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mdsnews
newsletter of the myelodysplastic syndromes foundation

MDS Join the Journey to Hope

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From the Guest Editor's Desk

Uncertainty and Distress Associated with Myelodysplastic Syndromes (MDS)

Joan M. Latsko
DNP, CRNP, OCN, AOCNP
Western Pennsylvania Cancer Institute
Pittsburgh, Pennsylvania
Member, MDS Foundation International Nursing Leadership Board

Over the past twenty years, many interactions with patients diagnosed with Myelodysplastic Syndromes (MDS) have afforded me a view of the disease beyond the diagnosis and treatment of such patients. My role as a nurse practitioner has allowed me entrance into the patient's world of uncertainty and distress associated with the disease. For example, one patient told me that he compared his diagnosis of MDS to "a terrorist inside, waiting to strike," another was inconsolable when told her growth factor therapy was very slowly losing its effectiveness after ten years of transfusion freedom, while another patient worried incessantly about leaving her house or participating in family activities as she "feared acquiring a deadly infection". By all physical, laboratory and MDS parameters, these patients have a stable disease, but the uncertainty associated with the disease was causing great distress and impairment in their quality of life.

Myelodysplastic Syndromes are a group of chronic hematologic diseases associated with a poorly functioning bone marrow and ineffective hematopoiesis resulting in peripheral blood cytopenias and potential conversion to acute leukemia. MDS afflicts the elderly with an average age of 76 years (range 65–85 years), more men than women (2:1), and more Caucasians compared to other races (3:1). The incidence of MDS, according to the most recently published SEER data, is estimated to be 4 cases per 100,000 population per year or 30,000 to 40,000 per year as compared to previous data that suggested the incidence to be only 10,000 to 20,000 per year. However, incidence and prevalence rates are changing rapidly due to earlier referrals to hematology clinicians, improved diagnostic procedures and the increased incidence of treatment-related MDS, which occurs as a result of previous radiation and chemotherapy exposures.[1-2]

Patients diagnosed with a potentially terminal disease such as MDS, face many challenges related to the disease: uncertainty, distress, and quality of life to name a few. Patients have individual responses to stressors related to the diagnosis of MDS, treatment, response, survival or the fear of death. Healthcare clinicians may lack sufficient time to clearly define this complex disease. Because MDS is a fairly uncommon disease, they may have limited experience with MDS patients and be less able to assess the impact of uncertainty and distress on the patient. Patients tend to underestimate the symptoms and impact of

their uncertainty and distress, and often minimize their distress when speaking to the clinical team. There are differences among a patient's, healthcare clinician's, as well as a nurse's attitudes and beliefs concerning uncertainty and distress. This may also influence the provision of appropriate psychological and psychosocial care.[3]

Patients with MDS are faced with a number of challenges including the uncertain clinical course of their disease. Constant distress from uncertainty can lead to additional conditions such as anxiety and depression, with an ultimate impact on quality of life. Uncertainty is rooted in the perception of outcomes or meaning of a situation.[4] These perceptions challenge the sense of confidence to control the type and approaches towards adaptation to the uncertainty.[4-7] However, uncertainty and distress are not synonymous with a patient's quality of life, but rather separate entities, which will ultimately affect the individual's quality of life.

Distress is recognizable as a psychological reaction to the stress of the cancer diagnosis. MDS is classified as a bone marrow malignancy thus, a cancer diagnosis.[8] Distress experienced by MDS patients is comprised of denial, depression, despair, loss, hopelessness, and a fear of the known or unknown. In addition, the inability to continue employment, tend to business affairs, or interact socially with family or friends in the usual manner are contributing factors. Finally, the patient's attributes (age, sex, race, religion, living locale, etc.), disease attributes (length of diagnosis, current treatment regime, treatment response, etc.), social system attributes (family, friends, support groups, etc.) and timing (disease interval, seasons, holidays, etc.) may have tremendous implication for uncertainty and distress among the MDS population. Consequently, continual disease uncertainty and distress experienced by the MDS patient will ultimately disrupt their overall quality of life.

The combination of these factors explains in part the wide variability in experiences for each patient with MDS. The lack of adequate knowledge about the disease may be due to general deficiencies in disease information, misinterpretation of the medical language, and a social misunderstanding of the disease. The aura of uncertainty relates to the constraints of the disease and the relative chronicity of the disease. However, the overall classification of MDS is not in the same context of other chronic diseases, as it has classification as a bone marrow malignancy. In addition, the variable symptoms of physiological well versus non-well in MDS patients is not congruent with the overall chronicity of the disease, including extended periods of stability, remission, potential relapse or progression to acute leukemia. Finally, disruption of emotional stability may result from the continual fear of complications including serious or fatal cytopenias and conversion to acute leukemia.

The uncertainty of MDS as a disease process challenges the patient to find meaning in the disease process and develop effective coping behaviors.

The uncertainty of MDS as a disease process challenges the patient to find meaning in the disease process and develop effective coping behaviors. The patient's uncertainty relates to their own internalized perceptions of the "cancer" diagnosis, variability in symptoms unpredictability of the disease course, erratic responses to treatment interventions and a potential terminal outcome. The individual MDS patient's response to uncertainty will vary according to their perception of their situation. Some will see their situation in a positive way and will develop and use effective coping strategies. Other patients may find this more challenging and will have difficulty developing effective coping strategies. This more negative view of the diagnosis (danger) and view of uncertainty may lead to a more emotional response and greater difficulty adapting to the challenges faced.

Research suggests there are many factors that contribute to each individual patients response to the uncertainty of a cancer diagnosis.[9-11] Uncertainty has the potential to occur with any individual, whether in health or illness, patients, caregivers or parents of ill children. Coping strategies to deal with uncertainty were evaluated through patterning over time, supportive care and communication indicating a need for healthcare clinician support throughout the uncertainty event.[12-13] Individuals dealing with either acute or chronic diseases experience uncertainty with many concerns, including the sequelae of the disease or disorder, symptoms, knowledge, and treatment responses as well as their future and potential mortality. Individuals have a very personal response to perceived stress, stressors, diagnosis, treatment, response and adaptation.

