteer pilots, corporate business jets, air ambulance services through Air Compassion America and donated airline tickets through Mercy Medical Airlift.

SPECIAL LIFT

888-675-1405

This special service provides for nationwide "single-point of contact" administration of clinical trial travel requirements in support of special/rare disease organizations and clinical research centers. Persons or organizations concerned with travel assistance arrangements for multiple patients at different time and to different places should investigate this program.

STRETCHER PATIENT TRANSPORT

800-296-3797

Mercy Medical Airlift operates a Federally-approved stretcher equipped Beech 36 aircraft (the Bonanza) for purposes of transporting patients who must be lying down en route. This service is for personnel who do not require any medical attention en route. Examples of such transports would be; elderly bedridden patient being relocated to a new long-term care facility, child in a full

body cast, etc. MMA operates this aircraft under a Federal Air Carrier Certificate and utilizes a cadre of MMA trained pilots. The Bonanza is based out of Manassas, Virginia and serves the Mid-Atlantic States. The service is provided free of charge to eligible patients and families.

AIR CHARITY NETWORK (ACN) SUPPORT

757-318-9174

Mercy Medical Airlift has several support initiatives that it undertakes on behalf of and at no cost to the Air Charity Network including nationwide pilot recruitment, government liaison/program development and liaison with national disease and patient support organizations and other national charities involved in patient services. Additionally, MMA operates the www.volunteerpilot.org web site on behalf of the Air Charity Network. This web site has referred thousands of potential volunteer pilots to ACN regions.

CHARITABLE AVIATION ASSOCIATION MANAGEMENT

757-318-9174

MMA contracts with other charitable medical air transportation organizations at both the national, regional and state levels providing fundraising, general administration and program services thus achieving maximum efficiency at minimal costs.

ANGEL FLIGHT AT NIH

301-451-9646

www.AngelFlightAtNIH.org

Angel Flight's corps of pilots, provide flights of hope and healing by transporting patients and their escorts in private aircraft, free of charge, to medical research and treatment facilities.

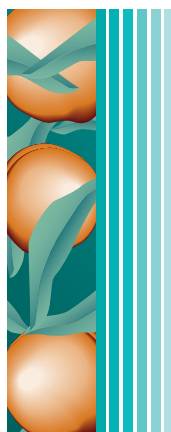
Patient Forums and Support Groups

US & European Patient and Family Forums

These Forums will assemble patients from across the United States and Europe for a Patient and Family Forum that will provide interactive and didactic updates from key clinicians and nurses. Invitations will be provided to representatives of governmental agencies that provide approval for and access to treatment as well as leaders in the pharmaceutical industry to listen to the needs of patients attending the forum and offer these groups the opportunity to provide information to regarding access, drug development, and pricing.

Objectives

- To bring together physicians, patients and caregivers, pharmaceutical and government representatives (FDA and NIH) for a two-day education oriented event
- To provide a platform for presentation and discussion of information for patients including:
 - Disease-specific update on MDS
 - Treatment-specific overviews & insights
 - Transfusion-dependency & iron overload
 - New MDS research and the hope for the future
 - Quality-of-Life in MDS
- To provide a forum for discussion of clinical research and drug development including:
 - Roles of the various participants in research
 - Issues in drug development and approval
 - Drug cost
 - Drug access
- To provide the opportunity for publicity regarding MDS to increase public awareness of the disease through:
 - Invitations to celebrities or political people to participate in the meeting
 - Invitation to journalists to participate in the meetings
 - Development of press releases and media events surrounding the meeting



SAVE THE DATE!

US Patient & Family Forum

February 23–24, 2009

Hyatt Regency ■ Atlanta, Georgia

For additional information, please contact The MDS Foundation at 800-MDS-0839, or E-mail: dmurray@mds-foundation.org.



PLAN TO ATTEND!

European Patient and Family Forum

6–7 March 2009

Hilton Frankfurt Hotel ■ Frankfurt, Germany

For additional information, please contact Sophie Wintrich at +44 20 7733 7558 or E-mail: swintrich@mds-foundation.org.

Overview

The Patient and Family Forums are for patients and family members who have myelodysplastic syndromes. An internationally renowned group of speakers have been organized to accomplish two main goals. The first goal is to provide comprehensive patient friendly information on diagnosis and treatment of myelodysplastic syndromes with specific workshops. In addition, the Forums will provide attendees information on many shared issues between patient and family members with myelodysplastic syndromes. This Forum will address many unmet needs that patients and their loved ones have rarely discussed in the exam room. It will also give attendees the opportunity to meet other patients and families in specially designed workshops allowing everyone the opportunity to connect with one other and share, not only knowledge, but concerns and questions. Time has been set aside at the

conference for a question and answer forum with experts, so attendees are able to have their particular concerns address. This information is crucial for people who are suffering from myelodysplastic syndromes.

This broad based Patient Forum is the first of its kind and will provide a unique opportunity for beneficial dialog between patients, their family members and a range of thought leaders from around the world.

Audience

This Patient and Family Forum is designed for current patients with myelodysplastic syndromes. Additional family members are welcome to register and attend the sessions.

Information and Registration

For additional information and to register online, please visit The MDS Foundation website:

www.mds-foundation.org

Highlights From Around the World...

**San Antonio, Texas
August 20, 2008**



Special Guest Speaker, Roger M. Lyons, MD, FACP; Cancer Care Centers of South Texas



Dr. Lyons addresses patients and their guests in San Antonio

MDS Foundation in France and Czech Republic



May 23, 2008: Groupe Français des Myélodysplasies Congress – Toulouse, France

Kathy Heptinstall, Operating Director The MDS Foundation



September 4, 2008: Prague Patient Forum, Dr. Jaroslav Cermák, Guest Speaker – Czech MDS Patient Group

(L to R) Bohumir Jezek, Hana Jezkova, and Jiri Vesely (Read Mr. Jezek's story on pg 18)



September 5, 2008: Czech & Slovak Congress in Hematology – Špindlerův Mlýn, Czech Republic

(Pictured L to R) Dr. Anna Jonášová, Dr. Lenka Walterová, Dr. Radana Neuwirtová, Dr. David Bowen, Alain Dostie, Dr. Jaroslav Cermák, Dr. Tom Ganz, and Sophie Wintrich, EU Patient Liaison.



San Antonio Patient and Family Forum Attendees in August



Kathy Heptinstall, Operating Director, The MDS Foundation moderates the quality-of-life session

UK Patient Support Group: Autumn Forum Meeting

**Institute of Physics
London, UK
September 26, 2008**

The MDS UK Patient Support Group Autumn Forum Meeting was held on September 26th, 2008 in London. Introductions were made by David Hall, Acting Chair of the MDS UK Patient Support Group. Topics and faculty included:

■ What is MDS?

Professor Dr. Ghulam Mufti
King College Hospital
London

■ Living with MDS and the Journey to Hope

Kathy Heptinstall
The MDS Foundation

■ New and Current Treatments in MDS

Dr. Paresh Vyas
John Radcliffe Hospital
Oxford

■ Bone Marrow Transplantation for MDS Patients

Dr. Michelle Kenyon
Kings College Hospital
London

The MDS UK Patient Support Group is affiliated with the MDS Foundation and provides continuous support to MDS patient and their caregivers, providing information and advice on the status and progress with MDS treatments in the United Kingdom.

For further information:

E-mail: info@mds-foundation.org

Website: www.mdsukpatients.org



Dr. David Hall presents the introduction at the MDS UK Patient Support Group Forum in London.

MDS Patient & Family Forum – Frankfurt, Germany



October 2, 2008: Patients and caregivers learning about the latest treatment options in MDS from Dr. Wolf-Karsten Hofmann, Campus Benjamin Franklin Charité—Universitätsmedizin Berlin.

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

Patient forums have been held to date in:

UNITED STATES

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

EUROPE

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

Future forums are scheduled in:

- Atlanta, Georgia (February 23–24, 2009)
- Frankfurt, Germany (March 6–7, 2009)
- Stockholm, Sweden (Spring 2009)

- Athens, Greece (Prior to 10th International Symposium on MDS)
- Tel Aviv, Israel (TBD)
- Baltimore, Maryland (TBD)
- Boston, Massachusetts (TBD)
- Minneapolis, Minnesota (TBD)
- Albuquerque, New Mexico (TBD)

On October 26th, 2004 we held our first MDS Patient Forum in New York City. Since then we have held 38 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)

Patient Support Group Initiative

The MDS Foundation has developed a strategy for setting up patient groups nationwide and assistance is now available to organize support groups for MDS patients. At this time, we would like to enlist the help of our patient members in facilitating these member-run groups.

Would you be interested in joining with a few other people to help start a needed support group for MDS?

Monetary assistance is now available to help you develop a self-help group. The purpose of this group is to exchange information and resources, to provide comfort and support to patients and caregivers, and to explore the challenges of living with myelodysplastic syndromes.

Studies and other literature show that patients facing chronic or terminal illnesses, as well as their families and friends, benefit in numerous ways from participating in patient support groups. These groups not only provide a source for obtaining current information on the disease, treatment options and research, they also offer a supportive environment in which to express fears and concerns and share experiences with others coping with similar conditions. In fact, patients who participate regularly in support groups report reductions in stress, depression, and even pain.

Any member of the Foundation, patients, friends, family members, and caregivers are invited to join with us to move this project forward.

My Story...

REPRINTED FROM *WOMAN'S DAY*

A Stranger Saved My Life

A rare disease threatened my future—until a hero stepped in

***by Rachael Leisy,
as told to Susan Sulich***

The day I had been anticipating for so long was finally here. My parents and I had traveled from Kansas to New York to meet my brother, and now we were all on a train headed to Connecticut. The sky was cloudy and gray, but nothing was going to dampen my spirits. Today I was going to meet the man who had saved my life.

As the train pulled into the station, I thought about how much had happened in the past year. In August 2006, I had just moved into my sorority house at Kansas State University and was excited for my sophomore year to start when my mom called. She told me I needed to come home because my doctor wanted to see me right away. Earlier that summer, I had developed a small infection on my foot. When antibiotics didn't clear it up, my doctor decided to run some tests. Still, I wasn't thinking it was anything serious as I waved to my sorority sisters, saying, "I'll see you tomorrow." It turned out I wouldn't be back for the rest of the school year.

The next few days were a blur as my doctor checked me into the hospital and I learned why my foot wouldn't heal: I had a myelodysplastic syndrome (MDS), a rare disorder in which the bone marrow doesn't produce enough normal blood cells. As a result, I was very susceptible to infection; my white blood cell counts were so low that even a cold or a small cut could have killed me. Even worse, I found out that MDS can develop into a deadly type of leukemia—and I already had a few leukemic blasts, or abnormal cells. I was completely shocked and overwhelmed.

My only hope for survival was a bone marrow transplant, and my doctor said I needed to find a donor fast. In the meantime, I would have to adjust to a new, germ-free life in the hospital. I couldn't see visitors without wearing a surgical mask, and if something dropped on the floor I couldn't pick it up. Everything had to be sanitized constantly. My boyfriend couldn't even hug me.

My parents and I hoped that my older brother Matthew would be my donor, since he had actually given bone marrow stem cells before (he didn't know the recipient; he was recruited during a blood drive). To find a suitable candidate—one whose stem cells would be least likely to attack the healthy cells in my body—my doctors tried to match 10 proteins found on the cells. Sadly, Matthew wasn't a match. We then turned to the National Marrow Donor Program (NMDP).

Searching for help

Out of 11 million registered marrow donors worldwide, I had four potential matches. The NMDP called and asked each of them to go for additional blood work, but I learned that one person responded in record time. He was a 9 out of 10 match, which meant there was a good chance that he could help me, but it wasn't ideal. Another donor turned out to be a 10 out of 10 match, but he couldn't meet the fast transplant schedule my doctors wanted. After a lot of praying and consultations with my doctors, we decided to go with the 9 out of 10 donor. Everyone was worried, but I was relatively confident because I knew he had his heart in it. After all, he was the one who had been so quick to respond to NMDP's call.

Right away, I started two weeks of extremely aggressive chemotherapy to kill off my own marrow (and all the cancer cells) and make room for the new stem cells. This meant that I temporarily had no immune system, so the smallest bacteria could be deadly.

Out of 11 million registered marrow donors worldwide, I had four potential matches. The NMDP called and asked each of them to go for additional blood work, but I learned that one person responded in record time.

On October 7, two months after I was diagnosed with MDS, my donor's stem cells arrived by special courier. I didn't know it at the time, but my donor had traveled from his home in Connecticut to the nearest transplant center in Boston to make the donation. When the shipment arrived at my hospital in Kansas City, I was in the middle of a party—mine! After taking the necessary sterilization precautions, my parents, our pastor, my boyfriend and his parents arrived in my room with party hats and balloons to celebrate my "new life."

Finally, around 1 A.M., my pastor prayed over me and my doctor started the infusion of stem cells. It was dark in the hospital, but a nurse gave me a flashlight so I could watch the blood flow through the IV and into my body. When it was over I felt a sense of peace come over me.

