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mds news
newsletter of the myelodysplastic syndromes foundation

MDS News Highlights

ASH 2012 – MDS FOUNDATION SYMPOSIUM

- ***Myelodysplastic Syndromes: Current Understanding and Management Approaches***

Effective management of MDS requires understanding of underlying disease-specific abnormalities as well as patient-related features. These issues as well as current standard and recent novel therapeutic advances for MDS patients will be discussed.

REVISED INTERNATIONAL PROGNOSTIC SCORING SYSTEM FOR MDS

IWG-PM
INTERNATIONAL WORKING GROUP FOR THE PROGNOSIS OF MDS

The manuscript describing the Revised IPSS (IPSS-R) for MDS is available now **in the September 23, 2012 issue of *Blood* (vol. 120, p. 2454)**.

FROM THE GUEST EDITOR'S DESK

- ***Recent Molecular Abnormalities in MDS***

Presented by Luca Malcovati, MD

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Recent Molecular Abnormalities in MDS

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Myelodysplastic syndromes (MDS) are a heterogeneous group of hematologic disorders characterized by ineffective hematopoiesis, peripheral cytopenias and increased risk of evolution into acute myeloid leukemia (AML).[1] MDS are included in the category of myeloid neoplasms in the World Health Organization (WHO) classification of tumors of hematopoietic and lymphoid tissues, together with myeloproliferative neoplasms (MPN), myelodysplastic/myeloproliferative neoplasms (MDS/MPN), and AML.[2]

MDS represent some of the most common hematologic malignancies in Western countries. They occur mainly in elderly people with a median age at diagnosis of 70–75 years. Incidence is approximately 5 per 100,000 persons per year in the general population, but increases to 20–50 per 100,000 persons per year over the age of 60.[3] Considering the progressive aging of the population in Western countries, the number of MDS patients is destined to increase over the next decades, making MDS one of the most challenging issues for hematologists and health care providers in the near future.

MDS are characterized by clonal proliferation of hematopoietic cells that differentiate inefficiently as a result of excessive apoptosis of hematopoietic precursors. The bone marrow is generally hypercellular and several morphological abnormalities are observed in one or more cell lineages, whereas peripheral blood cells are variably reduced. With time, differentiation and maturation of hematopoietic cells are progressively impaired, and there is an increasingly high risk of evolution to overt AML.

Unravelling the Molecular Basis of MDS

Until recently, the molecular basis of MDS had remained elusive. Recurrent chromosomal abnormalities, in particular deletions or amplifications of large chromosomal segments, were reported in approximately 50% of MDS patients using standard chromosomal banding analysis. Among the most frequent are –5/del(5q), –7/del(7q), trisomy 8, del(20q), and a complex karyotype.[4] However, the last few years have seen important progress in this field.

Gene Haploinsufficiency

Deletions of the long arm of chromosome 5 are the most frequent single chromosomal abnormality in MDS. Patients with isolated del(5q) may present a peculiar clinical phenotype, first described by Van den Berghe et al. in 1974 and defined as the 5q- syndrome.[5] Patients with the 5q- syndrome have a macrocytic anemia, with normal or elevated platelet counts associated with hypolobulated megakaryocytes in the bone marrow.

The determination of the commonly deleted region located at 5q33 was the first step towards clarifying the molecular basis of MDS.[6] Sequencing and high-resolution techniques failed to identify mutations in the commonly deleted region, whereas a functional screening of all these genes by an RNA-mediated interference-based approach determined that haploinsufficiency of RPS14, encoding a component of the 40S ribosomal subunit, is likely the cause of the erythropoietic defect in the 5q– syndrome.[7] Interestingly, heterozygous inactivating mutations in RPS19 and other ribosomal proteins were previously described in Diamond Blackfan Anemia, an inherited bone marrow failure syndrome.

Subsequent investigations showed that ribosomal deficiency in 5q– syndrome results in activation of p53 and defective erythropoiesis.[8] Other data from mouse models suggested that haploinsufficiency of the microRNA genes miR-145 and miR-146a may contribute to the dysregulated megakaryopoesis and thrombocytosis seen in this disorder.[9]

Acquired Somatic Mutations

Acquired somatic mutations have been recently detected in several genes. The genes mutated in MDS can be classified according to the function of the proteins they encode. The most commonly mutated class of genes in MDS encode splicing factors (SF3B1, U2AF1/U2AF35, ZRSR2, SRSF2, SF3A1, PRPF40B, U2AF2/U2AF65, and SF1).[10,11] Genes encoding epigenetic regulators are also commonly mutated in MDS, including TET2, DNMT3A, IDH1/2, ASXL1, and EZH2.[12,13] Transcription factors involved in hematopoietic progenitor cells are also mutated, including RUNX1 and ETV6.[14] Mutations that lead to activated tyrosine kinase signaling occur in the genes encoding JAK2, NRAS/KRAS, PTPN11, MPL, and CBL.[15] Mutations of the tumor suppressor gene TP53, involved in DNA damage repair pathway, are also common.[16]

Recently, two groups have published independent reports of mutations involving multiple components of the RNA splicing machinery. Somatic mutations of SF3B1, a gene encoding subunit 1 of the splicing factor 3b protein complex, were first described by investigators from the Chronic Myeloid Disorders Working Group (CMD-WG) of the International Cancer Genome Consortium.[10] Using massively parallel sequencing, the CMD-WG investigators found somatic mutations of SF3B1 in six of eight patients with refractory anemia with ring sideroblasts. A targeted resequencing of the gene in hematologic malignancies and solid tumors showed SF3B1 mutations in approximately 30% of patients with MDS, and 20% of patients with myelodysplastic/myeloproliferative neoplasm (MDS/MPN).

The gene was also found to be mutated in smaller proportions of patients with other types of tumor.

In patients with MDS, a close relationship was found between ring sideroblasts and SF3B1 mutations. Interestingly, a high prevalence of SF3B1 mutations was found in patients with 15% or greater bone marrow ring sideroblasts as well as in those with less than 15%.[17] SF3B1 mutations were associated with downregulation of key gene networks, including core mitochondrial pathways.[10] The association between SF3B1 mutation and ring sideroblasts was confirmed across all the myeloid neoplasms, including myeloproliferative neoplasms (MPN) and MDS/MPN. In fact, among MDS/MPN, a high prevalence of SF3B1 mutations was also observed in patients with RARS associated with marked thrombocytosis.[17] In addition, somatic mutations of SF3B1 were also observed in a small fraction of patients with primary myelofibrosis, and in all cases sideroblasts were detected in the bone marrow.[18]

In the same period, the CMD-WG described SF3B1 mutation in MDS with ring sideroblasts. Yoshida et al. performed whole exome sequencing in various subtypes of MDS and described mutations in multiple components of the spliceosome, including U2AF1, ZRSR2, and SRSF2, mainly in myeloid disorders without ring sideroblasts.[11] In particular, approximately one-third of patients with chronic myelomonocytic leukemia (CMML) had a somatic mutation of SRSF2. Although little is currently known about the downstream processes that are affected by spliceosome mutations, these data clearly suggest that genes encoding core components of the RNA splicing machinery play a major role in MDS pathophysiology.

Epigenetic modifications mediate changes in gene expression through chemical modifications of DNA, including methylation of dinucleotides, and methylation or acetylation of histone proteins. Aberrant DNA methylation has been implicated in the pathogenesis of MDS and AML, and aberrant methylation profiles were observed in both disorders. In addition, hypomethylating agents, such as azacitidine and decitabine, are effective in the treatment of MDS, and are indeed associated with changes in genome-wide methylation patterns in bone marrow cells of treated patients. However, no key genes or methylation signatures that may predict response to therapy have been recognized.

TET2 mutations have been identified in approximately 25% of patients with MDS.[19] These mutations cause a loss of function of the TET2 enzyme that converts 5-methylcytosine to 5-hydroxymethylcytosine. Additional evidence suggests that TET2 is important for normal myelopoiesis, and that disruption of TET2 enzymatic activity favors myeloid tumorigenesis.[20]

Mutations in DNA methyltransferase 3A (DNMT3A) were first discovered by whole genome sequencing in AML cases, and subsequently identified in 5–10% of MDS patients. DNMT3A adds a methyl group to the 5' position of CpG dinucleotides. Experiments in mice showed that disruption of DNMT3A results in impaired hematopoietic differentiation but not in hematologic malignancy, suggesting that transformation requires co-operating mutations.[21]

Mutations in genes involved in the regulation of histone function were also recognized, including EZH2, and ASXL1. Mutations in ASXL1 have been found in 10–15% of MDS patients. Loss of function of ASXL1 leads to increased expression of HOX genes and defective differentiation of hematopoietic progenitors.[22] Somatic

INTERNATIONAL PROGNOSTIC SCORING

Revised International Prognostic Scoring System for MDS

IWG-PM
INTERNATIONAL WORKING GROUP FOR THE PROGNOSIS OF MDS

The manuscript describing the Revised IPSS (IPSS-R) for MDS is available now **in the September 23, 2012 issue of *Blood* (vol. 120, p. 2454)**.

Under the aegis of the MDS Foundation, the International Working Group for Prognosis in MDS (IWG-PM) analyzed clinical features and outcome data from over 7000 patients and generated **an improved** method analyzing MDS patient prognosis more precisely than the initial IPSS.