The psychosocial complication of distress is a prevalent problem when patients are diagnosed and facing treatments for MDS. Distress can impair the patient's subsequent decision-making strategies, compliance and overall treatment response.[14] Distress research has identified a number of issues associated with relationships to age, sex, race, religion, as well as numerous other physical, psychological, personal, environmental and social variables, which affected coping skills among patients diagnosed and treated for cancer.[15-21] Three studies reviewed research instruments for evaluating and detecting distress, while determining that all three instruments identified the concept of distress. However, identification does not necessarily require a tool or instrument, but does require the time and effort for effective assessment and intervention on the part of the clinician.[22-24]

Current research on MDS has primarily focused on aspects of the disease, including pathology, treatment options, treatment outcomes and quality of life. The goals for treatment of MDS are to control symptoms, improve quality of life, improve overall survival and decrease progression of the disease to acute leukemia. A literature review identified studies related to quality of life with the disease, the treatment and responses. One published study[25] evaluated common troublesome symptoms and the impact on quality of life. The study confirmed that MDS patients experience a broad range of symptoms and impaired health with fatigue being the most debilitating factor.[25] Three published studies[26-28] evaluated the influence of the MDS patient's hemoglobin level and transfusion status on quality of life. These studies determined that quality of life was impaired secondary to symptoms of fatigue and dyspnea related to anemia, hemoglobin less than 10 grams/deciliter and the need for chronic transfusion therapy. Ultimately, the chronicity of fatigue associated with MDS will only enhance the uncertainty and distress experienced by patients.

An additional eight published studies[29-36] evaluated quality of life in MDS patients receiving specific treatments or therapies including growth factors, azacitidine, decitabine, and lenalidomide. The results of these studies indicated that enhancement of the MDS patient's quality of life was associated with improvement in the patient's anemia and subsequent transfusion independence secondary to an ongoing response by active treatment for the disease.

However, a clinical response to a pharmacologic treatment does not necessarily equate to an improvement in the uncertainty, distress or overall quality of life. A patient may have a physical, laboratory or pathological improvement, but not necessarily a psychological improvement to the prescribed treatment. The management of psychosocial coping proficiency in the face of illness or disease is a subcomponent in a majority of research instruments evaluating quality of life. Quality of life is an imperative factor when evaluating patient responses in the diagnosis and treatment of chronic, malignant and potentially life-threatening diseases such as MDS. However, the psychosocial aspects of distress, specifically uncertainty and distress, lack full incorporation within the instruments utilized for research associated with quality of life.

MDS is an increasingly common hematologic disorder that afflicts the older individual (age >60) with a conglomerate of physical, emotional, psychological and psychosocial components. The uncertainty associated with the MDS diagnosis is unique. Strategies for assessment of each patient and development of an individualized plan for support will require consideration of the individual patient attributes, the stage of disease, expected chronicity vs. terminality of the disease, and the ability of the patient to develop effective coping strategies. However, uncertainty and distress are not synonymous with a patient's quality of life, but rather separate entities, which will ultimately affect their quality of life. Thus, future research is needed to more clearly define the level of uncertainty and degree of distress faced by patients with MDS. Establishment of a multidisciplinary approach will promote more effective assessment of the patient's uncertainty, prompt intervention by members of the clinical team and may improve their overall quality of life.

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From The Foundation

"helping you give hope..."

The MDS Foundation is a multi-disciplinary, international organization devoted to support, research, treatment, and education for patients, caregivers, physicians, and other health care providers. The organization is based upon the premise that international cooperation will accelerate the process leading to the control and cure of these diseases.

Please join us as a member of the Foundation.

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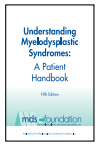
MDS FOUNDATION PUBLICATIONS

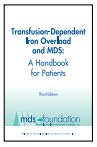
The MDS Foundation provides referrals to our Centers of Excellence and the following information to physicians and patients, free of charge:

- The MDS News
- The MDS Messenger (Free E-News)

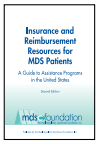
- Patient Diary
- What Does My Bone Marrow Do?

- Understanding Myelodysplastic Syndromes: A Patient Handbook*
- Transfusion-Dependent Iron Overload and MDS: A Handbook for Patients*
- It Takes Time to Realize Your Goals





- Insurance and Reimbursement Resources for MDS Patients



- Planned Giving Program: A Guide to Financial Planning

***The MDS Patient Handbooks and Iron Overload booklets are available in English and the following languages:**

NEW FROM THE FOUNDATION

- **A Caregiver's Guide to MDS: What Can You Do to Help?**

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

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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.

...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.

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 *The MDS Messenger*, 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
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ANNOUNCEMENT FROM MDS FOUNDATION

The MDS Foundation Says Regulatory Decision Approving Vidaza® In The Uk Provides An Essential Treatment Option To Patients

VIDAZA is the Only Licensed Drug Shown in Clinical Trials to Improve Survival

Yardville, NJ. USA (29 March, 2011) – The Myelodysplastic Syndromes (MDS) Foundation — an international organization devoted to the prevention, treatment, and study of the myelodysplastic syndromes— today issued a statement applauding a decision from the National Institute for Health and Clinical Excellence in the UK (NICE) to recommend VIDAZA (azacitidine) in its approved indications for certain MDS patients.

MDS is a malignant bone marrow disease with a median survival of less than one year that can also progress to an aggressive form of leukemia called AML. VIDAZA from Celgene is the only drug approved by the EMA for MDS and is crucial to the treatment of this disease, especially for the majority of MDS patients, those over the age of 65 who are not eligible for bone marrow transplants. The NICE decision reverses a previous negative decision issued last year.

In 2009, data published in the peer-reviewed medical journal The Lancet Oncology confirmed that VIDAZA extends survival for patients with higher-risk MDS. In 2010 a study in a subset of these patients in the Journal of Clinical Oncology concluded VIDAZA "prolongs survival and is well tolerated" in higher risk MDS patients and those with acute myeloid leukemia (AML) with 20–30% marrow blasts (previously called RAEB-T in the FAB classification). The study found that half of the older patients (median age 70) treated with VIDAZA survived at least two years, compared to only 16% of patients who received conventional care.

VIDAZA is specifically approved for use in the treatment of intermediate-2 and high-risk myelodysplastic syndromes (MDS), chronic myelomonocytic leukemia (CMML) and the subset of AML patients indicated above who are not eligible for stem cell transplantation.

ANNOUNCEMENT FROM MDS UK PATIENT SUPPORT GROUP/UK MDS FORUM

MDS Patients Achieve Access to Vital New Treatment Option

National Institute for Health and Clinical Excellence Recommend Azacitidine is Available Through the NHS

London (17 February 2011) – The National Institute for Health and Clinical Excellence (NICE) announced today that Vidaza (azacitidine), the only licensed drug available specifically to treat myelodysplastic syndromes (MDS) — a range of life-threatening bone marrow disorders — will be available through the NHS. The MDS UK Patient Support Group, which has been in consultation with NICE during the approval process and campaigned on behalf and in conjunction with MDS patients across the UK, welcomes this announcement.

There are nearly 3,000 new cases of MDS in the UK each year and many people newly diagnosed with MDS have not heard of this disorder before. A person with MDS will suffer from chronic tiredness and weakness due to the often extremely low levels of haemoglobin, owing to a malfunction in the bone marrow in producing the correct quantity and quality of blood cells. This is debilitating in itself and often requires regular blood transfusions.

