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From the Guest Editor's Desk

Hypomethylating Therapy in Myelodysplastic Syndromes





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Aberrant Methylation and MDS

Despite the large heterogeneity found in the initial clinical and biological presentation of patients treated for myelodysplastic syndromes (MDS), their fate is strikingly similar with the evolution, sooner or later, for at least 30% of patients, to a chemoresistant form of acute myeloid leukemia.1 One of the hallmarks of this phenomenon is the progressive increase in the DNA methylation content of the genome of the MDS cells.²⁻⁴ More precisely, this aberrant epigenetic imprinting will trigger the silencing of the transcription of key tumor suppressor genes implicated in apoptosis like P15, cell cycle regulation like P21, or differentiation pathways.^{5,6} The addition of these epigenetic lesions to the preexisting mutations or chromosomal abnormalities will open the way to the proliferation of more aggressive clone. The targeting of DNA methylation is so clearly appealing in order to prevent this evolution. The currently

available hypomethylating agents are both pyrimidic analogues of cytosine that act as DNA Methyl Transferase 1 inhibitors (DNMTi). Both were initially developed in the 70's and 80's as cytotoxic drugs and used at higher, and much toxic, dosages for AML and ALL patients. At lower dosage, both of them will deplete DNMT1, be incorporated in DNA and trigger G1-M cell cycle arrest, DNA damage and apoptosis.^{7,8}

Hypomethylating Agents

The first one is the 5-azacitidine (VIDAZA®). Only 1/3 of azacitidine is incorporated in DNA and 2/3 is incorporated in RNA, thus potentially interfering at the traduction level. Intracellular phosphorylation by uridine cytidine kinase is necessary for its activation and the half-life is short (41 minutes). Several phase II trials demonstrated its clinical activity including some complete remission and, interestingly, correction of cytopenias. The CALGB9221 phase III study⁹ randomized azacitidine 75 mg/m²/d s.c. for 7 days vs. best supportive care (BSC). The study showed a response rate of 47% (including only 10% CR) for azacitidine as compared to 17% in the BSC arm. Time to progression to AML was also improved but the study was not able to show an overall survival benefit due to a cross-over design. More recently, a European phase III study of azacitidine in high-risk MDS was published (AZA001 study). 10 It randomized azacitidine vs. conventional clinical care (i.e. a choice between BSC, low dose cytarabine, or AMLlike chemotherapy). The study confirmed the benefit in response rate and also demonstrated a survival advantage for the

azacitidine arm (24 months vs. 15 months). We learned from these studies that the time to respond may be delayed up to 6 or 7 cycles of treatment and that most of the patients will relapse or progress at some point including patients for which azacitidine is stopped in CR. It is currently recommended to maintain azacitidine until progression. Regarding safety, azacitidine is associated with mild GI and local injection site reactions. Hematological toxicity is mainly described in the first cycles of treatment and must be tolerated in order to allow time for the treatment to become efficient. Indeed, the phase III studies shown that azacitidine treatment leads to less hospitalization days than CCR. Oral formulation of azacitidine is still in evaluation phase.

The second one is the 5-Deoxy-azacitidine (decitabine, DACOGEN®). Decitabine is only incorporated in DNA and drug-induced gene expression patterns are different between the 2 DNMTi, Moreover, metabolic pathways implicated in decitabine intracellular activation differ from those used for azacitidine. Interestingly, no cross resistance has been demonstrated in cell lines. Similarly to azacitidine, a north American phase III study¹¹ of decitabine 15 mg/m²/8h IV for 3 days vs. BSC was conducted and showed an increased response rate for decitabine arm (30% vs. 7%) but no benefit regarding survival or time to progression to AML. A subsequent EORTC trial¹² confirmed the response data and showed a better progression free survival (6 months vs. 3 months). Nevertheless, this did not translate in a better overall survival. Toxicity profile is quite similar to azacitidine with an increased frequency of hematological toxicities leading, in some cases to stop the treatment prematurely. This may be one of the reasons explaining the relative low median number of administrated cycles in the clinical trials and thus may have an impact on the clinical results. Less toxic alternative dosage of decitabine (once daily for 5 days) are currently evaluated with promising results^{13,14} but have not yet entered phase III development. Of note, there is no available prospective comparison of decitabine and azacitidine.

To date, azacitidine and decitabine are registered by the US Food and Drug Administration (FDA) for the treatment of MDS based on the results of the 2 US phase III trials. In Europe, only azacitidine has been registered by the European Medical Agency (EMEA) for the treatment of Intermediate-2 and high risk MDS based on the publication of the AZA001 trial.

Optimizing Epigenetic Therapies

Based on the results of the phase III trials, we know that, even if the results are impressive in a group of diseases without previous efficient therapy for the majority of patients, there is still a great need for improvement. As previously mentioned 50% of the patients will not respond to therapy and a vast majority of the responding patients will experience relapse or progression. Of note, only few data published are available on patients in that situation but outcome seems strikingly poor. The MD Anderson group had recently reported a median survival of only 4 months after decitabine failure. 15 Results from the first clinical studies focusing on the treatment of these patients are pending. Optimization of frontline treatment is so mandatory and different strategies could be applied. Firstly, the recommended schedule of azacitidine could be refined. Shorter schedule of 5 days seems to be able to give comparable response rate but no data are available on survival.16 On the other hand longer exposure to azacitidine (10 to 15 days) may increase the demethylating effects and this is currently evaluated in clinical trial (ECOG E1905 trial). Secondly, combination approaches seems also promising. A large number of drugs are currently evaluated in these settings. Associations of DNMTi and histone deacetylase inhibitors (HDACi) are currently ongoing. HDACi are another kind of epigenetic agent with limited clinical activity as single agents but which synergize in

vitro with DNMTi¹⁷ and other drugs. 18 Combination Phase I and phase II studies with the first generation compounds (valproic acid, 19 phenylbutyrate 20) were not able to demonstrate a clear benefit but ongoing trials with the second generation of HDACi (Vorinostat, ²¹ Entinostat) seems more promising. Besides the combination of epigenetic targeted drugs, a wide variety of agents have been, or are currently, evaluated (lenalidomide, 22 gemtuzumab, TNF inhibitors, cytotoxic chemotherapy...). Response rates seem to be improved in some cases, combination of azacitidine and lenalidomide giving an overall response rate of 72% including 41% of CR. However, no survival data or comparative trials are available yet. Of note, sequential combinations of azacitidine and allogeneic stem cell transplantation are feasible using DNMTi as a preparative regimen or to prevent relapse after transplantation.

Towards Biomarkers of Response

Finally, in our search for the optimization of treatment, a deeper understanding of the disease biology and how DNMTi worked in MDS cells are important. To date, there are no straightforward biological characteristics that can allow us to predict response to treatment with DNMTi. The conventional biology variables such as cytogenetic risk stratification are no more relevant with DNMTi therapy. Neither are global methylation or gene specific techniques. Genome wide methylation and expression arrays have been performed but to date, none of these approaches gave enough robust and reproducible results allowing us to better select the patients and to evaluate the chances of response. This could be partially explained by the heterogeneity of the disease by itself and correlative studies from the large series of patients included in the phase II and phase III trials may be crucial. We can guess that the next ASH meeting will give us some insights on both clinical and biological level.

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The MDS Foundation Needs Your Help!

For individuals and families affected by MDS, it's more important than ever to raise funds for the Foundation in 2011.

For the past 15 years, The MDS Foundation (MDSF) has provided services to patients, their families, and healthcare providers working in the field.

With changes in regulations and restrictions on corporate support, we need your support more than ever this year to continue producing these vital programs.

For the first time, MDSF donors can dedicate the use of their contributions to one of the critical services we provide.

- Patient Advocacy: Patient forums, support groups, information requests, referrals
- Research: Clinical trial assistance, physician advisory boards, international working groups on cytogenetics, morphology, diagnostics, quality of life
- Healthcare Provider Education: International physician and nursing symposia, interactive/web-based continuing education initiatives, abstracts & manuscripts

Kindly use the enclosed donation envelope or go to:

www.mds-foundation.org to donate today.

Thank you for your continued support!

"helping you give hope..."

FOUNDATION INITIATIVES FOR 2011 & BEYOND...

- WORLDWIDE PATIENT QUALITY-OF-LIFE FORUMS
- WORLDWIDE PATIENT SUPPORT GROUPS
- US NURSING ADVISORY BOARDS
- **EU NURSING ADVISORY BOARDS**

MDS FOUNDATION RESOURCE CENTER

Understanding MDS –
A Primer for Practicing Clinicians
A CME/CE Series for Physicians,
Nurses, and Pharmacists

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



INTERNATIONAL WORKING GROUPS

These Working Groups are funded by the Foundation and focus on moving disease knowledge forward by developing essential information through innovative research.

- International Working Group on MDS Morphology
- International Working Group on MDS Cytogenetics
- International Working Group on Quality of Life in MDS
- International Working Group for Prognosis in MDS

THANK YOU TO OUR SPONSORS FOR THEIR SUPPORT THROUGH EDUCATIONAL GRANTS

The Foundation's work is supported by grants from:















VISIT OUR WEBSITE AND LINK TO OUR EDUCATIONAL RESOURCE CENTER:

www.mds-foundation.org

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The MDS Foundation is now on Facebook and Twitter. Sign up to connect with us now! **Keep up to date on all the news, events and happenings with the Foundation.**



To find our page on Facebook, type "The MDS Foundation" in the search box located in the top right corner. Once you are there, become a fan to receive updates. Then in the top left corner click the "more" button then "suggest to friends" and send to all your friends.