Novel components of this prognostic system include: five rather than three cytogenetic prognostic subgroups with specific and new classifications of a number of less common cytogenetic subsets, splitting the low marrow blast percentage value, and **assessing** depth of cytopenias. In addition to the major prognostic variables of marrow blasts, cytogenetics and peripheral cytopenias, additive features for survival include patient age, performance status, serum ferritin and LDH.

URLs for a web-based calculator tool to calculate the IPSS-R are located at the MDS Foundation website: http://www.mds-foundation.org/ipss-r-calculator or http://www.ipss-r.com.

This IPSS-R should prove beneficial for predicting the clinical outcomes of untreated MDS patients and aiding design and analysis of clinical trials in this disease. Copies of this manuscript are available upon request from the MDS Foundation and can also be accessed online at: http://www.mdsfoundation.org/revisedprognostic-system-for-mds/.

mutations in EZH2 were detected in 2–6% of MDS patients. EZH2 is part of a methyltransferase responsible for methylation of histone 3. Inactivating mutations in members of this complex result in activated gene expression.[13]

Additional studies will be required to clarify the specific mechanisms by which these mutated genes contribute to MDS pathogenesis and the patterns of association between mutations. Further studies will also help us understand the clinical implications of these mutations in terms of disease course, treatment response and survival.

Integrating Somatic Mutations in the Diagnosis and Classification of MDS

The current diagnostic approach to MDS includes morphological analysis to detect abnormalities of peripheral blood cells and hematopoietic precursors, bone marrow biopsy to evaluate marrow cellularity and topography, and cytogenetics to detect clonal chromosomal abnormalities. The combination of marrow dysplasia and clonal cytogenetic abnormalities allows a conclusive diagnosis of MDS to be made, but this is found in only a fraction of patients. In many instances, the diagnosis of MDS is exclusively based on clinical and morphological criteria, and may be particularly difficult in patients who do not have robust morphological markers, such as ring sideroblasts or excess of blasts.

A major effort should be made to identify novel diagnostic tools that may improve the accuracy of MDS diagnosis.

Although most of the genes recurrently mutated in MDS can be detected in different myeloid neoplasms and are not, therefore, specific for MDS, they may be a valuable means of obtaining evidence of a clonal disorder in patients with suspected MDS. In a recent comprehensive report, 52% of patients with normal cytogenetics had at least one point mutation.[14] These figures are even higher for mutations of the genes encoding for splicing factors.

Recent studies in chronic myelomonocytic leukemia reported cytogenetic aberrations in approximately 20% of patients, whereas a comprehensive mutation analysis revealed that 93% of patients with this disorder carried at least one somatic mutation.[23]

Although, at this stage, the screening of such molecular defects cannot be recommended on a routine basis, the spread of massive genotyping methods will soon make it possible for clinicians to detect a broad range of cytogenetic aberrations in peripheral blood at a reasonable cost, making it easier to confirm diagnosis in patients with suspected MDS.

Genotype-phenotype Correlations: The Foundation Stone for a Molecular Classification of MDS

In a group of disorders classified on the basis of morphological criteria, identifying specific associations between genotype and disease phenotype is essential for recognizing disease entities according to distinctive genetic profiles.

This genotype-phenotype correlation in MDS is illustrated by the 5q- syndrome. The typical hematologic phenotype includes macrocytic anemia, normal or elevated platelet count with hypolobated megakaryocytes, and a low rate of progression to AML. In 2001, the WHO classification recognized MDS with isolated del(5q) as a distinct disease entity. Although cases classified in this subtype show different morphological features, and most patients do not have the specific combination of signs that constitute the 5q- syndrome, this represents the first subtype of MDS defined by a genetic abnormality.[2]

A major step forward in genotype-phenotype correlation has been the identification of somatically acquired mutations in SF3B1 in MDS patients with ring sideroblasts. The specific association between SF3B1 and ring sideroblasts was unequivocally demonstrated by the analysis of a subgroup of patients in whom an accurate quantitative enumeration of ring sideroblasts was performed using recently established consensus criteria, irrespective of WHO categories. Overall, the SF3B1 mutation status had a positive predictive value for disease phenotype with ring sideroblasts of 97.7%, while the absence of ring sideroblasts had a negative predictive value for SF3B1 mutation of 97.8%. The causal relationship between SF3B1 mutation and ring sideroblasts was also supported by the significant association between the SF3B1 mutant allele burden and the percentage of ring sideroblasts.[17]

Although several issues still remain to be clarified, these observations are important for MDS classification. The RCMD-RS category was created in the 2001 WHO classification of myeloid neoplasms, but was then incorporated into the RCMD category in the updated 2008 WHO classification. These findings suggest that RCMD and RCMD-RS should instead be considered as separate categories, or a distinction should at least be made between patients with wild-type or mutated SF3B1.

In addition, the observation that SF3B1 mutations were found in patients with 15% or greater bone marrow ring sideroblasts as well as in those with less than 15%, suggests that this threshold, first adopted by the FAB and then by the WHO classification, does not recognize separate entities, and that, instead, the proportion of ring sideroblasts in the bone marrow appears to be a continuum of a unique biological process.

Prognostic Relevance of Somatic Mutations in MDS: Toward Next-Generation Prognostic Scoring Systems

Myelodysplastic syndromes are a heterogeneous group of disorders ranging from indolent conditions with a near-normal life expectancy to forms close to AML. A risk-adapted treatment strategy is mandatory for conditions showing such a highly variable clinical course. Prognostic assessment in patients with MDS is currently based on stratification systems that combine multiple clinical and hematologic variables, including the International Prognostic Scoring System (IPSS),[24] which

has been the reference for clinical decision-making as well as for design and analysis of clinical trials in these disorders, the WHO classification-based prognostic scoring system (WPSS),[25] the M.D. Anderson Prognostic Scoring System (MPSS)[26] and, more recently, the revised IPSS.[27]

The available evidence clearly indicates that a greater understanding of the molecular basis of MDS may improve our ability to stratify the prognosis of patients with MDS.

Mutations in several genes have been reported to influence overall survival and risk of disease progression in MDS. Recently, a comprehensive analysis of patients with MDS identified mutations in five genes (ASXL1, RUNX1, TP53, EZH2, and ETV6) that were significantly associated with poor survival after adjustment for demographic factors and IPSS risk groups.[14] A prognostic model was then developed to integrate the mutational analysis results into the IPSS, by including a variable for mutations in one or more of these five prognostic genes. More recently, SF3B1 mutations were found to be independent predictors of favorable clinical outcome after adjusting for IPSS or WPSS.[17]

Taken together, this evidence suggests that the integration of somatic mutations in next-generation prognostic scoring systems is resulting in more accurate stratification of individual patient risk, and further refines clinical decision making in MDS.

Conclusion

Our understanding of the molecular basis of MDS is improving rapidly. The identification of genetic defects and the recognition of their association to clinical features and outcome is going to have a major impact on our approach to MDS patients. The more widespread use of massive genotyping technology will soon enable us to detect a broad range of gene mutations at a reasonable cost. This will make diagnosis of these disorders easier, and will improve our assessment of individual patient risk, the selection of appropriate therapy and the monitoring of response to treatment.

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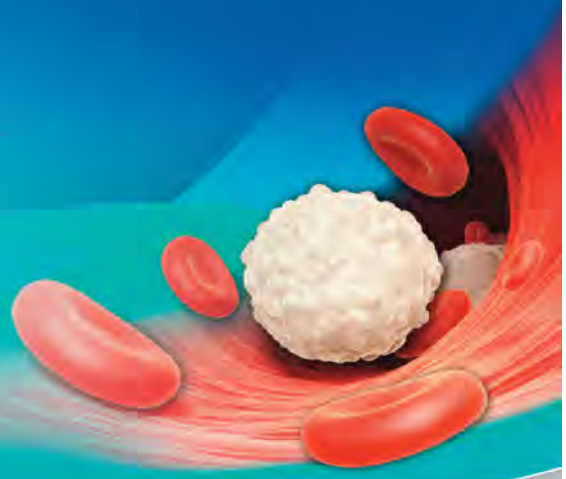
Join Us for a FREE CME/CE Breakfast Program

Myelodysplastic Syndromes:
Current Understanding & Management Approaches



FRIDAY
December 7, 2012

7:00 AM Breakfast & Registration
7:30 – 11:00 AM Presentation

Georgia World Congress Center
Sidney J. Marcus Auditorium
285 Andrew Young International Blvd., Atlanta, GA

TARGET AUDIENCE:

This activity is intended for physicians, oncology nurses, nurse practitioners, physician assistants, and other health care professionals interested in the treatment and management of patients with Myelodysplastic Syndromes.

OUTCOMES OBJECTIVES:

Upon completion of this course, the participant will be better able to:

- Discuss underlying pathogenetic molecular lesions and constitutional predispositions in MDS patients.
- Describe the connection between patients' comorbidities, treatments and clinical outcomes.
- Identify potentially novel agents being evaluated in clinical trials for patients not responding to standard therapy.
- Describe the current status of and indications for reduced intensity conditioning and umbilical cord blood as approaches for HSCT in MDS patients.
- Develop insight into the patients' perspectives of the impact of the disease and its treatment on their quality of life.
- Apply evidence-based interventions in the care of the MDS patient for better outcomes.