Azacitidine is an anticancer drug that is thought to work by re-establishing cells' natural mechanisms to control abnormal growth. The final appraisal determination by NICE recommends the use of azacitidine for the treatment of MDS, chronic myelo-monocytic leukaemia (CMML) and acute myeloid leukaemia (AML) following a revision to the patient access scheme provided by Celgene (the manufacturers of azacitidine). Rodney Taylor, Deputy Chairman of MDS UK Patient Support Group said, "I am delighted to hear of NICE's decision to recommend azacitidine for these patient groups which can benefit from this form of treatment. Having been on azacitidine myself, I know how effective it can be in promoting a good quality of life, giving independence from blood transfusions and allowing patients to lead a normal family life. Azacitidine is the only specific treatment for MDS that improves quality of life, prolongs survival and delays disease progression. It is great news that many more patients will now be able to benefit from it."

While the announcement is good news for MDS patients in England and Wales, MDS UK Patient Support Group is concerned that access to this vital new treatment is still denied to MDS patients in Scotland, as azacitidine has yet to be re-submitted to The Scottish Medicines Consortium (SMC) following a rejection in April 2010. We urge all concerned to apply both maximum effort and the highest priority to bring azacitidine to Scotland, in line with England and Wales. "Clearly I am delighted that NICE has approved azacitidine for use in England and Wales in conjunction with the associated patient access scheme," said Dominic Culligan, Consultant Haematologist, Aberdeen Royal Infirmary, Scotland. "I hope that Celgene will resubmit azacitidine to the SMC as a matter of urgency, so that further consideration can be given to making this important treatment for high risk MDS and some patients with AML available in Scotland."

It is a distressing reality that, during the protracted evaluation process attendant to the successful outcome of this appraisal, some MDS patients have progressed to AML, and some did not survive, in the absence of azacitidine. MDS UK Patient Support Group are aware of the complex financial constraints and cost effectiveness criteria attendant to the adoption of new drugs, and ask only that even more effort is applied in reaching speedier positive conclusions in critical, end of life situations such as MDS.

ANNOUNCEMENT FROM MDS FOUNDATION

MDS Foundation Says ASH 2010 Highlights New Prognostic Capabilities and A Deeper Understanding of Treatment Options For This Once "Untreatable" Condition

Studies Explain Role of Genes in Susceptibility to MDS and Response to Treatment

Studies Confirm Benefits and Extend Potential of Existing Drugs and Drug Combinations, Including Oral Medications

Yardville, NJ, Orlando, FL (Dec 3, 2010) –

The Myelodysplastic Syndromes (MDS) Foundation today said significant advances are being made in understanding and treating MDS and a related condition, AML (acute myeloid leukemia). Key studies being presented this week include data on new markers and genetic mutations to predict susceptibility to MDS and response to treatment. Studies also look at new dosing and new combinations of existing drugs, and include an early look at new drug formulations showing increased potential and presenting more options for patients. The new findings will be presented at the 52nd annual meeting of the American Society of Hematology (ASH), being held this week in Orlando, Florida.

MDS is a malignant condition of cells in the bone marrow. Patients require blood transfusions that can lead to iron overload, and the condition can progress to AML, a serious form of leukemia that has a median survival of less than one year. MDS affects the production and function of blood cells-red blood cells, white blood cells or platelets. The incidence of MDS and AML is underestimated, conservatively affecting tens of thousands of persons annually.

"These are challenging diseases that affect a growing number of persons each year with the graying of the US population; we are pleased to see the significant progress being made," said Stephen D. Nimer, MD, Vice Chair, Faculty Development & Alfred P. Sloan Chair at Memorial Sloan-Kettering Cancer Center in New York and MDS Foundation board member. "While there were very few options for MDS patients in the past, with the FDA approved therapies, patients are able to live a better quality of life, often free from the time-consuming and tiring process of receiving frequent blood transfusions. It is encouraging to see additional confirmation that these new therapies are providing benefits for patients and that additional drugs are in development."

Key MDS and AML studies to be presented at ASH include new ways to measure and determine susceptibility to MDS and predict response to treatment:

- data to validate the MD Anderson Risk Model (MDAS), a new, more accurate way to predict the natural history of a given patient's disease to guide appropriate therapy (abstract #444, 12/6, 11:45 am)
- genetic markers to predict susceptibility to MDS (#LBA3, 12/7, 7:30 am and #612, 12/6, 4 pm)
- and a specific genetic mutation that may help predict response to treatment with VIDAZA®(azacitidine)(#439, 12/6, 10:30 am)

While there were very few options for MDS patients in the past, with the FDA approved therapies, patients are able to live a better quality of life...

Another key group of studies provide new data on treatment options for patients:

- a reduced dose and longer cycle of VIDAZA compared to the standard of treatment (50 mg vs 75 mg; 10 days vs 7 days) doubles the rate of hematologic normalization (#601, 12/6, 2:45 pm)
- an early look at a new regimen CPX-351, a liposome (encapsuled) formulation of cytarabine and daunorubicin in a specific ratio to maximize synergy, demonstrates higher response rate in newly diagnosed elderly patients with AML and in particular, AML that evolves from MDS (#655, 12/6, 4:30 pm)
- an oral version of the drug VIDAZA shows encouraging clinical responses in early testing (#603, 12/6, 3:15 pm)

Other studies found positive effects with combinations of drugs, such as REVLIMID® (lenalidomide) plus intensive chemotherapy in elderly patients with higher-risk MDS and AML (#508, 12/6, 3:30 pm).

However, two studies dramatically show the need for a broader range of treatments, documenting a poor outcome for patients when current hypomethylator therapies fail and calling for clinical trials for this group of patients to take priority (#2913, 12/5, 6 pm; #443, 12/6, 11:30 am).

Alan List, MD, Physician-in-Chief at the Moffitt Cancer Center in Florida and board member of the MDS Foundation noted: "The growing ability to predict and assess disease incidence and outcome combined with a better understanding of current treatments makes this an important ASH conference for MDS patients and their physicians. Our arsenal is too small and we need more research, but we are encouraged by what we expect to see this year."

Patient Forums and Support Groups

Jacksonville Patient and Family Forum

Jacksonville, Florida • March 28, 2011

Guest speaker, Dr. Alvaro Moreno-Aspitia, Mayo Clinic.

Nurse Joan Latsko educating patients and their guests.

Patients enjoying their complimentary lunch.

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 at the Seattle Cancer Care Alliance Center. Contact Steve Kessler at smartmony@msn.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

Los Angeles Patient and Family Forum

Beverly Hills, California • February 28, 2011

Nurse Erin Demakos, Mt. Sinai School of Medicine and member of the MDSF Nursing Advisory Board, moderates the quality-of-life session with patients and caregivers.