When the page is updated with current Foundation information, a notice is sent to all the fans newsfeeds. The page also allows for Fans to leave comments for others to read or begin a topic in a Discussion Forum.



Twitter is a free service that lets you keep in touch with people through the exchange of quick, frequent answers to one simple question.

Follow us on Twitter at http://twitter.com/MDSFoundation to start receiving the MDS Foundation's tweets.

We hope to see you on the web!

OUR SITE TO SEE! www.mds-foundation.org



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.

The MDS Foundation recognizes that data on many aspects of MDS worldwide is sketchy or nonexistent. While individual investigators have developed databases to track MDS within their individual sites or working groups, that information is not located within one easily accessible database.

To assist in the development of useful information, the Foundation has recently initiated the first Patient Registry and data from the Foundation's Centers of Excellence are currently being entered.

Since it will be some time before these data are mature and usable, the Foundation has attempted to design a survey that we hope will assist in describing some of the issues related to MDS worldwide as well as the treatments being utilized in this disease. A pilot of this survey has already been completed with some selected Centers of Excellence. While we know that this information is, in most instances, based on subjective criteria, it can assist in identifying educational and research opportunities in the near term and until more accurate data are available.

Please assist us by completing a brief online survey.

Go to www.mds-foundation.org

and click on

Physician or Nursing Practice & Treatment Survey

(Surveys are available online in Spanish, Italian, German, and Dutch)



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

What is MDS?

- The myelodysplastic syndromes (MDS) are a family of similar diseases that share many common characteristics and affect tens of thousands of individuals worldwide. This number reflects only those patients who are properly diagnosed. These disorders are a primary disease of the bone marrow and share several characteristics of the acute leukemias; however, MDS far exceeds any of the leukemias in prevalence. We are seeing many more cases each year and that number will increase greatly over the next decade as the baby boomers age and diagnosis improves.
- The primary cause of these disorders is unknown; however, the chemotherapy

- regimens that are utilized to provide curative therapy to patients with certain malignancies (lymphomas, testicular cancer, and breast cancer) can lead to the development of secondary MDS.
- 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.

Meeting Announcements



THE 11TH INTERNATIONAL SYMPOSIUM ON MYELODYSPLASTIC SYNDROMES

EDINBURGH, UK, MAY 18 - 21, 2011

MDS 2011 will unite all professionals devoted to improving the quality of life of patients with Myelodysplastic Syndromes. World leaders will present the latest developments in the field in the hope of accelerating the process leading to the effective control and ultimate cure of these diseases — the mission of the MDS Foundation.

Combine your scientific interests with a chance to explore the enchanting city of EDINBURGH!

VIEW THE SCIENTIFIC PROGRAMME ONLINE & REGISTER NOW!

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MDS 2011 Symposium Secretariat c/o Kenes International

1-3 Rue de Chantepoulet, PO Box 1726, CH-1211 Geneva 1, Switzerland

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For MDS Foundation Contact: US number: 1-800-MDS-0839; Outside the US: 1-609-298-1035

11th International Symposium on MDS

Edinburgh, UK • May 18-21, 2011

Message from the Organizers

Dear Colleagues,

The Myelodysplastic Syndromes Foundation is proud to announce its 11th international meeting on MDS. The 10th symposium was held in Patras, Greece in 2009. Since then, there have been many exciting new developments in the field. Updates on evidenced-based research and management will be covered by world-renowned experts and there will be ample time for discussion during the congress.

At the previous symposium, over 1,400 professionals from the field of hematology enjoyed a stimulating scientific and social programme. We expect even more participants at the Edinburgh symposium and an equally inspiring programme.

The scientific program is designed to meet the aims of The MDS Foundation, which are "to provide an ongoing exchange of information relating to MDS and 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." The format will include plenary sessions (including a nursing symposium), debates, case-based discussion, topical workshops, oral and poster presentations.

This 11th symposium will again promote the clinical application of existing knowledge and the acquisition of new knowledge by bringing together clinicians, scientists and educators from around the world who deal with MDS.

I greatly look forward to welcoming you to Edinburgh and to a very successful congress.

David Bowen

Chair, Scientific Programme Committee

GENERAL INFORMATION

Faculty

Scientific Programme Committee and Symposium Chairperson

Professor David T. Bowen, UK

Local Organizing Committee

Prof. David Bowen, UK

Prof. Ghulam Mufti, UK

Dr. Helen Enright, UK

Prof. Terry J. Hamblin, UK

Dr. Jonathan Kell, UK

Dr. Mike Dennis, UK

Dr. Mark W. Drummond, UK

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Dr. Jane Parker, UK

Dr. Dominic Culligan, UK

Dr. Emma Das-Gupta, UK

Dr. Gail Jones, UK

Dr. Samir Agrawal, UK

Dr. Sally Killick, UK

Dr. Anton Kruger, UK

Dr. Christopher Dalley, UK

Prof. Charles Craddock, UK

Dr. David Hall, UK

Scientific Topics

- 5Q-Biology and the P53 Pathway
- Allogeneic Stem Cell Transplant: Whom and When?
- Bone Marrow Failure Syndromes including Inherited Syndromes
- Co-Morbidity and Quality of Life as Prognostic Indicators
- Hypomethylating Agents and Combination Therapies
- Hypoplastic MDS and PNH
- International Research Initiatives
- Molecular Dissection of Myelodysplastic/ Myeloproliferative Neoplasms

- Mouse Models of Myeloid Disease and the Microenvironment
- New Diagnostic Techniques including Flow Cytometry and Genomics
- New Prognostic Markers and Scoring Systems for Outcome
- Novel Supportive Care Strategies

Symposium Venue

Edinburgh International Conference Centre

The Exchange

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Website: www.eicc.co.uk

Symposium Website

URL: http://www2kenes/mds

Organizing Secretariat

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E-mail: mds@kenes.com

Registration

Registration information is available online at www.kenes/mds. Group Registration procedure will be valid for a minimum of 10 participants and up.

Hotel Reservations

As the official organizer of the congress, Kenes International is offering special reduced rates for various hotels in Edinburgh. Information is available online at www.kenes/mds.

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11TH INTERNATIONAL SYMPOSIUM ON MYELODYSPLASTIC SYNDROMES

ABSTRACT SUBMISSION IS NOW OPEN...

Abstracts submitted for the MDS 2011 Congress will be published in the *Leukemia Research Journal* by Elsevier.

The *Leukemia Research Journal* is indexed in the following databases:

Chemical Abstracts, Current Contents/Life Sciences; EMBASE; Elsevier BIOBASE;

Medline; PubMed; Reference Update; Science Citation Index; Scopus.

ABSTRACT DEADLINE: Monday, February 07, 2011



Participants who would like to present **poster presentations or oral presentations** must submit an abstract for consideration by the *Scientific Programme Committee*—and may be accepted for oral presentation, poster presentation, or rejected.

- Abstracts should be submitted in English and arrive no later than Monday, February 07, 2011.
- The Scientific Committee will determine whether abstracts will be accepted as oral presentations or poster presentations, with consideration to be given to the author's preference.
- The presenting author is required to ensure that all co-authors are aware of the content of the abstract before submission to the Secretariat.
- Only the abstracts of registered presenting authors will be included in the final programme.
- Abstracts accepted for presentation will be published on the website prior to the Congress.

Submission

Abstracts should be submitted only via the online submission form at:

http:www2.kenes.com/mds/abstract/ Pages/Call_Abstracts.aspx Abstracts submitted by fax will not be accepted. If you do not have access to the internet please contact the Congress Secretariat.

Preparation of Presentations

 Instructions for preparation of posters will be sent together with acceptance notifications.

Rules for Submission

- An author from each abstract is expected to attend the congress and present the poster or oral presentation.
- All abstracts must be submitted and presented in clear English with accurate grammar and spelling of a quality suitable for publication. If you need help, please arrange for the review of your abstract by a colleague who is a native English speaker, by a university scientific publications office (or other similar facility) or by a copy editor, prior to submission.
- Only abstracts of authors who have paid their registration fees by Wednesday, 16 March, 2011 will be scheduled for presentation.

Guidelines for Submission

Before you begin, please prepare the following information:

- Presenting author's contact details:
 - Email address
 - Full postal address
 - Daytime and evening phone number
- Presentation type: please choose from one of the following:
 - Poster presentation
 - Oral presentation
- Author and co-authors' details:
 - Full first and family name(s)
 - Affiliation details: department, institution/ hospital, city, state (if relevant), country
- Abstract title: Limited to 20 words in Sentence Structure
- Abstract text: Limited to 400 words (Please Note: Word count is affected when graphs/tables/images are added)

- Abstract topic: Abstracts must be allocated to a specific topic for the Scientific Program. Please choose from the list of topics.
- Tables: A maximum of 3 tables of up to 10 rows x 10 columns can be included per abstract
- Graphs and images: It is important to note that each image included in the abstract is worth 30 words. A maximum of 3 images can be included per abstract.
 - The maximum file size of each graph/image is 500 KB. The maximum pixel size of the graph/image is $600 \, (w) \times 800 \, (h)$ pixel. You may upload graphs in JPG, GIF or PNG format.
- Draft abstracts: The submission form at the link above allows you to store your abstract as a draft in order to make changes. Please note that abstracts must be SUBMITTED before the deadline in order to be sent to review for inclusion in the Scientific Program.