FUNDING:

Supported by educational grants from: Celgene Corporation, Amgen Inc., and Onconova Therapeutics, Inc.

PURPOSE:

Effective management of MDS requires understanding of underlying disease-specific abnormalities as well as patient-related features. These issues as well as current standard and recent novel therapeutic advances for MDS patients will be discussed.

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DISCLOSURES:

Faculty disclosures will be provided on the first page of the program syllabus.

ACCREDITATION:

This activity has been planned and implemented in accordance with the Essential Areas and Policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint sponsorship of the Foundation for Care Management (FCM) and The Myelodysplastic Syndromes Foundation. FCM is accredited by the ACCME to provide continuing medical education for physicians.

FCM designates this educational activity for a maximum of **3.5 *AMA PRA Category 1 credits™***. Physicians should only claim credit commensurate with the extent of the participation in the activity.

The Foundation for Care Management is an approved provider of continuing nursing education by the Washington State Nurses Association Continuing Education Approval & Recognition Program (CEARP), an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

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PLAN TO ATTEND: ASH 2012 SYMPOSIUM

Myelodysplastic Syndromes: Current Understanding and Management Approaches

December 7, 2012 • Georgia World Congress Center

AGENDA

PROGRAM OVERVIEW

Effective management of MDS requires understanding of underlying disease-specific abnormalities as well as patient-related features. These issues as well as current standard and recent novel therapeutic advances for MDS patients will be discussed.

7:30 am – 7:40 am

- **Program Overview and Objectives**
  Stephen D. Nimer, MD
  Sylvester Comprehensive Cancer Center
  University of Miami

Advances in Understanding Disease Pathogenesis

7:40 am – 8:15 am

- **Bone Marrow Failure in MDS: Role of Abnormal Telomere Dynamics**
  Neal S. Young, MD, MACP
  NHLBI, NIH

8:15 am – 8:50 am

- **Somatic Mutations in MDS: Insight into their Prognostic and Biological Importance**
  Timothy Graubert, MD
  Washington University

Therapeutic Advances

8:50 am – 9:25 am

- **Impact of Co-Morbidities and Treatment in Lower Risk MDS: Interim Results from the EU MDS Registry**
  Theo de Witte, MD, PhD
  University of Nijmegen

9:25 am – 10:00 am

- **Biomarker-Directed Treatment Approaches for MDS**
  Alan F. List, MD
  Moffitt Cancer Center

10:00 am – 10:35 am

- **Progress in Reduced Intensity Hematopoietic Stem Cell Transplantation in MDS**
  Mary M. Horowitz, MD, MS
  Medical College of Wisconsin, CIBMTR

10:35 am – 11:00 am

- **Questions/Answers/Discussion**

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 maintain not only this newsletter but also the development of continuing medical education programs, and the dissemination of patient information.

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The MDS Foundation is seeking members to join our Development Committee. Whether your contribution is time, skills, funds, or ideas you can make a difference! For more information contact Tracey Iraca at **tiraca@mds-foundation.org** or call **800.637.0839**.

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Please think of the MDS Foundation in your holiday giving this year and help people living with MDS.

Thank you for your continued support!

Sign up to volunteer!

If you are interested in helping out in the MDS Foundation office or in attending events as a representative of the MDSF, please call us at **800-MDS(637)-0839**.

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

The Myelodysplastic Syndromes: Challenges and Strategies for Effective Outpatient Management

Educational Symposium Held in New Orleans, LA

The MDS Foundation was pleased to participate in this year's Oncology Nursing Society (ONS) annual meeting held in conjunction with its 37th Annual Congress on May 3, 2012. More than 300 nurses from across the country joined us to learn more about MDS and its treatments.

Our distinguished faculty included 4 illustrious members of our Nurse Leadership Board: Sandra E. Kurtin, Jean A. Ridgeway, Jayshree Shah, and Sara M. Tinsley. Our presenters provided the oncology nursing professional with the tools to assist patients and their families in meeting the challenge of living with MDS. Learning objectives imparted by our presenters included recent advances in strategies for the treatment of MDS from prognosis to treatment; practical tools for effective management; web-based resources for patients and nurses; as well as information developed from our Patient and Family Forums that have been held around the world which formed the basis for the presentation on patient and family support throughout the continuum of care.

During this congress the International Nurse Leadership Board for the MDS Foundation introduced a supplement to the *Clinical Journal of Oncology Nursing* which incorporates an update on the science of MDS, practical tools for clinical management of MDS including iron overload, a discussion of quality of life in the patient living with MDS, and a review of strategies and resources for support. Copies of this CJON Supplement are available upon request from the MDS Foundation and can also be accessed online at http://www.mds-foundation.org/cjon-supplement/.

The Myelodysplastic Syndromes: Challenges and Strategies for Effective Outpatient Management

Reprinted with the permission of the Oncology Nursing Society

Laura J. Pinchot, BA

At A Glance

Myelodysplastic syndromes are a category of incurable malignancies that affect mainly older adults. Cytogenetic testing and advances in targeted therapies have provided a means to extend and improve the quality of life for these patients. However, patient education and overcoming barriers, such as ageism, complex and expensive treatment regimens, and adverse events, are critical to ensuring that patients with a myelodysplastic syndrome can fully benefit from evolving therapy options.

Myelodysplastic syndromes are a class of incurable diseases that originate in the bone marrow. The disease processes are quite complex and often difficult for healthcare professionals to articulate to patients and family caregivers. Sandra E. Kurtin, RN, MS, AOCN®, ANP-C, simplified the process by comparing myelodysplastic syndromes to a "broken factory." This group of disorders is associated with the bone marrow's inability to produce healthy leukocytes, erythrocytes, and platelets. Myelodysplastic syndromes are malignant processes that can be a precursor for acute myeloid leukemia (AML). Although no complete cure is currently available, treatments are available to support patient health for months to several years after diagnosis.

Kurtin noted that nurses must embrace the fact that treatment selection for myelodysplastic syndromes is moving toward molecular-driven models. The complexity of disease and treatment can be difficult for even seasoned health professionals to grasp, which poses a challenge for patient and family education.

Cytogenetic Evaluation

Jean A. Ridgeway, MSN, APN, NP-C, AOCN®, reported thatmapping the pathophysiology of this class of hematologic diseases has come a long way since they were first classified in the 1970s. Early classification models, including the French-American-British (FAB) classification in 1976 and the World Health Organization's late-1990s revision of this system focused on cell morphology and myeloblast (blast) counts. These systems describe the disease progression based on extent of refractory anemia and increase in blasts within the marrow.

Ridgeway noted that, also in the 1990s, advances in genetic research allowed clinicians to move toward a cytogenetic evaluation of myelodysplastic syndromes, and this shift in focus greatly enhanced the understanding of the disease process and treatment effects. In addition to the previously defined parameters of cell morphology, researchers discovered that these syndromes involve multiple cytogenetic defects. This discovery has allowed clinicians to use cytogenetics to drive diagnosis, prognosis, and treatment selection (Vardiman et al., 2009; Westers et al., 2011).

Conventional metaphase cytogenetic analysis is the gold standard for analyzing karyotypes associated with myelodysplastic diseases. This process uses an aspirated sample of bone marrow to examine 20 cells that are in the metaphase stage of cell division. Clinicians are then able to map the malignant defects within chromosomes. One drawback to the process is that the cells must be in active cell division because the errors are not apparent when this process is used on non-dividing cells.

Emerging technologies are overcoming limitations to metaphase cytogenetic analysis. For example, use of the singlenucleotide polymorphism (SNP, pronounced "snip") array analysis is able to identify abnormalities in non-dividing cells. In addition to helping in diagnosis and prognosis, the SNP array also can track response to treatment, particularly therapies that target the TET2 and TP53 genes (Garcia-Manero, 2010; Gondek et al., 2008; Graubert, 2011; Maciejewski & Mufti, 2008; Tiu, Visconte, Traina, Schwandt, & Maciejewski, 2011).

Flow cytometry is another emerging technology that may be useful in identifying prognostic features of myelodysplastic syndromes. This technology analyzes cell receptor and internal protein expression. The clinician can use this to evaluate cells from both qualitative and quantitative perspectives. Although flow cytometry has potential uses, studies indicate that standardization and refinement of quantification measures is needed (Vardiman et al., 2009; Westers et al., 2011).

Emerging technologies such as flow cytometry and SNP array analysis are helping researchers study potential targeted therapies that can be tailored to a patient's specific genetic makeup. Studies are under way to identify novel agents and targets in addition to *TET2* and *TP53* (Bejar, Levine, & Ebert, 2011; Kurtin,2011; Tiu et al., 2011).

Comprehensive Prognostic Indicator

The International Prognostic Scoring System (IPSS) takes variables from cytogenetic evaluation and cell morphology indicators identified by early classification systems (e.g., cytopenias and number of bone marrow blasts) to create a comprehensive score to predict survival. Patients' scores are then placed in four risk categories: low, intermediate-1, intermediate-2, and high. Low-risk patients are expected to live 5.7 years, intermediaterisk patients have a

prognosis of 1.2–2.5 years, and high-risk patients are expected to live only a few months (0.4 years) (Greenberg et al., 2011).