In the days that followed we anxiously waited to see if my blood counts would go up, a sign that the transplant had been a success. After one week my white blood cell count took a big jump and then continued to climb steadily—it was working!



A long recovery

I was in the hospital for about three months before I was allowed to move back to my now sterile home. My mom made sure everything I touched had been wiped down with soap and water or sanitizer. I even had my own bathroom, with a sign on the door that read “Rachael’s Loo!” There was also a sign on our front door warning everyone that they couldn’t come in if they had any symptoms of an illness. It would be another month before I could walk outside without wearing a mask.

I spent nine months recovering; during that time, I ended up back in the hospital a few times due to complications. I passed the time doing puzzles and painting, and even took a few online classes. And of course, I often thought about my donor.

The NMDP doesn’t allow donors and recipients to know anything about each other in the year after the transplant, but I couldn’t help wondering where he lived or what he looked like. I was so excited when my transplant coordinator told me that she could give him a letter—as long as I didn’t tell him my name, where I lived, or anything about the transplant.

My mom and I couldn’t believe the card store had a section specifically for donors. I picked out one that said, “To My Hero and My Wonderful Donor!” Within a month I had a response—and some more information. It turned out that his young son had won a tough battle against leukemia, and part of what saved his life was a series of blood transfusions. Being a bone marrow donor was this dad’s way of giving back for the gift he had been given.

As we continued to write to each other, our bond became stronger. I started signing my letters “Your other half.” I thanked him again and again for saving my life. When he wrote that he would be “my lifeboat”—and that if I ever needed marrow again or blood or anything else he would give it to me—I was in tears. We both looked forward to the one-year anniversary of my transplant, when we could finally talk to each other.

Connected at last

Just a few days after our “anniversary,” I was thrilled to get a call from my donor. He said his name was Michael Carneiro and that he lived in New Fairfield, Connecticut, a short train ride from New York City, where my brother was. My parents and I were planning to visit my brother for Thanksgiving in about a month; he said it would be the perfect time for us to meet.

Before I knew it we were on the train to Connecticut. I spotted Mike standing on the platform as soon as the train doors opened, and instantly we hugged each other like we would never let go. It was as if the whole world had stopped around us.

I had never met them before, but Mike, his wife and two sons instantly felt like my family. I couldn’t imagine a better way to spend Thanksgiving, because I’ve never felt more thankful.

Today Mike and I share more than just blood—we share a passion to get the word out about bone marrow donation and save more lives. Before all this happened, I was planning to be a teacher, but educating people about the importance of bone marrow donation is my new goal. I’m back in college now, but I also recently started the *Team Rachael “Thankful for Life” Foundation* to promote awareness and hold bone marrow drives. When I talk to potential candidates, I always share my story and tell them how Mike’s selfless act saved my life. My hopeful future is all because of him.



YOU COULD SAVE SOMEONE’S LIFE

Every year 10,000 Americans are diagnosed with a life-threatening disease that can only be cured with a bone marrow transplant, and only 30 percent of them find a match within their family, according to the National Marrow Donor Program (NMDP). That’s why getting enough volunteers to sign up for the bone marrow donor registry is crucial.

It’s easier than you think. While some transplants require surgery to extract stem cell-rich marrow from the pelvic bones, more than 70 percent of donations are done by a procedure that’s similar to giving blood. Called peripheral blood stem cell donation, it involves drawing blood from one arm and passing it through a machine that separates out the stem cells.

Anyone can do it If you’re between 18 and 60 and in good health, you can be a marrow donor. People with diverse ethnic and racial backgrounds are especially needed.

Joining the registry is simple. All it takes is a simple swab of the inside of your cheek, which picks up the proteins they look for in a match. You can do it at a donation center, during a bone marrow drive, or with a DIY kit that you can order online at marrow.org/wday (click “Join the Registry” for instructions). Tissue typing (to analyze your sample) costs \$52, but if you register at a drive the cost may be covered by a sponsor. If you’re a potential match, you’ll be contacted by NMDP and asked to undergo some blood tests. The cost of these tests and any other expenses will be covered.

For more info, go to marrow.org/wday or call 800-MARROW2 (800-627-7692). **To donate to Rachael’s foundation,** mail a check to 1055 Broadway, Suite 130, Kansas City, MO 64105. Please make checks payable to the Greater Kansas City Community Foundation and put Team Rachael “Thankful for Life” Foundation in the memo line.

Reprinted with permission from the September 16, 2008 issue of Woman’s Day.

Our Stories...

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

SUBMITTED FROM THE CZECH REPUBLIC

My Story – or How to Live With MDS – Myelodysplastic Syndromes

Bohumír Ježek
Prague, Czech Republic

I was born in May 1945. In Prague, you could still hear the final shots of the war, but as a baby I did not recognize them. Afterwards, my life went on in quite a normal way. Schools, work, and the years passed. Then came old age and with it, diseases. First, diabetes of the B type. A relatively low glycemia level — a diet will do. Until once during a checkup, the physician's face became gloomy. "Do I have a high sugar level?" I asked. "No, but something is wrong with your blood," said the physician. Then a whirlwind of examinations started. It took quite some time and it was not all pleasant. Then I got the results, it was MDS — myelodysplastic syndrome. All the basic components of my blood were damaged. Red corpuscles remain small, white corpuscles transform themselves into blasts without the ability to protect the organism, and blood platelets are despairingly rare. The only possible way is a bone marrow transplant, said Associate Professor Jaroslav Čermák. CSc., the Chief Physician of an outstanding institute — UHKT (*Ústav hematologie a krevní transfuze*) [Institute of Hematology and Blood Transfusion]. This institute closely collaborates with U.S. experts and also with the MDS Foundation. The search for a suitable donor now began.

Together... we founded, in the Czech Republic, a civic association similar to MDS Foundation. The Foundation was kind of an inspiration for us. We are at the beginning of our path, but we do hope that we will manage to bring a good disposition to patients suffering from this disease and help them live with (it).

None of my family members were suitable, and nobody suitable was found in the Czech register either. Only a foreign register revealed one. I endured the actual transplant relatively well, although I ended up with more time to think than it was comfortable. Well, maybe every patient goes through that. I began to appreciate life much more than before, that is, those common daily events of joy. Unfortunately, I had to leave the job I kind of identified with. As it happens, some of my friends forgot about me, but others, new friends, entered my life. It has now been three years since the transplant. I have an outstanding wife who helps me live and, among other things, is an excellent cook. However, I do experience some difficulties—I have very little physical strength and I have some trouble with my kidneys. But I am alive. Together with some other patients, we founded, in the Czech Republic, a civic association similar to MDS Foundation. The foundation was kind of an inspiration for us. We are at the beginning of our path, but we do hope that we will manage to bring a good disposition to patients suffering from this disease and help them live with this disease. I am sending my greetings and a wish for a good health to all my colleagues in our disease and also to all those who help us live.

Let us pluck up our courage!

I Was Diagnosed With MDS Five Years Ago...

Vera Talianova
Czech Republic

My name is Vera Talianova and I am 61 years old. I was diagnosed with MDS five years ago. I have never been ill for such a long period before. I had an active social life and enjoyed sports. This illness caused me to experience extreme fatigue.

I feel very fortunate to have found Dr. Jaroslav Cermak. He is a kind and modest doctor that treats all patients in the same way. From the first moment I had absolute confidence in him and I believed that the medical treatment would be successful thanks to his care.

In the year 2006, Dr. Cermak invited his MDS patients to meet the representatives of the MDS Foundation. This event was held by Kathy Heptinstall, Operating Director, of the Foundation. She informed us about the new progress concerning this illness. This Foundation along with their MDS Centers of Excellence assists people with this disorder worldwide. During this meeting, Dr. Cermak mentioned the medicine called Revlimid, which helps patients with a specific form of anemia, which I actually suffer from.

I believe that thanks to such kind people like Mrs. Heptinstall and Dr. Cermak, this medicine finally came to the Czech Republic. Since June of 2008, I have been taking Revlimid. The beginning was not so easy and I experienced high temperatures and headaches. Already after just one month, my red blood cells have begun to grow. After five long years, it seems like a miracle. I can breathe again and I am sure that my life will have better quality and bring more happiness. Every day I think of all the ill people and wish they could meet a doctor like mine. At the same time I think of all the doctors and I wish they could rely on a new medicine which could end the suffering of MDS patients.

Disease as a Gift

Zdenek Svehla
Czech Republic

When I look back to the springtime of 1999, I realize that the disease manifested itself quite inconspicuously. I was gradually losing strength, I was short of breath at work, and I was bruising very easily while playing sports, particularly during volleyball. I am surrounded by physicians in my family and had my first examination by my brother-in-law at the Department of Internal Medicine. I was initially told that I had anaemia possibly caused by a lack of iron, however after having a subsequent bone marrow biopsy clouds started to gather. The first preliminary findings revealed a more serious condition.

I was also referred to and shortly after visited the IHBT in Prague, where the bone marrow biopsy and collection of blood samples were repeated. Specialized examination confirmed the most dreadful worries and the diagnosis of RAEB-T type myelodysplastic syndromes or MDS was made. This is a more advanced form of haematological malignancy, somewhere on the edge of transition to acute leukaemia. The first examining physician that I met was head physician Dr. Cermak. He was very honest with me (there is nothing else that can be done in the given situation anyway) and he told me that without intensive treatment my chances of living were equal to zero. With treatment, which he recommended to initiate immediately, my chances to survive would increase and proposed chemotherapy could lead to even long-term remission. However, in the given situation the best solution for long term recovery seemed to be the bone marrow transplantation if, of course, a suitable donor could be found.

The illness was also taking a toll on me psychologically. I was not able to deal with

the situation in any way. I had never been seriously ill, I had no injuries, and the only time I went to the hospital was with my children to visit my wife who is a paediatrician. There were only a few days remaining before my admission to IHBT and I had to make arrangements at home and work. I had to sign letters of authorization at my bank, just in case... and I had to discontinue business partnerships because I could not complete the jobs. I felt desperate and cried at times.

However, once I was admitted to the IHBT Intensive Care Unit for my chemotherapy treatments, I instantly felt inner peace and relief. Suddenly the world full of joy on one side and full of worries on the other side ceased to exist and everything was reduced down to me — my illness — and the hospital environment. I became quite a favourite and cooperative patient, who was interested in everything (that is my nature) and who learned to be thankful for everything and not only for things that were pleasant. Every drug, every chemotherapy was a gift on the way to my recovery.



August 2008: Zdenek Svehla at Grossvenediger Peak, Altitude 3666 m.

I was grateful for every new morning. There were days when I did not think of MDS at all. Thanks to the disease I started to discover new dimensions of life around me, and I made time for things that I used to take for granted.

I was discharged in July — while I was sort of in remission — into excellent home care. I was cared for extensively by my nurses and physicians during my regular weekly visits to Prague and transportation back and forth was provided by my precious and caring wife.

Amplified by the will to live, I started thinking about everything, “I begged, knocked, searched” and surprisingly the help came. The books, people, new thoughts and experiences along with new pieces of the puzzle of fate, which we all shape by our everyday work. I learned to enjoy the beauty of every day life and my significant role in the therapeutic process.

And so I changed my approach to the disease without much effort. I was grateful for every new morning. There were days when I did not think of MDS at all. Thanks to the disease I started to discover new dimensions of life around me, and I made time for things that I used to take for granted. This marked connection — thanks to the disease — was not accidental; it came entirely spontaneously and became a permanent part of me.

The time went by fast. We celebrated Christmas as well as the beginning of a new millennium with family and friends. Unfortunately, my remission did not last and I once again felt ill. I experienced disappointment; I probably had great expectations and I lacked humbleness. Belief and appetite for life were always there

and I continued on with newly gained knowledge and understanding. Follow-up visits in Prague were more frequent and my wife never ceased to amaze me with her unwavering support. Although I did not have a bone marrow match in my family, a suitable donor was found in England through the world registries. I would like to communicate my deep admiration and esteem to the one human being behind the Channel, which I had a chance to meet personally at a later time. So I thank you Karen once again (but certainly not for the last time) from all of my heart.

This was followed by an uneasy decision-making process and the decision itself. Thereafter, with determination I was admitted to the IHBT for the preliminary pre-transplantation regime in the spring of 2000. My bone marrow transplant was performed on April 6. The bone marrow was well accepted, however, I contracted cytomegalovirus sepsis, which delayed my homecoming. I was finally discharged into homecare in the summer. Health complications in the fall caused by herpes virus resulted in another three-week stay at the Intensive Care Unit. Eventually, I managed to overcome all obstacles without major complications. After one year I put aside all drugs and gradually returned back to life.

Today, after eight years, I perceive all that I have been through with great dignity and thankfulness that I extend to all my relatives who have been through all of this with me, all employees of IHBT, which has become my second home and... of course I cannot forget myself.