SOCIAL PROGRAM

Opening Ceremony

Wednesday, May 18, 2011

Edinburgh International Conference CentrePlease join us at the MDS 2011 Symposium

Please join us at the MDS 2011 Symposium Opening Ceremony at 18:00.

Welcome Reception

Participation in our Welcome Reception is complimentary and will be taking place in **The National Galleries of Scotland** at 19:00.



Coaches will take participants from the Congress Venue to the Galleries at 18:45.

The event will be taking place in the National Collection Hall and The Royal Scottish Academy Building—where wine and canapes will be served.

The National Gallery Complex is one of Scotland's top free visitor attractions and Edinburgh's second most-visited attraction after the Castle. It is made up of three interconnected buildings, right in the heart of Edinburgh. The National Gallery of Scotland is home to a major part of Scotland's sensational national collection of fine art; the Royal Scotlish Academy Building (RSA) is one of Europe's premier venues for international exhibitions; and the Weston Link, which lies beneath the two buildings, connects them together.

The National Collection

The National Gallery houses the national collection of fine art from the early Renaissance to the end of the nineteenth century. Spend an hour strolling around this peaceful setting with the floor plan and you'll find masterpieces from Raphael, Titian, El Greco, Velázquez, Rembrandt and Rubens to Van Gogh, Monet, Cézanne, Degas and Gauguin. For a nation of Scotland's size, the collection is rightfully regarded as one of the very best in the world. The most comprehensive part of the collection covers the history of Scottish painting. All the major names, including Ramsay, Raeburn, Wilkie and McTaggart, are represented in depth. Works on show include Raeburn's much-loved The Reverend

Robert Walker Skating on Duddingston Loch or, as it has become known, the 'Skating Minister'.

Special Exhibitions

The newly refurbished Royal Scottish Academy Building, in front of the National Gallery, re-opened in 2003 as a world-class venue for special temporary exhibitions. It has two floors of exhibition space, and connects to the Weston Link.

Congress Gala Dinner

Thursday, May 19, 2011

The Gala Dinner will be taking place at Prestonfield House Edinburgh.

The dinner will be a traditional Scottish event—including Caleigh dancing and the use of Scottish flavours throughout.



A Bit About Prestonfield

The lands of Prestonfield, or Priestfield, as the estate was known until the late 17th century, were ceded in medieval times to the Cistercian monastery at Harehope in Northumberland. Henry, Earl of Huntington—son of David I of Scotland, had founded this wealthy order in 1150. In 1376, after the bloody War of Independence, the order's Scottish lands were confiscated and given to the Earl of Carrick, son of King Robert II—who sold them to the wealthy and powerful Wardlaw family.

A Dutch garden, verdant lawns and parterres with all manner of statuary and fountains surround the house. The interiors were embellished with plasterwork by Italian artisans and tooled and gilded leather wall-coverings from Cordova in Spain, were

transferred to provide the décor for the principle bedchamber, now the atmospheric Leather Room.

Other rooms are filled with tapestries and fine furnishings such as the magnificent Chinoiserie lacquer cabinets.

Half a century ago, the house remembered its past reputation for hospitality, and opened as a hotel. Stars of the sixties, seventies and eighties delighted in its tranquil setting, its unique architecture, its handsome antiques and precious artworks. Sandie Shaw walked barefoot across the marble floor of the front hall. Winston Churchill and Margaret Thatcher each dined at Prestonfield under the watchful eyes of early Dick-Cunyngham family portraits. Sean Connery, Elton John and Catherine Zeta Jones all partied the night away. And Oliver Reed raised the hell for which he was so very well known.

Now, James Thomson, owner of Edinburgh's celebrated Witchery by the Castle and Tower restaurants, has breathed new life into the stately old pile following its acquisition. The patina of age has been gently lifted from the house and its treasures; its fading splendours have been sympathetically restored; its atmosphere transformed from one of faded grandeur to a new exuberance. It is ready to be rediscovered, once more Edinburgh's most handsome hotel in the city's most wonderful setting — once more, as William Burn noted over a century ago, "a picture of Arcadia." Today the Palace is used as a conference center and houses many halls — each more spectacular than the one before.

Prestonfield was transformed into the most hospitable and congenial of retreats and hotel guests enjoy the luxury of being surrounded by art and antiques, much bought and commissioned for the house centuries ago.

Guests at the MDS 2011 Gala Dinner will have the opportunity to wander between the rooms and other fine spaces of the grounds before descending into the breathtaking main hall for dinner, drinks, and of course some dancing!

III SIMPOSIO LATINOAMERICANO DE SÍNDROME MIELODISPLÁSICO

Third Latin American Myelodysplastic Syndromes Symposium

March 3-6, 2011 ● Catagena, Colombia

For more information, please call +1 (571) 6363890 or contact via e-mail at scho@etb.net.co/achoc@etb.net.co

Notable faculty will include:

Dr. Guillermo Garcia-Manero (USA), Dr. Mario Cazzola (Italy), Dr. Pierre Fenaux (France), Dr. Virginia Prates (Argentina), Dr. Carlos Vallejo (Spain), Dr. Aristoteles Giagounidis (Greece)



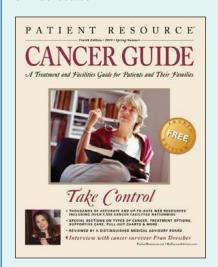
Sign Up for MDS Essentials E-News

The Foundation has created an 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

FREE... Patient Resource Cancer Guide

Patient Resource Cancer Guide was created to empower and prepare newly diagnosed and newly restaged cancer patients to become their own advocates.



It is a comprehensive resource, a tool to help map the cancer journey for these patients and their families.

Go to PatientResource.net to order your complimentary copy today or call (816) 333-3595, ext. 26.

MDS Foundation Nurse Advisory Board

MDS Mission for Global Nursing Education

The MDS Foundation Nurse Advisory Board (MDSF-NAB) was established in January 2008. Members include nursing experts representing MDS Centers of Excellence throughout the United States and Europe. The mission of the MDSF-NAB is to provide an international nursing forum for development of patient and nursing initiatives that promote excellence in the comprehensive care of the patient with bone marrow disorders.

The MDSF-NAB is an important component of the MDS Foundation with Tracey Iraca as the foundation liaison, Dr. Lewis Silverman as the medical advisor and Dr. Peter Greenberg as the liaison to the MDS Foundation Executive Committee and International Board. The United States co-chairs for the MDS-NAB are Erin Demakos, Sandy Kurtin, and Jean Ridgeway. Members include Jayshree Shah, Mary Thomas, Lenn Fechter, Ilene Galinsky, and Joan Latsko. European members represent 12 countries, including the United Kingdom, France, Germany, Italy, Greece, Spain, Sweden, Denmark and Scotland.

Since January of 2008 members of the board have been involved in a number of initiatives in support of patients, families, and health care providers. Facilitating patient and family forums throughout the United States and in Europe is one of the most important activities of the board. These forums provide an educational overview of MDS followed by open discussion with patient and their families. Physician leaders also participate in these sessions providing a scientific update followed by open discussion. More than 70+ patient forums have been held world-wide to date (42 in the US and 31 overseas).

Promoting excellence in nursing management of patients with bone marrow disorders (MDS, MPD, and AML) is a primary objective of the MDSF-NAB. In addition to

Facilitating patient and family forums throughout the United States and in Europe is one of the most important activities of the board.

presenting numerous local and regional educational sessions, the MDSF-NAB provides a satellite symposium each year at the annual Oncology Nursing Society Congress. The most recent ONS Congress held in San Diego, California in May 2010, included topics such as How Do We Integrate Scientific Information into Our Clinical Practice?, Strategies for Effective Management of Oral Medications, and Tools for Communicating Emerging Clinical Information to Colleagues and Patients. The next ONS Congress will be held in Boston. MA in April/May 2011. A session is planned with topics including: Advances in strategies for treatment of MDS and AML in the Elderly, Treatment Triggers and Supportive Care Strategies, and Quality of Life; What the patients tell us.

The European Nurse Advisory Board convened a meeting in conjunction with the MDS meeting held in Mandelieu, France, in October of 2009. The participants worked over a two day period to develop an educational slide set for educating nursing colleagues throughout Europe. Several of the EU members of the MDF-NAB together with US representatives will conduct nursing sessions to be held at the 11th International MDS Symposia in Edinburgh, Scotland in May 2011.

Additional activities of the board include review and revision of educational materials for patients and health care providers as well as collaboration with other agencies involved in the care of patients with bone marrow disorders. Board members have authored or co-authored over 80 peerreviewed publications pertaining to MDS, clinical trials, quality of life, supportive care and clinical management of patients with MDS and other bone marrow disorders.

International Patient Support Groups – We Need Your Help!

The MDS Foundation is embarking on a very exciting project in 2011 — Patient Support Groups Worldwide!