Ridgeway noted that IPSS also serves to help clinicians to form a treatment strategy. In low-risk patients, the priorities are to manage cytopenias and their associated symptoms by administering packed red blood cells and thrombopoietin receptor agonists, as well as erythropoiesis-stimulating, immunomodulatory, and immunosuppressive agents (Ridgeway, Fechter, Murray, & Borràs, 2012). Prolonging survival is the focus of treating high-risk patients. These patients typically receive hypomethylating agents. Also, the only known "cure" for myelodysplastic syndromes is allogeneic hematopoietic stem cell transplantation; therefore, patients who fall into the high-risk category should be evaluated as potential candidates for transplantation (Ridgeway et al., 2012). Ridgeway and Kurtin both hesitated to use the word "cure" because myelodysplastic syndromes behave differently than other malignancies in that stem cell transplantation may not offer a complete response.

Complete Patient Care

Although the IPSS indicator is a handy tool that helps determine treatment strategy and risk, Kurtin noted that these prognostic categories were determined before current treatments were available. Therefore, high-risk patients have a prognosis of only a few months *without treatment*. The implications of this are that clinicians must identify and administer treatment quickly once a myelodysplastic syndrome is diagnosed.

In addition, Kurtin noted that although this is a disease that occurs in mostly older adults with the average age at diagnosis being aged 73, chronological age should not be the only indicator of treatment planning and prognosis evaluation. Performance status, frailty (failure to thrive), and comorbidities also should be considered (Balducci & Exermann, 2000; Pal, Katheria, & Hurria, 2010). Kurtin illustrated this point by noting that the average life expectancy for a 75-year-old in the United States is 12.5 years, and low-risk patients have an average time to progression to AML of 9.4 years (Greenberg et al., 1997). A diagnosis at older age does not indicate a death sentence. With proper treatment, an older adult can live an active life despite myelodysplastic diseases.

Family caregivers have an important role in ongoing care. Kurtin likes to call them her "truth squad" because family members and friends often can see things that the patient does not realize are occurring regarding the patient's health, such as cognitive problems and mood or personality changes. In addition, some patients may not want to admit certain symptoms for many reasons, including fear of disease progression or not wanting to be a burden. Family caregivers, including significant others, children, siblings, and friends, can provide an accurate assessment of daily life that clinicians are unable to observe in the brief window of an office visit (see **Figure 1**). Family can observe indicators of wellness, such as appetite, activity level, weakness, lack of endurances, shortness of breath, and sleeping habits (Pal et al., 2010). These indicators are important for identifying prognostic factors not included in standard

Physical

Decreased strength, decreased body organ function, altered immune response, diminished physiologic reserve, increased risk of developing concurrent illness, asthenia, exacerbation of other health conditions (e.g., CHF), dyspnea, bone pain and discomfort, malaise, fever, bleeding, weight loss, skin rash, symptoms from therapy, night sweats, and limited ability to adequately treat other conditions (e.g., hip replacement)

Social

Altered role function, diminished social interaction with friends and family, diminished economic resources, diminished social network, increased financial burden from health care, time associated with therapy, activity restrictions, planning for future, transportation challenges, altered support from family and friends, economic challenges, and alteration in sexuality

Emotional

Anxiety, loneliness, despair, uncertainty, anger and frustration, depression, communication with the healthcare team, and patient-provider relationship

Functional

Fatigue, potential for decreased cognitive function, diminished stamina, decreased mobility, missed work associated with illness and therapy, diminished ability to perform IADLs or ADLs, diminished independence, cognitive dysfunction, and demands of illness

Spiritual

Renewed appreciation for life, renewed appreciation for relationships, enhanced faith and beliefs, hopelessness, abandonment, loss of self, and search for balance (e.g., positive and negative aspects of life)

ADL—activities of daily living; CHF—congestive heart failure; IADL—instrumental ADL

Note. Five quality-of-life domains are delineated here; however, other issues are not listed that may have a significant impact.

Figure 1. Quality-of-Life Issues by Domain for Patients With Myelodysplastic Syndromes

Note. From "The Importance of Quality of Life for Patients Living With Myelodysplastic Syndromes," by M.L. Thomas, N. Crisp, & K. Campbell, 2012, *Clinical Journal of Oncology Nursing*, 16(Suppl. 1), p. 48. Copyright 2012 by the Oncology Nursing Society. Adapted with permission.

laboratory or physical examinations, such as undiagnosed comorbidities, quantifying functional status, and determining frailty.

Treatment Options

Unlike other cancers, such as lymphoma, where clinicians have a multitude of agents in their arsenal, Kurtin likened the treatments for myelodysplastic disorders as a tasting menu rather than an extensive buffet. Although research for novel therapies is ongoing, currently only three agents are approved by the U.S. Food and Drug Administration for treatment of myelodysplastic disorders: azacitidine, lenalidomide, and decitabine (Kurtin & Demakos, 2010). Therefore, clinicians need to adequately pace themselves so they do not run out of treatment options.

Although allogeneic stem cell transplantation offers hope for a cure, this is not an option for most patients, and not every patient who undergoes transplantation will experience a complete response (Kurtin, 2011; Kurtin & Demakos, 2010). However, stem cell transplantation does offer the benefits of stabilizing disease, improving hematologic status, and minimizing the need for transfusions.

In regard to treating older adults with myelodysplastic syndromes, treatment usually aligns with the National Comprehensive Cancer Network's approach to oncology care. This guideline provides a range of characteristics that encompass older adults who are functionally independent and are candidates for most treatment options to those with poor prognosis and functional status where the focus of treatment is supportive care and symptom management (National Comprehensive Cancer Network, 2011, 2012). However, one formula does not apply to all patients with myelodysplastic diseases, and treatment plans can change throughout the disease trajectory. Kurtin noted that treatment triggers can alert clinicians as to the need to modify therapy. These triggers include when a patient becomes dependent on transfusions, progression or increased symptom burden of cytopenias, increased blasts, and progression to high-risk disease.

Patient and Caregiver Education

Sara M. Tinsley, ARNP, AOCN®, expressed the importance of clear communication and patient and family education when treating myelodysplastic syndromes. "Patients really want clear information about what their diagnosis is. It's not like when patients with breast cancer tell their friends, and everyone knows what they have, so they don't have to go into a lot of explanation. Patients with myelodysplastic syndromes have the task of explaining what their disorder is, not only to their friends and family, but also to other healthcare providers who may not care for many patients with these syndromes."

Jayshree Shah, APN-C, AOCN®, MSN, BSN, BS, RN, CCRP, indicated that nurses are in a position to empower patients and families to be active participants in their care. Oncology nurses can directly affect outcomes by thoroughly understanding the disease state and available treatment options, educating patients and families in plain language about elements of treatment such as duration of therapy and potential adverse events, and providing strategies for how the patients can positively affect outcomes through healthy lifestyle choices (Kurtin, 2012). Shah also reminds nurses that a multidisciplinary approach to care using effective communication strategies among all healthcare professionals (e.g., specialists, primary care physicians, pharmacists, other nurses) results in better patient outcomes (Kurtin, 2012).

Healthcare professionals also can help by considering lifestyle factors, such as older adults who are able to drive but need to schedule appointments in the daytime because they have poor night vision. Although some older adults are retired, many still may need to schedule treatments around work schedules or social commitments. Offering this flexibility will not only allow patients to maintain active lifestyles but also will help motivate them to stick with the treatment schedule.

Kurtin said that it is important for patients and families to understand that, unlike many cancers that have a definitive beginning and end to treatment, myelodysplastic syndromes are chronic illnesses that require management for the remainder of the patient's life span. Patients may express frustration with this, and nurses should frequently remind them that treatment is "a marathon, not a sprint."

Although life-sustaining, treatment for myelodysplastic syndromes is difficult and time intensive. Patients can be subjected to many transfusions over the course of their lifetime. "Unfortunately, cytopenias are expected to become worse before they get better because treatment cleans the marrow to allow for the new growth of healthy cells," Kurtin explained. Worsening cytopenias will naturally lead to a more intense symptom experience. In addition, treatments also will suppress patients' immune systems, thus requiring them to take extra precautions to avoid infections. Kurtin stressed that patients and families need to thoroughly understand this trajectory at the outset of treatment so that they avoid frustration and discouragement. Patients who understand the disease process and that they need to "get to the other side of the [cytopenias] ravine" before their condition can improve are more likely to comply with the treatment regimen.

In addition to the effects of immunosuppressive therapies and worsening cytopenias, patients also will have to deal with toxicities related to multiple transfusions. Shah noted that healthcare professionals should be aware of the potential for iron overload because each unit of packed red blood cells that a patient receives contains 25 mg of inextricable iron. This extra iron cumulates in the heart, liver, and endocrine system, which can lead to toxicities in these organs. Iron chelation therapy can correct this, but Shah warns that this is not without side effects. Patients who undergo chelation therapy can experience pancytopenia, high-frequency hearing loss, and ocular disorders, such as

cataracts and increased pressure (Jabbour, Garcia-Manero, Taher, & Kantarjian, 2009; Kurtin, 2007; Malcovati et al., 2005).

