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mds news
newsletter of the myelodysplastic syndromes foundation

MDS Join the Journey to Hope

Contents

From the Guest Editor's Desk

Why is comorbidity so relevant in MDS patients?

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Innsbruck Medical University
Innsbruck, Austria

Prognostication in MDS

Myelodysplastic syndromes (MDS) are a cluster of clonal stem cell disorders displaying a highly variable clinical course dominated by ineffective hematopoiesis and a tendency to transition to acute myeloid leukemia. Relying on morphologic features as well as the medullary blast count, MDS is classified according to the French-American-British (FAB) or World Health Organization (WHO) proposal.[1,2] To predict the clinical outcome in a particular patient, attention has focused on the identification of prognostic indices. The International Prognostic Scoring System (IPSS) was introduced in 1997 and has since become the generally accepted standard for risk assessment in patients with primary MDS.[3] This classification system is based on cytogenetic risk categories together with the bone marrow blast count and the number of cytopenias in peripheral blood. Several attempts, like the inclusion of elevated serum lactate dehydrogenase (LDH), have been made to refine the IPPS.[4] By including the magnitude of transfusion requirements, another forthcoming score addresses dynamic aspects of the MDS disease.[5] The armamentarium of therapeutic strategies available in MDS, ranging from best supportive care including hematopoietic growth factors and iron-chelators to high-dose therapy and hematopoietic cell transplantation (HCT), is increasingly effective and complex. Therefore, validated prognostic scores are urgently needed to refine tailored treatment concepts in MDS patients.

The concept of comorbidity

Comorbidity is defined as an existing or occurring illness other than the principal diagnosis. Comorbidities are an essential component of clinical outcome and treatment decisions in several types of tumors. The relevance of comorbidities is obvious to hematologists, when they prevent the application of distinct treatment options, e.g. of anthracyclines in cardiac impairment. Importantly, some ailments can even limit a patient's life expectancy, which also has to be considered when making treatment decisions.[6-10] The significance of comorbidities is highlighted by the frailty index, which is calculated from the chronological age and the comorbidity of a given patient. The frailty index defines the personal biological age of an elderly person and is a strong predictor of survival.[11] Advanced age is not only associated with a growing incidence of MDS, but also with the increased occurrence of illnesses and health problems. However, presence and severity of comorbidity are not directly correlated with advanced age. Thus, age cannot be applied as a surrogate marker of comorbidity, but instead comorbidity must be evaluated and considered as a distinct dimension.

Comorbidity scales

Several comorbidity scales have been developed to classify ailments and quantify the severity of comorbid conditions.[6-10,12] The Charlson Comorbidity Index (CCI) is widely used and validated for several types

of tumor;[13] its 19 items cover various diseases. The CCI is simple and can be determined easily and retrospectively using the patient's charts. Its limitations include the fact that it can not rate dementia or coronary heart disease, nor does it address health problems like decreased lung function. Because of these limitations newer indices based on the CCI have been developed (*vide infra*).

The Cumulative Illness Rating Scale (CIRS) assesses comorbid diseases in a comprehensive way.[14] It rates the severity of comorbidities in a manner similar to the Common Toxicity Criteria (CTC) grading, ranging from 0 to 4 (0=no problem, 4=extremely severe). The CIRS score can be presented as the number of categories involved, the total score achieved or as the number of categories displaying a grade 3 and/or 4 severity. The CIRS for geriatricians (CIRS-G) was created to meet the needs of the elder population.[15]

Evaluation of comorbidity in the elderly is often performed as part of a geriatric assessment (GA). A GA is a multidisciplinary examination, in which many dimensions like function, comorbidity, depression, cognition and socioeconomic situation are described, evaluated and rated.[10-12] The literature contains convincing evidence that comorbidity and performance independently predict outcome.[16] Thus, indices have been developed that combine both these predictors to provide a more comprehensive evaluation in any particular patient. The composite Kaplan-Feinstein scale rates 12 ailments. The functional aspect is addressed by applying an item for impaired locomotion.[17] A prognostic index, integrating comorbid conditions, functional capacities, age and sex, was recently developed. It is easy to use, gives an estimation of life expectancy and helps identify older low-risk patients who may benefit from diagnostic and therapeutic strategies.[18]

Based on these above-mentioned indices, an estimate of remaining lifetime expectancy and the implications of MDS for quality of life and survival, patients should be divided into the following three groups:[10-12]

- Fit patients, who are functionally independent with no comorbidity. They are thus similar to younger persons, in that they are candidates for most forms of standard treatment.
- Patients displaying moderate comorbidities and/or intermediate functional impairment, who cannot tolerate life-prolonging curative therapy such as AML-like induction therapy, but who are candidates for tailored approaches.
- Frail patients with complex comorbidities and/or major functional impairment, who benefit mainly from palliative treatment and symptom management.

Comorbidity in MDS patients

The largest body of data existing to date concern the evaluation of the performance status in MDS patients as measured using the Eastern Cooperative Oncology Group (ECOG), the World Health Organization (WHO) or the Karnofsky Performance Scale (KPS). However, as these scores were mainly used as criteria for inclusion in clinical studies, these data are biased by the fact that they reflect selection of patients with particularly good performance status.[19] In addition, the above-mentioned performance scales clearly underestimate comorbidities and limitations in functional capacities. Thus, patient evaluation must include additional, specific instruments.[20] To date, data on the impact of comorbidity in MDS are predominantly available from analyses in hematopoietic cell transplantation (HCT). Non-myeloablative HCT procedures as well as improvements in supportive care have resulted in the fact that more patients of an advanced age and with more severe comorbidities are considered for HCT. Therefore, scores were developed that quantify comorbidity and predict mortality and survival in HCT. Because of the usefulness of the CCI in predicting outcome in MDS patients undergoing HCT, the HCT-specific comorbidity index (HCT-CI) was developed. This new index proved to be more sensitive and a better predictor of survival than the CCI.[21] By assessing ECOG status as well as comorbidities using two indices (CCI, KFS) in parallel, a prognostic predictor that distinguishes between high- and low-risk HCT patients was recently developed.[22] However, the results of these studies are limited to patients who underwent HCT. Patients who did not qualify or were not referred to a transplant center were not analyzed. The majority of MDS patients seen in clinical practice, i.e. those displaying moderate or complex comorbidities and/or of advanced age and/or those with low-risk MDS, in general do not qualify for HCT and therefore were not included and evaluated in these analyses. Taken together, comorbidity scores have been established to define the patient risk for intensive therapies, particularly HCT. However, for the majority of MDS patients profound data on comorbidity are scarce. Thus, indices assessing comorbidity must be implemented and integrated in MDS evaluation.

Conclusion

Due to the increase in the elderly population in western countries and the number of survivors following successful primary tumor therapy, MDS have become a disease of increasing relevance. The availability of new and complex therapeutic options imposes the need to develop individualized decision and treatment algorithms. Besides chronological age, aspects of comorbidity and function must be included. So far, comorbidity scores have been successfully established and integrated in risk evaluation for high-dose strategies. Moreover, comorbidity scores must be implemented and applied in the large cohort of elderly MDS patients, in whom the main therapeutic goal is not only to prolong survival time, but also to improve and maintain quality of life. Age should not exclude a patient from appropriate treatment and age *per se* should not be used as a surrogate marker for comorbidity. Treatment decisions in any particular patient

should be based on the patient's age-adjusted life expectancy and, most importantly, on the impact of comorbidity on the clinical prognosis and feasibility of various treatment options. The issue of comorbidity in MDS patients needs to be evaluated in clinical trials and should be integrated into clinical practice.

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From the Operating Director's Desk

Kathy Heptinstall
Operating Director
The MDS Foundation

9th International Symposium on MDS: Florence, Italy

As I write this we are making final plans for the 9th International Symposium on MDS that will be held in Florence, Italy on May 16–19. The scientific content is superb and the interest in the symposium is very high. We would like to thank Professor Mario Cazzola of Pavia, Italy for his leadership in Chairing what is certain to be a successful meeting!