Patient Support Groups are an excellent resource in assisting MDS patients and their caregivers. Those groups in existence have been vital to educating public awareness of this disease and promoting and supporting scientific research into the treatment and care of patients with MDS. Unfortunately, only a few such local groups exist, mostly in the US and the UK, and a few European countries. There is a pressing need to establish such groups worldwide.

The Foundation has devoted selected members of its staff to establish and provide technical assistance to patient support groups outside of the United States in late 2010, with the goal of continuing this progress into 2011 and beyond.

By years end we will be reaching out to our International Centers of Excellence to request patient support needs specific to their geographical regions. International patient leaders and all healthcare professionals are also encouraged to forward patient support needs, specific to you and/or your geographical region, to the Foundation at patientliaison@mdsfoundation.org or 609-298-1035. We look forward to hearing from you!

Patient Forums and Support Groups

Patient Support Group Initiative

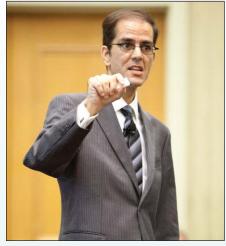
The MDS Foundation has developed a strategy for setting up patient groups nationwide and assistance is now available to organize support groups for MDS patients. At this time, we would like to enlist the help of our patient members in facilitating these member-run groups.

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.



Photos by Jesse Jones/University of Florida

Gainesville Patient and Family Forum Gainesville, Florida September 9, 2010

Dr. Christopher R. Cogle, University of Florida Shands Hospital, shares the latest advances in MDS research.



Jayshree Shah, Nurse Practioner at Hackensack University Hospital and member of the MDSF Nursing Advisory Board.



Group discussion with patients and caregivers.



Durham Patient and Family Forum Durham, North Carolina November 9, 2010

Dr. Carlos deCastro, Jayshree Shah, Audrey Hassan, and Veronica Taylor.



Patients and caregivers learn about the latest treatment options in MDS from Dr. Carlos M. deCastro, Duke University Medical Center.

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

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.
- Stanford Cancer Center MDS Patient & Family Support Group meets the 3rd Monday of the month, 6:30–8:00 pm at the Stanford Cancer Center, 875 Blake Wilbur Dr., Palo Alto, 2nd Floor Conference Room CC2105. Group Leader: Lenn Fechter, RN, BSN 650-725-0744.

CANADA

 Toronto, Ontario Support Group Contact William Pearson at william.pearson@sympatico.ca or call 905-561-6999 for information on upcoming meetings.

JAPAN

 Japanese Support Group Email: mdsrenraku@yahoo.co.jp for more information Website (only in Japanese): http://www.geocities.jp/mdsrenraku

EUROPE (Countryside Groups)

- France: Association Connaître et Combattre les Myélodysplasies
- United Kingdom: UK MDS Patient Forum
- Czech Republic: Czech Republic MDS Forum

Spreading the Word Worldwide – Patient and Caregiver Education Forums

FREE One-Day Conferences for MDS Patients and Their Families

Thank you to all who have attended our MDS Patient and Caregiver Conferences in 2010. Ongoing meetings in the US and Europe addressing quality of life issues for MDS patients will be planned for 2011. Learn the latest on the diagnosis and treatment of MDS from leading experts in the field. Complimentary breakfast and lunch. Please check our website and facebook for updates. We look forward to another successful year in 2011!

The Foundation serves as an effective educational conduit for information regarding the most updated treatment options, clinical studies, referrals to Centers of Excellence, and other information concerning the Myelodysplastic Syndromes. Patient forums have been held to date in:

UNITED STATES

- New York, New York (Oct 2004, Dec 2006)
- Tampa, Florida (Nov 2004)
- Palo Alto, California (Dec 2004, Oct 2010)
- Scottsdale, Arizona (Feb 2005)
- Chicago, Illinois (Mar 2005, July 2009, Oct 2010)
- Philadelphia, Pennsylvania
 (Dec 2005, Feb 2006, Apr 2007, Feb 2008, July 2009, Oct 2010)
- Pittsburgh, Pennsylvania (Feb 2006, Oct 2009)
- Oak Brook, Illinois (Jan 2007)
- Dallas, Texas (Jan 2007)
- Seattle, Washington (Mar 2007, Aug 2009)
- Covina, California (March 2007)
- Rochester, Minnesota (June 2007)
- Baltimore, Maryland (Sept 2007, June 2009)
- Rochester, New York (April 2008)
- Los Angeles, California (May 2008, Aug 2009)
- Scottsdale, Arizona (May 2008)
- San Antonio, Texas (Aug 2008, Sept 2009, Aug 2010)

- Atlanta, Georgia (Nov 2008)
- Columbia, South Carolina (Mar 2009)
- Bethesda, Maryland (Aug 2009)
- Birmingham, Alabama (Aug 2009)
- Hackensack, New Jersey (Sept 2009)
- Boston, Massachusetts (Nov 2009)
- Roslyn, New York (Dec 2009)
- Detroit, Michigan (July 2010)
- Gainesville, FL (Sept 2010)
- Durham, NC (Nov 2010)

CANADA

■ Toronto, Ontario (Oct 2009)

EUROPE

- Edinburgh, UK (March 2005)
- Paris, France (Jan 2006)
- Bournemouth, UK (Feb 2006, Nov 2009)
- London, UK (Feb 2006, Sept 2008)
- Hamburg, Germany (April 2006)
- Leeds, UK (May 2006, April 2009)
- Marseille, France (May 2006)
- Vienna, Austria (July 2006)

- Prague, Czech Republic (Sept 2006)
- Stockholm, Sweden (Sept 2006)
- Freiburg, Germany (Feb 2007)
- London, UK (May 2007)
- Florence, Italy (May 2007)
- Dubrovnik, Croatia (Sept 2007)
- Sinaia, Romania (October 2007)
- Toulouse, France (May 2008)
- Copenhagen, Denmark (June 2008)
- Lund, Sweden (Sept 2008)
- Ontario, Canada (Sept 2009)
- Tel Aviv, Israel (Jan 2009)
- Frankfurt, Germany (Mar 2009)
- Stockholm, Sweden (April 2009)
- Patras, Greece (May 2009)
- Berlin, Germany (June 2009)
- Cambridge, UK (Nov 2009)
- Glasgow, UK (April 2010)

SOUTH AMERICA

Buenos Aires, Argentina (Nov 2008)

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!



About the Foundation

Who Are We?

The Myelodysplastic Syndromes Foundation, Inc., was established in 1994 by an international group of physicians and researchers to provide education about MDS to physicians and patients, support for MDS research, patient support, and advocacy.

During the past decade, we have independently solicited funding for ten international symposia that have been attended by over 7,000 individuals—physicians and patients. These symposia are held biannually and have greatly improved our knowledge of these disorders as we continue to provide physicians worldwide with the most up-to-date information on research in MDS. The 10th International Symposium was held in Patras, Greece May 6–9, 2009.

At the Third International MDS meeting, attended by epidemiologists, pediatricians (yes, this does occur in children), pathologists, hematologists, oncologists, and bone marrow transplantation experts, a survey indicated a very strong interest in, and a great need for, developing a permanent working group of scientists and patient advocates. Up until that time, no formal working group was devoted to these syndromes. The MDS Foundation was born.

What Does the Foundation Do?

The Foundation works to maintain an international information network to share new research and new treatment options as rapidly as possible, to provide information and educational support for both physicians and patients, and, ultimately, to provide funding and oversight for international studies of MDS. Currently the Foundation supplies patients, physicians, and other interested parties with information in the form of a quarterly newsletter, the MDS News, and

MDS Essentials, our e-newsletter. The Foundation's website includes patient and physician information. Our web address is http://www.mds-foundation.org.

The Centers of Excellence Program designates institutions that meet the highest standards for diagnosis, treatment, and patient care. These Centers form the referral base for patients seeking first or second opinions and/or additional treatment options from experts in MDS. The Foundation provides patients with a priority referral to any Center of Excellence.

Patient advocacy groups are being formed worldwide, and information is available that assists MDS patients and their loved ones in understanding these diseases and the treatment options that are available.

How Can You Help?

Funding for the Foundation comes from pharmaceutical companies, Foundation memberships, memorials, and donations from private individuals. While we have come a long way in the 15+ years since the Foundation was established we have a long way to go. Funding is the base for realizing the Foundation's research and education goals.

The MDS Foundation is a publicly supported not-for-profit organization, exempt from federal income tax under section 501(c)(3) of the IRS code.

How Can We Help You?

Please do not hesitate to contact the Foundation if you have any questions.

MDS Headquarters:

4573 South Broad Street, Suite 150 Yardville, NJ 08620

Within the US: 1-800-MDS-0839 Outside the US: 609-298-1035

Fax: 609-298-0590 www.mds-foundation.org

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

MDS Patients Share Their 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 TORONTO, CANADA

My Story...

Mark Rutherford

Who Gets Cancer? Why Me?

Before cancer and I became personally acquainted, I used to pretty much agree when anyone suggested that people became susceptible to the disease by constant lifestyle choices; by avoidance of all the good things—healthy eating, fresh air, and exercise—which are acknowledged to keep the wasting wolf away from your door.

Not that I would now disagree with that, but at least I intrinsically understand now that there are no guarantees. Taking a look at my history in this regard will explain why, in light of the above, I was in denial even some months after diagnosis.