More important than counting birthdays is the message that the disease had me realize and which — I believe — I have from the most part understood and taken to heart. Thank you for the gift of extremely valuable life experience. The disease should mean a change in our thinking and way of life. I know that cancer is a malignant disease, physically devastating our body and it is hard to comprehend emotionally. Today I

know that cancer is not deceitful. I can tell you from my experience that it was a hard competitor that fought honestly and truthfully, with open eyes, never hitting below the belt. The same was however expected from me and so I have learned a lot, thanks to the disease.

It is not important how many more days we have to live, but how we live in the present. My attitude has changed compared to the time before the illness. I live with a much greater understanding for others and I accept circumstances that happen beyond my control.

I admit that I do not follow everything I have resolved to do. I have learned to live without reproach for what I was unsuccessful in and for what could be better. It is not important how many more days we have to live, but how we live in the present. My attitude has changed compared to the time before the illness. I live with a much greater understanding for others and I accept circumstances that happen beyond my control.

I am in no way special; I am like every one of you. I know that even these thoughts cannot be taken as a general guide. We all walk in our own independent way, which allows us to learn. However, I know one thing for sure and that is we are never alone on our way. God is in our heart in every situation.

My Motto:

*My Lord, who lives in my heart,
please, help me and I will do everything
for you to be able to help me.*

Jan Konfrst

AN OPEN LETTER FROM THE CZECH REPUBLIC

Dear All,

I can legitimately suppose that I am probably older than most of you at 86 years of age. Throughout my life I have seen many doctors, but most recently I have been taken care of by Dr. Cermak at The Institute of Hematology and Blood Transfusion (IHBT). As opposed to the others, I can always be sure that Dr. Cermak will examine me completely.

Believe me I have seen many different doctors in my lifetime, old and young, experienced and inexperienced. I am one of the few on earth who had to look into the face of the ill-famed German Dr. Josef Mengele on the ramp of the annihilation camp in Auschwitz-Birkenau (Oswiecim).

I would like everybody here to realize that despite all of the bad that I have encountered with respect to my health, I have also been very fortunate to have received quality care at IHBT. I think it is important for us to have hope and to join with the MDS Foundation on their journey to hope. I still enjoy being part of this world. Dr. Cermak is the only member of the medical community who I really enjoy meeting with, particularly when he has good news regarding my health.

I wish everybody a lot of strength and hope for whatever obstacles may come our way.

***Jaroslav Kraus
Czech Republic***

A Recipe to Fight MDS: Keep Laughing As Much As You Can...

**Colin Campbell
Leeds, UK**

I suppose that throughout 2007 I knew something wasn't quite right. Every few months a minor nosebleed—but then that's O.K. isn't it? Nosebleeds can be healthy—or so I read. They can be brought on by dizzying heights, or excitement and stress brought on by watching Liverpool on the box.

After spending the new year with friends in County Meath, Ireland, my wife and I were driving back towards Dublin when I had a chronic nosebleed—a real beauty. Liz whisked me into a Dublin hospital and in A and E they shoved tampons (or something similar) up my nostrils and there they remained for five days. A blood test was carried out and I was admitted to a ward where I was told my platelets were down to eight. No problem there then I thought, until the Doc announced they should be over a hundred. “A bone marrow biopsy for you, my man,” Doc announced cheerfully. Horrors!!! I'd heard about these things, used I know, by the Spanish Inquisition to extract information on the devil and all his works from innocent blokes like me. Anyway, I had the biopsy the next day and it really wasn't too bad at all. Doc comes later and announces the good news—“You haven't got leukemia,” he smiled. Oh goody, thinks me, that's fair enough. “However,” he goes on, “I think you may have Myelodysplastic syndrome, but I want a second opinion and I'll have that tomorrow.” “What's that?” I inquire. So he explains roughly what this strange sounding disease is and how it was screwing up my platelets.

Next day, two doctors come and see me, confirm this thing called MDS, and suggest my time on this planet had strictly limited possibilities. That was January—this is now. I'm back home in the U.K. and being treated in St. James hospital in Leeds. I have a great doctor and all the nursing staff are excellent. I trot in every Wednesday for a platelet transfusion and sometimes extra red blood. My life is pretty good right now, although that four-week trip to South America is on hold. I have pills to stop the nosebleeds and steroids that may improve my platelet level. Next year I may face a bone marrow transplant. At 62 I thought I may have been a little old. Apparently not, as I have the body and energy of a 24-year old (actually the transplant specialist said a 50-year old, but you are what you feel I say)

One of the peculiar things about MDS is that you don't look sick—unless I haven't had a red blood cell transfusion for a month or so, when my nearest and dearest says that I start to resemble an extra from the set of the Addams family.

Meeting friends for the first time after I've told them the jolly news on the telephone usually brings about the same response—“You look fine to me, you old fraudster. Is this your way of getting out of the housework?” That's the problem with MDS—many of us look fit and well and it's difficult to get folk to put a warm arm around us. “Don't tell a book by it's cover,” I say to no avail. “You're having us on,” they say. “Typical Scouser, always on the lam.” To be truthful, I enjoy looking well and not having a fuss made by the fact I look like death warmed up. I feel sort of normal.

Anyway, apparently there is a lot going on in the area of research so there is always plenty of hope. I'm positive and don't dwell on it. Life is too short—seize the day—and make the most of your life. I tend to treat my illness with a certain amount of disdain. I do not let it run my life and I try hard not to dwell on it. I am happy to joke about it and am pleased when my friends

do the same. Humour, I believe, can help to improve your well-being and assist in dealing with adversity.

Dr. Fry, psychiatrist and professor emeritus of the Stanford University School of Medicine has said that in all his years of study he only ever came across the death of three individuals who were laughing at the time of their demise—“*There are very few people who die laughing.*” According to Dr. Fry, laughter may help prevent cancer by relieving depression, an emotional state that may make people more susceptible to the disease. A study at the University of Maryland School of Medicine found that 95% of volunteers experienced increased blood flow while watching a comedy and the benefits lasted between 12 and 24 hours.

I would say to fellow MDS sufferers — do not let it ruin your life. Keep laughing as much as you can... play plenty of music. Music and laughter... a recipe to fight our problem child.

In Norman Cousins's book *Anatomy of an Illness*, he described how watching comedies and reading funny books and articles helped him recover from a life-threatening tissue disease which left him in chronic pain.

In conclusion, then, I would say to fellow MDS sufferers—*do not let it ruin your life. Keep laughing as much as you can.* I suppose as a Liverpudlian, I have a certain advantage in that you need a sense of humour to come from there.

One last thought—*play plenty of music.* It doesn't matter what kind of music—whatever you like. It relaxes you and takes your mind away from your troubles. Music and laughter, then. A recipe to fight our problem child.

Patient Tributes

The MDS Foundation Mourns the Loss of Patient Advocate Kaete Angel



Kaete Angel

We met Kaete at our very first patient forum held in New York City on October 26th, 2004. She touched our hearts immediately and we were honored to have known her.

When the FDA Oncologic Drug Advisory Committee met to review the new drug application for Revlimid back in September of 2005, Kaete contacted the Foundation and expressed her desire to participate. She provided invaluable

Kaete faced her illness for seven years with bravery and her trademark wit and laughter. She was an inspiration to all who knew her, including the doctors and nurses who treated her.

insight from a patient's perspective and the effect of MDS on quality-of-life, including transfusion dependence. We are certain that Kaete's personal statement about life with MDS had a positive effect on the members of the committee. With her help, the ODAC Committee voted to recommend approval. She was also featured in a 2006 issue of *Cure Magazine*. Without the support and dedication of people like Kaete, we would find it very hard to further the causes of the Foundation.

In a statement announcing Kaete's death, it was disclosed that Kaete had a passion for gardening and world travel, having toured Europe extensively, as well as having visited China and Australia. While her illness kept her from doing many of the things she loved, she was able to continue her framed, intricate, crochet work which was featured in the Joy of Survival Art Show at the Praxair Cancer Center. Many of her pieces were sold for charitable causes. Kaete faced her illness for 7 years with bravery and her trademark wit and laughter. She was an inspiration to all who knew her including the doctors and nurses who treated her.

The MDS Foundation shares the sorrow of the patient community regarding the untimely loss of Kaete Angel. She has made an extraordinary contribution to the patient world of MDS, and she will be sorely missed. With our heartfelt sympathy to her beloved husband of 46 years, Alfons and her cherished daughter, Birgit O'Connell and family.

Karen A. Wenzel Memorial Golf Tournament

***Saturday, August 16, 2008
Windham Country Club
Windham, NH***

On August 16th, 2008 Paul Wenzel held a charity golf tournament in memory of his beloved mother, Karen A. Wenzel. His mother passed away in June of 2006 from MDS. It is Paul's hope that this event will be the first of many and will be a day to get family and friends together to remember his mother, and to help raise money for research and awareness of MDS.



We applaud Paul for his valiant efforts. Our work as a non-profit organization depends on public funding. If you would like to contribute in this way, or if you have a unique idea of your own, please contact us at 1-800-MDS-0839 or email patientliaison@mds-foundation.org.

MDS Foundation Patient Liaisons

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Vitamin/Mineral Supplement Use After Cancer Diagnosis: Safe? Effective?

As a result of living longer, the number of Americans with cancer has soared from about three million in 1970 to more than 10 million in 2004. And experts expect that number to double by 2050. People undergoing treatment for cancer as well as those fighting to keep it from returning—now all called cancer survivors—are increasingly determined to control their disease.

Many of these survivors—about 75%, according to a recent review of 32 studies—are turning to dietary supplements, in hopes of quelling the side effects of treatment, reducing the risk of recurrence and improving survival odds. This is despite little evidence that supplements can make a difference.

EN explores this controversial topic to uncover the best advice for survivors on what constitutes safe and sensible supplementation after a cancer diagnosis.

Evidence Weak for Supplements

In an effort to offer science-based guidance, scientists addressed the nutrition needs of survivors last fall with the unveiling of the report *Food, Nutrition, Physical Activity, and the Prevention of Cancer: a Global Perspective*. The World Cancer Research Fund (WCRF) and the American Institute for Cancer Research (AICR) convened a panel of experts to perform this comprehensive review of the science and uncover what measures might be beneficial as well as those that pose potential for harm.

The panel reviewed 39 randomized, controlled trials and, according to panel member Tim Byers, M.D., M.P.H., of the University of Colorado Health Sciences

As a result of living longer, the number of Americans with cancer has soared from about three million in 1970 to more than 10 million in 2004. And experts expect that number to double by 2050. People undergoing treatment for cancer as well as those fighting to keep it from returning—now all called cancer survivors—are increasingly determined to control their disease.

Center, “so far, the evidence doesn’t show that supplements offer anything over and above what food offers.”

“And in some cases,” says Byers, “they’ve shown harm.” Byers’ advice? Aim to eat the most healthful diet possible, and if you take a supplement, “stick with a multi that provides most nutrients at one to two times the Daily Value. Byers notes there’s no evidence that multivitamins are harmful to survivors, and they may, in fact, provide some protection. A Mayo Clinic study found better survival and quality of life in lung cancer patients who took vitamin/mineral supplements.

Single Supplements With Promise

There are two possible exceptions to the “just a multi” advice—calcium and selenium. Both have research behind them that links them to a lower risk of developing cancer. What’s still unknown is whether supplementation could also help cancer survivors stay disease-free longer.

Calcium. While studies of supplemental calcium have yielded mixed results, the consensus is that calcium does offer some protection against both colon and rectal

cancers. Scientists don’t know the exact mechanism, but calcium seems to play roles in hampering cells from turning cancerous, slowing the growth of cancer cells and in the death of cancer cells. An analysis of 14 studies on calcium supplements and the risk of colorectal cancers or adenomas (polyps that could be precursors to cancer) led the WCRF/AICR report to conclude that calcium offers “probable” protection against colorectal cancer.

“People who take supplemental calcium seem to get fewer colon and rectal adenomas,” says Byers. A combined analysis of 10 studies involving more than half a million participants found that those who took in the most milk and calcium were the least likely to develop colorectal cancer. But a note of caution: The WCRF/AICR report also cites diets high in calcium as a “probable” cause of prostate cancer. What to do?

Byers’ advice: “People who tend to form polyps or have had colon cancer may rationally consider taking supplements to reduce their risk of forming new polyps,” but until more is known, he recommends—men especially—keeping calcium intake at 1,000 milligrams daily from diet and supplements combined.

Selenium. The WCRF/AICR report concludes that selenium offers “probable” protection against prostate cancer, a finding that emerged incidentally from a large randomized, controlled trial aimed at determining whether a daily dose of selenium could lower skin cancer risk (it didn’t). Of 974 participants in the study, half were given 200 micrograms of selenium from yeast as selenomethionine and half got placebo. After more than six years of follow-up, there was only one-third as many cases of prostate cancer in the selenium group compared to the control group. Scientists speculate that selenium deficiency can decrease levels of compounds called selenoproteins, several of which have important antioxidant and anti-inflammatory properties. However, usual dietary intake

of selenium tends to meet needs for selenoproteins, which don't increase with supplementation anyway. In fact, high doses of selenium can be toxic. One additional caution: The same skin cancer trial that linked selenium with lower prostate cancer risk suggested the possibility of a slightly increased risk of non-melanoma skin cancer in people taking the supplements.