Friday Satellite Breakfast Symposium: Atlanta, GA

Our 9th consecutive Friday Satellite *Breakfast Symposium*— ***Paradigms in MDS Prognosis and Treatment*** — was held on December 8, 2006 in Orlando! More than 1200 physicians and other health-care professionals participated in this meeting. We now have available on CD ROM and online the full video and slides from this symposium. Thank you to the tremendous faculty and to Dr. Alan List for his work as Chairman for this important meeting. Our 2007 symposium submission has been made — ***Changing the Characterization of MDS: Diagnosis to Therapy***. This meeting will be chaired by Dr. Stephen Nimer of Memorial-Sloan Kettering in NYC.

Oncology Nursing Society: Las Vegas, Nevada

On April 24 we attended the Oncology Nursing Society's meeting in Las Vegas, Nevada. Our booth was extremely well attended and we presented the Foundation's first symposium in conjunction with ONS. Our distinguished faculty included Lewis Silverman, MD (Mt. Sinai Medical Center in New York City), Erin Demakos, RN, CCRC (Mt. Sinai Medical Center), Sandy Kurtin, RN, MS, AOCN, ANP-C (Arizona Cancer Center, Tucson) and Kathleen Weaver, Grant and Funding Director for the MDS Foundation. Information developed from the 28 Patient and Family Quality of Life Forums that have been held around the world formed the basis for this meeting.

We know that healthcare professionals are constantly learning about disease states and the human body's response to disease. We know that physicians, nurses, and the entire clinical team also need to be aware of patients' psychological and emotional response to disease. Like many diseases and conditions, myelodysplastic syndromes (MDS) affects patients physically, psychologically, emotionally, spiritually, economically, and socially. It is only through communication with patients and their caregivers that healthcare professionals can appreciate the full impact that this disease has on individual patients and a diagnosis of MDS has a much greater impact on patients' quality of life than is generally appreciated. MDS and its management take a heavy toll on patients physically and account for patients' diminished quality of life. The impact of MDS on patients' quality of life is difficult to quantify, but data are accumulating documenting the wide-ranging effects that MDS has on patients' lives — both negative and positive.

During this symposium the Faculty imparted information on improving communication with patients, allowing clinicians to better understand and appreciate the impact of an MDS diagnosis, understanding the needs of the patients and families living with MDS every day, the thought processes that physicians face in diagnosing MDS patients, imparting that diagnosis to patients and their families, and assessing the impact of MDS specific management approaches and treatments.

Thank You

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

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

From all of us at the Foundation, I wish you a wonderful Spring!

Participating in the MDS Candle Lighting Ceremony are (L to R): Joe Theismann, Dr. Alan List, Kathy Heptinstall, Bruce Fleisher and Nancy Volpe.

Bruce Fleisher signs a tournament flag at the H. Lee Moffitt Cancer Center Charity Golf Tournament for MDS in February.

MDS in the spotlight at the beautiful Candle Lighting Ceremony in Tampa.

Registration Desk at the Tournament.

Curtis Strange shares his professional advice at the Moffitt Tournament golf clinic.

MDS Foundation staff greet members of the Oncology Nursing Society at their Annual Meeting in Las Vegas in April.

Ways to Support Us

Charitable IRA Donations

On August 17, 2006, President Bush signed the Pension Protection Act of 2006 into law. This allows taxpayers over 70.5 years old to donate money to charity directly from their IRA account. The distributions will be tax-free and avoid the penalty on early withdrawals. Taxpayers are allowed to donate up to $100,000 per year from their IRA. This provision will be effective for the **REMAINDER OF 2007 ONLY**.

To qualify for this tax exemption, the funds must be sent electronically by the custodian of your IRA. Please note that you will be subject to tax if you withdraw the funds and deposit them into your bank account. The only way to receive this tax-free status is to transfer the gift directly from your account to the MDS Foundation.

This is an excellent way for individuals to make charitable donations that optimize the financial and tax benefits for the donors while supporting the work of the Foundation in the battle against myelodysplastic syndromes.

PHARMION

Pharmion has provided the MDS Foundation with an educational grant to support the Foundation's work.

Foundation Initiatives for 2007 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

ADOPT REGISTRY

Sponsored by a grant from:

genzyme

PATIENT QUALITY-OF-LIFE FORUMS

Sponsored by grants from:

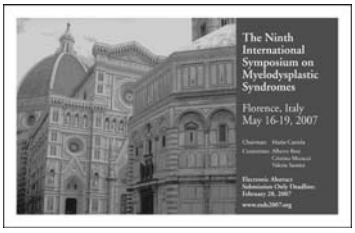
Celgene NOVARTIS PHARMION

WORLDWIDE PATIENT SUPPORT GROUPS

Sponsored by grants from:

Celgene NOVARTIS PHARMION

9TH INTERNATIONAL MDS SYMPOSIUM FLORENCE, ITALY: May 16–19, 2007



Sponsored by grants from:

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JANSSEN-CILAG NOVARTIS

CME AWARENESS PROGRAM

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.

The first three 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

Celgene MGI PHARMA PHARMION

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

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

ADDITIONAL PROGRAMS

- Differentiating Anemia (CME Program)
- MDS Practice and Treatment Survey
- The International Working Group on MDS Morphology
- Transfusion Burden Registry
- The International Working Group on MDS Cytogenetics

Celgene PHARMION

MDS Young Investigator Grants Program

2007 marked the third annual series of Grants for Young Investigators (under 40 years of age) from institutions that form our Centers of Excellence. The initial awards are set at $40,000 over 2 years [$20,000 in Year 1; $20,000 in Year 2]. Two awards will be announced this year for the years of 2008–2009. Subsequent awards will be announced for 2009 and beyond.

Eligibility

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

Submission

All MDS Centers of Excellence are invited to nominate one candidate from their institution. A mandatory brief letter of intent (L.O.I.) is to be submitted no later than **June 15, 2007**. The L.O.I. should contain a brief paragraph describing the background of the candidate and 1–2 paragraphs describing the proposed project and the name of the mentor. If approved, a formal application will be sent to you shortly after receipt of the L.O.I.

Deadline

The application deadline is **August 15, 2007**. Notification of the awards will occur by **October 1, 2007** with activation on **January 1, 2008**.

Young Investigator Grants Award Reception

The MDS Foundation presented its third annual MDS Foundation's Young Investigator Grants at a lunch reception during the 2006 meeting of the American Society of Hematology in Orlando, Florida. The Grant Review Committee headed by Stephen Nimer, MD of Memorial Sloan-Kettering Cancer Center and member of the Foundation's Board of Directors, selected Martin Jädersten's (Karolinska Institutet, Stockholm, Sweden) study entitled "The Role of the SPARC Tumor Suppressor Gene in the Pathogenesis and Treatment of MDS with 5q Deletion" and Arjan A. van de Loosdrecht's (Vrije Universiteit Medical Center, Amsterdam, Netherlands) study entitled "Multicolour Flow Cytometry in Myelodysplastic Syndromes."

The Young Investigator's Grant program was initiated in 2004 to provide assistance to outstanding Young Investigators who are committed to furthering the research into the causes and treatment of MDS. These awards are provided from the proceeds of our MDS Foundation's Charity Golf Tournaments.

(Pictured L to R) Drs. David Bowen, Theo de Witte, Martin Jädersten (award recipient), Arjan A. van de Loosdrecht (award recipient), Eva Hellström-Lindberg, John M. Bennett, Peter Greenberg, Stephen D. Nimer, and Alan F. List (members of the Foundation's Board of Directors).

Young Investigator Grant Program Steps into the Future

Inaugural MDS Foundation–H. Lee Moffitt Cancer Center Charity Golf Tournament for MDS

We are grateful to all of our old friends and our new ones who helped make the Inaugural Myelodysplastic Syndromes Foundation–H. Lee Moffitt Cancer Center Charity Golf Tournament (presented by Champions Tour Professional Bruce Fleisher) such a great success.

Participants enjoyed the golf clinic, rounds of golf where they got a chance to play with professional athletes such as Curtis Strange, Joe Theismann, and Jim Thorpe, and the spectacular awards dinner where they had the opportunity at the live auction to bid on the chance to win exciting golf packages with some of the top players on the Champions Tour.