Dr. H. Phillip Koeffler from Cedars-Sinai Medical Center speaks to patients.

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, and the dissemination of patient information.

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.

Mercy Medical Airlift®
AMERICA'S CHARITABLE MEDICAL TRANSPORTATION SYSTEM

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
National Institutes of Health

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.

Spreading the Word Worldwide – Patient and Caregiver Education Forums

FREE One-Day Conferences for MDS Patients and Their Families

Ongoing meetings in the US and Europe addressing quality of life issues for MDS patients are planned for 2011. Learn the latest on the diagnosis and treatment of MDS from leading experts in the field. These conferences will occur in eleven cities around the world in 2011. A global patient forum will be held alongside the 11th International Symposium on MDS in Edinburgh, UK. Check our website and facebook for updates.

CALENDAR OF EVENTS:

- February 28, 2011
  Los Angeles, CA
- March 28, 2011
  Jacksonville, FL
- April 16, 2011
  Atlanta, GA
- May 20, 2011
  Edinburgh, United Kingdom
- May 26, 2011
  Baltimore, MD
- June 29, 2011
  San Antonio, TX
- July 9, 2011
  Seattle, WA
- Date TBD
  Chicago, Illinois
- Date TBD
  Nashville, Tennessee
- Date TBD
  Scottsdale, Arizona
- Date TBD
  Boston, Massachusetts

Please contact the MDS Foundation at 1-800-MDS-0839 for reservations/inquiries.

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.

Patient Support Groups have been vital to educating public awareness of this disease and promoting and supporting scientific research...

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@mds-foundation.org or 609-298-1035. We look forward to hearing from you!

Please let us know – we will help!

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!

Fundraising Cookbook to Benefit MDS

Nancy Cosenza Nussbaum

November 21st is a day that will always sadden my heart and burden my soul as it is the day that my sister, Ann Cosenza Hallberg, left this life, as we know it.

Ann was diagnosed with MDS early 2009; our brother, Alan, was a perfect match for her stem cell transplant which took place in June 2009, with all markers at the optimum readings. Her prognosis was good. We figured the rest of 2009 would be spent watching her getting stronger and getting well. There were plans for 2010, though. Ann's son, Rob, was graduating from high school and a family trip would have been in order early summer. Ann wanted to see him settled in his dorm in fall, 2010 and she and I were going to spend a week in New York. Dinners, shopping, and theater... you name it... it was on our agenda. She talked with her husband, Steve about a romantic holiday to Paris. Their 20th wedding anniversary would have been in May, 2010 and she wanted everyone to go to a certain restaurant in NY that she loved where we would all celebrate.

Having been trained in the arts, Ann had a career change in mind for when she was well, and that was to work with MDS patients. She had already spoken with her doctor about starting a support group at Yale for people awaiting transplants and support for thereafter.

Ann – Age 5

2010 was going to be a wonderful year of love, celebration of life and service.

But, what happened was that while the stem cell transplant was successful, graft versus host disease set in and took our beloved sister, wife, mother, daughter, aunt and niece from us. We watched her slowly fading from us, always with the hope that she was reacting poorly to meds and once off them, she would bounce back. Unfortunately, it was not to be.

Ann left us on November 21, 2009 at 9:45 pm.

How this has affected our family has been heart wrenching. As each of us had our own special relationship with Ann, our expressions of loss are all very different.

Right after we lost her, I felt the need to do something immediately to honor her and keep her with me so *The Ann Cosenza Hallberg Toy Drive* was established and we collected multiple cartons of new toys for the hospital's Toy Closet for the young patients.

There was communication with Audrey Hassan with the MDS Foundation about fund raising ideas. The idea of a walk was mentioned, but I was already planning a walk for the Connecticut Food Bank and our team name, of course, was Team Ann Hallberg.

In the interim, our sister, Christine set up a memorial fund in Ann's name with MDS for research. I was still trying to figure out what I could do for MDS Foundation... and one evening it just came to me... a cookbook! I talked it over with my family and decided we would publish a cookbook with recipes from family and friends, local restaurants in the greater New Haven area and some well known bakers and chefs. All profits will go to *Ann Cosenza Hallberg Memorial Fund* with MDS Foundation for research to help eradicate the disease and complications.

At this time, the recipes have been collected and we await the finished cookbooks from the publisher. They are

Ann Cosenza Hallberg

$10 each and 100% of this money will be donated to the MDS Foundation. We are also requesting $3.00 for shipping & handling. For further information please email me at AnniesSweetTooth@gmail.com. Please also check out www.anniessweettooth.blogspot.com as we continue sharing recipes and food talk.

So, for me, continuing charitable work in my sister's name keeps her with me and allows others to know her and become aware of MDS.

For Ann...

i carry your heart

...i carry your heart with me (i carry it in my heart) i am never without it (anywhere i go you go, my dear; and whatever is done by only me is your doing...)...

...here is the deepest secret nobody knows (here is the root of the root and the bud of the bud and the sky of the sky of a tree called life; which grows higher than soul can hope or mind can hide) and this is the wonder that's keeping the stars apart

i carry your heart (i carry it in my heart)

– e.e. cummings

Family Fun for Fundraising Ideas A to Z...

We try to make your fundraising efforts a little easier by providing a wide variety of fundraising ideas. One of them may be perfect for your next fundraiser!

A Auction • Arts and crafts sale • Autograph sale...

B Blood/bone marrow drive • Bike-a-thon Bake sale • Book sale • Benefit concert or party • Band/Choir Fundraiser • Barbecue • Bridge tournament • Bowling • Bingo...

C Cake bake • Candy Fundraiser • Car wash • Celebrity auction • Church fundraiser • Collection boxes • Cookbook (produce a community cookbook that you can sell) • Calendar production and sale • Cheese and wine evening • Cheerleader fundraiser • Christmas cards...

D Dinner dance/ball • Darts tournament...

E eBay (register and auction off your old, unwanted items) • Eating contest • Easter party (easter egg hunt, easter egg auction, etc.)...

F Fundraising night out at a local restaurant Fairs • Face painting • Fashion show • Flower/fruit sales • Foreign coins collection • Fun run...

G Galas • Game night • Golf tournament Garage/yard/estate sale • Greeting cards...

H Home fundraising party (Tupperware, PartyLite, Pampered Chef, Silpada, etc.) House Party • Halloween Party...

I Individual gifts (pledges, an hour's pay, donations, membership, payroll giving, etc.) • Ice-skating • Ice cream social...

J Jog-a-thon • Jewelry sale • Judo competition or demonstration...

K Karaoke night/competition • Kite flying Knitting...

L Lawn mowing • Luncheon...

M Marathons • Musicals • Murder mystery dinner/event • Movie premiere...

N New Year's Eve party • Netball match...