Reliable Resources for Patients

Shah noted that the International Nursing Leadership Board of the Myelodysplastic Syndromes Foundation has created a patient education tool called *Building Blocks of Hope: A Patient and Care Giver Guide for LIVING With MDS*. The guide answers questions about the syndromes and their treatment options, and offers suggestions about how patients can adopt healthy strategies and be an active part of the treatment team. The guide encourages patients to continue with usual activities while using common sense to avoid illnesses associated with suppressed immunity.

Tinsley suggested that, in addition to information nurses can provide during appointments, a wealth of resources are available on the Internet from many organizations, such as the Myelodysplastic Syndromes Foundation (www.mds-foundation.org), the Leukemia and Lymphoma Society (www.lls.org), and the American Cancer Society (www.cancer.org). These sites offer patient-specific information written in clear language that helps to cut through medical jargon. Some sites offer access to support groups, message boards, and clinical trial information.

Summary

To effectively manage myelodysplastic syndromes, clinicians must have a thorough grasp of the disease state, treatment trajectory, and expected side effects. In addition, effective communication, both through patient education and among multidisciplinary team members, will help improve treatment compliance and patient outcomes.

Kurtin stressed that continued treatment provides the best opportunity for positive responses. She noted that barriers to treatment, including clinicians' ageism toward patients, patients' and caregivers' perceptions of lack of treatment benefit, treatment noncompliance, and toxicities and adverse events, can be overcome by clear expectations and care plans, rapid identification and management of side effects and adverse events, and a partnership with the patient and family (Eliasson, Clifford, Barber, & Marin, 2011). Overcoming these barriers can help to ensure that patients with myelodysplastic syndromes can live full, active lives despite their illness.

– Reporting by Laura J. Pinchot, BA

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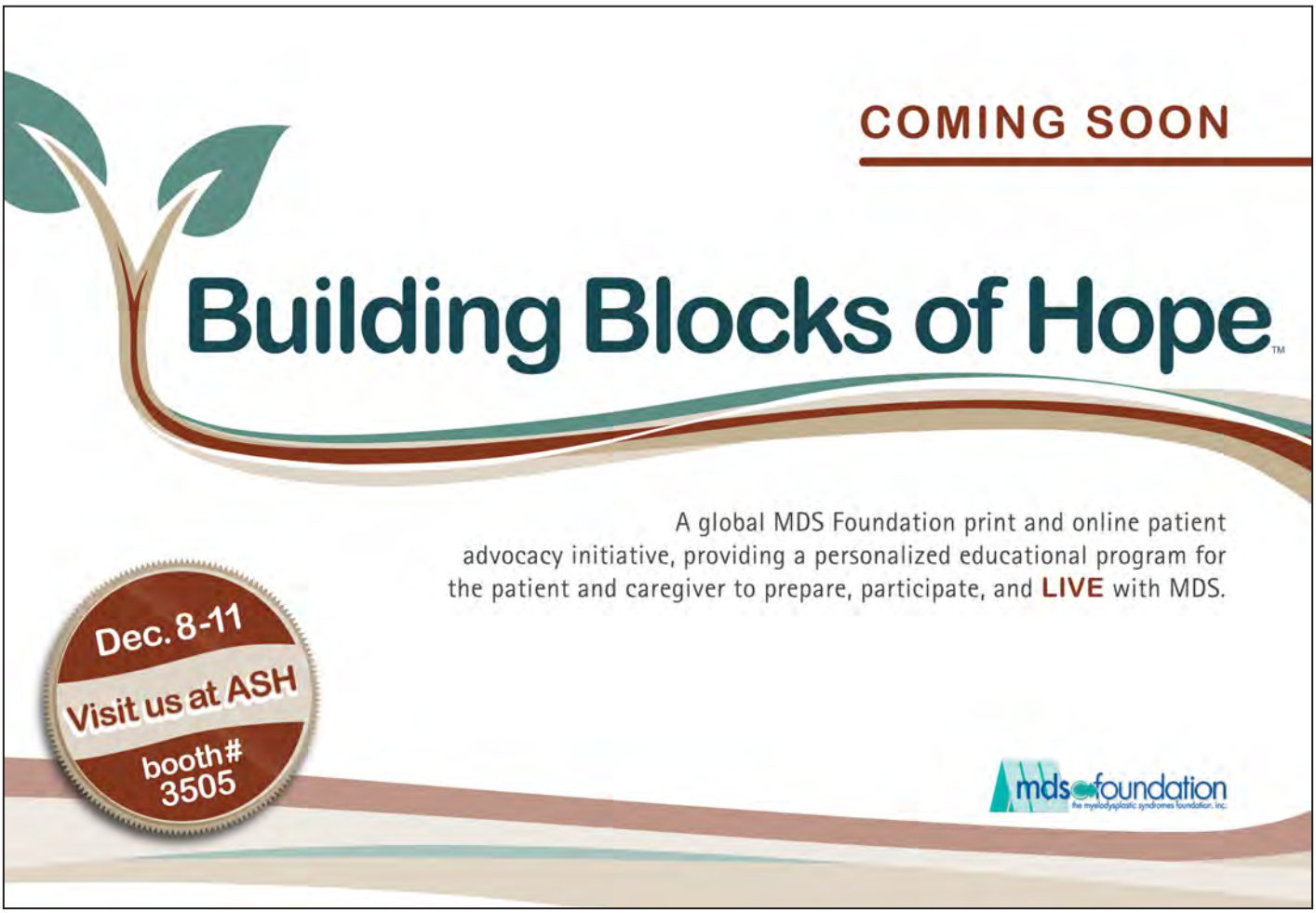
Pinchot, Laura J. (reporter). *Spotlight on Symposia From Oncology Nursing Society 37th Annual Congress: The Myelodysplastic Syndromes: Challenges and Strategies for Effective Outpatient Management.* 2012;5–8.

JUST BACK:
AARP National Event in New Orleans

A special thank you to Joan Weidenfeld, a member of our MDSF Development Committee, for suggesting that we attend the AARP Convention to spread MDS awareness. Our booth was well attended and we were able to distribute a great amount of information. It was the first time that we had an MDS patient joining us at our exhibit booth. We look forward to another successful event next year.

Her idea made a difference!



mds foundation
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The 12th International Symposium on MYELODYSPLASTIC SYNDROMES

PRELIMINARY TIMETABLE *subject to change

Plenary Session	Interactive Session	Poster Session
Social Event	Oral Session	Best Abstracts

WEDNESDAY, MAY 8, 2013

14:00-17:00	Morphology in MDS (Microscopy, basic-course, advanced course)
17:00	Opening Ceremony
19:00	Welcome Reception

THURSDAY, MAY 9, 2013

8:30-10:00	Plenary I: PathogenOMEs in MDS – new players and well known gamblers 1. The Genome 2. The Spliceosome 3. The Epigenome 4. Impact of alterations of OMEs for Classification: IWG-PM/Molecular
10:00-10:30	Coffee Break
10:30-11:30	Plenary II: Diagnosis in 2013– state-of-the-art 1. WHO 2013 2. Cytogenetic Advances 3. IPSS-R(evised)
11:30-12:30	Interactive I: Challenging diagnostic cases – does molecular genetics lead the way? 1. RA/RCMD – RAEB-I – RAEB-II - AML 2. CMML 3. RARS-T
12:30-13:30	Lunch
13:30-14:30	Plenary III: What can MDS-specialists learn from ... 1. Childhood MDS 2. Progeria 3. Overlap of BMF and MDS
14:30-16:00	Oral Session I – Pathogenesis
16:00-16:30	Coffee Break
16:30-18:00	Poster Session (+ guided poster discussion)

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SUBMIT YOUR ABSTRACT FOR A CHANCE TO PRESENT IN THESE SESSIONS

FRIDAY, MAY 10, 2013

8:30-10:00	Plenary IV: Treatment of low risk MDS patients – the standard, the new 1. Immunosuppressive therapy 2. Iron chelation – initiation based on LIC rather than serum ferritin? 3. ESAs/TSAs – The higher the dose, the better the response? 4. Lenalidomide as a standard treatment for low risk MDS with 5q abnormality?
10:00-10:30	Coffee Break
10:30-11:30	Plenary V: Treatment of high risk MDS patients 1. Molecular targets – treatment options 2. Hypomethylating agents for treatment of high risk MDS 3. Combination regimens in high risk MDS
11:30-12:30	Interactive II (allo SCT) 1. Patients selection 2. Pre treatment 3. Management of graft versus host disease
12:30-13:30	Lunch
13:30-14:30	Best abstracts (Bastianello-Awards)
14:30-16:00	Oral Session II – treatment and trials
16:00-16:30	Coffee Break
16:30-18:00	Poster Session (+ guided poster discussion)

SATURDAY, MAY 11, 2013

8:30-10:00	Oral Session III – prognostication and QoL
10:00-10:30	Coffee break
10:30-12:00	Plenary VI: Future perspectives and new drug development 1. Microenvironment 2. Next generation sequencing – diagnostic/prognostic key? 3. Therapy related MDS 4. Pipeline overview: Disease modifying drugs in MDS
12:00-12:30	Closing Remarks

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Symposium Chairmen:

Arnold Ganser, M.D., Ph.D.
Hannover Medical School, Germany

Wolf-Karsten Hofmann, M.D., Ph.D.
University Hospital Mannheim, Germany

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. Maynadie M et al. Survival of European patients diagnosed with myeloid malignancies: a HAEMACARE study. *Haematologica*. 2012, Sep 14. [Epub ahead of print]

   The report presented analysis of 58,800 cases incidence between 1995-2002 from 48 population-based cancer registries in 20 European countries. Among myeloid malignancies, the five-year overall survival estimates were 17% for AML, 20% for MDS/MPD neoplasms, 31% MDS and 63% MPD.