"Trials are near completion to help clarify who might benefit from selenium supplements and who should avoid them," says Byers, but in the meantime he believes taking up to 200 micrograms of selenomethionine (the beneficial form in most supplements) is unlikely to be risky.

High-Dose Nutrients: Help or Harm?

Just because something is natural doesn't mean it's safe. This may be the case with high-dose nutrient supplements taken during chemotherapy and radiation. This May, the *Journal of the National Cancer Institute* published a review of the research on antioxidant use (including vitamins C and E and beta-carotene) during chemotherapy and radiation and concluded they should be avoided during treatment.

The concerns? While some research suggests antioxidants protect normal cells from damage caused by treatment, other studies counter that high-dose antioxidant nutrients might (1) compete with the intentional pro-oxidative effects of chemotherapy and radiation, (2) interfere with the metabolism of chemotherapy or (3) even protect cancer cells from destruction. For example, a Canadian study on vitamin E in head and neck cancer survivors found significantly higher mortality rates in those who started taking 400 International Units of vitamin E during radiation and continued it for three years.

Scientists also point to research that found that high doses of beta-carotene increased the risk of lung cancers in smokers, and that folic acid might stimulate colon polyps to become cancerous.

What does help people get through treatment? Be sure to eat a healthful diet that's adequate in lean protein and fluids, low in saturated fats and has a natural balance of disease-fighting nutrients (lots of fruits, vegetables and whole grains). Exercise can help manage the stress and side effects of treatment.

8 Tips on What to Do After a Cancer Diagnosis

The expert panel for the WCRF/AICR global report made the same recommendations improving survival and quality of life as it did for reducing the risk of getting cancer:

- Maintain a healthy weight.
- Be physically active every day.
- Curb your intake of high-calorie foods.
- Eat mostly plant foods.
- Limit red meat to less than 18 ounces weekly, and avoid processed meats.
- Moderate your intake of alcohol and salty foods.
- Aim to meet most of your nutrient needs with healthful foods, not supplements.
- Seek advice from a trained nutrition professional — a registered dietician (R.D.).

The Bottom Line

So far, research has not found benefit from the use of high-dose supplements during or after cancer treatment. However, taking a daily multi that provides about 100% of the Daily Values for vitamins and minerals can improve nutrient intake and may provide some benefit, with little or no downside. If you do take any individual supplements, mention them to your oncologist.

What *does* help people get through treatment? Be sure to eat a healthful diet that's adequate in lean protein and fluids, low in saturated fats and has a natural balance of disease-fighting nutrients (lots of fruits, vegetables and whole grains). Exercise can help manage the stress and side effects of treatment. After treatment, follow the WCRF/AICR report's recommendations for survivors (see "8 Tips on What to Do After a Cancer Diagnosis," top left).

— Hillary M. Wright, M.Ed., R.D.

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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.

REPRINTED FROM *ENVIRONMENTAL NUTRITION*

9 Foods You Shouldn't Live Without...

And A Few To Add Back To Your Menu

Nutritionists will tell you all foods can fit into a balanced diet. But let's face it, some foods *are* better than others. Here, *EN* highlights nine foods that are a cut above and points out how they can give your eating plan a nutrition boost while broadening your dietary horizons.

Blueberries

These petite powerhouses boast ellagic acid, a known cancer-fighter, and tannins that thwart urinary tract infections, as well as four grams of fiber per cup—all for only 85 calories. Blueberries also are rich in anthocyanins, natural pigments that provide the fruit's deep hue, while enhancing its exceptional antioxidant prowess. Blueberries hold particular promise for preserving brain health. In one study, aging lab animals that ate the equivalent of one-half to one cup of blueberries every day for two months performed better on tests of memory, coordination and balance than those that didn't eat the fruit. Not a fan of blue? A recent study from Finland found that eating berries of any kind twice a day lowered blood pressure, increased high-density lipoproteins (HDLs, the "good" cholesterol) and reduced the risk of dangerous blood clots.

To use: For the most antioxidants, choose wild blueberries (available in specialty stores and frozen), though cultivated are healthful too. Add to smoothies, cereal, salads or yogurt and stir into batter for pancakes or quick breads.

Kale

Kale's leafy appearance belies its true lineage; it's actually a relative of cauliflower, broccoli and Brussels sprouts. Kale and

Forbidden? Think Again

If you've banished these foods ostensibly in the name of good health, there are reasons to put them back on the menu.

■ AVOCADO

An excellent—and yummy—way to get a healthful dose of vitamin E and heart-healthy fats.

■ BEEF

Choose lean cuts (sirloin, eye of round, brisket) for a plethora of protein, B vitamins, iron and zinc.

■ EGGS

Superb for high-quality protein, choline and the eyesight-saving carotenoids lutein and zeaxanthin.

■ OLIVES

What better way to get heart-healthy fats and natural anti-inflammatory compounds... and delish to boot.

■ PORK

Choose tenderloin, a leaner source of protein than boneless, skinless chicken breast. Who knew?

its cruciferous cousins supply several cancer-busting phytonutrients, including isothiocyanates and indole-3-carbinol. These powerful compounds have shown they can thwart the growth of human prostate cancer cells in the lab and can reduce the presence and growth of mammary tumors in mice. And 48,000 middle-aged men who ate more than five servings a week of cruciferous vegetables halved their risk of bladder cancer in a 10-year Harvard study when compared to participants who ate one or fewer weekly servings.

Kale is an excellent source of the mineral manganese, important for nervous system functioning, energy production and defending against free radicals, and it's off the charts in vitamin K, needed for proper blood clotting and bone health. In fact, if you take the blood thinner *Coumadin* (warfarin), inform your doctor or dietitian if you increase your kale consumption; your medication may need adjusting.

To use: Wash fresh kale well to get rid of grit, and toss the tough center rib. Enjoy sautéed with olive oil and minced garlic. Add finely chopped fresh or frozen kale to lasagna, pizzas, omelets, soups and stews.

Lentils

Eating lentils and other legumes is linked to less risk of cancer and type 2 diabetes, improved blood glucose levels and better weight control. Like all legumes, fresh or canned, lentils serve up ample protein, folate, fiber and iron. MyPyramid—the government's icon for good eating—recommends three cups a week of legumes (1/2 cup cooked legumes=2 ounces cooked meat, seafood, poultry or two eggs).

To use: Lentils are easier to prepare than beans—no soaking required. Cook lentils for soup or combine with rice or quinoa as a main or side dish. Or puree lentils to extend meatloaf, meatballs and burgers.

Quinoa

This pseudo-grain (really a seed) was the cornerstone of the Incan diet and is still prized for its protein content (four grams per half-cup, cooked). In addition, the United Nations Food and Agriculture Organization likens quinoa's protein profile to that of milk, a high-quality protein. It's rich in fiber, iron, potassium and magnesium, too. And it's gluten-free.

To use: Add cooked quinoa to soups, chili, stews, casseroles and salads, or enjoy alone as a side dish or breakfast cereal.

Rice

Brown or white, rice may help keep you healthier. One study suggests that rice eaters are more likely to weigh less and less likely to have high blood pressure or metabolic syndrome than people who don't eat rice. Brown rice is a whole grain, abundant in manganese, phytonutrients and fiber, while enriched white rice supplies B vitamins and iron. Both are gluten-free. Cooked, cooled rice supplies resistant starch, a carbohydrate that dodges digestion in the small intestine, serving as fiber and becoming fuel for "good" bacteria in the large intestine. This process yields butyrate, a fatty acid with anti-cancer, anti-inflammatory promise.

To use: Delicious as a side dish or as part of a main dish, like chicken and rice. Perfect for soups and stews; a natural as a meat extender (think stuffed peppers).

Sardines

For such a small fish, sardines offer a boatload of benefits, supplying omega-3 fatty acids that boost heart health by calming inflammation, promoting normal heart rhythm, keeping blood triglycerides in check and thwarting harmful blood clots. Omega-3s may also help preserve cognitive function with age. Recent research suggests that eating fatty fish like sardines sustains or improves muscle strength in older adults. And sardines help shore up your skeleton: three ounces (with the bones intact) supply about as much calcium as a glass of milk. Sardines' scant mercury levels make them a safe fish to eat, and they are an environmentally sound choice too.

To use: Sauté fresh or canned sardines in garlic and olive oil; add to pasta dishes. Grill fresh sardines. Mash canned sardines onto whole-wheat toast. Top a salad with the little fishies, some Kalamata olives and a sprinkling of feta cheese to make it a Mediterranean meal.

Sunflower Seeds

These gems are particularly rich in phytosterols, plant compounds that curb cholesterol. For 180 calories, an ounce of sunflower seed kernels is a good source of folate, iron and zinc. And it packs a healthful 37% of the Daily Value for vitamin E plus hefty doses of selenium and copper; all help shield cells from damage that could lead to heart disease or cancer.

To use: Sprinkle on tossed salads, fruit salads and cooked vegetables; add to chicken or tuna salad for crunch; sprinkle on top of cereal. For a munchie, combine sunflower seeds, raisins and a whole-grain cereal.

Sweet Potato

You can't hide its nutrition; that orange flesh broadcasts beta-carotene, the plucky plant compound that squelches free radicals, boosts immunity and which the body converts to vitamin A. In a recent Dutch study of more than 650 healthy older adults, those with high blood levels of beta-carotene suffered fewer upper respiratory infections like the common cold.

Sweet potatoes also serve as a fat-free source of vitamin E, which helps prevent low-density lipoproteins (LDLs or "bad" cholesterol) from becoming "stickier" and more likely to clog the arteries to your heart and brain.

To use: Toss peeled sweet potato wedges with olive oil and roast on a baking sheet for 20 minutes at 400°F or until tender. Steam chunks of peeled sweet potato until tender, then mash with orange juice. Thinly slice cooked, peeled sweet potatoes for sandwiches or salads.

Tea

Drinking tea can be calming; recent research suggests it does your body good in other ways as well. Chinese researchers monitored more than 63,000 people for 12 years and found that those

who drank the most black tea were 71% less likely to develop Parkinson's disease than those who sipped the least. And researchers at Alexandria University in Egypt found that drinking green tea when taking antibiotics significantly increases the drug's effectiveness, even against drug-resistant bacteria.

To use: Drinking tea is a healthful habit. When it's too hot to brew a pot, keep a pitcher in the fridge of green or black tea with slices of any citrus fruit, which protects beneficial phytonutrients in tea and fosters the body's ability to use them.

— Elizabeth M. Ward, M.S., R.D.

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Too Little or Too Much Iron Poses Serious Health Consequences

Q. I'm confused. Should I worry about getting too much iron or not enough?

A. Both, just to confuse you more. The truth is, it can be either, depending on your situation and age. Here's the deal:

Iron is an essential mineral throughout life, as a carrier of oxygen in blood and as an integral part of proteins and enzymes involved in metabolism. A deficiency of iron limits oxygen delivery to cells, resulting in symptoms that range from fatigue to impaired immunity. Iron-deficiency anemia is more typically a problem for children and premenopausal women. For men and postmenopausal women, a greater risk is from too much iron.

Too Much of a Good Thing. Remember those old *Geritol* ads? If so, chances are you grew up thinking more iron is better and that it could boost lagging energy.

But experts now question the wisdom of supplemental iron for everyone because of concerns over the commonly inherited condition called hemochromatosis, or iron overload disease, in which the body stores too much iron. It affects about one of every 250 people, though it's more common in men.

How much harm can it do? A lot. If undetected—as it often is—iron builds up over time and damages organs like the heart and liver, as well as causes arthritis, diabetes and impotence. Doctors may not realize that iron is the root cause of all these problems. But if detected, it can be treated by donating blood regularly plus avoiding iron supplements and iron-fortified foods.

Too Little Less of a Problem. Although iron-deficiency anemia is an all-too-common problem in the U.S., it's actually uncommon in older people. Less-than-optimal iron levels affect 9% of women aged 50–69,

6% of women (and 3% of men) 70 and up. Besides fatigue, what's the risk? Borderline-low iron levels can affect mental functioning in children; it isn't known if this holds true for older people as well.

Inadequate iron has also been linked to restless legs syndrome, a condition characterized by a crawling, fidgety feeling deep inside the legs that affects 2% to 15% of the population. This may be the result of poor iron delivery in the brain rather than inadequate intake. High-dose iron supplements may help, but get tested for hemochromatosis first.

Blood Testing Is Crucial. A blood test is the only way to know your iron status. A routine battery of tests typically includes hematocrit and hemoglobin, but not transferrin saturation and serum ferritin, which are necessary for an accurate picture. Here's what the tests can tell you:

Low hematocrit+low hemoglobin—typically signals anemia, though not necessarily from a deficiency of iron.

Low serum ferritin+normal hemoglobin—suggests borderline iron-deficiency anemia.

Serum transferrin saturation >45%—suggests iron overload and the need to test for serum ferritin.