O Old gold (send us your old and broken jewelry or bring it to a Cash for Gold jewelry store and donate the proceeds) Obstacle course • Opera night...

P Pancake breakfast • Parties (birthday, anniversary, etc.) • Plant sale • Poker/blackjack/backgammon/bridge tournament • Picnics • PTA fundraiser...

Q Quiz night…

R Run/Walk/Hike/Bike • Raffles • Read-a-thon • Recipe sales...

S Spaghetti Dinner fundraiser • School fundraiser • Silent/live/online auction • Sports tournaments (soccer, golf, basketball, bowling, etc.) • Super Bowl party • Scavenger hunt • School fair • Sorority fundraiser...

T Triathlon • Talent show • Tea party • Treasure hunt • Tennis tournament...

U University activities/fundraisers...

V Volleyball tournament • Vendor fair • Valentine's ball...

W Wacky races • Wine/food tasting...

X Xmas stocking bazaar • Xmas cake sale Xmas card donation...

Y Youth group fundraiser • Yoga marathon Yacht race • Yo-yo competition...

Z Zany parties • Zoo trips • Zodiac readings...

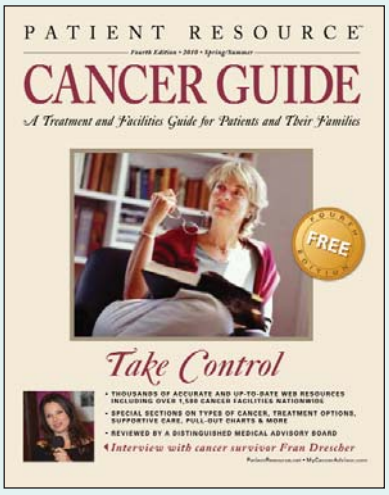
CAN YOU COME UP WITH MORE ?

If you have some fundraising ideas that you are willing to make available, send them to us via email at patientliaison@mds-foundation.org and we will include them in this section.

The MDS Foundation is very grateful for the heartfelt support of its donors. Our work as a non-profit organization depends on public funding...

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 centers of excellence

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

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

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

The following centers have qualified as MDS Centers of Excellence:

UNITED STATES

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

UCLA Center for Health Science
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

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
Wayne State University
Detroit, Michigan
Charles A. Schiffer, MD

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

MINNESOTA

Mayo Clinic
Rochester, Minnesota
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 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
University of Texas
Health Science Center
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

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 Iastrebner, 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

BELGIUM

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

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

BRAZIL

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

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
São Paulo, Brazil
Elvira R.P. Velloso, MD, PhD

Universidade Federal de Ceará
Ceará, Brazil
Silvia Maria M. Magalhães, MD, PhD

Universidade Federal de São Paulo
São Paulo, Brazil
Maria de Lourdes Chauffaille, MD, PhD

CANADA

Princess Margaret Hospital
Toronto, Ontario, Canada
Karen Yee, MD

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

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

CHINA

Institute of Hematology
and Blood Diseases Hospital
Chinese Academy of
Medical Sciences
Tianjin, China
Zhijian Xiao, MD

CROATIA

University Hospital Center Zagreb
School of Medicine
Zagreb, Croatia
Boris Labar, MD, PhD
Ranka Serventi-Seiwerth, MD

CZECH REPUBLIC

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

DENMARK

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

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

University of Århus
The University Hospital
Århus, Denmark
Mette Skov Holm, MD, PhD

FRANCE

Centre Henri Becquerel
Rouen University
School of Medicine
Rouen, France
Aspasia Stamatoullas, MD

Centre Hospitalier
Universitaire (CHU) de Angers
Service des Maladies du Sang
Angers, France
Norbert Ifrah, MD

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

Centre Hospitalier
Universitaire (CHU) de Limoges
Hôpital Dupuytren
Limoges, France
Dominique Bordessoule, MD

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

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

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

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

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

Institut Paoli-Calmettes
Marseille, France
Norbert Vey, MD

GERMANY

Georg-August-Universität Göttingen
Göttingen, Germany
Detlef Haase, MD, PhD

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

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

Johann Wolfgang
Goethe Universität
Frankfurt Main, Germany
Gesine Bug, MD

Klinikum Rechts der Isar
Technical University of Munich
Munich, Germany
Katharina Götze, MD

MLL Münchner Leukämielabor
Munich, Germany
Torsten Haferlach, MD

Saarland University
Medical Center
Homburg/Saar, Germany
Ulrich Mahlknecht, MD, PhD

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

Albert-Ludwigs-Universität Freiburg
Freiburg, Germany
Michael Lübbert, MD, PhD

Universität Hamburg
Hamburg, Germany
Nicolaus Kröger, MD, PhD

Universitätsklinikum Carl Gustav Carus
Dresden, Germany
Uwe Platzbecker, MD

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

University of Cologne
Cologne, Germany
Karl-Anton Kreuzer, MD

Universitätsklinikum Benjamin Franklin
Berlin, Germany
Olaf Hopfer, MD

University Hospital Mannheim
Mannheim, Germany
Wolf-Karsten Hofmann, MD, PhD

GREECE

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

University General Hospital Attikon
Athens, Greece
Vassiliki Pappa, MD

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

HUNGARY

Semmelweis University School of Medicine
Budapest, Hungary
Judit Várkonyi, MD, PhD

INDIA

Tata Medical Centre
Kolkata, India
Col (Dr.) Deepak Kumar Mishra, MD

Tata Memorial Hospital
Mumbai, India
Purvish Parikh, MD

IRELAND

Adelaide and Meath Hospital
Dublin, Ireland
Helen Enright, MD

ISRAEL

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

ITALY

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

Istituto di Ematologia Universita' Cattolica Sacro Cuore
Roma, Italy
Giuseppe Leone, MD
Maria Teresa Voso, MD

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

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

University Tor Vergata Ospedale S. Eugenio
Roma, Italy
Elisabetta Abruzzese, MD, PhD

JAPAN

Kyoto University Hospital
Kyoto, Japan
Akifumi Takaori, MD

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

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

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

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

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Catholic Blood and Marrow Transplantation Center The Catholic University of Korea
Seoul, Korea
Yoo-Jin Kim, MD

Seoul National University Hospital Seoul National University College of Medicine
Seoul, Korea
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Kraków, Poland
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St. James's University Hospital St. James's Institute of Oncology
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University Hospital of Wales
Cardiff, Wales
Jonathan Kell, MD

Management of Iron Overload in MDS

Peter L. Greenberg, MD
Stanford University Cancer Center and
Professor of Medicine/Hematology
Stanford University School of Medicine
Palo Alto, California

Red blood cell (RBC) transfusions are a major component of the supportive care for symptomatically anemic MDS patients. Although the specific therapies patients receive may alleviate RBC transfusion need, a substantial proportion of MDS patients may not respond to these treatments and may develop iron overload as well as its consequences.[1]