Participation in this worthwhile event helps fund the Foundation's Young Investigator Grants program. The Moffitt Cancer Center serves one of the nation's largest state populations of patients with MDS. Our partnership with H. Lee Moffitt Cancer Center will foster not only regional but national awareness and understanding of MDS. We thank all the participants who joined "*The Journey to Hope*" for MDS patients around the world.

We look forward to seeing you next year.

Meeting Highlights and Announcements

48th ASH Annual Meeting Highlights

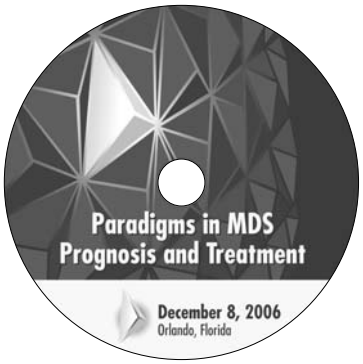
Orlando, Florida
December 9–12, 2006

Orange County Convention Center served as the venue for ASH 2006.

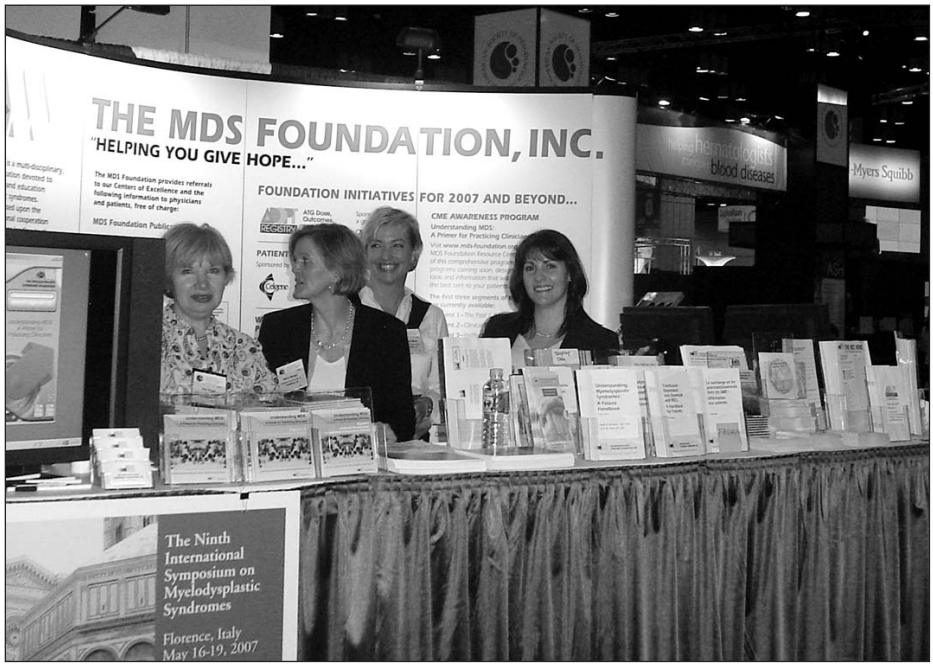
The MDS Foundation held its 9th consecutive satellite symposium on Friday preceding the American Society of Hematology's annual meeting. This symposium entitled "Paradigms in MDS Prognosis and Treatment," was chaired by Dr. Alan List of the H. Lee Moffitt Cancer Center in Tampa, Florida and a member of the Foundation's Board of Directors. This symposium focused on evolving morphologic and response assessment criteria, the impact of clonal karyotypic abnormalities, and acquisition of new abnormal karyotypes (including lesser known genetic abnormalities) as they relate to disease progression, implications of current molecular genetic research on therapeutic targeting of the epigenome, the effect of transfusion-dependence and chelation therapy on prognosis, and the need for targeting, monitoring, and evaluating therapeutic interventions based on disease stability or progression. More than 1200 people attended this symposium.

The topics and international faculty for this symposium included:

- **Evolution of MDS Morphologic and Response Assessment Criteria**
  John M. Bennett, MD
  University of Rochester
  Rochester, New York
- **Interrogating Less Common Genetic Abnormalities in MDS**
  Detlef Haase, MD
  University of Göttingen
  Göttingen, Germany
- **Therapeutic Targeting of the EpiGenome in MDS**
  Michael Lübbert, MD, PhD
  University of Freiburg
  Freiburg, Germany
- **Integrating Transfusion-Dependence and Iron Chelation into Prognostic and Management Models in MDS**
  Luca Malcovati, MD
  University of Pavia Medical School
  Pavia, Italy
- **Emerging Treatment Strategies in MDS**
  Alan F. List, MD
  H. Lee Moffitt Cancer Center
  Tampa, Florida



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



The Foundation has participated at ASH for nine consecutive years by hosting its booth for physician attendees. Our booth is well stocked with all of our MDS educational resource publications including our CME accredited CDs. Physicians from every corner of the globe who treat patients with MDS are surveyed on their practice and treatment practices which will provide crucial information for development of future educational initiatives. (Pictured left to right) Susan Hogan, Nancy Mrzljak, Kathleen Weaver, and Tracey Iraca.

9th International Symposium on MDS

Florence, Italy
May 16–19, 2007

Message from the Organizers

Dear Colleagues,

It gives us great pleasure to invite you to the forthcoming 9th International Symposium on Myelodysplastic Syndromes, which will be held in Florence, Italy, from May 16th to 19th, 2007, and will be sponsored by the Myelodysplastic Syndromes Foundation.

This meeting follows those of Innsbruck (1988), Bournemouth (1991), Chicago (1994), Barcelona (1997), Prague (1999), Stockholm (2001), Paris (2003) and Nagasaki (2005), which were all successful. As in previous meetings, we will try to cover all aspects of basic and clinical research, and will do our best to ensure that Florence 2007 provides a venue for discussion of the latest advances in our understanding of myelodysplastic syndromes.

We have limited the space for invited lectures and will give more room to selected oral and poster presentations. There will be awards for young investigators and, more generally, we would like to involve as much as possible young scientists working in both basic and clinical research.

Finally, the Symposium will provide attendees with opportunities to earn continuing medical education credits within the European Hematology Association CME program.

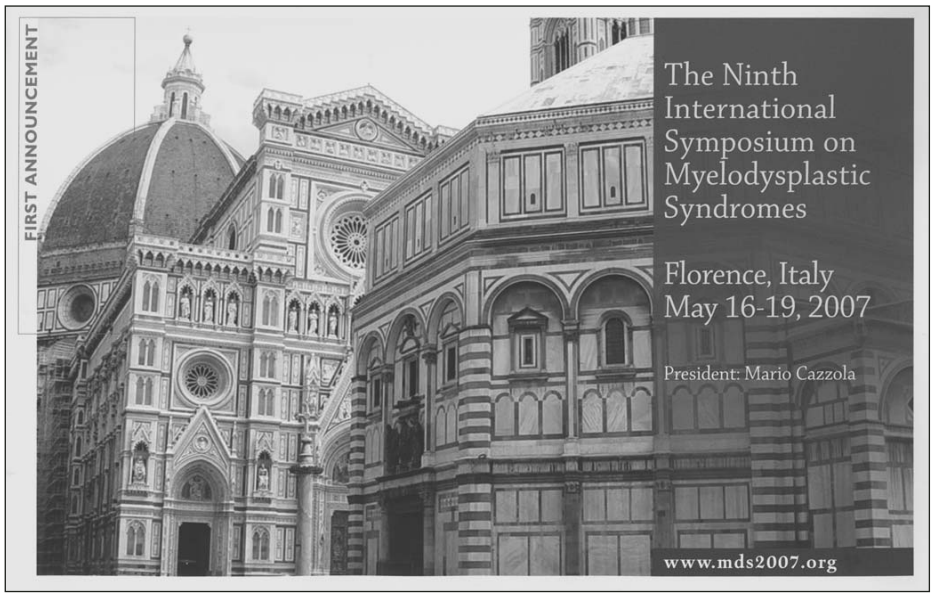
We hope you will join us in Florence to learn about the most recent basic and clinical advances in the field of myelodysplastic syndromes.

Mario Cazzola, Chairman
Alberto Bosi
Cristina Mecucci
Valeria Santini

General Information

Dates of the Symposium

May 16–19, 2007 (Wednesday–Saturday)



Meeting Location

Palazzo dei Congressi, Piazza Adua 1, 50123 Firenze (Florence), Italy. The meeting venue is very close to the central railway station (Santa Maria Novella).