Serum ferritin >200—signals iron overload for premenopausal women and borderline for everyone else.

Serum ferritin >300—signals iron overload for everyone.

EN's Bottom Line. Ask your doctor to include a transferrin saturation and a serum ferritin along with your regular blood tests. As a rule, *EN* doesn't recommend multis with iron for people over 50. However, it's best not to alter your current intake of iron-rich foods or supplements without talking to your doctor first.

For more information about Environmental Nutrition, visit: www.EnvironmentalNutrition.com or call 800-829-5384.

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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

Recent FDA Ruling Could Restrict Patient Usage of Aranesp and Procrit

On July 31st, the Food and Drug Administration (FDA) ordered Amgen and OrthoBiotech to change the labels for their flagship anemia drugs, Aranesp® (darbepoetin alfa) and Epogen®/Procrit® (epoetin alfa), in a way that could further restrict their use in patients undergoing curative chemotherapy. Many MDS patients rely on Erythropoiesis Stimulating Agents (ESAs) like Procrit, Aranesp, and Epogen, which can support the bone marrow and delay the need for blood transfusions. This is the first time the FDA has used the authority granted under a 2007 law empowering the agency to order changes in a drug's prescribing information. Previously, the FDA could only negotiate with a manufacturer for label changes.

The MDS Foundation (MDSF) is concerned about the FDA and CMS decisions regarding the use of ESAs in MDS. We have contacted the organizations involved in this issue and have spent considerable time and effort in attempts to positively influence the direction of both CMS and the FDA.

There are few studies looking specifically at patient survival and use of ESAs in MDS patients. One recent study compared the long-term outcome of MDS patients treated with an ESA plus G-CSF (n=121) with untreated MDS patients (n=237). The erythroid response rate to ESA plus G-CSF was 39%, and the median response duration was 23 months. A positive association was seen in patients requiring fewer than 2 units of RBCs per month. There was no difference in conversion rate to acute myeloid leukemia (AML) between the two groups. The authors concluded that treatment of anemia in MDS with an ESA

plus G-CSF may have a positive impact on outcome in patients with no or low transfusion need, while not affecting the risk of leukemic transformation.¹

Another recent study, specific to MDS analyzed prognostic factors of response, response duration, and possible impact on survival of epoetin alpha, epoetin beta, or darbepoetin alpha (DAR) with or without granulocyte colony-stimulating factor in 403 MDS patients. Sixty-two percent erythroid response (40% major and 22% minor) with median response duration of 20 months according to IWG 2000, and a 50% erythroid responses with median response duration of 24 months according to IWG 2006 criteria were seen. Multivariate adjusted comparisons of survival between the treated MDS group and the untreated MDS group showed similar rate of progression to AML, however, a significantly better overall survival was seen in the treated group, suggesting that epoetin or DAR treatment may have a favorable survival impact in MDS.²

Studies specific to MDS using ESAs are beginning to emerge, however additional information is needed, and the MDSF is supportive of efforts to develop comprehensive data on the use of ESAs in MDS. This is the only way that we can demonstrate clearly the benefits of ESAs in MDS. The use of this supportive and comprehensive data can then serve to have a positive influence over future decisions by CMS or to changes possibly change in labeling for ESAs to include approval use in bone marrow failure diseases by the FDA.

The Foundation has accumulated a large reservoir of information on ESA use through our Practice and Treatment Surveys and through our Centers of Excellence as well as quality-of-life information on ESA use, and transfusion dependence from our international Patient Forums. This data may prove to be useful

as new information is developed. This information is continually reviewed and analyzed to see how it can best be utilized to further the treatment and quality of life of MDS patients.

References:

1. Jädersten M, Malcovati L, Dybedal I, Della Porta MG, Invernizzi R, Montgomery SM, Pascutto C, Porwit A, Cazzola M, Hellström-Lindberg E. Erythropoietin and granulocyte-colony stimulating factor treatment associated with improved survival in myelodysplastic syndrome. *J Clin Oncol.* 2008;26(21): 3607–3613.
2. Park S, Grabar S, Kelaidi C, et al. Predictive factors of response and survival in myelodysplastic syndrome treated with erythropoietin and G-CSF: the GFM experience. *Blood.* 2008;111(2):574–582.

Amgen to Provide New Evidence for Determination of CMS Coverage of ESAs

Amgen is planning to submit new evidence to the Centers for Medicare and Medicaid Services (CMS) to support a reconsideration of the agency's National Coverage Determination (NCD) on Erythropoiesis Stimulating Agents (ESAs).

The oncology community, Amgen, and CMS have worked collaboratively to arrive at consensus-based, patient provisions for most aspects of the NCD. However, the Company, as well as physicians are concerned that the hemoglobin ceiling of 10 grams per deciliter (g/dL) is too restrictive and prevents oncologists from effectively managing chemotherapy-induced anemia with ESAs. In addition, the ceiling of 10 g/dL subjects Medicare beneficiaries to unsubstantiated treatment regimens, and may also result in Medicare patients requiring otherwise avoidable red blood cell transfusions.

The goal is to put into place a policy that allows physicians... to exercise their best clinical judgment to treat their patients based on their individual medical needs.

The goal is to put into place a policy that allows physicians to follow evidence-based clinical practice guidelines developed by experts in oncology and hematology and to allow them to exercise their best clinical judgment to treat their patients based on their individual medical needs. After consultation with leading scientific and clinical experts, practicing physicians, and their patients, Amgen intends to base its formal request for reconsideration on the growing body of new evidence that supports the need for a change in the hemoglobin ceiling of 10 g/dL, to enable oncologists to manage patients within the range of 10–12 g/dL recognized to represent the safe and effective use of ESAs. The body of new evidence includes the following:

- The American Society of Hematology and the American Society of Clinical Oncology revised their evidenced-based clinical practice guidelines to reflect a target range of 10 g/dL to 12 g/dL.
- The Aranesp® (darbepoetin alfa) and EPOGEN®/PROCRIT (Epoetin alfa) package inserts in collaboration with the U.S. Food and Drug Administration (FDA) strengthen their warnings about ESA risks and highlight that physicians should use the lowest dose that avoids transfusions. The label also provides for a physician's discretion to use ESAs to achieve a hemoglobin level not to exceed the upper safety limit of 12 g/dL in patients.
- The European Agency for the Evaluation of Medicinal Products (EMA) is currently making changes to product information

for ESAs stipulating a uniform target hemoglobin range for all ESAs of 10 g/dL to 12 g/dL with a warning not to exceed a concentration of 12 g/dL.

- Major U.S. health plans continue to base their coverage policies on evidence-based clinical practice guidelines and not adopt the NCD, creating a two-tiered healthcare system: one for patients covered by Medicare and another for those with private healthcare coverage.
- Recently released, interim results of one of the largest randomized trials of ESAs in patients with Hodgkin's Lymphoma conducted by the German Hodgkins Study Group (GHSg) showed no significant difference between Epoetin alfa and placebo on overall survival and serious adverse events. Additionally, there were significantly less RBC transfusions in the Epoetin alfa group compared to placebo.

FDA To Expand Vidaza® Label to Include Overall Survival Data

The U.S. Food & Drug Administration (FDA) has decided to extend the label for VIDAZA® (azacitidine) to include data from the AZA-001 clinical trial. Results from the trial found that azacitidine extended survival in MDS patients. VIDAZA is currently indicated for patients with the following FAB (French, American, British) MDS subtypes: refractory anemia (RA) or refractory anemia with ringed sideroblasts (RARS), refractory anemia with excess blasts (RAEB), refractory anemia with excess blasts in transformation (RAEB-T), chronic myelomonocytic leukemia (CMML).

Data from the AZA-001 trial was recently presented at this year's American Society of Clinical Oncology (ASCO) Annual Meeting and found that azacitidine nearly doubled the two-year survival rate for higher-risk MDS patients compared to conventional

care regimens (CCR) with a mean survival of 24.5 months compared to 15 months for patients who received CCR.

The AZA-001 trial for the first time showed that survival could be extended for patients with higher-risk MDS. Approximately 30 percent of patients diagnosed with MDS will progress to acute myeloid leukemia (AML). Treatment with azacitidine was shown to delay the progression of MDS to AML.

The AZA-101 trial also showed that azacitidine reduced the need for blood transfusions in higher-risk MDS patients with nearly half (45 percent) of patients who were transfusion dependent at the start of the trial achieving transfusion independence.

CHMP to Approve Vidaza® for MDS

VIDAZA (azacitidine) received a positive opinion from the European Union's Committee for Medicinal Products for Human Use (CHMP), recommending the approval of the drug for treatment of specific types of MDS patients, including those with high-risk MDS, chronic myelomonocytic leukemia (CMML), and acute myeloid leukemia (AML).

The CHMP positive opinion was based upon data from the AZA-001 trial, which found that VIDAZA nearly doubled the two-year survival rate for higher-risk MDS patients compared to conventional care regimens (CCR) as well as delay the progression of MDS to acute myeloid leukemia (see above).

FDA Approves Nplate™ (Romiplostim)

The United States (U.S.) Food and Drug Administration (FDA) has approved Nplate™ (romiplostim), the first and only platelet producer for the treatment of thrombocytopenia in splenectomized (spleen removed) and non-splenectomized adults with chronic immune thrombocytopenic purpura (ITP). Nplate, a peptibody protein, works by raising and sustaining platelet counts.

Chronic ITP is a serious autoimmune disorder characterized by low platelet counts in the blood (thrombocytopenia), which can lead to serious bleeding events. Chronic ITP affects an estimated 60,000 adult patients in the U.S.

The FDA approval of Nplate was based on efficacy and safety results from two pivotal Phase 3 studies of adult patients with chronic ITP, including both splenectomized and non-splenectomized patients. The overall response rate for Nplate was 83 percent (n=69/83, p less than 0.0001) of treated splenectomized and non-splenectomized patients, and platelet counts were raised and sustained in these six month studies. Additionally, patients treated with Nplate were able to reduce or discontinue their use of concomitant ITP medications and emergency medications (i.e., corticosteroids, IVIG, Win-Rho, Anti-D therapy).

Combined data from both trials shows clinically relevant bleeding events were significantly reduced by half in patients treated with Nplate compared to placebo (15 percent vs. 34 percent, $P=0.018$). Amgen continues to study the long-term efficacy and safety of Nplate for which there is more than three years of follow up safety and efficacy data.

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 transfusions (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.

Nplate is not indicated for the treatment of thrombocytopenia due to MDS or any cause of thrombocytopenia other than chronic ITP. Nplate stimulation of the TPO receptor on the surface of hematopoietic cells may increase the risk for hematologic malignancies. In controlled clinical studies among patients with chronic ITP, the incidence of hematologic malignancy was low and similar between Nplate and placebo. However, in a separate single-arm clinical study of 44 patients with myelodysplastic

syndromes (MDS), 11 patients were reported as having possible disease progression, among whom 4 patients had confirmation of acute myelogenous leukemia (AML) during follow-up.

Nplate has also been approved for ITP by Australia's Therapeutic Goods Administration (TGA), July 2008. Amgen has filed for regulatory approval of Nplate in the European Union (EU), Canada, and Switzerland and these applications are currently under review.

Patient Registries and Referrals

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

Outside the US please call: +44 20 7733 7558

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

Bone Marrow and Cord Blood Transplantation:

<http://bloodcell.transplant.hrsa.gov>

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 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

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 and Treatment Survey*.

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

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 Tufts 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
Larry Cripe, MD

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 Zalken 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
Mino 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
Jaroslav Maciejewski, MD, PhD

OREGON

Oregon Cancer Center at Oregon Health and Science University
Portland, Oregon

PENNSYLVANIA

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TEXAS

Cancer Care Centers of South Texas
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Roger Lyons, MD

Cancer Therapy & Research Center Institute for Drug Development
San Antonio, Texas
Swaminathan Padmanabhan, MD

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University of Texas MD Anderson Cancer Center
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Düsseldorf University Hospital**

Düsseldorf, Germany
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**Saarland University
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**Albert-Ludwigs-
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Freiburg, Germany
Michael Lübbert, MD, PhD

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University Children's Hospital

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Charlotte Niemeyer, MD

**Universitätsklinikum
Benjamin Franklin**

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Patras, Greece
Nicholas C. Zoumbos, MD

**University General
Hospital Attikon**

Athens, Greece
Theofanis Economopoulos, MD

University of Athens

Laikon Hospital
Athens, Greece
Nora Viniou, MD

HUNGARY

**Semmelweis University
School of Medicine**

Budapest, Hungary
Judit Várkonyi, MD, PhD

INDIA

**Army Hospital
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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.

Please contact us for a detailed listing featuring new protocols:

Website:

<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.

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!**

Myelodysplastic Syndromes (MDS) and Anemia: Potential New Treatments Through Clinical Research

EPO-ANE-3018 Study

Anemia (a drop in the body's red-blood-cell count) is the most common blood abnormality in the early stages of MDS. Treatments that can reduce or delay the need for blood transfusions may improve and extend better quality of life for persons with early stage MDS. More research is needed to evaluate such treatments and to obtain FDA approval for use in patients with early disease who are not yet transfusion dependent.