Long-term athletic activities from a young age included:

- 1. League hockey: Ages 6–19.
- Skied seasonally from age 6-22 (downhill); age 28 to the present (crosscountry), increasing intensity over time to Canadian Ski Marathon (160 km) 3 × and Gatineau Loppet (100 km) 1× in the last 5 years.
- 3. Cycled competitively in my late teens; touring 8000 km Europe, 5000 km Canada in the '70s; sporadically thru '80s; back into it in the '90s to the present with regular training, and completing at least 10 century (100 miles) competitive rides in Canada and US in the interim.
- 4. Running: I started regular daily or at least 2× weekly 6–10 km from my early 30's

- to 2009. I did this all year round, year after year.
- 5. Yoga: I began dabbling in yoga from my early 20's. Over the years, the intensity of my approach had fluctuated, but rarely over the past 35 years had I let it slide for more than a couple of months at a time. At points I had been very flexible and strong as a result, which always felt great

After a period of some transition after being 'terminated' from my long-time sales job with *Auto Trader* in December 2007 (after *Yellow Pages* bought *Trader*), I put focus over the next year on developing my music career. I was involved in some great projects but unfortunately produced little money. I also increased my skiing activity in 2008–09 to a level where I was training 20–40 km/day and never felt stronger. Then when I started working with *Wheels* in June 2009, my fitness and healthy lifestyle was interrupted by the following:

- 1. Wheels was a startup with performance bonuses, so I needed to focus on making that happen.
- 2. All the work I had been doing for the past year to re-energize my music career started bearing fruit. I became super busy, averaging 4 jobs/week on top of my regular workday with *Wheels*.
- 3. I had a hernia slowly developing over the past 15 years that finally started to bug me. By the time I started with *Wheels* in May 2009, I really could not run or do yoga. Biking was even uncomfortable.
- 4. Though I had stopped drinking alcohol on Valentines Day 2009, my busy schedule did not encourage a regular healthy diet. That has always seemed to be best accomplished by home cooking. On the road all the time I drank more coffee, and ate more stuff like muffins and baking. Though I never got into real road food—fast, fried stuff like burgers etc.—I did eat a lot of restaurant food, deli sandwiches etc.

I obviously can't speak for anyone else here, but was there a correlation between the development of my cancer and my recent change in lifestyle? Luckily, I had a blood test in September of 2009 that was normal on all counts. Two months later I was severely anemic in the initial stages of MDS (pre-leukemia). It is ironic how that was discovered in November. I had booked myself into the Shouldice Clinic to get my hernia done by specialists. On a routine CBC (blood test) they discovered my anemia, and refused to do my hernia. In most cases anemia associated with MDS occurs very slowly—often over a 10 year period. My case had the doctors scratching their heads. Later my oncologist suggested to me that I had a very aggressive malignancy when my MDS progressed to AML (acute myeloid leukemia) in such a brief time—from late July to mid August.

Diagnosis of MDS was suggested by early December and confirmed by mid-January by the result of a cytogenetic study which confirmed chromosome abnormalities associated with MDS. From late November I received red blood cell transfusions twice weekly until April 15. I became a vampire, realizing quickly that without those transfusions I would soon be 6 feet under. Then in the beginning of March I spoke with Dr. Nay about the new drug called azacitidine-5. Many MDS patients were having success with it and it was just on the scene — officially recognized in Canada only months before. We agreed that I would get on the access program (so it didn't cost me \$6G/mo) and start it right away. The trade name for this drug is Vidaza. Of course Heather and I jokingly referred to it as the V-drug... which always got a few laughs. The drawback with Vidaza is that you often had to wait 6 months before it was effective. The good news was that for me it was effective in 5 weeks, and I was off transfusions by April 15th. I was even able to get my hernia repaired and life became almost normal for a few months. But then the bad news 4 months later was that it had lost it's effectiveness and my MDS transformed to AML. Oh well, you roll with the punches...

Patient Tributes

Keeping My Mother's Memory Alive...

Paul Wenzel, Jr. Wakefield, MA

My mother, Karen Wenzel, was diagnosed with Myelodysplastic Syndromes in February of 2006. At the time I had never heard of MDS. It was described to us as a pre form of leukemia. My mother was my world! I remember when I was 10 years old my grandfather on my mom's side passed away. There were nights after his passing when I would lay in bed unable to fall asleep because I wondered what I would do if I ever lost my mother. It scared me so much!

On June 19th, 2006, only 4 months after my mother was diagnosed, and only 6 weeks after we celebrated her 50th birthday, my fear became a reality. I will never forget that morning for the rest of my life. I got a call from one of the doctors at Massachusetts General Hospital in Boston telling me that her heart had stopped, and I better come in. This was the third time in a week that this had happened. Up until the phone rang that morning, myself and my family all thought she was going to be okay and pull through. I drove to the hospital that morning and did the hardest thing I have ever had to do — and probably ever will do in my life. I had to say goodbye to the person I loved the most in this world!

Mom had been diagnosed with breast cancer about 4 years prior to her MDS diagnosis, and to this day my family still believes the radiation treatment she was administered had something to do with her getting MDS. Unfortunately, there is no way of knowing for sure.

Since Mom's passing I have held 3 golf tournaments in her memory, raising over \$10,000 for MDS research. I also ran a half marathon in 2007, and competed in a triathlon in 2009 with the Leukemia & Lymphoma Society. This is my way of trying to help by raising funds—as little as it might be—to someday find a cure for MDS

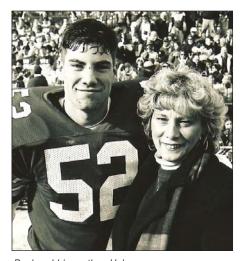


The Wenzel Family (left to right): Paul, Kristine, Helen, and Paul Jr.

and other blood related diseases. Mostly though, it's to keep the memory of my mother alive. It helps me to cope. When I would train for the marathon and triathlon I would constantly ask my mother to help me finish that last mile, or make sure I didn't drown. Putting together the golf tournaments each summer gives me the chance to talk about her, and remember all the good times we had together. We have a wonderful group of family and friends that come out each year to support MDS and to remember what a wonderful person my mother was. I love her and miss her everyday!



Paul (second from right) and his foursome at the annual Wenzel Memorial Golf Tournament.



Paul and his mother, Helen.



Third Annual Karen A. Wenzel Memorial Golf Tournament. 2010.

For Caregivers...

REPRINTED FROM THE MDS BEACON

Caring For A Loved One With Myelodysplastic Syndromes: Attending Doctor Appointments

Gillian Losh

For many caregivers, visiting the doctor's office can be one of the most daunting aspects of caring for a loved one with myelodysplastic syndromes (MDS). However, it is also one of the most important jobs you can do as a caregiver. With MDS, two heads are better than one when it comes to asking questions, making sure all possible treatment options are being pursued, and remembering what the doctor said after the appointment.

In some cases, the physical fight with MDS can leave a loved one too exhausted to fully focus on medical details. Making the most of every visit with the doctor can therefore become a caregiver's responsibility.

Be Prepared

Anticipation and preparation can often be the key to a successful medical visit, which means knowing exactly where to go, who to see, why the visit is taking place, and what needs to get done at the appointment.

It may be helpful to keep a notebook at home in which you can write information and questions that you want to remember for the next medical appointment.

Keep track of all medications and dosages, as well as a schedule of treatments, transfusions, or other supportive care. It may be helpful to write everything down, or to bring medication containers to appointments.

Record all symptoms and side effects, specifically those that are new or changing, or that the doctor mentioned previously. Although it is a doctor's responsibility to always ask about symptoms, if you or your loved one do not mention a symptom,

then the doctor cannot know about it or do anything about it.

Stay vigilant about pain management. It is important to remember that in this day and age, your loved one does not need to suffer through pain because there are many ways to manage it. By asking the doctor for ways to manage the pain, your loved one can focus on healing or enjoy a better quality of life. A doctor should always ask about pain levels, but it is both you and your love one's job during an office visit to keep the doctor aware of any and all aches and pains.

Keep a running list of questions for the physician. This way, you will not forget your questions when you are at the appointment. It can be very frustrating to leave the doctor's office and realize that you forgot to ask a question.

In addition, collecting and organizing a patient's medical information to bring to doctor appointments can help you and your loved one feel more in control of your loved one's medical future. Writing down all questions, concerns, and anything else the doctor should know beforehand also ensures that no one loses track of what they want to accomplish at a doctor visit.

It Is Normal To Be Confused

At any doctor appointment about MDS, there will most likely be a lot of information to absorb. Therefore, it is important to take notes, use a recorder, or otherwise ensure that all information given by the doctor can be remembered, understood, and utilized.

Your primary role as a caregiver at a medical appointment is to make sure that everything surrounding your loved one's illness is clearly understood or documented so that you can research it when you get home. If you do not understand something, ask the physician to clarify. If a doctor cannot answer questions or concerns to you or your loved one's satisfaction, ask for other resources to find these answers. You should not give up until both you and your loved one are satisfied with your understanding of the details concerning your loved one's MDS and treatment.