Studies in patients requiring relatively large numbers of RBC transfusions (e.g., thalassemia and MDS) have demonstrated the pathophysiology and adverse effects of chronic iron overload on hepatic, cardiac and endocrine function. Increased nontransferrin bound iron (NTBI) levels, generated when plasma iron exceeds transferrin's binding capacity, combines with oxygen to form hydroxyl and oxygen radicals. These toxic elements cause lipid peroxidation and cell membrane, protein, DNA and organ damage.[2]

Retrospective evidence suggests that organ dysfunction may result from iron overload in patients with MDS and that transfusional iron overload might be a contributor to increased mortality and morbidity in early stage MDS.[3,4] The WPSS has shown that requirement for RBC transfusions is a negative prognostic factor for patients with MDS.[4]

For patients with chronic RBC transfusion need, serum ferritin levels, number of RBC transfusions received and associated organ dysfunction (heart, liver, and pancreas) should be monitored to determine iron stores. Monitoring serum ferritin may be useful, aiming to decrease ferritin levels to <1,000 mcg/L. Such measurements, though useful, are less precise than use of specific measurement of hepatic (and more recently cardiac) magnetic resonance imaging (MRI) evaluations of hepatic iron content.[5]

The current clinical availability of two iron chelators in the U.S, deferoxamine (Desferal) for subcutaneous (SC) or IV use and deferasirox (Exjade) for oral use, now provides potentially useful drugs for treating this iron overload state. A third chelating agent, available in Europe, deferiprone for oral use is not available in the US.

Clinical trials in MDS are ongoing with iron chelating agents to address the question whether iron chelation alters the natural history of patients with MDS who are transfusion dependent. Reversal of some of the consequences of iron overload in MDS and other iron overload states (e.g., thalassemia) by iron chelation therapy using deferasirox orally[6] and deferoxamine subcutaneously (SC)[7] have been shown. Such findings have potential implications for altering the morbidity of MDS patients, particularly those with preexisting cardiac or hepatic dysfunction. A recent U.S. National Comprehensive Cancer Network (NCCN) task force report discusses in detail the available evidence regarding iron chelation in patients with MDS.[8]

Based on the available, but limited evidence, both the MDS Foundation (mds-foundation.org), and the NCCN MDS Guidelines Panel, have recommended that chelation therapy be considered to decrease iron overload in selected MDS patients. Deferasirox 20 mg/kg orally once daily or deferoxamine 8 hrs Sc infusion nightly 5–7 nights per week, are acceptable alternatives for low or intermediate1 MDS patients who have received or are anticipated to receive greater than 20 RBC transfusions, for whom ongoing RBC transfusions are anticipated and for those with serum ferritin >2500 ng/mL, aiming to decrease ferritin levels to <1,000 ng/ml.[9] In addition, evidence suggests the potential value of iron chelation in patients who subsequently undergo allogeneic hematopoietic stem cell transplantation.[7]

Although deferasirox is generally well tolerated other than episodes of gastro-intestinal distress and renal dysfunction in some patients, recently a safety warning by the FDA and Novartis was added to deferasirox treatment guidelines. Following post-marketing use of deferasirox, there were rare case reports of acute renal failure or hepatic failure, some with a fatal outcome. Additionally, there were post-marketing reports of cytopenias, including agranulo-cytosis, neutropenia and thrombocytopenia and GI bleeding in patients treated with deferasirox. The relationship of these episodes to treatment with deferasirox has not yet been established. However, it is recommended to closely monitor patients on deferasirox therapy including measurement of serum creatinine and liver function tests prior to initiation of therapy and regularly thereafter.

Currently, a large international Phase III clinical is ongoing comparing treatment of deferasirox to placebo, which should help establish the clinical value of deferasirox in iron-overloaded MDS patients.

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9. Greenberg PL, Attar E, Bennett JM, et al: NCCN Practice Guidelines for Myelodysplastic Syndromes, Version 1.2011. Available at www.nccn.org/professionals/physician_gls/PDF/mds.pdf

Information on Clinical Trials

New Research Protocol Listing

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.

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

Abramson Cancer Center of the University of Pennsylvania
Philadelphia, PA
Noelle Frey, MD

Albert Einstein Cancer Center at the Montefiore Medical Park
Bronx, NY
Amit Verma, MD

Arlington Fairfax Hematology Oncology
Arlington, VA
John Feigert, MD

Bon Secours Saint Francis Hospital
Greenville, SC
Gary Spitzer, MD

Cancer Care Centers of South Texas
New Braunfels, TX
Roger Lyons, MD

Cancer Care Centers of South Texas
San Antonio, TX
Roger Lyons, MD

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Neil Lachant, MD

Fairfax Northern Virginia Hematology Oncology
Fairfax, VA
John Feigert, MD

Johns Hopkins University School of Medicine, The Sidney Kimmel Comprehensive Cancer Center
Baltimore, MD
Steven Gore, MD

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Gracy Joshua, MD

Stanford University Cancer Center
Stanford, CA
Peter Greenberg, MD

Tufts Medical Center
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Veteran Affairs Medical Center
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Suman Kambhampati, MD

Washington University School of Medicine
St. Louis, MO
Camille Abboud, MD

The West Clinic
Memphis, TN
Bradley Somer, MD

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: patientliaison@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.

Announcing New Clinical Trials

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, Double-blind, 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.

NAME OF INSTITUTION:
Onconova Therapeutics

TRIAL NUMBER: NCT01241500

Title of Trial or Description:
A Phase III Study of ON 01910.Na in Myelodysplastic Syndrome (MDS) Patients Who Have Failed or Relapsed After Azacitidine or Decitabine Treatment (ONTIME)

Currently Recruiting Participants.

The primary purpose of this study is to compare overall survival (OS) in patients receiving ON 01910.Na infusion administered every other week + best supportive care (BSC) to OS of patients receiving BSC in a population of patients with MDS with excess blasts (5% to 30% bone marrow blasts) having failed, being intolerant, or relapsing after azacitidine or decitabine treatment.

Contact the Onconova Clinical Trials Helpline at 1.855.609.6564 toll free or go to www.clinicaltrials.gov for additional information.

NAME OF INSTITUTION:
Celgene Corporation

TRIAL NUMBER: NCT01029262

Title of Trial or Description:
A Study of Lenalidomide Versus Placebo in Subjects With Transfusion Dependent Anemia in Low Risk Myelodysplastic Syndrome (MDS) Without Del 5Q (MDS-005)

Currently Recruiting Participants.

The primary purpose of this study is to compare the efficacy of Lenalidomide (Revlimid®) versus placebo in achieving red blood cell transfusion independence in the overall study population and in a pre-specified subgroup of patients with an erythroid differentiation gene expression signature predictive of Lenalidomide response.