In the EPO-ANE-3018 study, epoetin alfa will be evaluated in patients with early stage MDS, who are not yet treatment dependent, to see if it can delay the need for transfusion. Transfusion dependence is defined as the requirement of an average of two units of adult sized red blood cell units per month. Patients with early stage MDS who have no or low red blood cell transfusion requirements are included in this study because there currently are limited treatment options for MDS patients who have anemia but are not requiring red blood cell transfusions on a regular basis.

Research to date suggests that epoetin alfa is effective in reducing the need for transfusions in patients with early stages of MDS. Epoetin alfa is a manufactured form of the human hormone erythropoietin, which stimulates the production of red blood cells.

Epoetin alfa is distributed in the United States, the European Union, and other countries under several brand names including PROCRIT®, EPREX®, and ERYPO® for the treatment of other related disease conditions.

If you are a patient with early stage MDS and anemia who is not yet transfusion dependent or a health professional caring

for a patient, and would like to receive more information about this study, please refer to the contact information at the end of this article.

What is the purpose of this study?

The purpose of the EPO-ANE-3018 clinical research study is to explore the use of epoetin alfa, to see if it will decrease the need for blood transfusions and increase the hemoglobin level in patients with early stage MDS and anemia.

Who qualifies for this study?

To qualify for this study you must:

- Be at least 18 years of age
- Have been diagnosed with MDS
- Have an International Prognostic Scoring Systems (IPSS) score of Low- to Intermediate-1 Risk Disease
- Have anemia (a hemoglobin count of 10 g/dL or below)
- Not transfusion dependent (<4 red blood cell units during a consecutive 8-week period) in the past 6 months

What can you expect if you are eligible and enroll in this study?

- Before any study related procedures are performed, the study doctor will discuss the study in detail with you, including any potential risks or benefits.
- If you participate, you will be randomly assigned (by chance, like flipping a coin) to one of three investigational treatment schedules:
 - Epoetin alfa 40,000 IU (1 mL) given once a week by subcutaneous (under the skin) injection
 - Epoetin alfa 80,000 IU (2 mL) given once a week by subcutaneous injection
 - Placebo given once a week by subcutaneous injection. Half of this group will be assigned to 1 mL dosing and the other half will be assigned to 2 mL dosing.
- You will visit the study center each week during a 48-week Study Treatment Phase for blood tests, assessment of disease progression, to receive study drug and periodic measurement of iron stores.

- You may continue to receive the investigational study drug beyond the 48-weeks if you do not require transfusions and your doctor feels that you are benefiting from the treatments.
- All patients will receive current standard of care for anemia management.
- You will continue to have safety evaluations for 4 and 1/2 years following study participation. These visits for the most part should coincide with routine scheduled visits to your doctor for your condition.

For doctors caring for a patient(s) with early stage MDS who may be a candidate(s) for this study:

- Approximately 450 subjects will be randomly assigned to one of the study drug schedules
- The Study Phases Include:
 - Pre-randomization (Screening) Phase: Day –1 to –14
 - Study Treatment Phase: Day 1/Week 1 to Week 48
 - Safety Assessment Phase, consisting of:
 - Short Term Safety (Week 52) or Early Withdrawal from treatment visit
 - Long Term Safety Assessments—until progression to AML, death, or the clinical cutoff is reached, whichever occurs first
- An Independent Data Monitoring Committee (IDMC) will periodically review overall safety data throughout the study.
- An Independent Central Pathology Reviewer will review bone marrow samples and peripheral blood counts for assessment of disease progression.

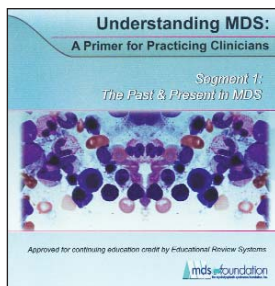
To learn more about participating in the EPO-ANE-3018 study or to refer a patient to this study, please contact the MDS Foundation by E-mailing us at: CTC@mds-foundation.org or by calling our toll free EPO-ANE-3018 study number: 1-888-813-1260 (within the US) or 609-298-7741 (outside of the US).

We look forward to talking with you and working together to find new and better treatments for patients with early stage MDS.

Educational Resources

Understanding MDS: A Primer for Practicing Clinicians

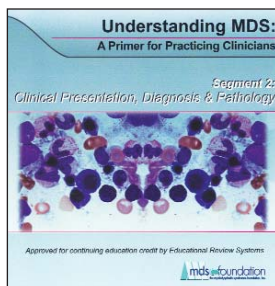
Visit www.mds-foundation.org and click on The MDS Foundation Resource Center to take advantage of this comprehensive program, and other informative programs coming soon, designed to provide you with tools and information that will assist you in administering the best care to your patients.



Segment 1

The Past & Present in MDS

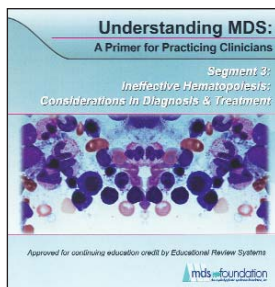
Segment 1 provides insight into the history of MDS, development of the MDS classification and prognostic systems, and a glimpse into the future of MDS diagnosis, research and treatment.



Segment 2

Clinical Presentation, Diagnosis & Pathology

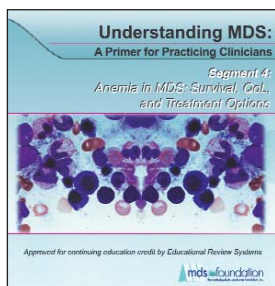
Segment 2 provides insight into the clinical picture of adult and pediatric MDS, primary and secondary MDS, FAB and WHO Classification system, and rationale for the proposed MDS pediatric classification system.



Segment 3

Ineffective Hematopoiesis: Considerations in Diagnosis & 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

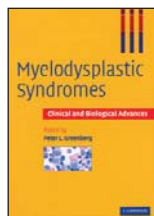
Segment 4 is an overview of supportive care with a focus on RBC transfusions and its effect on the morbidity and mortality of MDS patients. This segment also looks at the quality of life issues from the perspectives of the physical, functional, emotional, social and cost impacts on the patient with MDS.

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, online in our technologically advanced MDS Foundation Educational Center, or via CD-ROM on their personal computer. **This multi-segment program is available in the following languages: English, French, German, Italian, Japanese and Spanish.**

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!



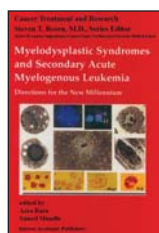
Myelodysplastic Syndromes: Clinical and Biological Advances

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

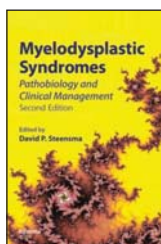
June 2001/278 pp., illus.

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".



Myelodysplastic Syndromes, Pathobiology and Clinical Management, Second Edition: (Basic and Clinical Oncology)

Edited by:

David P. Steensma, MD

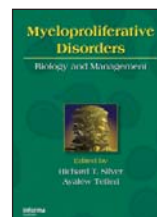
November 2008/536 pp., illus.

ISBN: 978-01420074390/\$225.42**

Informa HealthCare

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.

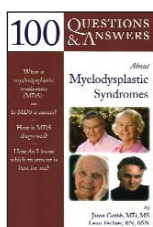
ISBN: 9781420061628/\$161.96**

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
The MDS Foundation:
1-800-MDS-0839**

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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. Nimer S. Myelodysplastic syndromes. *Blood*. 2008;111(10):4841–4851.

Overview of biology and treatment options

2. Srinivasan S and Schiffer C. Current treatment options and strategies for myelodysplastic syndromes. *Expert Opin Pharmacother*. 2008;9(10):1667–1678.

Review of the state-of-the art in the treatment of MDS with a proposed algorithm of therapeutic options for low vs. high-risk disease.

3. Rollison D et al. Epidemiology of myelodysplastic syndromes and chronic myeloproliferative disorders in the United States, 2001–2004, using data from the NAACCR and SEER programs. *Blood*. 2008;112(1):45–52.

A first report by the North American Association of central Cancer Registries (NAACCR), based on more than 40,000 observations between 2001–2003, showed the incidence rates for MDS and CMD of 3.3 and 2.1 per 100,000 US population. The follow up through 2004 via SEER database estimated 3 yr survival at 45% and 80% respectively. The authors conclude that MDS may be underestimated in the US.

4. Gattermann N. Overview of guidelines on iron chelation therapy in patients with myelodysplastic syndromes and transfusional iron overload. *Int J Hematol*. 2008;88(1):24–29.

A comparative perspective on global guidelines for iron chelation therapy.

DIAGNOSIS AND PROGNOSIS:

1. Orazi A and Germing U. The myelodysplastic/myeloproliferative neoplasms: myeloproliferative diseases with dysplastic features. *Leukemia*. 2008;22(7):1308–1319.

Fourth edition of WHO fascicle on diagnostic classification to be published after this year will replace the term MPD with myeloproliferative neoplasm (MPN). This article reviews relevant clinico-pathological considerations.

2. Tsimberidou A et al. The prognostic significance of cytokine levels in newly diagnosed acute myeloid leukemia and high-risk myelodysplastic syndromes. *Cancer*. 2008 Aug 5. [Epub ahead of print]

A single center study of patients registered between Sept 1994 and Jan 2001 at the MD Anderson Cancer Center, Houston, TX, USA, showed that among different serum cytokines assessed in MDS, only TNF α levels ≥ 10 pg/mL were prognostic for survival and event-free survival.

7. Kao J et al. International MDS risk analysis workshop (IMRAW)/IPSS reanalyzed: Impact of cytopenias on clinical outcomes in myelodysplastic syndromes. *Am J Hematol*. 2008 Jul 10. [Epub ahead of print]

IMRAW assessed the impact of the depth of cytopenias and found that hemoglobin levels added to the prognostic value of IPSS particularly in int-1 and int-2 categories in terms of predicting survival but not time to leukemic transformation. Platelet count or ANC on the other hand were not found additive.

8. Kantarjian H et al. Proposal for a new risk model in myelodysplastic syndrome that accounts for events not considered in the original prognostic scoring system. *Cancer*. 2008 Jul 10. [Epub ahead of print]

A single center study of 1915 patients demonstrated an additive prognostic value of the depth of all three cytopenias at Hb < 12 g/dL, WBC > 20 × 10⁹/L and platelets < 30 v 30–49 v 50–199 × 10⁹/L, along with a performance status, old age and prior transfusions. An alternative model to IPSS is proposed that again categorizes patients into low, int-1, int-2 and high- risk categories with significant survival differences.

TREATMENT:

Growth Factor:

1. Jädersten M et al. Erythropoietin and granulocyte-colony stimulating factor treatment associated with improved survival in myelodysplastic syndrome. *J Clin Oncol*. 2008;26(21):3607–3513.

Updated long-term outcome assessment of Nordic patients treated with EPO±G-CSF as compared to the untreated historical controls confirmed erythroid response rate of 39% and duration for response of 23 mo in treated patients. Importantly, in this analysis treatment was positively associated with an improved survival, particularly in those requiring <2 units of PRBC/mo. Furthermore, treatment was not linked with increased risk of leukemic transformation.

2. Gabrilove J et al. Phase 2, single-arm trial to evaluate the effectiveness of darbepoetin alfa for correcting anaemia in patients with myelodysplastic syndromes. *Br J Haematol*. 2008;142:379–393.

Darbepoetin was tested at a starting dose of 500 mcg every three weeks in low-risk MDS patients. Dose could

be increased for poor response after 6 weeks (44% patients needed dose increase). At 13 weeks (primary end-point) the erythroid response rate was 49% in ESA naïve and 26% in prior ESA-treated patients. The target Hb of 11 g/dL was achieved in 82% ESA-naïve and 55% prior ESA-treated patients. Thromboembolic events or related adverse events occurred in 2% patients.

Demethylating Agents:

1. Fabre C et al. A novel effect of DNA methyltransferase and histone deacetylase inhibitors: NFκB inhibition in malignant myeloblasts. *Cell Cycle*. 2008;7(14):2139–2145.

A novel mechanism of action demonstrated for demethylating drugs like azacytidine and decitabine, and HDAC inhibitors like trichostatin and valproic acid as suppression of NFκB via reduction in phosphorylation of activating kinase IKKα/β.

Immunosuppressive Treatment:

1. Sloan E et al. Factors affecting response and survival in patients with myelodysplasia treated with immunosuppressive therapy. *J Clin Oncol*. 2008;26(15):2505–2511.

The long-term assessment (med follow up 3 yrs) of low risk MDS patients receiving ATG and/or Cyclosporin A showed that, as compared to the IMRAW untreated patients, the treated patients had improved survival. Additionally, among the treated patients, younger age and combined ATG+CsA regimen demonstrated better survival outcome.