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: 609-298-1035

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

Know What To Ask

The best way to make sure that you get all the information you and your loved one need to know is to plan what questions to ask beforehand, especially if the appointment is the first following diagnosis. Some key questions to remember include:

- What subtype of MDS does he or she have?
- How severe is the MDS?
- Will he/she need more tests?
- What is his/her prognosis?
- What is his/her risk of progressing to leukemia?
- What are the treatment options?
- Can any treatments cure his/her myelodysplastic syndrome?
- Which treatment would be the best for him/her? Why?
- How will he/she know that the treatment is working? How long will it take to start working, and will it ease his/her symptoms?

- Is the treatment new or experimental, or is it well-tested?
- What are the potential side effects of each treatment? How long will they last?
- Are there any trials you would recommend? Why?
- How much will treatment cost? Will insurance cover it?
- He/she has other health conditions. How can he/she best manage them together?
- Are there any diet or health restrictions that he/she needs to follow?
- Are there any brochures or other printed material that we can take? What websites do you recommend?

Additionally, you can also ask questions specific to your role as a caregiver, such as:

- Are there any symptoms I should keep track of?
- How can I help my loved one prepare for treatment?

- What side effects of treatment should I watch for?
- How can I help my loved one feel better during and between treatments?
- Can I be there during treatment?

Be An Advocate For Your Loved One

Above all, it is important for you to be an outspoken advocate as your loved one battles MDS. At no time is this more necessary than when dealing with medical and health care professionals.

Diagnosis was probably the first time you heard the words "myelodysplastic syndromes." By finding the best MDS specialists or health care teams in your area and investigating MDS treatments, trials, and developments online or through health care professionals, you can help give your loved one the edge over MDS.

Helping your loved one through doctor visits is one of the most important ways you can show your loved one that you are there to make sure he or she does not have to face MDS alone.

For more information about caring for a loved one with MDS, please see The MDS Beacon's additional resources on the topic, which include articles about making your own health a priority, coping with your feelings of loss and grief, and understanding your loved one's perspective.

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The MDS Beacon is an online service provided by Light Knowledge Resources, an independent Internet publishing company based in Princeton, New Jersey. The Beacon provides objective and unbiased news and other information related to myelodysplastic syndromes for MDS patients, their families, and others interested in MDS. http://www.mdsbeacon.com

Patient Services

Air Transportation Options for Patients

Angels Donate Frequent Flyer Miles

The need for charitable airline tickets for patients traveling to distant specialized medical evaluation, diagnosis or treatment continues to grow.



During the previous year, programs administered by *Mercy Medical Airlift* provided almost 10,000 free airline tickets to financially-stressed patients, but many more were required. Unfortunately, resources to assist all were not available.

Help patients in need of distant transportation by donating Frequent Flyer Miles and make a difference in the life of a patient requiring distant specialized treatment. For further information go to http://www.donatefrequentflyermiles.org.



Angel Flight – For Those in Need

Air transportation resources may be available for patients considering travel to one of the participating sites that are part of the NIH Rare Diseases.

Angel Flight at NIH provides air transportation for patients who are in financial need and cannot afford the cost of air travel. The Angel Flight at NIH program is administered by **Mercy Medical Airlift**.

If you are interested in finding out if Angel Flight meets your air transportation needs, contact Marita Eddy at 301-451-9646 or email meddy@mail.nih.gov or check www.angelflightatnih.org.

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.



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
- Recognized morphologic expertise in MDS
- Available cytogenetics and/or molecular genetics
- 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

ARIZONA

Mayo Clinic Hospital

Phoenix, Arizona Ruben Mesa, MD/James 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

IICLA 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 Casey L. O'Connell, MD

FLORIDA

All Children's Hospital

St. Petersburg, Florida Gregory Hale, MD

Mayo Clinic

Jacksonville, Florida Alvaro Moreno-Aspitia, MD

University of Florida Shands Hospital

Gainesville, Florida Christopher R. Cogle, MD

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

Tampa, Florida Alan F. List, MD

GEORGIA

Emory Winship Cancer Institute Emory University School of Medicine

Atlanta, Georgia Amelia Langston, MD

The Blood and Marrow Transplant Program at Northside Hospital

Atlanta, Georgia Asad Bashey, 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 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 David P. Steensma, MD Richard M. Stone. MD

Tufts University School of Medicine

Tufts Medical Center

Boston, Massachusetts Kellie Sprague, MD

MICHIGAN

Barbara Ann Karmanos Cancer Institute

Wavne State University

Detroit, Michigan Charles A. Schiffer, MD

William Beaumont Hospital **Cancer Center**

Royal Oak, Michigan Ishmael Jaiyesimi, MD

MINNESOTA

Mayo Clinic

Rochester, Minnesota Mark R. Litzow, MD

University of Minnesota

Medical Center

Fairview University of Minnesota

Medical School

Minneapolis, Minnesota Erica D. Warlick, 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

Columbia University Medical Center

New York. New York Azra Raza, 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 James E. Thompson, 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 Jaroslaw Maciejewski, MD, PhD

PENNSYLVANIA

The Western Pennsylvania Cancer Institute

Pittsburgh, Pennsylvania 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

Vanderbilt University Medical Center

Nashville, Tennessee Madan Jagasia, MD Stephen Strickland, MD

TEXAS

Cancer Care Centers of South Texas

San Antonio, Texas Roger Lyons, MD

Cancer Therapy & Research Center Institute for Drug Development

San Antonio, Texas Swaminathan Padmanabhan, MD

Southwest Regional Cancer Center

Austin, Texas
Richard Helmer, III, MD

University of Texas MD Anderson Cancer Center

Houston, Texas Guillermo Garcia-Manero, MD Hagop Kantarjian, MD

WASHINGTON

Fred Hutchinson Cancer Research Center University of Washington Seattle Cancer Care Alliance

Seattle, Washington Joachim Deeg, MD/Elihu Estey, MD

WASHINGTON, DC

Georgetown University Hospital Lombardi Comprehensive Cancer Center

Washington, D.C. Catherine Broome, MD Khaled El-Shami, MD, PhD

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

AFRICA

Constantiaberg Medi-Clinic Stellenbosch University and Tygerberg Academic Hospital

Cape Town, South Africa Peter Jacobs, MD, PhD

Hôpital Aziza Othmana

Tunis, Tunisia Balkis Meddeb, MD

University of Cape Town Groote Schuur Hospital

Cape Town, South Africa Nicolas Novitzky, MD, PhD

ARGENTINA

Sanatorio Guemes Buenos Aires University

Buenos Aires, Argentina Marcelo lastrebner, MD

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

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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

Hemocentro da UNICAMP

University of Campinas Campinas, Brazil Irene Lorand-Metze, MD

Servico de Hematologia do Hospital das Clinicas da Faculdade de Medicina da Universidade de São Paulo

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Ceará, Brazil Silvia Maria M. Magalhães, MD, PhD

Universidade Federal de São Paulo

São Paulo, Brazil Maria de Lourdes Chauffaille, MD. PhD

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Toronto, Ontario, Canada Karen Yee, MD

Toronto Sunnybrook Regional Cancer Centre

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University of Toronto Hospital for Sick Children

Toronto, Ontario, Canada Yigal Dror, MD

CHINA

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Odense, Denmark Gitte Birk Kerndrup, MD

Rigshospitalet National University Hospital

Copenhagen, Denmark Lars Kjeldsen, MD, PhD

University of Århus The University Hospital

Århus, Denmark Mette Skov Holm, MD, PhD

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Nancy, France Agnés Guerci-Bresler, MD, PhD

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Johann Wolfgang Goethe Universität

Frankfurt Main, Germany Gesine Bug, MD

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St. Johannes Hospital Heinrich-Heine Universität

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Budapest, Hungary Judit Várkonyi, MD, PhD

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Tata Memorial Hospital

Mumbai, India Purvish Parikh, MD

IRELAND

Adelaide and Meath Hospital

Dublin, Ireland Helen Enright, MD

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Tel-Aviv, Israel

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Istituto di Ematologia Universita' Cattolica Sacro Cuore

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University Tor Vergata Ospedale S. Eugenio

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Kyoto, Japan Takashi Uchiyama, MD

Nagasaki University Hospital School of Medicine

Atomic Bomb Disease Institute

Nagasaki City, Japan Masao Tomonaga, MD

Nippon Medical School

Tokyo, Japan Kiyoyuki Ogata, MD, PhD

Saitama International Medical Center

Saitama Medical University

Saitama, Japan Akira Matsuda, MD

Tokyo Medical College

Tokyo, Japan *Kazuma Ohyashiki, MD*

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Seoul National University Hospital Seoul National University College of Medicine

Seoul, Korea

Dong Soon Lee, MD, PhD

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Nijmegen, The Netherlands Theo J.M. de Witte, MD, PhD

Vrije Universiteit Medical Center

Amsterdam, The Netherlands Gert J. Ossenkoppele, MD, PhD

ΡΟΙ ΔΝΙΠ

Jagiellonian University Collegium Medicum

Kraków, Poland Aleksander Skotnicki, MD, PhD

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Hospital de Santa Maria

Lisbon, Portugal Joao F. Lacerda, MD

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King Faisal Specialist Hospital & Research Centre