2. Zandberg DP et al. Tertiary center referral patterns for patients with myelodysplastic syndrome are indicative of age and race disparities: a single-institution experience. *Leukemia Lymphoma*. 2012, Sep 8. [Epub ahead of print]

   A retrospective chart review of MDS patients (N=252) seen between 2000–2010 at a single large American academic institution demonstrated that the median age of black men at diagnosis was remarkably younger than the white men (62 vs. 68 years respectively, p=0.03) and a longer time to referral was noted with the black men as well (9 mo vs. 1.5 months in white men, p=0.03). No such differences were noted in women.

3. Foran JM and Shammo JM. Clinical presentation, diagnosis and prognosis of myelodysplastic syndromes. *Am J Med*. 2012;125(7, suppl):S6-13.

   The article describes a flow chart for a primary care physician with different indicators of the need for differential diagnosis of MDS. This flow chart suggests immediate referral to specialty physician if bi- or multi-lineage cytopenias are seen. For a mono-lineage cytopenia the referral is advised after ruling out the common causes of cytopenia.

4. Kurtin SE et al. Patient and family resources for living with myelodysplastic syndromes. *Clin J Onc Nursing*. 2012;16:58-64.

   The authors have identified a communication gap between MDS treaters, patients and their caregiver and have provided listing of valuable knowledge resources to assist in bridging the gap.

5. Niscola P et al. Transfusions at home in patients with myelodysplastic syndromes. *Leukemia Res*. 2012;36(6):684-688.

   A 5-year home care program evaluating 211 patients treated during its implementation has underscored the feasibility of at-home transfusions preserving the quality of life. The report however, warrants regarding the provision of a dedicated home care service for this purpose.

DIAGNOSIS/PROGNOSIS:

1. Greenberg PL et al. Revised international prognostic scoring system for myelodysplastic syndromes. *Blood*. 2012;120(12):2454-2465.

   Combining MDS patient databases from several international institutions offered a pool of 7012 MDS patients in the revised analysis (IPSS-R) compared to 816 patients included in IPSS. Cytopenias, cytogenetics and marrow blast counts remained foundational in IPSS-R, albeit with more detailed categorization and addition of several new entities. The new model recommends five prognostic categories as opposed to the original four. The new categories are very low, low, intermediate, high and very high risk with overall survival of 8.8, 5.3, 3, 1.6 and 0.8 years respectively.

2. Shukron O et al. Analyzing transformation of myelodysplastic syndrome to secondary acute myeloid leukemia using a large patient database. *Am J Hematol*. 2012;87(9):853-860.

   By using a model to estimate the risk of leukemic transformation as a function of time from the diagnosis in 1079 patient records from Düsseldorf MDS registry, the authors have demonstrated the risk of transformation remained constant especially in low, int-1 and int-2 IPSS categories. As a result the report concluded that there may be a single random genetic event that causes a leukemic transformation as opposed to a multi-event process.

3. Westers TM et al. Standardization of flow cytometry in myelodysplastic syndromes: a report from an international consortium and the European LeukemiaNet working group. *Leukemia*. 2012;26(7):1730-1741.

   A multi-national working group tasked in 2008 to propose standards for flow cytometry has refined the minimum criteria to assess dysplasia by flow cytometry to potentially categorize subjects as normal, or suggestive of MDS or diagnosed of MDS. The working group has suggested that flow cytometry should be a part of the integrated diagnostic panel for MDS rather than being a stand-alone technique.

4. Germing U et al. Survival, prognostic factors and rates of leukemic transformation in 381 untreated patients with MDS and del(5q): a multicenter study. *Leukemia*. 2012;26(6): 1286-1292.

   The median survival for the entire group was 74 months (44 months in transfusion dependent vs. 97 months in transfusion-independent, p<0.0001). Of the total of 381, 48% progressed to AML with a calculated risk of transformation being 4.9% at 2 years and 17.6% at 5 years. The associated prognostic factors were transfusion dependency, >5% marrow blasts and high WPSS score.

TREATMENT:

Hematopoietic Cell Transplantation (HCT):

1. Gyurcocza B and Deeg HJ. Allogeneic hematopoietic cell transplantation for MDS: For whom, when and how? *Blood Rev*. 2012, Sep 13 [Epub ahead of print].

   Treatment-related mortality and relapse have continually posed barrier to the success of HCT therapy. To this end, with the availability of cord blood stem cells and success with HLA-haploidentical donors, authors suggested a possibility of offering HCT to all patients and expressed optimism for cure in 25–75% based on the disease burden with 70% experiencing good to excellent quality of life.

2. Gerds AT et al. Pretransplantation therapy with azacitidine vs. induction chemotherapy and posttransplantation outcome in patients with MDS. *Biol Blood Marrow Transplantation*. 2012;18(8):1211-1218.

   A retrospective review of 68 cases of MDS or MDS AML with high-dose (40%) or reduced dose (60%) azacitidine in 35 patients and induction chemotherapy in 33 patients prior to HCT, showed 1 year post transplant survival of 57% with azacitidine vs. 36% with induction chemotherapy. The risk of post-HCT mortality, non-relapse mortality and relapse rates were lower with azacitidine.

Hematopoietic Growth Factors:

1. Crisà E et al. Long-term follow-up of myelodysplastic syndrome patients with moderate/severe anaemia receiving erythropoietin+ 13-cis-retinoic acid and dihydroxylated vitamin D3: independent positive impact of erythroid response on survival. *Brit J Haematol*. 2012;158(1):99.

   Previously authors reported 60% erythroid response rate with the above combination in

63 elderly patients with clinical features otherwise unfavorable to erythroid response. The present update with a 7-year follow up showed that especially in non-RAEB patients, the median duration of response was 22 months, overall survival was 55 months and among the erythroid responder subset the survival at 3-year from diagnosis was 90%.

Iron Chelation:

1. Neukirchen J et al. Improved survival in MDS patients receiving iron-chelation therapy–a matched pair analysis of 188 patients from the Düsseldorf MDS registry. *Leukemia Res*. 2012;36(8):1067-1070.

   A comparison of two groups of 94 MDS patients each with or without iron chelation treatment for transfusion related iron overload demonstrated a significant overall survival difference in favor of chelation (74 months in treated vs. 49 months untreated patients, p=0.002).

2. List AF et al. Deferasirox reduces serum ferritin and labile plasma iron in RBC transfusion-dependent patients with myelodysplastic syndrome. *J Clin Oncol*. 2012; 30(17):2134-2139.

   A three year prospective multicenter trial treated 173 patients with iron overload (serum ferritin ≥1000 g/L and had received ≥20 RBC transfusions with a continued requirement) with deferasirox (20 mg/kg/day–escalation allowed to 40 mg/kg/day). Mean serum ferritin decreased with a 23%, 36.7% and 36.5% among those treated for a length of 1 year, 2 year or 3 year respectively. In addition, in all patients with abnormal baseline labile plasma iron, normalization was seen by week 13. Overall, 28% patients showed hematologic improvement (HI) response. The common drug-related adverse events included gastro-intestinal disturbances and elevated serum creatinine.

3. Gatterman N et al. Hematologic responses to deferasirox therapy in transfusion-dependent patients with myelodysplastic syndromes. *Haematologica*. 2012;97(9):1364-1371.

   A post-hoc analysis of the EPIC study in an eligible subset of patients without any concomitant medications demonstrated hematologic improvement; 21.5% erythroid response, 13% platelet response, and 22% neutrophil response after 109, 169 and 226 days of treatment with deferasirox respectively. Labile plasma iron reduction ≤0.4 M/L was observed starting from week 12.

IMiDs:

1. Komrokji RS et al. Combined treatment with lenalidomide and epoetin alfa in lower risk patients with myelodysplastic syndrome. *Blood*. 2012, Aug 30 [Epub ahead of print].

   Low/Int-1 patients failing prior EPO were treated with 10 or 15 mg/day lenalidomide first (N=39). At week 16 non-erythroid responders were initiated on additional treatment with 40,000 IU/week rhu-EPO. With lenalidomide monotherapy, erythroid response (HI-E) was higher in del 5q patients (86%) than the others (25%). Among 23 non-responders to monotherapy and receiving combined treatment the eventual HI-E rate was 26%. The combination is being studied further in a phase III study by ECOG.

2. Sekeres MA et al. Phase 2 study of the lenalidomide and azacitidine combination in patients with higher-risk myelodysplastic syndromes. *Blood*. 2012, Aug 22 [Epub ahead of print]

   A combination of azacitidine (75 mg/m^2/day x 5 day) and lenalidomide (10 mg/day x 21 days) in a 28 day cycle was administered to a group of Int-1/Int-2 and high-risk MDS patients (N=36). The most common grade 3/4 adverse event was febrile neutropenia (22%). Overall response rate was 72% (CR-44%, HI-28%). Median CR duration was 17+ months and median overall survival for all patients was 13.6 months.