IMiDs:

1. Tamburini J et al. Effectiveness and tolerance of low to very low dose of thalidomide in low-risk myelodysplastic syndromes. *Leuk Res*. 2008, Jul 18. [Epub ahead of print]

The French MDS GFM group reported on Thal-SMD-2003 trial evaluating efficacy and toxicity of Thalidomide in low/int1-2 risk transfusion dependent patients (av- 6 PRBC units/2 mo) at a starting dose of 200 mg/d (n=59), which later due to high pt drop out rate was reduced to 50 mg/d (n=28). 44% patients had lost response or were refractory to prior ESA treatment. The overall erythroid response rate per IWG 2000 criteria was 40% in patients completing 12 wk treatment and 25% in ITT population. Per IWG2006 criteria the erythroid response rate were 33% and 21% respectively in the two analyses. Due to toxicity (primarily GI-gr III constipation), the treatment had to be stopped in 27% of patients receiving 200 mg/d and in 25% of those with 50 mg/d dose.

2. Kelaidi C et al. Treatment of myelodysplastic syndromes with 5q deletion before the lenalidomide era; the GFM experience with EPO and thalidomide. *Leuk Res*. 2008;32(7):1049–1053.

The erythroid response rate and duration of response were significantly lower with EPO/darbepoetin in patients with 5q deletion as compared those without. Thalidomide in contrast showed comparable response in both groups. However, the response to both modalities in patients with 5q deletion was lower than the reported outcome in these patients with the US FDA approved agent, lenalidomide.

PATHOBIOLOGY:

1. Novotna B et al. Oxidative DNA damage in bone marrow cells of patients with low-risk myelodysplastic syndrome. *Leuk Res*. 2008, Aug 6. [Epub ahead of print]

Increased oxidative DNA damage in gly-A⁺ cells of low-risk MDS as compared to the controls.

2. Starczynowski D et al. high-resolution whole genome tiling path array CGH analysis of CD34+ cells from patients with low-risk myelodysplastic syndromes reveals cryptic copy number alterations and predicts overall and leukemia-free survival. *Blood*. 2008, Jul 28. [Epub ahead of print]

Almost 80% (36/44) patients showed cryptic gene copy number changes by array CGH as compared to only ~35% (16/44) showing abnormal karyotype. Genomic integrity defined as a total genomic alteration spanning <3Mb was associated with better survival and lower leukemic transformation rate.

3. Wang L et al. Genome-wide analysis of copy number changes and loss of heterozygosity in myelodysplastic syndrome with del(5q) using high-density single nucleotide polymorphism arrays. *Haematologica*. 2008;93(7):994–1000.

In SNP array analysis of 5q- syndrome vs. del (5q) in comparison with healthy donors, no additional gene copy number changes were found in 5q- syndrome in contrast to del(5q) patients. Both groups however showed uniparental disomy in regions >2Mb. (Please also see Editorial by Cazzola M, pp 967–972.)

4. Gyan E et al. Spontaneous and Fas-induced apoptosis of low-grade MDS erythroid precursors involves the endoplasmic reticulum. *Leukemia*. 2008, Jul 10. [Epub ahead of print]

The report demonstrates caspase-8 mediated cleavage of BCL-2 associated protein (BAP31) localized in endoplasmic reticulum as an event upstream of mitochondrial involvement, which can be inhibited by erythropoietin.

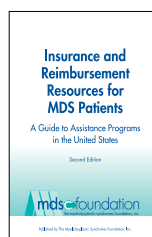
5. Chee C et al. Neither serum ferritin nor the number of red blood cell transfusions affect overall survival in refractory anemia with ringed sideroblasts. *Am J Hematol*. 2008;83(8):611–613.

In a retrospective study of 126 RARS patients at the Mayo Clinic, Rochester, MN, USA, a transfusion requirement at diagnosis was correlated with inferior survival. However, in this subcategory of MDS no impact on survival was seen with the number of transfusion units during the disease course or with serum ferritin levels.

We would like to thank Suneel Mundle, a member of the MDS Foundation, for his assistance in monitoring these important peer-review publications on MDS.

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.



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 Foundation Publications

MDS Handbooks Now Available in Multiple Languages

■ Understanding Myelodysplastic Syndromes: A Patient Handbook



Available in the following languages:

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

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

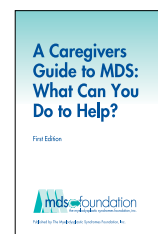


Available in the following languages:

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

New MDS Publications Coming Soon...

- A Caregivers Guide to MDS: What Can You Do to Help?
- 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
- 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:

Henry Blume, *Menno Park, CA*
Monroe Bank & Trust, *Monroe, MI*
Julia Cochrane, *Chicago, IL*
Vyron Schmidt, *Hot Spring, AR*
Stanley Robin, *Kalamazoo, MI*
Mabel Rocamora, *Rochester Hills, MI*
Elmer Rawls, *Locust Grove, VA*
Jerry A. Theiler, *Stockton, CA*
Margaret Donnelly, *Delray Beach, FL*
Richard & Julita Christian, *Alexandria, VA*
John C. Ballard, *Irvine, CA*
Robert Baxter, *Maldon, Essex, UK*
M. Marlene Godoy, D.D.S., *Irvine, CA*
David and Harriet Cohn, *Blue Bell, PA*
Stacy Lessing, *Millstone Twp, NJ*
Philip L. Gore, *Tarzana, CA*
Jeanne Idzikowski, *Ann Arbor, MI*
Dyan Dawson, *Chantilly, VA*
Lauren M. Hollander, *New York, NY*
Ed and Susan Johnson, *Clifton, NJ*
Ed Pickard, *Highland Beach, FL*
Debra Jackson, *East Quogue, NY*
Paul M. Nemiroff, *Gibsonia, PA*
Myrna H. James, *Sun City, CA*
Barrington Area Chamber of Commerce
Barrington, IL
Lauren M. Hollander, *New York, NY*
David Bayer, *Bourbonnais, IL*
Michael J. Maher, *Summit, NJ*
James & Coral Coffey, *Salt Lake City, UT*
Marilyn J. Josephson, *Red Wing, MN*
Jerald and Peggy Olson, *Red Wing, MN*

Ways to Support the Foundation's Work

Individual donations of *any amount*. Every penny helps.

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.

Charitable Giving During the Holiday Season

If you wish to support the work of the Foundation in the battle against myelodysplastic syndromes, please remember us during the holidays and consider donating a year-end gift.

All donations are tax-deductible.

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

Jeanne E. Polak-Recht, *Northridge, CA*
Goetz James, *Springfield, VA*
Preceptor Zeta Beta Chapter, *Stockton, CA*
Len Yool, *Palo Alto, CA*
Dr. Arnold and Mrs. Barbara Berman
Bryn Mawr, PA
Joseph Artuso, *Berwyn, PA*
Susan J. Ferber, *New York, NY*
Richard & Patricia Strazza, *Ringoes, NJ*
Marvin and Sue Horwitz, *Niantic, CT*
Estate of Susan M. Pax, *Dayton, OH*
Elizabeth Bush, *Brooklyn Center, MN*
Seal Family Foundation, *Bay St. Louis, MS*

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.

A Living Endowment donation has been made in honor of:

Tom Josephson, MDS Patient

This donation was submitted by:

Jerald and Peggy Olson, *Red Wing, MN*

A Living Endowment donation has been made in honor of:

Donald and Edith Sherwood's 50th wedding anniversary

This donation was submitted by:

Lee and Alice Wright, *Anchorage, AK*

Living Endowment donations have been made in honor of:

Mort Silverman – Get Well Wishes! Joel and Miriam Silbert's Wedding

These donations were submitted by:

David and Harriet Cohn, *Blue Bell, PA*

Living Endowment donations have been made in memory of:

**Richard Seidenberg
Father of Susan Rush & Family
Mother of Cheryl Schlackman**

Living Endowment donations have been made in honor of:

**Tina Meshberg's birthday
Judy Collepari's birthday
Jane Davis' generosity**

These donations were submitted by:

Geoffrey and Sandy Goldworm
Cherry Hill, NJ

In Memorium

A memorial fund has been established in the name of **Mr. George J. Acton**

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

Gary and Vicki Hanson <i>La Palma, CA</i>	Christopher and Elizabeth Heaton <i>Fullerton, CA</i>
Joseph and Patricia Simmons <i>Long Beach, CA</i>	Rubin Postae & Associates <i>Santa Monica, CA</i>
Phillip and Mary Hedwall <i>Buena Park, CA</i>	James D. Conley <i>South Bend, IN</i>
Lee Elementary Teachers <i>Los Alamitos, CA</i>	Colin and Cynthia Gray <i>Elmhurst, IL</i>
Stephen Fordham <i>Slingerlands, NY</i>	William R. Penrice <i>Brighton, MI</i>
Michael & Catherine Wrenn <i>Chicago, IL</i>	

A memorial fund has been established in the name of **Ms. Irene Adams**

Donations have been made in Ms. Adams' memory by:

Marilyn J. Litvin, *Framingham, MA*

A memorial fund has been established in the name of **Ms. Bessie Albert**

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

All Your Friends at Cedar Village <i>Ocean, NJ</i>	Dona Preston <i>Union, NJ</i>
	Leonard and Irene Fink <i>Beckley, WV</i>

A memorial fund has been established in the name of **Mr. John Anderholm**

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

Hazel Marie Anderholm, *Walnut Creek, CA*

A memorial fund has been established in the name of **Mrs. Kaete Angel**

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

Frederick M. Bering <i>Redding, CT</i>	George & Helga Schweiger <i>Newark, DE</i>
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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:

Stacy Lessing

Millstone Twp, NJ

Edward Fleischman

Prescott, AZ

A memorial fund has been established in the name of **Ms. Josefina de Jesus Arcilla**

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

Fran Stancavage <i>Boulder Creek, CA</i>	Jonathan Halling <i>Pleasanton, CA</i>
Josie Haleco <i>Rodeo, CA</i>	Kyunghee Suh <i>Sacramento, CA</i>
Roberta L. Collier <i>Oakland, CA</i>	Pamela Wong <i>Palo Alto, CA</i>

A memorial fund has been established in the name of **Ms. Joan Husebye Balder**

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

Karen M. Vozeh <i>Ramsey, NJ</i>	Reena Mancuso <i>Tuxedo, NY</i>
Dorothy Holmes <i>Ramsey, NJ</i>	Greg Karczewski <i>Chicago, IL</i>
The Wichler Family <i>Upper Saddle River, NJ</i>	Ramona Allen <i>Hesperia, CA</i>
John and Diane Picyk <i>Park Ridge, NJ</i>	Paul Murphy <i>New York, NY</i>
Richard and Aileen Wilson <i>Tarpon Springs, FL</i>	Joseph Brancato <i>Cortlandt Manor, NY</i>
Gerald and Marjorie Weems <i>Upper Saddle River, NJ</i>	Paul and Suzanne Greene <i>Ridgewood, NJ</i>
Kathleen Walsh, <i>County Kildare, Ireland</i>	

A memorial fund has been established in the name of **Mr. David Banta**

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

Bob and Maidie Strellman <i>Port Orchard, WA</i>	George and Shirley Bressler <i>Simi Valley, CA</i>
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A memorial fund has been established in the name of **Mr. Arthur H. Baron**

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

Dr. and Mrs. Jay and Marilyn Basch <i>Wyndmoor, PA</i>	Stephen and Elizabeth Bitterman <i>Glenside, PA</i>
Bernard and Paula Cross <i>Boca Raton, FL</i>	Theresa Mc Cooe <i>Philadelphia, PA</i>
Lenore K. Eliaser <i>Los Angeles, CA</i>	David and Julia Schwartz <i>Horsham, PA</i>
Martha Coons Craine <i>Jenkintown, PA</i>	Linda Umla, L.Ac. <i>Wellington, FL</i>
Dr. & Mrs. William and Marianne Mebane <i>Wyndmoor, PA</i>	

A memorial fund has been established in the name of **Mr. Don Bills**

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

Barbara B. Gaab <i>New Haven, CT</i>	Marcia Rizzo <i>Germantown, MD</i>
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A memorial fund has been established in the name of **Mr. Donald Bridenstine**

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

Zippora, Carl and Melissa Zimmerman, *Owings Mills, MD*

A memorial fund has been established in the name of **Mr. Ted Ray Canote**

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

Victoria Tsang <i>Houston, TX</i>	Joe and Margaret Harling <i>Lincoln, CA</i>
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A memorial fund has been established in the name of **Ms. Beatrice Carol Carlson**

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

Mike and Penny Carlson <i>Moorhead, MN</i>	John and Ruth Goode <i>Cumming, GA</i>
Charles and Betty Herdina <i>Blooming Prairie, MN</i>	Pamela J. Bragg <i>Beach, ND</i>
Richard and Dolores Rosett <i>Embarrass, MN</i>	Sharon R. Jerabek <i>Spooner, WI</i>
John and Sharon Nelson <i>Birchwood, WI</i>	Fibrebond, <i>Minden, LA</i>
Samuelson Insurance Agency, Inc., <i>Virginia, MN</i>	Will Bowman, <i>Cumming, GA</i>