Riyadh, Saudi Arabia Mahmoud Deeb Aljurf, MD

King Khaled University Hospital King Saud University

Riyadh, Saudi Arabia Ak Almomen, MD

SINGAPORE

Singapore General Hospital

Singapore Lay-Cheng Lim, MD

SPAIN

Hospital Universitario de Salamanca

Salamanca, Spain Consuelo del Cañizo, MD. PhD

Hospital Universitario La Fe

Valencia, Spain Miguel A. Sanz, MD, PhD

Hospital Universitario, Vall d'Hebron Laboratorio del Citologia-Citogénetica

Barcelona, Spain

Maria Teresa Vallespi-Sole, MD, PhD

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Karolinska Institutet Huddinge University Hospital

Stockholm, Sweden

Eva Hellström-Lindberg, MD, PhD

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National Taiwan University Hospital

Taipei, Taiwan Hwei-Fang Tien, MD, PhD

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King Chulalongkorn Memorial Hospital

Pathumwan, Bangkok, Thailand *Tanin Intragumtornchai, MD*

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Ankara University School of Medicine Hospital

Ankara, Turkey Osman Ilhan, MD

UKRAINE

Research Center for Radiation Medicine

Kiev, Ukraine Dimitry Bazyka, MD

UNITED KINGDOM

King's College Hospital University of London

London, England Ghulam J. Mufti, MD

Leeds General Infirmary The Leeds Teaching Hospitals

Leeds, England

David T. Bowen, MD

Addenbrookes Hospital Cambridge University Hospitals NHS Foundation Trust

Cambridge, England

Alan J. Warren. PhD. FRCP. FRCPath

Queen Elizabeth Hospital University Hospital Birmingham NHS Trust

Birmingham, England Charles Craddock, MD

Radcliffe Hospitals and University of Oxford

Oxford, England Paresh Vyas, MD

Royal Bournemouth Hospital

Bournemouth, England Sally Killick, MD

Aberdeen Royal Infirmary Aberdeen University School of Medicine

Foresterhill, Aberdeen, Scotland Dominic Culligan, MD

University Hospital of Wales

Cardiff, Wales Jonathan Kell, 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.cancer.gov. This information includes basic study information, study lead organizations, study sites, and contact information. To access the information:

- Log on to www.cancer.gov
- 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. For telephone support, call the National Cancer Institute at 1-800-4-CANCER.

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.

Clinical Research Trial with Eltrombopag – Now Open for Accrual

PMA112509

We would like to announce a clinical trial for patients with advanced Myelodysplastic Syndrome (MDS) or secondary Acute Myeloid Leukemia after MDS (sAML/MDS), or de novo AML who have associated thrombocytopenia (low platelet counts).

The Myelodysplastic Syndromes Foundation is assisting in the accrual of patients for **Clinical Trial PMA112509**. The purpose of this phase I/II placebo-controlled study is to test the safety of eltrombopag in patients with low platelet counts due to MDS, sAML/MDS, or de novo AML, and also to see how well eltrombopag may work at different doses in this patient population.

Eltrombopag is an orally available, small molecule thrombopoietin receptor agonist that is approved as a treatment for chronic immune (idiopathic) thrombocytopenic purpura (ITP) to increase platelet counts. The present study is designed to evaluate the safety and

tolerability of eltrombopag, administered as oral tablets once daily in adult thrombocytopenic subjects with advanced MDS, sAML/MDS, or de novo AML.

In an effort to move the clinical development of eltrombopag for the treatment of MDS, sAML/MDS, or de novo AML forward as rapidly as possible, the Foundation would appreciate hearing from you.

If you are a physician and would like to refer a patient for enrollment into this clinical trial *or* if you are an MDS patient who has low platelet counts, please contact The MDS Foundation at 1-800-MDS-0839.

PMA112509 Clinical Trial Site List (at date of publication)

UNITED STATES

Albert Einstein Cancer Center at the Montefiore Medical Park

Bronx, NY, Amit Verma, MD

The West Clinic

Memphis, TN, Bradley Somer, MD

Washington University School of Medicine

St. Louis. MO. Camille Abboud, MD

Henry Ford Health System,

Detroit, MI, Ding Wang, MD

FLORA Research AssociatesLake Worth, FL. *Gracv Joshua. MD*

The University of Texas
MD Anderson Cancer Center

Houston, TX, Hagop Kantarjian, MD

Fairfax Northern Virginia Hematology Oncology

Fairfax, VA, John Feigert, MD

Tufts Medical Center

Boston, MA. Kenneth Miller, MD

Abramson Cancer Center of the University of Pennsylvania

Philadelphia, PA, Noelle Frey, MD

Stanford University Cancer Center Stanford, CA, *Peter Greenberg, MD*

Cancer Care Centers of South Texas

San Antonio, TX, Roger Lyons, MD

Veteran Affairs Medical Center

Kansas City, MO, Suman Kambhampati, MD

Announcing New Clinical Trial

NAME OF INSTITUTION:

Novartis Pharmaceuticals

TRIAL NUMBER: NCT00940602

Title of Trial or Description:

Myelodysplastic Syndromes (MDS) Event Free Survival With Iron Chelation Therapy Study (TELESTO)

A Multi-center, Randomized, Doubleblind, Placebo-controlled Clinical Trial of Deferasirox in Patients With Myelodysplastic Syndromes (Low/ Int-1 Risk) and Transfusional Iron Overload

Currently Recruiting Participants.

The primary purpose of this study is to prospectively assess the efficacy and safety of iron chelation therapy with deferasirox compared to placebo in patients with myelodysplastic syndromes (low/int-1 risk) and transfusional iron overload.

Contact the Novartis Clinical Trials Hotline at 800-340-6843 or go to www.clinicaltrials.gov for additional information and to view the active sites.

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: www.mds-foundation.org Email: uspatientliaison@mds-foundation.org or call 800-MDS-0839 and the current clinical trials will be sent to you.

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.

Online Search Tool for Clinical Trials



TrialCheck Coalition of Cancer Cooperative Groups

TrialCheck is another online search tool that helps you gather information about cancer clinical trials to discuss with your doctor. This user-friendly tool allows you to search for trials according to your type of cancer and according to your zip code. This will help you locate physicians and hospitals near your home that offer trials.

TrialCheck searching is based on nine simple questions. Depending upon the answers you provide, TrialCheck generates a list of trials in which you may be eligible to enroll.

www.CancerTrialsHelp.org

BONE MARROW TRANSPLANTATION

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:

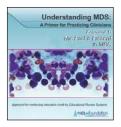
http://bloodcell.transplant.hrsa.gov

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.

Educational Resources

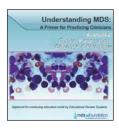
Understanding MDS: A Primer for Practicing Clinicians

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, & 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/\$168.00** 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)

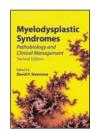
Edited by:

Azra Raza, MD; Suneel D. Mundle, PhD

June 2001/278 pp., illus. ISBN: 0792373660/\$228.00** Springer Press

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."



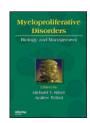
Myelodysplastic Syndromes, Second Edition: Pathobiology and Clinical Management (Basic and Clinical Oncology)

Edited by:

David P. Steensma, MD

November 2008/536 pp., illus. ISBN: 978-01420074390/\$250.00** 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:

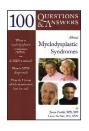
Richard T. Silver, MD; Ayalew Tefferi, MD

October 2007/240 pp., illus. ISBN: 9781420061628/\$200.00** Informa HealthCare

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
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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.

To order, call the MDS Foundation: 1-800-MDS-0839

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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.

EPIDEMIOLOGY:

- Lindquist KJ et al. Health care utilization and mortality among elderly patients with myelodysplastic syndromes. *Ann Oncol.* 2010, Nov 1 [Epub ahead of print].
 - Among 1864 MDS patients studied from the SEER registry, 3 yr incidence of anemia, neutropenia and thrombocytopenia was 81%, 25% and 41% respectively with a median survival of 22 months.
- Maynadié M et al. Twenty-five years of epidemiological data on myeloid malignancies: data from the specialized registry of hematological malignancies of Cote d' Or (Burgundy, France). Haematologica. 2010, Oct 22 [Epub ahead of print].
 - This French registry has demonstrated incidence/median survival rates per 100,000 inhabitants per year of 2.5/8.9 mo for AML, 1.3/33.8 mo for MDS and 3.2/91.7 mo for Myeloproliferative neoplasms.

TREATMENT:

Growth Factors:

 Sekeres MA et al. Subcutaneous or intravenous administration of romiplostim in thrombocytopenic patients with lower risk myelodysplastic syndromes. *Cancer*. 2010, Oct 13 [Epub ahead of print].

This Ph II multicenter, open label study with thrombocytopenic low risk MDS patients (n=28) treated with romiplostim at 750 µg demonstrated complete platelet response of 57% among those completing 8 weeks treatment with 61% requiring no platelet transfusion during treatment. Most common adverse events were fatique and headache.

IMiDs:

1. Tehrarchi R et al. Persistent malignant stem cells in del(5q) myelodysplasia in remission. *N Engl J Med.* 2010;363(11): 1025–1037.

The study showed persistence of a fraction of CD34+, CD38-/low, CD90+ cells with del 5q even after CR with lenalidomide and their expansion with recurrence of the disease.