Organizing Secretariat

Studio ER Congressi–Gruppo Triumph
Mail address: Via Marconi 36,
40122 Bologna, Italy
Tel: +39 051 4210559
Fax: +39 051 4210174
E-mail: ercongressi@gruppotriumph.it.
Website: http://www.ercongressi.it

Registration

The registration fee will be Euro 375,00 before February 28, 2007, and Euro 425,00 thereafter. Registration information is available on this web site (Online Registration Program).

Hotel Reservations

Information concerning hotel reservations is available on this web site (Online Housing Program).

Faculty

International Scientific Committee

Mohan B. Agarwal (Mumbai, India)
Carlo Aul (Duisburg, Germany)
John Bennett (Rochester, USA)
Jacqueline Boultwood (Oxford, UK)
David T. Bowen (Leeds, UK)
Consuelo del Cañizo (Salamanca, Spain)
Theo de Witte (Nijmegen, Netherlands)
Elihu Estey (Houston, USA)
Pierre Fenaux (Paris, France)
Michaela Fontenay (Paris, France)
Arnold Ganser (Hannover, Germany)
Guillermo Garcia-Manero (Houston, USA)
Norbert Gatterman (Düsseldorf, Germany)
Ulrich Germing (Düsseldorf, Germany)
Aristoteles Giagounidis (Duisburg, Germany)
Stuart L. Goldberg (Hackensack, USA)
Steven D. Gore (Baltimore, USA)
Peter Greenberg (Stanford, USA)
Terry Hamblin (Southampton, UK)
Eva Hellström-Lindberg (Stockholm, Sweden)
Heather A. Leitch (Vancouver, Canada)
Alan List (Tampa, USA)
Michael Lübbert (Freiburg, Germany)
Ghulam Mufti (London, UK)
Sucha Nand (Chicago, USA)
Charlotte M. Niemeyer (Freiburg, Germany)
Stephen D. Nimer (New York, USA)
Rose Ann Padua (Paris, France)
J. Pedersen-Bjergaard (Copenhagen, Denmark)
Timothy E. Quill (Rochester, USA)
Guillermo F. Sanz (Valencia, Spain)
Charles A. Schiffer (Detroit, USA)
John F. Seymour (Melbourne, Australia)
Lewis R. Silverman (New York, USA)
Radek Skoda (Basel, Switzerland)
David P. Steensma (Rochester, USA)
Masao Tomonaga (Nagasaki, Japan)
James S. Wainscoat (Oxford, UK)
Neal S. Young (Bethesda, USA)
Nicolaos C. Zoumbos (Patras, Greece)

Satellite Symposium Supported by the MDS Foundation at the 12th Congress of the European Hematology Association

Thursday, June 7th, 2007
Neue Messe, Vienna, Austria

08:00–10.00 hours
Room: Léhar 3 and 4

The MDS Foundation will be presenting their second adjunct symposium to be held in conjunction with the 12th Congress of the European Hematology Association (EHA) annual meeting in Vienna, Austria. The program is entitled:

Myelodysplastic Syndromes — Innovations, Understanding, and Advances.

Topics for the symposium and faculty speakers include:

Introduction/Summary
Ghulam Mufti (King's College Hospital, London, United Kingdom) and Pierre Fenaux (Hôpital Avicenne, Bobigny, France), Co-Chairmen

Growth Factors: Impacting Survival in MDS?
Eva Hellström-Lindberg (Karolinska Institutet, Stockholm, Sweden)

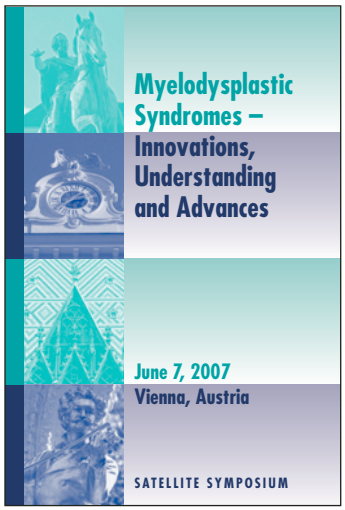
MDS Prognosis–Unveiling a Real-Time Assessment Tool
Luca Malcovati (University of Pavia Medical School, Pavia, Italy)

The Role of Reduced-Intensity Regimens in High-Risk MDS: Decision Guidelines
Theo de Witte (Nijmegen St. Radboud University Medical Center, The Netherlands)

Epigenetic-basis for Treatments in MDS
Jean-Pierre Issa (MD Anderson Cancer Center, Houston, TX, USA)

Current Revisions to WHO: Clinical Implications
John M. Bennett (University of Rochester Medical Center, Rochester, NY, USA)

Summary
Pierre Fenaux



PLEASE MAKE SURE TO VISIT THE MDS FOUNDATION BOOTH #42

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.

Patient Forums and Support Groups

News About Our MDS Patient Forums and Patient Support Groups

The Foundation has conducted a total of 25 Quality-of-Life patient forums around the world. All of the sessions were very well attended and we were very fortunate to have had our MDS Centers of Excellence physicians attend as our guest speakers.

Dr. Lewis Silverman from Mount Sinai School of Medicine at the MDS Patient Forum in New York City, December 15th, 2006

The next of our European series will be held on May 4th in London and May 19th in Florence, Italy. Groupe Francais des Myelodysplasies, the first formal MDS Patient Support Group, was established in France. This permanent group was developed around the Patient Forum that was held in Paris last year, a second group is being formed within the United Kingdom and a third in Austria.

United States Patient Forums are being planned within the next 6 months in Portland, Oregon; Los Angeles, California; Rochester, Minnesota; and Philadelphia, Pennsylvania. Established MDS Support Groups can be found in Chicago, Illinois; Puget Sound, Washington; and San Francisco, California. Patients, family members, and caregivers are invited to join. If you are interested in joining an existing group or starting a new group in your area, please contact Audrey Hassan, Patient Liaison at patientliaison@mds-foundation.org or call 1-800-MDS-0839.

Spreading the Word Worldwide

Patient Quality-of-Life Forums

Patient forums have been held to date in:

UNITED STATES

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

EUROPE

- Edinburgh, Scotland UK
- Paris, France
- Bournemouth, England UK
- London, England UK
- Leeds, England UK
- Marseille, France
- Vienna, Austria
- Prague, Czech Republic
- Stockholm, Sweden
- Freiburg, Germany

Future forums are scheduled in:

- London, United Kingdom (May 4, 2007)
- Florence, Italy (May 19, 2007)
- Rochester, Minnesota (June 28, 2007)
- Portland, Oregon (July 2007)
- Los Angeles, California (July 2007)
- Philadelphia, Pennsylvania (July 2007)

Dr. Scott Smith from Loyola University Chicago addressing patients in Oak Brook, Illinois, January 16th, 2007

Dr. Simrit Parmar, University of Texas Southwestern Medical Center, Dallas, Texas, January 22nd, 2007

Dr. Joachim Deeg, Fred Hutchinson Cancer Research Center, offering information on new therapies and patient treatment options at the Seattle, Washington forum, March 8th, 2007

Dr. Mark Kirschbaum from the City of Hope National Medical Center, presenting New Drugs, New Targets, New Hope in MDS Therapy to patients in Covina, California, March 9th, 2007

Share Your Stories

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

My Story...

Sandy Madrigal

My name is Sandy Madrigal. In memory of my sister Linda and our mother, Betty, who both had MDS, I have created a beautiful MDS awareness bracelet. My website, www.lovinkissesbeading.com, is named after our father's WWII plane and our folks' boat. It's my goal to draw as much attention to MDS as I can. I will be donating a portion of the proceeds to The MDS Foundation. This project is so important to me, because I know the pain and frustration MDS caused my mother, my sister and our entire family. My greatest hope is a cure for MDS will be found during my lifetime, so the next time I stand with Mom, Dad and Linda, I can proudly tell them I contributed to finding a cure for this horrible disease.

I am the third of four daughters born to Richard and Betty DeGarmo. The first time I heard of Myelodysplastic Syndromes, MDS, was in May 2005, when Mom, 85, was diagnosed with MDS.