A memorial fund has been established in the name of **Ms. Doris Cherkasky**

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

Evelyn Diehl <i>Pittsford, NY</i>	Patricia H. Nichols <i>Rochester, NY</i>
Elaine A. Sarna <i>Rochester, NY</i>	Phil and Bernice Kassirer <i>Rochester, NY</i>
Linda Szeft <i>Rochester, NY</i>	Heidi Friederich <i>Rochester, NY</i>
Marianne Fiorella <i>Rochester, NY</i>	Harold and Claire Thurston <i>Rochester, NY</i>
John and Annette Naughton <i>Rochester, NY</i>	Mary Inzinga <i>Rochester, NY</i>
Larry and Paulina Kovalsky <i>Pittsford, NY</i>	John and Elaine Lewis <i>Birmingham, AL</i>
Adria Freeling <i>Rochester, NY</i>	Gerri Vinci, Nicholas Rotolo <i>Pittsford, NY</i>
Chuck and Joni Kiner <i>Pittsford, NY</i>	Stanley and Marjorie Prewasnicak <i>Rochester, NY</i>
Mel and Cindy Gurell <i>Rochester, NY</i>	Richard & Roxanne Gifaldi <i>Holley, NY</i>
Nancy Herrera <i>Henrietta, NY</i>	David and Debra Dastyck <i>Fallbrook, CA</i>
Cindy Bianchi <i>Rochester, NY</i>	Sharon Fitelson <i>Chesterfield, MO</i>
Robert and Barbara Levine <i>Coconut Creek, FL</i>	Yale and Estelle Handleman <i>Coconut Creek, FL</i>
Harry and Adele Gan <i>Rochester, NY</i>	George and Mary Dastyck <i>Tucson, AZ</i>
Mary T. Pittick, <i>Pittsford, NY</i>	Sam and Claire Utter <i>Spencerport, NY</i>
Myron and Rheva Kleinberg <i>Rochester, NY</i>	Donna R. Weinstein <i>New York, NY</i>
Hy and Barbara Seldowitz <i>Rochester, NY</i>	

A memorial fund has been established in the name of **Dr. Paul Cherkasky**

Donations have been made in Dr. Cherkasky's memory by:

Ted and Shirley Levy, *Canandaigua, NY*

A memorial fund has been established in the name of **Mr. Peter Clancy**

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

Diane Friedman, *Abingdon, MD*

A memorial fund has been established in the name of **Mrs. Margaret Louise McCoy Clarke Horak**

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

Barbara J. Fawkes, Patricia Martin, Suzanne Herron, Bernard Stehle, Jay Carr, Deborah Wicker, Carolyn O'Leary, Bari Bako, Robert Henel, Jr., Melinda Gibbons, Christine Sindt, Jeffrey Glynn & Mary Jo Greenley, PNC Bank, *Annapolis, MD*

**A memorial fund has been established in the name of
Mr. Shelton Colson**

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

Crothall CES, *Hatboro, PA*

**A memorial fund has been established in the name of
Ms. Delores Coughenower**

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

Lynn M. Durnin, *Oak Forest, IL*

**A memorial fund has been established in the name of
Mr. Arthur R. Cramer**

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

Thomas F. Sammons, P.C. <i>Palatine, IL</i>	Michael and Susan Materer <i>Arlington Heights, IL</i>
John D. Hancotes, Barrington Bank & Trust, N.A. <i>Barrington, IL</i>	Lorraine Dunterman <i>Barrington, IL</i>
Jeffrey Gray & Family <i>Palatine, IL</i>	Greg & Georgeanna Mehr <i>Barrington, IL</i>
Dan and Lorraine Johnson <i>Barrington, IL</i>	Jim and Barb Schwantz <i>North Barrington, IL</i>
Robert Peterson <i>Palatine, IL</i>	Keith and Amy Malooley <i>Fox River Grove, IL</i>
Builders Chicago Corporation <i>Huntley, IL</i>	Roger and Charleen Young <i>Barrington, IL</i>
John and Carrie Hogarty <i>Maineville, OH</i>	Dr. Ernest J. Laenertz <i>Sun Lakes, AZ</i>
Russ Rupolo <i>Fox River Grove, IL</i>	Karen Laenertz <i>Chicago, IL</i>
Robert and Amy Peterson <i>Palatine, IL</i>	Tina Hanisch and Family <i>Palatine, IL</i>
George and Jane Volland <i>Barrington, IL</i>	

**A memorial fund has been established in the name of
Mr. Walter Cumbo**

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

Norvell and Shirley Johnson <i>Bellevue, WA</i>	T. R. and Phyllis Homchick <i>Wenatchee, WA</i>
--	--

**A memorial fund has been established in the name of
Mrs. Maria del Castillo**

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

Elaine Sosa and Maritza Achecar, *Dominican Republic*

**A memorial fund has been established in the name of
Mr. Dale DeSharone**

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

Robert M. Williams
Newtonville, MA

**A memorial fund has been established in the name of
Mr. Al I. Fineman**

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

Geraldine G. Fineman
Boca Raton, FL

**A memorial fund has been established in the name of
Ms. Mary Fredley**

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

Joe and Julie Hauptmann <i>Zionsville, IN</i>	Jean Atwood <i>Bexley, OH</i>
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**A memorial fund has been established in the name of
Ms. Marilyn Ginter**

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

Eleanor Christensen <i>Elk Grove Village, IL</i>	The Christensen Family <i>Port Barrington, IL</i>
Ladies Auxiliary of V.F.W. <i>Elk Grove Village, IL</i>	James Ginter, Kurt Ginter, Corinne Galladora <i>Elk Grove Village, IL</i>

**A memorial fund has been established in the name of
Mr. James Goetz**

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

Marty and Patricia Gilmour <i>Lake Orion, MI</i>	Jill Goetz <i>Springfield, VA</i>
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**A memorial fund has been established in the name of
Mr. Daniel Grudzien**

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

Thomas and Christine Culp <i>Las Vegas, NV</i>	Theresa Koulentis <i>Las Vegas, NV</i>
Eugene and Marie Kloss <i>Libertyville, IL</i>	Harry Koulentis <i>San Francisco, CA</i>
David and Vivian Hock <i>Cary, IL</i>	Fred and Gladys Sage <i>Oregon, WI</i>
Yutaka Sakamoto <i>San Diego, CA</i>	Jerry and Cathy Cholak <i>Peoria, AZ</i>
Spiro and Mary Koulentis <i>Gresham, OR</i>	Isabelle Kowalski <i>Palatine, IL</i>
Patricia Koulentis <i>Las Vegas, NV</i>	Kristen Johnson <i>Phoenix, AZ</i>

**A memorial fund has been established in the name of
Mr. John J. Hart**

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

Timothy & Marguerite Paige <i>Southwick, MA</i>	William Campbell and Jean Rousseau <i>South Hadley, MA</i>
Ed and Anne Hart <i>Holyoke, MA</i>	Clare Hart, <i>Holyoke, MA</i>
Richard and Carol Robillard <i>Easthampton, MA</i>	Dan and Maureen Fitzpatrick <i>Holyoke, MA</i>
Michael Hart <i>Brooklyn Heights, NY</i>	Ed & Anne Hart, <i>Holyoke, MA</i>
David and Lise Bourque <i>Holyoke, MA</i>	Riverwood Terrace Condominium Assoc. <i>Granby, MA</i>

**A memorial fund has been established in the name of
Ms. Mattie Ingraham**

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

Heart Center of Central Louisiana, *Alexandria, LA*

**A memorial fund has been established in the name of
Mr. Clement Edwin Jay**

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

Kent Conrad <i>North Salt Lake, UT</i>	Rose Park Friends <i>Salt Lake City, UT</i>
Charles and Debra Hammerschmid <i>Salt Lake City, UT</i>	

**A memorial fund has been established in the name of
Mr. Jack Jensen**

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

Joe and Peggy Piotrowicz <i>Walkerton, IN</i>	Mary Lou Riley <i>LaPorte, IN</i>
Ron and Melody Smutzer <i>LaPorte, IN</i>	Romayne Graham <i>LaPorte, IN</i>

**A memorial fund has been established in the name of
Mr. Steven Kapsaskis**

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

Carol Simpson <i>Mays Landing, NJ</i>	Barbara L. Eichhorn <i>Brooklyn, NY</i>
Joseph H. Reichman, MD <i>Gibbsboro, NJ</i>	Mary Ellen De Biasio and Mary Graziano <i>Oakhurst, NJ</i>
George and Kasandra Moutis <i>West Long Branch, NJ</i>	Lucia Cardarelli Susan Diveley Gail Rounds Sandy Victor <i>Lawrenceville, NJ</i>
Jan, Barry & Rebecca Barnet <i>Allentown, NJ</i>	Judith Martin Waterman <i>Highland Park, NJ</i>
Nick and Domna Poulos <i>Monmouth Beach, NJ</i>	Stephen F. Freifeld, MD, FACS, PA <i>Springfield, NJ</i>
James and Gertrude Bozza <i>Toms River, NJ</i>	Sigrid Patsch <i>Mountainside, NJ</i>
Mary M. Hamer <i>Lambertville, NJ</i>	Angel Feet L.L.C. <i>New York, NY</i>
George Paras <i>Madison, NJ</i>	Jerome Kootman <i>Meuchen, NJ</i>
Diego and Ilana Saporta <i>Springfield, NJ</i>	Robert Huang <i>South Plainfield, NJ</i>
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Dr. & Mrs. Robert and Susan Fuhrman <i>Westfield, NJ</i>	Patricia Klemm <i>Lakewood, NJ</i>
John and Mildred McLaughlin <i>Clark, NJ</i>	Stephen and Xenia Morris <i>Rumson, NJ</i>
MBloGluckShaw <i>Trenton, NJ</i>	Richard and Jane Lorber <i>Scotch Plains, NJ</i>
Patricia Coleine <i>New York, NY</i>	Spiro and Elayna Pappas <i>Middletown, NJ</i>
George and Sharon Shinas <i>Mountainside, NJ</i>	Richard H. Sharrett, MD <i>North Plainfield, NJ</i>
Robert Oberhand, MD <i>Westfield, NJ</i>	Dr. and Mrs. Gerry Novik <i>Hamilton Square, NJ</i>
Laura Valentine <i>Pittsburgh, PA</i>	

**A memorial fund has been established in the name of
Mrs. Kathryn M. Karam**

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

Timothy Booth, *Dallas, TX*

**A memorial fund has been established in the name of
Mr. Richard Kiesling**

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

Linda Kiesling <i>California, MO</i>	Rita Hammerly <i>California, MO</i>
Jerry and Pamela Murphy <i>California, MO</i>	Lashley and Joyce Rohrbach <i>Jamestown, MO</i>
S.M. Murphy <i>California, MO</i>	

**A memorial fund has been established in the name of
Mr. Byron Klute**

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

Carolyn & Betty Gardner <i>Richmond, IN</i>	Mary Kay Hankosky <i>Richmond, IN</i>
Jacob and Frances Smith <i>Sun City, AZ</i>	

**A memorial fund has been established in the name of
Ms. Dorothy R. Kolodziej**

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

The Czach Family <i>Hoffman Estates, IL</i>	June C. Tinaglia <i>Park Ridge, IL</i>
Carl and Pat Patek <i>S. Barrington, IL</i>	Julia (Peggy) Cochrane <i>Chicago, IL</i>
Nancy McGonagle <i>Nordland, WA</i>	Rosa Perez, <i>Chicago, IL</i>
Frank and Eleanor Pascher <i>Hallandale Beach, FL</i>	Jim and Ben Rupany <i>S. Barrington, IL</i>
Dolores Jedd <i>Chicago, IL</i>	Grayce Papp, <i>Oak Park, IL</i>
Evelyn Finegan <i>River Forest, IL</i>	Jocelyn Ang, <i>Chicago, IL</i>
Frank and Rose Kolodziej <i>Villa Park, IL</i>	Patricia Czach, <i>Palatine, IL</i>
Carol Bynoe, <i>Lake Zurich, IL</i>	Dominic Castino, <i>Edina, MN</i>
Macy J. Mruk, <i>Elmhurst, IL</i>	Dolores Reilly & Family <i>Downers Grove, IL</i>
	Edward and Barbara Burnes <i>Chicago, IL</i>
	Beth Sanborn, <i>Gregory, MI</i>

**A memorial fund has been established in the name of
Mrs. Maria Kontras**

Donations have been made in Mrs. Kontras' memory by:

Dr. & Mrs. Charles M. Muran <i>Chesterfield, MO</i>	D. and S. Crowell <i>Chesterfield, MO</i>
Lou and Betty Kontras <i>Columbia, MO</i>	Lorraine Venezia <i>Chesterfield, MO</i>
Gordon, S. Kathleen Madison <i>Chesterfield, MO</i>	Officers and Employees of The Daniel and Henry Co. <i>St. Louis, MO</i>
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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.