Access www.clinicaltrials.gov for additional information.

Online Search Tool for Clinical Trials

TrialCheck® | Clinical trials information and products powered by: 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

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:

1. Ma X et al. Cigarette smoking shortens the survival of patients with low-risk myelodysplastic syndromes. *Cancer Causes Control*. 2011 Feb 2 [Epub ahead of print]

   Compared to non-smokers, the patients who smoked at the initial clinical encounter had an increased risk of death particularly among the low-risk IPSS category. Interestingly, the smoking related risk was restricted only to men.

2. Greenberg PL et al. Myelodysplastic Syndromes. *J Natl Compr Cancer Network*. 2011;9(1):30–56.

   A comprehensive update review of epidemiology, diagnosis and management of MDS.

3. Price EA et al. Anemia in older persons: etiology and evaluation. *Blood Cells Mol Dis*. 2011;46(2):159–165.

   Of the 190 participants in this single center study, 35% had unexplained anemia with concomitant mild increase in inflammatory markers. The unexplained anemia patients also demonstrated correlating low Hb and low erythropoietin levels. Sixteen percent were suspicious MDS.

TREATMENT:

Growth Factors:

1. Villegas A et al. Darbepoetin alfa for anemia in patients with low or intermediate-1 risk myelodysplastic syndromes and positive predictive factors of response. *Curr Med Res Opin*. 2011 Mar 7 [Epub ahead of print].

   This is a single arm, open-label, multicenter, phase II study that evaluated efficacy and safety of a weekly 300 µg dose of darbepoetin alfa in a well-selected low-/intermediate-1 risk MDS population with Hg<10 g/dL, endogenous EPO levels <500 IU/L and transfusions <2 units/month. For patients not showing major response to darbepoetin alone in 8 weeks, filgrastim was added at 300 µg/week. Majority of major erythroid responses (31/44 or 71%) were evident after week 8 with only one additional response at week 24. Darbepoetin was well tolerated.

2. Passweg JR et al. Immunosuppressive therapy for patients with myelodysplastic syndrome: a prospective randomized multicenter phase III trial comparing antithymocyte globulin plus cyclosporine with best supportive care-SAKK33/99. *J Clin Oncol*. 2011;29(3):3030–309.

   A combination of Horse ATG 15 mg/kg and oral cyclosporine was assessed (n=45) with or without best supportive care (n=43). The primary endpoint was hematopoietic response at 6 months. The hematopoietic response rates after 6 months of treatment were significantly higher with ATG+ cyclo-sporine (13/45, p=0.0156) as compared to the best supportive care alone (4/43). However, no difference was noted in transformation free survival or the overall survival between the two groups.

IMiDs:

1. Xiao Z et al. Cyclosporin A and thalidomide in patients with myelodysplastic syndromes: Results of a pilot study. *Leuk Res*. 2011; 35(1):61–65.

   A small study with 37 MDS patients treated with a combination of cyclosporin A and thalidomide demonstrated hematologic improvement in 51.4% patients and transfusion independence in 46.9% patients. The treatment was well tolerated and the responses were durable.

Demethylating Agents:

1. Silverman LR et al. Continued azacitidine therapy beyond time of first response improves quality of response in patients with higher-risk myelodysplastic syndromes. *Cancer*. 2011 Jan 10 [Epub ahead of print].

   This study undertook secondary analysis of the phase III AZA-001 study that used 75 mg/m^2/day sc for days 1–7 every 28 days. Ninety one of 179 patients in AZA-001 had demonstrated response with 91% of the first responses occurring by cycle 6. The present study showed that continued azacitidine improved response category in 48% of these responders with a median time from the first response to best response being 3.5 cycles.

PATHOBIOLOGY:

1. Tang G et al. high level CD34 expression on megakaryocytes independently predicts an adverse outcome in patients with myelodysplastic syndromes. *Leuk Res*. 2011 Feb 28 [Epub ahead of print].

   A high CD34 expression was detected on mature looking megakaryocytes in 14% bone marrows of the total of 202 MDS patients assessed. The elevated CD34 expression was correlated with severe cytopenia, higher number of myeloblasts, higher cytogenetic abnormalities and poorer overall survival.

2. Pardon E et al. Biology and treatment of the 5q- syndrome. *Expert Rev Hematol*. 2011; 4(1):61–69.

   Lenalidomide may suppress a haplodeficient phosphatase PP2A activity in 5q- patients, which by way of hyperphosphorylating and stabilizing MDM2 may allow p53 degradation, cause G2 arrest and lead to a clonal suppression.

3. Tiu RV et al. Prognostic impact of SNP array karyotyping in myelodysplastic syndromes and related myeloid malignancies. *Blood*. 2011 Feb 1 [Epub ahead of print].

   A combined karyotyping with metaphase cytogenetics(MC) and single nucleotide polymorphism (SNP) array demonstrated higher detectability of cytogenetic abnormalities than the MC alone (74 vs. 44%, p≤0.0001). This analysis with 430 patients also revealed that SNP array-detected abnormalities may have independent predictability for overall and event-free survival.

4. Muguruma Y et al. Establishment of xenograft model of human myelodysplastic syndromes. *Hematologica*. 2010 Dec 29 [Epub ahead of print].

   MDS patients' CD34+ cells were injected along with human mesenchymal stem cells into the bone marrow of SCID/IL2gammaR null host mice. A successful engraftment of MDS CD34+ cells was seen with a maintenance of immunophenotype, genomic abnormalities and trilineage differentiation of the patients' CD34+ cells. Two AML samples demonstrated leukemic clone engraftment and expansion.

5. Zhou L et al. Reduced SMAD7 leads to overactivation of TGF-beta signaling in MDS that can be reversed by a specific inhibitor of TGF-beta receptor I kinase. *Cancer Res*. 2011;71(3):955–963.

   The study reports on decreased expression of SMAD7; a negative regulator of TGF-beta R-kinase, in MDS-derived bone marrow CD34+ cells. Furthermore, the study also demonstrated that LY-2157199, an ALK-5 kinase inhibitor, could inhibit TGF-beta signaling as indicated by inhibition of downstream SMAD2 activation. This kinase inhibitor when administered in vivo, ameliorated anemia in a TGF-beta overexpressing transgenic mouse model of bone marrow failure.

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.

Contributions to the MDS Foundation

Thank You!