My sister, Linda, 58, called me eight weeks later, to say she also had been diagnosed with MDS. I hadn't found the MDS Foundation website yet. Nothing else I read about MDS explained it in a way I could understand, but I knew it was very rare for multiple family members to be diagnosed, much less within eight weeks of each other.

Both Mom and Linda experienced similar symptoms, including fatigue, anemia, low platelet and blood cell counts. Initially they were each treated at The University of South Florida, H. Lee Moffitt Cancer Center in Tampa, FL. Each had numerous transfusions and bone marrow aspirations.

Mom continued the routine of blood and platelets transfusions. Linda was a candidate for a bone-marrow transplant and each of her three sisters was tested as a possible donor. Thankfully, Diane was a 10-point match.

Mid-October 2005, Mom was hospitalized. Her doctor said more transfusions could be helpful, but would also complicate her congestive heart failure. Mom knew the risks and the reality. She wanted to go home, with the assistance of Hospice. She asked for a final transfusion and she was brought home the next day. She was as sassy as ever. For the next two days we made Mom as comfortable as possible, but on the third day, October 28, 2005, she took her last breath while my father and I held her hands.

The following days were a blur. All four daughters were there, trying to comfort Dad, who had lost his wife of nearly sixty-three years. Days later, Linda was admitted for the chemo prior to her transplant. Dad told Linda he wanted her to hurry and get well, so he could "go be with Mom".

Linda was in her aftercare phase for eight weeks. She was gaining strength and her doctors seemed happy. Our father wasn't doing well. He'd lost his will to live, but held out until Linda came home on January 13, 2006. The next day Dad passed away.

Linda's doctors suggested she go visit with her son and his family for a while. They referred her to doctors at Nashville's Vanderbilt Cancer Center. In July her MDS became Acute Myeloid Leukemia. She'd been given 4–6 weeks to live. With an incredibly positive attitude and strong faith, she made the most of her remaining time. She visited with friends and family, traveled with family and ate all her favorite foods. August 17, 2006 Linda passed away.

The ten months prior to her death brought Linda and I closer. We had always been close and she'd seen positive growth and change in me recently. She made me promise I would use my passion and creativity to move forward. That's why I've created the awareness bracelets. I know she is my biggest fan and one of my guardian angels.

Join the Journey to Hope Bracelets

In memory of her mother and sister, Sandy Madrigal has created handcrafted bracelets dedicated to promoting awareness to MDS. A portion of the proceeds will be donated to The MDS Foundation to further research and create awareness.

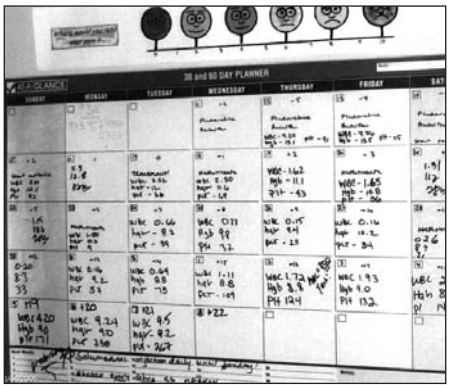
"Join the Journey to Hope." Each bracelet is made with a combination of Swarovski crystals, fine Japanese glass beads, antique Rhodium (a lead-free pewter), silver plated and sterling silver accents. The price is $20.00 (US dollars) plus $2.00 shipping and handling. International orders may have additional shipping costs.

To place an order visit: www.lovinkissesbeading.com and email sandy@lovinkissesbeading.com or call 800-MDS-0839.

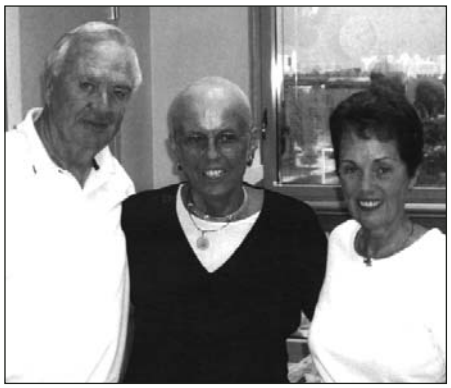
B.A.'s Story...

At the age of 68, Betty Ann Hickey underwent a bone marrow transplant at H. Lee Moffitt Cancer Center in Tampa. We are happy to announce that she is nearing her two year anniversary post transplant and is doing remarkable well. Now here's B.A.'s story.

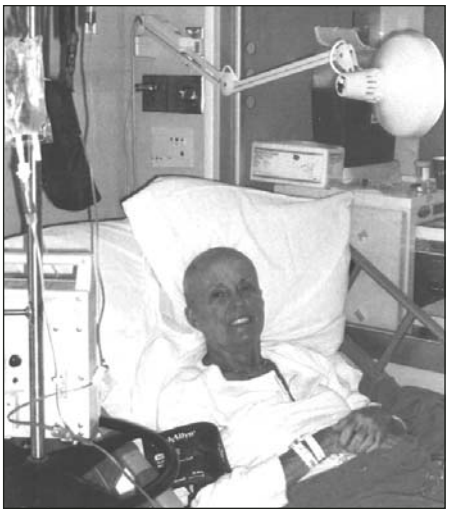
Betty Ann Hickey
Born October 31, 1937
Vero Beach, Florida



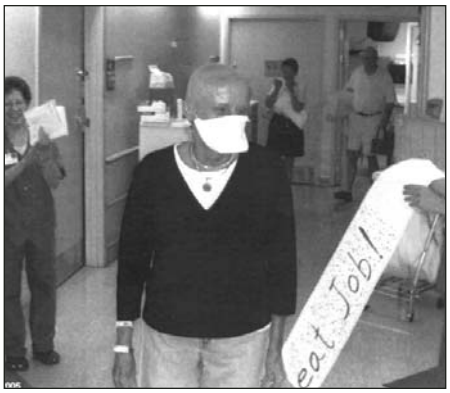
May 11 – June 7, 2005: *Hospital bulletin board Showing: White Blood Count (WBC), Hemoglobin (HGB) and Blood Platelets Count (PLT)*



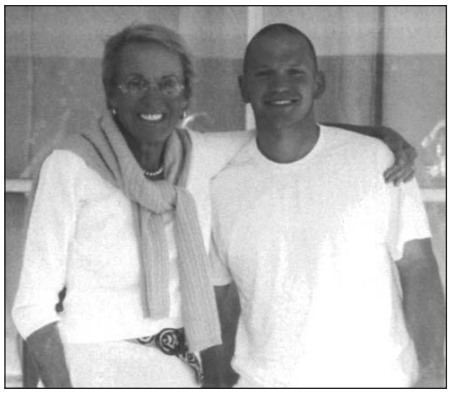
B.A.'s sister and full-time caregiver Joyce Parker



May 1, 2005: *B.A. receiving the transplant from donor Jason Alford*



June 8, 2005:
Going Home Day – 22 Days from transplant



October 7, 2006: *B.A. and "Her Hero" Jason*

Be a Bone Marrow Donor

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

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

Other sites of interest:

ASBMT™ American Society for Blood and Marrow Transplantation: www.asbmt.org
International Bone Marrow Transplant Registry: www.isbmtr.org
National Marrow Donor Program®: www.marrow.org
Blood & Marrow Transplant Information Network: www.bmtinfonet.org
Blood & Marrow Transplant Resources: www.BMTresources.org

Over 140 Things You Need to Know about Your Autologous Bone Marrow or Stem Cell Transplant is available online at www.BMTresources.org or call (414) 870-4850, ISBN# 0-9768060-0-2/Price: $11.95. Contains over 140 invaluable tips to help transplant patients sail through their procedures.

Drug News

FDA Approval of Vidaza NDA Supplement for IV Administration

On January 29, 2007, it was announced that the U.S. Food and Drug Administration (FDA) approved Pharmion's new drug application (NDA) supplement to add intravenous (IV) Vidaza® (azacitidine) as a new route of administration to the instructions in the approved prescribing information.

Vidaza is the only approved DNA demethylation agent with Labeled IV administration of less than one hour. With this approval, Vidaza may now be administered intravenously over a period of 10 to 40 minutes in a clinic or hospital setting.