Demethylating Agents:

- Itzykson R et al. Prognostic factors of response and overall survival in 282 higher-risk myelodysplastic syndromes treated with azacitidine. *Blood*. 2010, Oct 12 [Epub ahead of print].
 - The study included 282 patients treated with azacitidine under compassionate access program. Prior low dose aract treatment, marrow blasts >15% and abnormal karyotype were independent predictors of poor response and additionally high transfusion requirement predicted poor OS.
- 2. Fenaux P et al. Practical Use of azacitidine in higher-risk myelodysplastic syndromes: an expert panel opinion. *Leuk Res.* 2010;34(11):1410–1416.
 - In this article, a European panel of clinical experts provides practical guide on the use of azacitidine in high risk MDS and AML patients.
- 3. Götze K et al. Azacitidine for treatment of patients with myelodysplastic syndromes (MDS): Practical recommendations of the German MDS study group. *Ann Hematol.* 2010;89(9):841–850.
 - In this article, a German MDS study group experts provide practical guide for the use of azacitidine and management of common side effects in MDS patients.
- Jabbour E et al. Outcome of patients with myelodysplastic syndrome after failure of decitabine therapy. *Cancer*. 2010;116(16): 3830–3834.

A review of 67 MDS and 20 CMML patients with a median follow up of 21 mo revealed poor survival subsequent to a failure on decitabine therapy (median OS-4.3 mo).

^{**}All prices are in US dollars.

Iron Overload Management Therapies:

 Gatterman N et al. Deferasirox in ironoverloaded patients with transfusiondependent myelodysplastic syndromes: Results from the large 1-year EPIC study. Leuk Res. 2010;34(9):1143-1150.

This prospective 1 year study of 341 MDS patients with baseline iron burden of >2500 ng/mL showed significant decrease in median serum ferritin levels irrespective of patient's prior iron-chelation status. A significant decrease in alanine aminotransferase correlated with the decrease in serum ferritin.

Combination Regimens:

 Jabbour E et al. A Phase 1-2 study of a farnesyltransferase inhibitor, tipifarnib, combined with idarubicin and cytarabine for patients with newly diagnosed acute myeloid leukemia and high-risk myelodysplastic syndromes. *Cancer*. 2010; Oct 19 [Epub ahead of print].

Tipifarnib was administered with idarubicin and cytarabine at 200 mg po bid to first 6 patients at and at 300 mg po bid for the rest for 21 days in induction course followed by 300 mg po bid for 14 days in 5 consolidation 28 day courses with the same combination and then subsequently as a single agent maintenance at 300 mg po bid for 21 days every 4–6 weeks. With a median follow up of 33 months, 61 patients evaluated showed 64% CR rate and median OS of 17 months.

 lastrebner M et al. Decitabine in myelodysplastic syndromes and chronic myelomonocytic leukemia: Argentinian/ South Korean multi-institutional clinical experience. *Leuk Lymphoma*. 2010, Oct 7 [Epub ahead of print].

Decitabine was administered at 20 mg/ $m^2 \times 5$ days in a 4 week cycle. CR was observed in 19% and OS at 2 years was 71%. Treatment related adverse events included febrile neutropenia, thrombocytopenia/bleeding, asthenia, fatigue and eosinophilia.

New Agents/Therapies:

 Fischer T et al. Phase IIB trial of oral Midostaurin (PKC412), the FMS-like tyrosine kinase 3 receptor (FLT3) and multitargeted kinase inhibitor, in patients with acute myeloid leukemia and highrisk myelodysplastic syndrome with either wild-type or mutated FLT3. *J Clin Oncol*. 2010;28(28):4339–4345.

AML/high-risk MDS patients with wild type (n=60) or mutated FLT-3 (n=35) were randomized to receive 50 or 100 mg po bid midostaurin. A higher percentage of patients with mutated FLT3 (71%) showed $\geq 50\%$ reduction in bone marrow blasts as compared to those with a wild type gene (42%).

Cripe LD et al. Zosuquidar, a novel modulator of P-glycoprotein, does not improve the outcome of older patients with newly diagnosed acute myeloid leukemia: a randomized, placebocontrolled trial of the Eastern Cooperative Oncology Group (ECOG 3999). *Blood*. 2010, Aug 17 [Epub ahead of print].

The study involved 449 AML/high-risk MDS patients. Patients receiving combination of cytarabine + daunorubicin were randomized 1:1 to 550 mg Zosuquidar vs. placebo. Consolidation consisted of intermediate dose of cytarabine followed by second induction. Median OS-7.2 mo vs. 9.4 mo, 2-yr survival-20% vs. 23% on study drug vs placebo. The study concluded that Zosuquidar may not be effective due to presence of P-glycoprotein independent resistance mechanisms.

PATHOBIOLOGY:

 Li X et al. The helix-loop-helix transcription factor TWIST is dysregulated in myelodysplastic syndromes. *Blood*. 2010; 116(13):2304–2314.

The study showed elevated expression of TWIST in CD34+ cells of patients with high grade MDS and downregulation of TWIST by co-culturing with stroma or with interference RNA, increased their susceptibility to TNF-induced apoptosis.

- 2. Schroeder T et al. Distinguishing myelodysplastic syndromes (MDS) from idiopathic cytopenia of undetermined significance (ICUS): HUMARA unravels clonality in a subgroup of patients. *Ann Oncol.* 2010;21(11):2267–2271.
 - Out of the 23 ICUS patients eligible for HUMARA, 6 showed clonal patterns and 2 of these 6 developed AML, while none of the 17 patients without the clonal patterns developed AML.
- 3. Diamantidis MD et al. High prevalence of *Helicobacter pylori* infection in Greek patients with myelodysplastic syndromes. *Acta Haematol.* 2010;124(3):141–149. *MDS patients (n=73) and control subjects (n=40) were evaluated using serologic, histologic and urease breath tests for* H. Pylori *antigen Hp-I with a positivity rate of 75%, 80% and 58% respectively in MDS patients. Clinical significance of this finding needs further investigation.*

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.

MDS Foundation Publications

MDS Handbooks Now Available in Multiple Languages

Understanding Myelodysplastic Syndromes: A Patient Handbook



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- It Takes Time to Realize Your Goals
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- 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

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

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Thank You!

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Every penny helps. All donations are tax-deductible.

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Thank you for your support.

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Loveland, OH

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

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Donations have been made in Mr. Greenberg's memory by: Susan Taubes, *Teaneck*, *NJ*

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

Donations have been made in Mr. Greenblott's memory by: Naomi Greenblott, *Pittsburgh, PA*

A memorial fund has been established in the name of Mrs. Ann Leslie Cosenza Hallberg

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

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Branford, CT
Wan & Margarita Lansberg
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West Haven, CT

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

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

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William M. Denny, Jr.

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Donations have been made in Mrs. Hoffman's memory by: Gary Hoffman, *Oregon City, OR*

A memorial fund has been established in the name of Mr. Robert Hoffman

Donations have been made in Mr. Hoffman's memory by: Terry and Renee Green, *Wildwood Crest, NJ*

A memorial fund has been established in the name of Mr. George C. Holmes

Donations have been made in Mr. Holmes' memory by: Victoria F. Wasmund, *Silver Springs, MD*

A memorial fund has been established in the name of Mr. Jack Huffman, Sr.

Donations have been made in Mr. Huffman's memory by: Ronald W. Flesch. *Lebanon. TN*

A memorial fund has been established in the name of Mr. Erik Johnson

Donations have been made in Mr. Johnson's memory by: Susan Johnson, *Clifton, NJ*

A memorial fund has been established in the name of Mr. Clyde A. Jones

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

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Mr. and Mrs. D.J. Snee, Bel Air, MD

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Donations have been made in Ms. Irene Katz' memory by: Sumner and Dee Burstein, *Framingham, MA*

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

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Donations have been made in Mr. Meadows' memory by: Patricia Meadows. *Novato. CA*

A memorial fund has been established in the name of Mr. Wayne Meling

Donations have been made in Mr. Meling's memory by: Patricia Meling, *Arlington Heights, IL*

A memorial fund has been established in the name of Mr. Ralph Mocci

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A memorial fund has been established in the name of Ms. Lillian Morris

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

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Fred and Donna Maynard
Sahuarita, AZ
Daniel and Nancy Jones
Green Valley, AZ
Bresser
Green Valley, AZ
Batty Soli
Green Valley, AZ
Betty Soli
Green Valley, AZ
Betty Soli
Green Valley, AZ
Richard Stringer
Tucson, AZ
Dr. & Mrs. F.V. Brown
Green Valley, AZ

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A memorial fund has been established in the name of Mrs. Lina Nessouli

Yssa and Jinan Saaddine

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A memorial fund has been established in the name of Mrs. Arlene M. Rau

Donations have been made in Mrs. Rau's memory by: Donald A. Rau, *San Diego, CA*

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Donations have been made in Mr. Sandler's memory by: Sue Schiller, *Cranbury, NJ*

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A memorial fund has been established in the name of **Mr. Bradley Warren**

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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:

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

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Donations have been made in Mr. Wright's memory by: Jerry and Renee Green, Boynton Beach, FL

A memorial fund has been established in the name of Mrs. Eleanor L. "Ellie" Wright

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

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

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A memorial fund has been established in the name of Mrs. Gladys Zwart

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

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Membership benefits include 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 4573 South Broad Street, Suite 150 Yardville, NJ 08620

Phone: 800-MDS-0839 Fax: 609-298-0590 Outside the US only: 609-298-1035

Our Website

The MDS Foundation website 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.

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