Demethylating Agents:

1. Wang R et al. The impact of hypomethylating agents on the cost of care and survival of elderly patients with myelodysplastic syndromes. *Leukemia Res*. 2012;36(11): 1370-1375.

   A model comparing 6556 MDS patients diagnosed between 2001–2007 (≥66.5 years) and taking into account MDS survival probability, estimated MDS-related-5 year cost to be higher than 18 most prevalent cancers in the USA. Furthermore for MDS, when a time period prior to the availability of hypomethylating agents (Jan 2001–Jun 2004) was compared to period after their availability (Jul 2004–Dec 2007), in parallel with an improvement in 24-month survival, the cost of patient management for 24 months was also found to be increased ($97,977 after, 2004–2207, vs. $42,628 before, 2001–2004, the availability of hypomethylating agents)

2. Greenberg PL et al. A randomized controlled trial of romiplostim in patients with low- or intermediate-risk myelodysplastic syndromes (MDS) receiving decitabine. *Leukemia Lymphoma*. 2012, Aug 20 [Epub ahead of print]

   Development of thrombocytopenia is common with hypomethylating agents. The present study tested romiplostim (n=15) vs. placebo (n=14) given concomitantly with decitabine. Mean platelet counts at the beginning of each new cycle of decitabine were higher. Also, the bleeding events and platelet transfusion rates were notably lower in romiplostim treated patients. The overall therapeutic response too was better with simultaneous administration of romiplostim.

Other Agents:

1. Sokol L et al. Randomized, dose-escalation study of the p38α MAPK inhibitor SCIO-469 in patients with myelodysplastic syndrome. *Leukemia*. 2012, Sep 11. [Epub ahead of print].

   SCIO-469 was tested at four total oral daily dose levels 90, 180,270,360 mg/day in low/int-1 MDS patients who previously did not respond to EPO (N=62). Hematologic improvement was seen in 29% patients with a median time to respond as 72 days and duration of response ranging from 63 days to >2 years. One patient each had complete or partial response and 58% patients had stable disease. Approximately 18% (11 patients) discontinued treatment due to adverse events.

2. Natarajan-Amé S et al. Bortezomib combined with low-dose cytarabine in intermediate-2 and high risk myelodysplastic syndromes. A phase I/II study by the GFM. *Brit J Haematol*. 2012; 158(2):232-237.

   Forty three higher-risk MDS patients received bortezomib (1.5 mg/m^2 on days 1,4,8,11) and low dose cytarabine arabinoside (10 mg/m^2, then 20 mg/m^2 on days 1–14) every 28 days for four cycles. With a median 29.7 months follow up, overall 28% response was seen including 1 CR. Response seemed to be limited to previously untreated patients and the responders had a superior overall survival (18.2 months) as compared to the non-responders (10 months). Major side-effects included hematologic toxicities and neuropathy.

3. Olnes MJ et al. Directed therapy for patients with myelodysplastic syndromes (MDS) by suppression of cyclin D1 with ON01910.Na. *Leukemia Res*. 2012;36(8):982-989.

   In a preclinical part of the study, ON01910.Na suppressed cyclin D1 expression in MDS patients' bone marrow mononuclear cells. Additionally in the Phase I clinical study with 12 higher risk MDS and 8 AMLs with trisomy 8, three patients showed ≥50% decrease in marrow blast counts (15%) and 3 had hematologic improvement (15%). The latter

responders showed drop in cyclin D1 expression in their marrow CD34+ cells.

PATHOBIOLOGY:

1. Zhao Y et al. Methylation of the p73 gene in patients with myelodysplastic syndromes: correlations with apoptosis and prognosis. *Tumour Biol*. 2012, Sep 28. [Epub ahead of print].

   A methylation-specific PCR in 126 de novo MDS patients demonstrated p73 gene methylation in the bone marrow mononuclear cells of 36.5% patients, which correlated with blast count and WHO classification. In vitro, decitabine restored p73 expression via its demethylation activity and increased Ara-C induced apoptosis of the bone marrow cells. The median survival was shorter in patients with methylated p73gene as compared to those without methylation (15 vs. >33 months respectively, p=0.002).

2. Ohba R et al. Clinical and genetic characteristics of congenital sideroblastic anemia: comparison with myelodysplastic syndrome with ring sideroblast (MDS-RS). *Ann Hematol*. 2012, Sep 16. [Epub ahead of print]

   A nationwide survey in Japan for sideroblastic anemia collected records of 137 patients with RCMD (n=72), RARS (n=47) or congenital sideroblastic anemia (CSA, n=18). The genetic analysis data demonstrated distinct genetic mutations in CSA. The SF3B1 mutation common to MDS with ringed sideroblasts was absent in CSA and 70% cases of the latter had ALAS2 gene mutation.

3. Mailloux AW et al. Expansion of effector memory regulatory T cells represents a novel prognostic factor in lower risk myelodysplastic syndrome. *J Immunol*. 2012;189(6): 3198-208

   T-regulatory (Treg) cell compartment was found to be altered in 34.6% of a total of 52 MDS patients with low risk of leukemic transformation. Expansion of Treg may be indicative of a change in bone marrow microenvironment. An increase in the absolute count of CD4(+) FOXP3(+) CD25(+) CD127 (low) CD45RA(–) CD27(–) Tregs (effector memory Tregs) was significantly associated with anemia (p=0.046), reduced hemoglobin (p=0.038), and blast counts ≥5% (p=0.006).

REVIEWS AND PERSPECTIVES:

The following articles provide significant review of literature and/or innovative perspective on the state-of-the-art in MDS and identify need for additional prospective studies.

1. Steensma DP. Dysplasia has a differential diagnosis: Distinguishing genuine myelodysplastic syndromes (MDS) from mimics, imitators, copycats and impostors. *Curr Hematol Malig Rep*. 2012, Sep 27. [Epub ahead of print]
2. Steensma DP. Historical perspectives on myelodysplastic syndromes. *Leukemia Res*. 2012, Aug 23. [Epub ahead of print]
3. List AF. New therapeutics for myelodysplastic syndromes. *Leukemia Res*. 2012, Sep 7. [Epub ahead of print]
4. Vardiman J. The classification of MDS: From FAB to WHO and beyond. *Leukemia Res*. 2012, Aug 30 [Epub ahead of print]

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.

MDS News Briefs

Launch of Fast Track for First Prescription Service through Celgene Patient Support

Fast Track for First Prescription™ is a new opt-in service from Celgene Patient Support® which helps patients on an oral Celgene product receive their first prescription faster.

Which patients are eligible for this program?

- Patients on an oral Celgene product receiving their first prescription
- Patients with documented proof of insurance
- Patients who are registered in a Celgene risk management (REMS) program and have a valid authorization number

How are eligible patients enrolled in this program?

- Prescriber must fax the Fast Track Cover Sheet and the Patient Prescription Form with the authorization number and the patient risk category (i.e., adult female of childbearing potential, adult male, etc) to 1-800-822-2496
- Patient's contact information and insurance
- Prescriber must ensure patient has completed their Celgene risk management (REMS) survey

What can a patient expect after being enrolled in this program?

The specialty pharmacy will contact the patient to:

- Review their insurance benefits for the prescribed product (i.e., co-pay responsibilities and potential financial co-pay assistance options)
- Provide appropriate counseling (if applicable)
- Set up a delivery date for shipment of the medication

For more information, or for any questions, call Celgene Patient Support® at 1-800-931-8691.

New Published MDS Supplement in the American Journal of Medicine

View the recently published, supplement on MDS in the American Journal of Medicine. These articles are available on the internet through open access, allowing interested parties to download the entire supplement for free.

http://www.amjmed.com/supplements

New Website Resource for Iron Overload Management

Iron Health Alliance is a new global initiative dedicated to increasing awareness and sharing up-to-date information about iron toxicity with physicians and patients around the world.

http://www.ironhealthalliance.com/index.jsp

mds foundation
the myelodysplastic syndromes foundation, inc.

What is MDS?

Myelodysplastic Syndromes (MDS) are a group of diverse bone marrow disorders in which the bone marrow does not produce enough healthy blood cells. MDS is often referred to as a "bone marrow failure disorder". MDS is primarily a disease of the elderly (most patients are older than age 65), but MDS can affect younger patients as well. To help you better understand MDS, it might be helpful to first consider some basics about bone marrow and blood. The bone marrow functions as a factory that manufactures three kinds of blood cells: red blood cells, white blood cells, and platelets. Healthy bone marrow produces immature blood cells—called stem cells, progenitor cells, or blasts—that normally develop into mature, fully functional red blood cells, white blood cells, and platelets. In MDS, these stem cells may not mature and may accumulate in the bone marrow or they may have a shortened life span, resulting in fewer than normal mature blood cells in the circulation. Many patients have no noticeable symptoms of MDS and are diagnosed on routine screening. Others present with vague symptoms such as fatigue, shortness of breath, palpitations, fever, recurrent or prolonged infections, bruising, petechiae, or bleeding.