FDA Acceptance of IND for Oral Azacitidine

On January 31, 2007, Pharmion Corporation announced in their press release that the Investigational New Drug (IND) application for the Company's oral formulation of azacitidine is now active following its acceptance by the U.S. Food and Drug Administration (FDA). The Company submitted the IND for oral azacitidine in December 2006.

Phase 1 Clinical Trials to Initiate in February 2007. This represents the first oral DNA demethylating agent in human trials.

Bringing MDS into the Limelight

Raymond Malles learned that he had MDS on November 4th, 2005. He was determined to learn as much as possible and attended the MDS Foundation-sponsored patient forum. He developed an MDS PowerPoint presentation for his senior Florida community and since then he has made it his calling to educate the public on MDS. Following is a letter that Ray sent to the media to spread awareness. Ray is an example of how we can all use our unique resources to help bring MDS into the limelight. Let's all follow in Ray's footsteps and "Join the Journey"!

March 23, 2007

Dr. Peter Gott, c/o United Media
200 Madison Avenue, Fourth Floor
New York, NY 10016

Dear Dr. Gott:

I write hoping to educate your readers about a medical condition many doctors still fail to recognize. Your recent column concluded an 87 year old was experiencing malaise and weakness as a result of a normal, age-related phenomenon common in patients in his age group. There can be another legitimate reason; hence my letter.

I was diagnosed with MDS (Myelodysplastic Syndrome) in November 2005, at age 76. Since then, I have investigated and discovered much about this disease. It is a recently recognized disease, among the aged, as our population's life span increases. In the past, people died before this disease had a chance to appear and be recognized. The disease's literal translation means: Abnormal growth of the bone marrow. I am fortunate to be in the group of affected patients who can be treated with biweekly injections of either Procrit or Aranesp. Both drugs act as a vitamin for the marrow so the production of red and white cells, along with platelets, increases. This treatment serves to depress the outward symptoms of tiredness and losing one's breath from slight exertion. Easy bruising is another telltale outward symptom of this disease. Unfortunately, MDS can progress to leukemia. It is not a curable disease but it is treatable. Mine started when an astute physician, in the same practice, considered my "below normal" readings for HGB and HCT to deserve further blood studies along with a bone marrow aspiration. The rest is history. My life journey has improved because a young observant physician recognized what many fail to do. The quality of my life has definitely been improved.

I recommend you contact the MDS Foundation, Inc., 36 Front Street, P.O. Box 353, Crosswicks, NJ 08515 for further information. Their website is: www.mds-foundation.org. Your daily column reaches untold citizens who need not suffer but instead need to be helped. I trust this letter helps close the gap between understanding, diagnosis and the treatment of MDS.

Sincerely, Raymond W. Malles

Purchase MDS Awareness Pins

The MDS Foundation has enameled lapel pins for you to wear with pride and to increase public awareness about MDS. The pins are available with a $3.99 donation to The MDS Foundation. To order your pins, call The MDS Foundation at 1-800-MDS-0839.

This item was created especially for The MDS Foundation to contribute to the effort to help people worldwide living with myelodysplastic syndromes. Your donation will help increase awareness of this little known disease, which is the most common of the hematologic malignancies. **Please ask your family and friends to wear these pins in support of our mission!**

Patient Registries and Referrals

MDS Patient Registry

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

The Foundation looks forward to building the Patient Registry with our Centers of Excellence.

If you would like to become a Center of Excellence, please contact The Foundation at the address below.

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

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

Slone Patient Registry

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

You are eligible to join if:

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

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

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

ICD9 Coding Changes

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

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

Patient Referrals

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

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

Please contact us at:
1-800-MDS-0839 (phone)
or 609-298-0590 (fax).

Outside the US please call:
609-298-1035.

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

mds centers of excellence

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

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

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

The following centers have qualified as MDS Centers of Excellence:

UNITED STATES

ALABAMA

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

ARIZONA

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

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

CALIFORNIA

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

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

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

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

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

FLORIDA

Mayo Clinic
Jacksonville, Florida
Alvaro Moreno-Aspitia, MD

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

ILLINOIS

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

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

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

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

INDIANA

Indiana University Medical Center
Indianapolis, Indiana
Larry Cripe, MD

MARYLAND

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

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

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

MASSACHUSETTS

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

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

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

MICHIGAN

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

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

MINNESOTA

Mayo Clinic
Rochester, Minnesota
David P. Steensma, MD

MISSOURI

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

NEBRASKA

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

NEW JERSEY

The Cancer Center of Hackensack University Medical Center
Hackensack, New Jersey
Stuart Goldberg, MD

NEW MEXICO

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

NEW YORK

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

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

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

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

North Shore University Hospital
Lake Success New York
Steven L. Allen, MD

Roswell Park Cancer Center
Buffalo, New York

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

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

NORTH CAROLINA

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

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

OHIO

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

OREGON

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

PENNSYLVANIA

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

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

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

UPMC Cancer Centers University of Pittsburgh Cancer Institute
Pittsburgh, Pennsylvania
Anastasios Raptis, MD

TENNESSEE

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

TEXAS

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

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

University of Texas Southwestern Medical Center Dallas VA Medical Center
Dallas, Texas
Simrit Parmar, MD

WASHINGTON

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

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

WASHINGTON, DC

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

WISCONSIN

Medical College of Wisconsin
Bone Marrow Transplant Program
Milwaukee, Wisconsin
Parameswaran Hari, MD

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

OUTSIDE THE UNITED STATES

AUSTRALIA

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

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

AUSTRIA

University Hospital of Innsbruck
Innsbruck, Austria
Reinhard Stauder, MD

University of Vienna
Vienna, Austria
Peter Valent, MD

BELGIUM

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

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

BRAZIL

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

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

CANADA

Toronto Sunnybrook Regional Cancer Centre
Toronto, Ontario, Canada
Richard A. Wells, MD

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

CZECH REPUBLIC

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

DENMARK

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

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

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

FRANCE

Centre Hospitalier Universitaire (CHU) de Grenoble
Grenoble, France
Jean-Yves Cahn, MD

Centre Hospitalier Universitaire de Nancy
Nancy, France
Agnés Guerci-Bresler, MD, PhD

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

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

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

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

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Sally Killick, MD

Information on Clinical Trials

International Clinical Trials: An Update

NATIONAL CANCER INSTITUTE TRIALS

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

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

This search will provide you with all the trials currently underway in MDS. You may also sort by trials that only focus on treatment or trials that only focus on supportive care.

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

If you are an MDS patient, you may wish to discuss a trial with your primary treating physician to see if you qualify as a candidate.

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

A clinical trial falls into one of four phases:

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

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

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

Phase IV. In phase IV the drug, already approved by the FDA and available to the public, undergoes continued evaluation. The phase IV designation is rare. Some trials—screening studies evaluating supportive care or prevention—are not conducted in phases. In these trials a group following a certain disease combating strategy, such as a detection method, is compared to a control group.

New Research Protocol Listings

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

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

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

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

Important Research Study Opportunity

Researchers at the H. Lee Moffitt Cancer Center and Research Institute in Tampa, FL are looking for people who have recently been diagnosed with MDS to participate in a research study designed to better understand why people get myelodysplastic syndrome. Specifically, researchers are studying a part of the chromosome called the telomere to see if telomeres are shorter in people with MDS as compared to people who don't have MDS. A specific gene, called human telomerase reverse transcriptase, or hTERT, will also be studied, to see if hTERT is related to telomere length. People who participate in this study will be asked to complete a questionnaire and provide a blood sample. Participation in this research study will not in any way affect an individual's medical care or MDS treatment options. To find out more information about this important research study, please contact Kristen Jonathan at 813-745-8395 or email kristen.jonathan@moffitt.org.