Gifts to the Foundation

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

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

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Janet Discepolo, *Wolcott, CT*

A memorial fund has been established in the name of

Ms. Cathy Jean Avants

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

Nancy A. Smith
Surprise, AZ

Ana Perez
Glendale, AZ

Carl and Kathy Moore
Phoenix, AZ

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Auburn Hills, MI

A memorial fund has been established in the name of

Dr. Henry Banal

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

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A memorial fund has been established in the name of

Mr. Harold Baron

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

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Bernie and Nora Friedman
Boca Raton, FL

Les Wallman
Jackson, NJ

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A memorial fund has been established in the name of

Mr. Tito Bastianello

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

Francesca Bastianello Camerino, *Venezia, Italy*

A memorial fund has been established in the name of

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

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A memorial fund has been established in the name of

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

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Cynthia L. Young
Lawrenceville, GA

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Floyd and Julie Franklin
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Debbie Baker
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A memorial fund has been established in the name of

Dr. Harold H. Blecker

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

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

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A memorial fund has been established in the name of

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United Kingdom

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Robbie Whitehall
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Maidenbower, UK

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Alan and Terri Turner
Maresquel, France

Rose, Irene and Win Price
Crawley, West Sussex, UK

N.K. Tuckley
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Mrs. Judith Stephens DeVore

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Sidney and Mary Cranfill, *Vonore, TN*

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Anastasia Fokas, *Astoria, NY*

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Mr. Jack Lambert Frost

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Ms. Elaine Frye

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A memorial fund has been established in the name of

Ms. Jennifer Sharon Gallagher-Welch

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

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Raleigh, NC

Mara Lewis
Cary, NC

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Mr. George J. Graf, Sr.

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

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St. Louis, MO

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Michael and Linda Klein
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Baden, PA

Bob and Kaye Brown
Butler, PA

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Drew Cucuzza
New Haven, CT

Nancy Nussbaum
Guilford, CT

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Ms. Mary Elizabeth Hanson

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A memorial fund has been established in the name of

Mr. William Haskell

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

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Ballston Spa, NY

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A memorial fund has been established in the name of

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Mr. Abraham J. Hoffman

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

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A memorial fund has been established in the name of

Mrs. Laurie Hoffman

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

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A memorial fund has been established in the name of

Mr. John C. Horner

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

Peggy J. Horner, *Winter Park, FL*

A memorial fund has been established in the name of

Ms. Patricia Janevic

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

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A memorial fund has been established in the name of

Mrs. Virginia Ann Jordan

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

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Elinor Halligan
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Baltimore, MD

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A memorial fund has been established in the name of

Ms. Thelma Joseph

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

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A memorial fund has been established in the name of

Ms. Irene Katz

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

Jane G. Evans

Suzanne Fleischman Memorial Fund for Patient Advocacy

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

New donations have been made by:

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Commonwealth of Virginia, Department of State Police
Fairfax, VA

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Ocala, FL

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A memorial fund has been established in the name of

Mr. Joseph Kryzak

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

Mary Tarczynski
Oakland, CA

A memorial fund has been established in the name of

Mrs. Hermine "Ina" Kulka

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

John and Judy Hemmert
East Brunswick, NJ

Jodi Smallwood
Old Bridge, NJ

A memorial fund has been established in the name of

Mr. Herb Kupersmit

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

Peggy Cherkasky
Pittsford, NY

A memorial fund has been established in the name of

Mr. Roy Kussner

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

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Farmington, CT

Art and Susan Israel
West Hartford, CT

Karen MacVeigh
Guilford, CT

Richard and Judy Levy
Bloomfield, CT

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Brighton, MA

Mary Webb
Philadelphia, PA

Ken and Carol O'Briot
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Ron and Pat Lapp, *Paso Robles, CA*

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Mr. Jerry Latimer

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Mrs. Irena R. Pawlik Litzenberger

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Leonard Litzenberger, *Allentown, PA*

A memorial fund has been established in the name of

Dr. Grace Yu-Sheng Lo

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Madison, WI

Yulan C. Tong
Walnut Creek, CA

Theresa Chiu, *Midland, MI*

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Marilyn Gillaspie
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Mr. Robert W. Love

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Bucks County Iron MC, *Feasterville, PA*

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Mr. Jim Lyall

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Ms. Carrie Kirkland Martin

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A memorial fund has been established in the name of

Mr. Gary Eugene Martin

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

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Buena Park, CA

Mary Martin
Buena Park, CA

Richard Yazloff
Linda, CA

Eric Prater
Buena Park, CA

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Ms. Grace S. Miyawaki

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Mary Miyawaki, *Honolulu, HI*

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Mr. Lavere C. Munn

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Gary Munn, *Dalton, GA*

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Mr. Chuck Navasky

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Covington, GA

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

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A memorial fund has been established in the name of

Mr. Michael Oertelt

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

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Ms. Muriel Oliverio

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A memorial fund has been established in the name of

Mrs. Mary Ann Opanowicz

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Mr. Ronald Pare

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A memorial fund has been established in the name of

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Joan F.D. West
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Feasterville Trevose, PA

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Ms. Wanda Sobieski

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Bill and Ann Cochran
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A memorial fund has been established in the name of

Dr. Thomas E. Sooy

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

Diane M. Sooy
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A memorial fund has been established in the name of

Mr. Raymond E. Thomas

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Claire Rider
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Mr. Robert Edward Thomas

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Chapel Hill, NC

A memorial fund has been established in the name of

Mr. William Thomas

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

Amy Gotham
Lake Placid, NY

Sally Thomas
South Colton, NY

A memorial fund has been established in the name of

Mrs. Jeanette Toth

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

Dave and Donna Bunton
Arlington, VA

Joseph Toth
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A memorial fund has been established in the name of

Mr. Joseph A. Vaccaro

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Glendale, AZ

Dee Vaccaro
Timonium, MD

Donald Breen
Theresa, NY

A memorial fund has been established in the name of

Ms. Lois VanHorn

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Mercer Island, WA

A memorial fund has been established in the name of

Mrs. Grace Vieraitis

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

Melinda Mann
Brookline, MA

A memorial fund has been established in the name of

Mr. John Walsh

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

Ed and Ronny Wahl
Naples, FL

A memorial fund has been established in the name of

Mr. Derek Harold Wells

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

Wendy Wells
Suffolk, UK

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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Ann Arbor, MI

A memorial fund has been established in the name of

Mr. David Yoh

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

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Sylvia Ostrow, Miami, FL

David and Nancy Ristow
Ada, MI

A memorial fund has been established in the name of

Mrs. Lisa Post Zahler

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

STAC (Students and Teachers Against Cancer)
Sewanhaka Central High School
Floral Park, NY

MDS Foundation Information

The Foundation's Board of Directors

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the myelodysplastic syndromes foundation, inc.

Become a Member

The MDS Foundation would like to have you as a member. Membership is US$50 a year for physicians and other professionals. Patients, their families, and others interested in MDS may join at the reduced rate of $35.

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.

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

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If you wish to support the work of the Foundation in the battle against MDS, please remember us and consider donating all year long.

Every penny helps. All donations are tax-deductible.

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

Thank you for your support.