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

Learn More About P02978

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

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

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

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

Clinical Research/Trial with Lonafarnib–Now Open for Accrual

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

Study Background

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

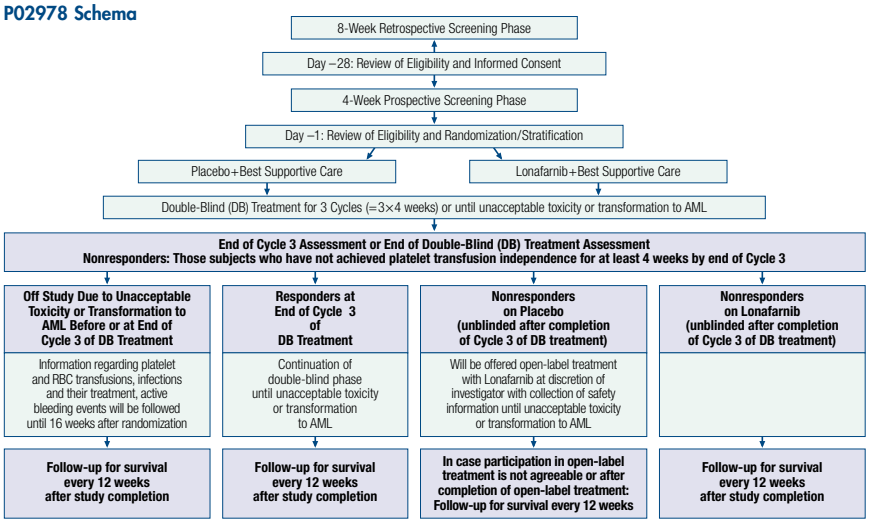
Key Eligibility Criteria

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

Additional Eligibility Criteria

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

P02978 Schema



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

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

mds foundation
the myelodysplastic syndromes foundation, inc.

Schering-Plough is the sponsor of this trial. This ad was supported by a grant from Schering-Plough.

(Clinical trial site list on next page)

Schering-Plough

Schering-Plough has provided the MDS Foundation with an educational grant to support the Foundation's work.

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

UNITED STATES

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

University of Minnesota
Minneapolis, MN
Mark Reding, MD

Georgia Cancer Specialists
Tucker, GA
Mansoor Saleh, MD

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

New York Medical College
Valhalla, NY
Karen Seiter, MD

Bethesda Research Center
Boynton Beach, FL
Roger Brito, MD

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

University of Texas Southwestern Medical Center
Dallas, TX
Robert Collins, MD

James A. Haley Veterans Hospital
Tampa, FL
Hussain Saba, MD

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

Mayo Clinic Hospital
Phoenix, AZ
James Slack, MD

Scripps Cancer Center
La Jolla, CA
James Mason, MD

CANADA / LATIN AMERICA

Canada

Cross Cancer Institute
Edmonton, Alberta
Robert Turner, MD

Sunnybrook Regional Cancer Center
Toronto, Ontario
Rena Buckstein, MD

Princess Margaret Hospital
Toronto, Ontario
Andre Claudius Schuh, MD

Colombia

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Bogota, Colombia
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Amado Karduss, MD

Hospital Militar Central
Bogota, Colombia
Benjamin Ospino, MD

Cardio Diagnostico SA
Barranquilla, Colombia
Miguel Urina, ME

Ecuador

Hospital Carlos Andrade Marin
Quito, Ecuador
Jose Paez, MD

Hospital SOLCA Guayaquil
Guayaquil, Ecuador
Bella Maldonado, MD

Cruz Rojo Ecuatoriana
Quito, Ecuador
Juan Sghirla, MD

El Salvador

Hospital Nacional Rosales
San Salvador, El Salvador
Hector Valencia, MD

Peru

Hospital Nacional Edgardo Rebaglianti
Jesus Maria, Peru
Juan Navarro, MD

Puerto Rico

Doctors Cancer Center
Manati, Puerto Rico
Kenel Fernandez-Barbosa, MD

San Juan Hospital
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San Juan VA Medical Center
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Vienna, Austria
Thomas Noesslinger, MD
Michael Pfeilstoecker, MD

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Institute of Hematology
Prague, Czech Republic
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Düsseldorf, Germany
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Roma, Italy
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Salamanca, Spain
Consuelo Del Canizo, MD

Announcing New Clinical Trials

NAME OF INSTITUTION:
Pharmion Corporation

TRIAL NUMBER:
AZA PH GL 2003 CL001

Title of Trial or Description:
A Multicenter, Randomized, Open-Label, Parallel-Group, Phase 3 Trial of Subcutaneous Azacitidine (Vidaza) Plus Best Supportive Care Versus Conventional Care Regimens Plus Best Supportive Care for the Treatment of Myelodysplastic Syndromes (MDS).

Primary Objective is to determine the effect of azacitidine plus Best Supportive Care, as compared with Conventional Care Regimens plus Best Supportive Care, on survival in MDS patients. This international trial is being conducted in 15 countries and has completed enrollment of 358 patients.

NAME OF INSTITUTION:
Pharmion Corporation

TRIAL NUMBER:
AZA PH US 2004 CL003

Title of Trial or Description:
A Multicenter, Randomized, Open-Label Study Comparing Three Alternative Dosing Regimens of Subcutaneous Azacitidine (Vidaza) Plus Best Supportive Care for the Treatment of Myelodysplastic Syndromes. Also evaluating if response can be maintained with maintenance regimens of 75 mg/m^2/day of Azacitidine given for 5 days every 28 days or every 42 days. This US Phase 2 trial is being conducted in approximately 30 centers. Enrollment goal is 144 patients with enrollment ending in February 2007.

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.

Educational Resources

The Foundation Resource Center is Now Online!

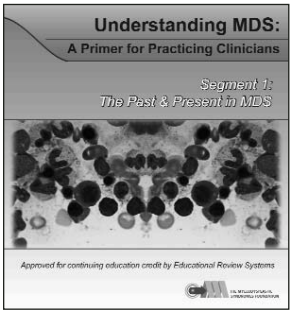
This educational center is designed to provide clinicians, researchers, and other healthcare professionals with a comprehensive source for the latest information and educational programming on the myelodysplastic syndromes.

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

Understanding MDS: A Primer for Practicing Clinicians

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

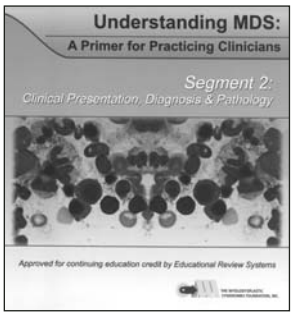
Written programs are available in Spanish, French, Italian, German and Japanese.



Segment 1:

The Past and Present In MDS

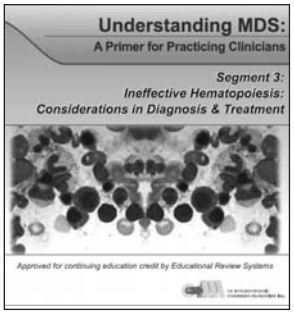
Segment 1 provides insight into the history of MDS, development of the MDS classification and prognostic systems, and a glimpse into the future of MDS diagnosis, research and treatment.



Segment 2:

Clinical Presentation, Diagnosis & Pathology

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



Segment 3:

Ineffective Hematopoiesis: Considerations in Diagnosis and Treatment

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

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

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

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

Highlights of Latest Literature in MDS

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. Corey SJ et al. Myelodysplastic syndromes: the complexity of stem-cell disease. *Nat Rev Cancer*. 2007;7:118–29.

   Extensive review describing the shifts in biology associated with the evolution of disease from low risk MDS to transformation into leukemia

2. Sekeres M. The myelodysplastic syndromes. *Expert Opin Biol Ther*. 2007;7: 369–377.
3. Mundle S. Advances in erythropoietic growth factor therapy for myelodysplastic syndromes. *Expert Opin Biol Ther*. 2006;6:1099–1104.

   A Review of the evolution of therapeutic strategies incorporating erythropoietic agents for the treatment of MDS and the refinement in response rates to these agents seen lately.

DIAGNOSIS AND PROGNOSIS:

4. Verburgh E et al. A new disease categorization of low-grade myelodysplastic syndromes based on the expression of cytopenia and dysplasia in one versus more than one lineage improves on the WHO classification. *Leukemia*. 2007; Feb 15 [Epub ahead of print].

A proposal for cytopenia-dysplasia scoring system that subcategorizes low risk MDS into distinct groups with significant differences in overall and leukemia-free survival.

5. Valent P et al. Definitions and standards in the diagnosis and treatment of the myelodysplastic syndromes: Consensus statements and report from a working conference. *Leuk Res*. 2007 Jan 24 [Epub ahead of print].

   Updated and newly proposed markers, criteria and standards in MDS with minimum diagnostic criteria and recommendation for patients not fitting into these criteria to be regarded as "idiopathic cytopenia of uncertain significance (ICUS)."

6. Singh ZN et al. Therapy-related myelodysplastic syndrome: morphologic subclassification may not be clinically relevant. *Am J Clin Pathol*. 2007;127: 197–205.

   No survival difference and uniformly poor outcome were noted in subgroups of therapy related MDS in WHO classification.

7. Germing U et al. Prospective validation of the WHO proposals for classification of myelodysplastic syndromes. *Hematologica*. 2006;91:1596–1604.

   A classification of 1095 patients from single institution validates WHO categories for differences in survival, and cumulative risk of AML transformation.

8. Kuendgen A et al. Myelodysplastic syndromes in Patients younger than age 50. *J Clin Oncol*. 2006;24:5358–5365.

   A large series of MDS patients younger than 50 years (N=232) showed significant survival difference as compared to patients >50 years of age. This difference was attributed primarily to low risk category and no difference was noted in Intermediate or high risk categories.

TREATMENT:

9. Kantarjian HM et al. Results of a randomized study of 3 schedules of low-dose decitabine in higher-risk myelodysplastic syndrome and chronic myelomonocytic leukemia. *Blood*. 2007; 109:52–57.

   This articles describes the results of a randomized study evaluating three modes of monthly outpatient administration of decitabine for MDS and CMML patients, with an improved response rate being noted in the patients receiving 20 mg/m^2 IV daily for 5 days. Confirmation and extension of this route of decitabine administration are warranted.

10. Aribi A et al. Activity of decitabine, a hypomethylating agent, in chronic myelomonocytic leukemia. *Cancer*. 2007;109: 713–717.

    OR-69%, CR-58% and median survival 10 mo, no concerning extramedullary toxicities.

11. Fenaux P et al. A multicenter phase 2 study of the farnesyltransferase inhibitor tipifarnib in intermediate- to high-risk myelodysplastic syndrome. *Blood*. 2007; Jan 30 [Epub ahead of print].

    A phase II study with 300 mg po twice daily dosing for 21 days of 28 day cycle, per revised IWG 2006 criteria yielded OR of 32% including 15% CR and 17% HI. Among CR, median DOR was 11.5 mo and TTP of 12.4 mo. Median OS was 11.7 mo with Gr 3–4 neutropenia (18%) and thrombocytopenia (32%) as major toxicities.

12. Lancet JE et al. A phase 2 study of the farnesyltransferase inhibitor tipifarnib in poor-risk and elderly patients with previously untreated acute myelogenous leukemia. *Blood*. 2007;109:1387–1394.

    OR-23%, CR14%, Median Duration of CR-7.3 mo, median OS in CR-18 mo. Inhibition of farnesylation surrogate HDJ-2 occurred in a majority of patients.

13. Goss TF et al. Cost effectiveness of lenalidomide in the treatment of transfusion-dependent myelodysplastic syndromes in the United States. *Cancer Control*. 2006;13 suppl.:17–25.

    Cost-effectiveness of lenalidomide without EPO was evaluated in comparison with the best supportive care (BSC) including EPO over 1 year in transfusion dependent low/int-1 patients with del 5q± additional cytogenetic abnormalities. At 1 year lenalidomide showed incremental gain of 0.53 transfusion-free and 0.25 quality-adjusted life years compared to BSC. One-year total treatment costs were estimated at $63,385 for lenalidomide and $54,940 for BSC.

14. Giraldo P et al. Darbepoetin alpha for the treatment of anemia in patients with myelodysplastic syndromes. *Cancer*. 2006;107:2807–2816.

    A retrospective analysis showed OR 55% with most responding d 8 wk. The majority of patients received 150 mcg/wk (65%) or 300 mcg/wk (30%) as a starting Darbepoetin dose. No safety concerns were noted.

PATHOBIOLOGY:

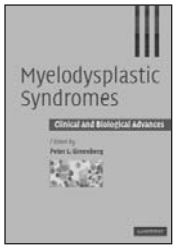
15. Sanada M et al. Unbalanced translocation der(1:7)(q10;p10) defines a unique clinicopathological subgroup of myeloid neoplasms. *Leukemia*. 2007;Feb 22 [Epub ahead of print].

    Monosomy 7 or 7q- are associated with poor prognosis. In contrast der (1;7) (q10;p10) appears to be associated with lower blast count, higher Hb and slower progression to AML.

16. Aivado M et al. From the cover: Serum proteome profiling detects myelodysplastic syndromes and identifies CXC chemokine ligands 4 and 7 as markers for advanced disease. *Proc Natl Acad Sci USA*. 2007;104:1307–1312.

    Large multicenter study with 218 patients conducting proteomic profiling showed lowered serum levels of CXCL-4 and -7 in advanced MDS.

Help the Foundation and Buy Your MDS Textbooks From Us!



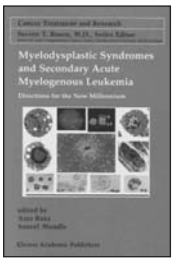
Myelodysplastic Syndromes: Clinical and Biological Advances

Peter L. Greenberg, MD
Stanford University Medical Center

Hardback, Nov. 2005/320pp., illus.
ISBN: 0521496683/$125.00**
Cambridge University press

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

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

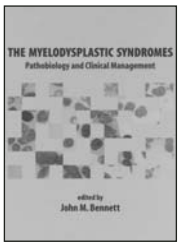


Myelodysplastic Syndromes & Secondary Acute Myelogenous Leukemia: Directions for the New Millennium (Cancer Treatment and Research)

Edited by:
Azra Raza, MD, Suneel D. Mundle, PhD

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

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



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

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

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

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

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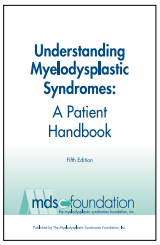
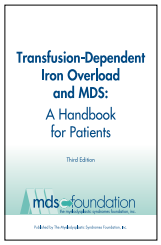
MDS Foundation Publications

Patient Information and Educational Materials Available from The MDS Foundation

- The MDS News
- MDS Essentials: The Foundation's E-Newsletter is now available
- Understanding Myelodysplastic Syndromes: A Patient Handbook
- Transfusion-Dependent Iron Overload and MDS: A Handbook for Patients





Translations available in the following languages: French, German, Italian, Spanish, Czech, Japanese, Dutch, Hungarian, Polish and Swedish.

- Patient Diary
- Insurance and Reimbursement Resources for MDS Patients
- Emerging Treatment Options for Adult MDS: A Clinical Perspective
- Planned Giving Program: A Guide to Financial Planning
- Your Journal: Learning About Myelodysplastic Syndromes (MDS)

Supported by a grant from Celgene Corporation.

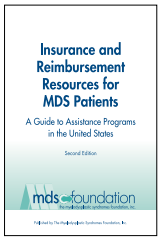
- PBS Program — Videotape Healthy Body, Healthy Mind: Learning About Myelodysplastic Syndromes
- PBS Program — DVD Healthy Body, Healthy Mind: A Menace in the Blood

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

Now Available From The Foundation

We have assembled a listing of insurance and drug reimbursement resources for MDS patients. It is important to know that there is support for those who cannot afford medicine or other healthcare costs. We hope this new resource will be beneficial in helping you with your medical needs.

This guide to assistance programs in the United States is available for download from the Foundation's website or can be ordered in booklet form upon request.



MDS White Paper Available Through The MDS Foundation

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

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

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

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

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Membership benefits include quarterly issues of the MDS News, a special subscription rate of $116 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 eight international symposia — in Austria, England, the United States, Spain, Czech Republic, Sweden, France, and Japan. The Ninth International Symposium is being held in May 2007 in Florence, Italy.

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

In response to the needs expressed by patients, families, and physicians, we have established Patient Advocacy Groups, research funding, and physician education.

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

Our Website

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

The website is constantly being updated to better serve the needs of our patients, their families, and the physicians who treat them. Please visit us at http://www.mds-foundation.org.