About Us

The MDS Foundation, Inc. is a multi-disciplinary, international organization devoted to support, research, treatment, and education for patients, caregivers, physicians, nurses 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.

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*
- Anemia, Blood Transfusions, Iron Overload, & Myelodysplastic Syndromes: A Handbook for Adult MDS Patients
- Insurance and Reimbursement Resources for MDS Patients

Foundation Initiatives

- Worldwide Patient Quality-of-Life Forums
- Worldwide Patient Support Groups
- International Nurse Leadership Board
- Professional Education

International Working Group for Prognosis in MDS

This international group of physicians, coordinated through the MDS Foundation, is dedicated to the revision and refinement of the International Prognostic Scoring System (IPSS).

Contact Us

Please contact the MDS Foundation for additional information.

E-mail: patientliaison@mds-foundation.org

Visit us on Facebook and Twitter!

facebook twitter

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

ARABIC CZECH GERMAN GREEK HEBREW HUNGARIAN ITALIAN JAPANESE POLISH PORTUGUESE ROMANIAN RUSSIAN SPANISH TURKISH

VISIT OUR WEBSITE TO JOIN AS A MEMBER OF THE FOUNDATION AND TO LINK TO OUR EDUCATIONAL RESOURCE CENTER:

www.mds-foundation.org

MDS Foundation, Inc., 4573 South Broad Street, Suite 150, Yardville, NJ 08620
Within the US: 1-800-MDS-0839, Outside the US: 609-298-1035

Worldwide Patient Forums and Support Groups

SPREADING THE NEWS WORLDWIDE

NOW FORMING: MDS PATIENT AND FAMILY SUPPORT GROUPS

Whether you are interested in starting a much needed support group in your area or looking to join one, please contact the MDS Foundation at: 800-MDS(637)-0839 or email ahassan@mds-foundation.org.

The MDS Foundation has developed a strategy for setting up patient groups and assistance is now available to organize support groups for MDS patients. Any member of the Foundation, patients, friends, family members, and caregivers are invited to join with us to move this project forward.

PLEASE MAKE SURE TO REGULARLY CHECK OUR ONLINE UPCOMING EVENTS CALENDAR FOR MEETINGS TAKING PLACE IN A CITY NEAR YOU!

Lakeland Patient Support Group

Lakeland, Florida

"It was a great opportunity for each person to express their expectations for the group, not just for now, but for the future. As this cancer is rare, many patients feel isolated and singular. Our goals for the group are to encourage and support one another and to gain more knowledge about this rare disease. Everyone felt that the above goals were accomplished and are looking forward to meeting again!"

Katherine Dempster

(L to R) Linda and Richard Brackett, Bonnie and Arnold Henig, Don and Katherine Dempster, Dave Paul. Vivian Paul, photographer

Our goals for the group are to encourage and support one another and to gain more knowledge...

The Lakeland Regional MDS Support Group was held at the home of Dave and Vivian Paul in Lakeland, Florida. For more information, contact the Dempsters at (863) 816-8482 or the Pauls at (863) 698-5137.

Southern California MDS Patient Support Group

"People started talking, asking questions and before we knew it 2 hours had gone by. It seemed like everyone that had questions got the answers that they were looking for."

Susan Urban

The Southern California MDS Support Group meets every third Saturday of the month at St. Mary Star of the Sea Church, 609 Pier View Way in Oceanside, California at 2:30 PM. For more information, contact Susan Urban at (760) 966-0895 or susanurb@gmail.com. Access the following link to view their website: http://robnixonii.wix.com/socalmdssupport#!home/mainPage

Toronto, Canada MDS Patient Support Group

"...we had 41 attendees (much larger than we had expected)... Dr. Karen Yee did a presentation for the first hour. She presented a general overview of MDS and then spent a lot of time talking about the different treatment options with a great overview of current clinical trials. Participants had an opportunity to ask questions. In the second hour, David Walkup facilitated a support/educational session using an MDS tool that his company (Healthy Interactions) has developed with some health care providers and a patient. It was a very powerful, engaging session. He was asking for participants' feedback prior to finalizing the tool."

Cindy Murray
Nurse Group Leader
Princess Margaret Hospital

The Toronto, Ontario MDS Support Group has 4 meetings a year; every 3 months at Trinity Presbyterian Church, 2737 Bayview Avenue, North York 10:00 am to 12:00 pm. For more information, contact Cindy Murray at (416) 946-4501 Ext. 5919 cindy.murray@uhn.ca or Nancy-Ann Pringle at (416) 946-4501 Ext. 5337 nancy-anne.pringle@uhn.ca

Patient and Family Education Forums

FREE One-Day Conferences for MDS Patients and their Families

Thank you to all who have attended our MDS Patient and Family Conferences in 2012. Ongoing meetings addressing quality of life issues for MDS patients will be planned and these conferences will occur in ten cities around the world in 2013. A global patient forum will be held alongside our 12th International Symposium on MDS in Berlin, Germany. Check our website and facebook for updates. We look forward to another successful year!

Request Your FREE Patient Information Packet Today

The MDS Foundation has many resources on MDS-related topics, straight from leading experts in the field of MDS. Request your FREE patient information packet from the MDSF, containing up to date education on MDS in patient-friendly language. Many are also available in other languages. Order your patient packet today by calling 800-MDS-0839 or email jbutchko@mds-foundation.org.

Hamilton, Ontario MDS Patient Support Group

"Our attendance was the best ever, 40 people. My MDS hand outs were well received. The excitement surrounding our webpage was unbelievable. Dr. Leber hopes we can get it up and running before year end. He also wants to know if videos can be attached. People were in awe about the webpage."

William Pearson
Hamilton, Ontario MDS Patient Support Group

The Hamilton, Ontario group meets at the Emmanuel United Church, 871 Upper Ottawa Street, Hamilton 10:00 am to 12:00 noon. For more information, contact Tammy DeGelder, RN at (905) 521-2100, ext. 73435 or William Pearson (905) 561.6999 or e-mail to: william.pearson@sympatico.ca.

Patient Contributions

PATIENT TESTIMONIALS

Our Patients Speak Out...

"Thank you for all of your help."

We are moving along with good advice and information now and a lot less fear!

John Custer

"You have been so encouraging to Nancy and I over the years and you have helped so many other patients."

Your referrals of other Jehovah's Witnesses to me have been very encouraging to all of us fighting MDS. I feel that I've known you for years. Thanks for all your help over the last almost 8 years that I've battled MDS successfully. Keep up your good work.

Nancy and Kirby Stone

"It was so kind of you to call back when you did."

Life has been so challenging lately for a number of reasons and you made me smile... For you to have acknowledged our conversation and to have implemented ideas immediately is truly commendable... Our first introduction to the nitty gritty of MDS was the unbelievable combination of your most welcome dissemination of information coupled with our relationship with Dr. Nimer... Jerry and I thank you and your entire staff who has always been welcoming, informative and generously supportive! Of course, we would want to attend each and every symposium that you sponsor; however, the one in Miami in particular pulls at our heart strings due to Dr. Nimer's participation and the all inclusive participation of quite a roster of specialists... In appreciation of your courtesy always...and, the compassion each and every one of you at your offices have always extended to us... we are eternally grateful.

Randy and Jerry Genet

"THANK YOU!!!"

From the first meeting with Dr. Mesa I knew I was going to be provided excellent care and understanding of me and my concerns. He and the staff at Mayo have been great at helping me with my cancer treatments, fatigue and dealing with the impact on my life.

Diane Johnson

"Thanks so much for sending the slides from the presentation last week."

Again I have to tell you how much I appreciated having the opportunity to attend; it was educational and affirming, telling me that the treatment my mom is getting is pretty much on target. My mother and father were very happy to hear that I attended and they are really looking forward to reading all the handouts that were so generously provided (thanks again for the second book!). My mom was also glad to be signed up as a member of the Foundation and looks forward to receiving in the mail whatever is sent over the course of the year.

"Thank you and the Foundation for the terrific work you are doing, especially with so little money."

Susan Luciano

"Tom and I were extremely impressed with our first MDS Conference."

We realized that there is so much we didn't know about MDS. You did a great job. Thank you.

Joan and Tom Weidenfeld

"I'd like to thank you so very much for a WONDERFUL and helpful seminar."

I was sad to see the number of people there with MDS... I wouldn't wish this on my worst enemy. I think for the number of us, we found that we "aren't" alone.

Richard Brackett

MDS FOUNDATION STORE

NEW ITEM ADDED – MDS SILICONE BRACELETS

Help Spread Awareness of MDS and Order Your Silicone Bracelets Today!

For a donation of your choice, receive your custom silicone bracelet(s) as a "Thank You" for your generosity. To order, call 800-MDS(637)-0839 or order by mail with check enclosed to:

The MDS Foundation, Inc.
4573 South Broad Street
Suite 150
Yardville, NJ 08620

Thank you for your support!

When the Doctor Tells Your Wife, "You Have Blood Cancer"

John Bugay

When your doctor tells you, "you have blood cancer," it's certainly one of the major challenges in life. I was with my wife Bethany when she heard those words.

She is a fighter, and thanks to a bone marrow transplant at Pittsburgh's West Penn Hospital, most of the fight is behind us. But I wanted to share, from a family member's point of view, what's involved with those challenges.

The Road to Leukemia

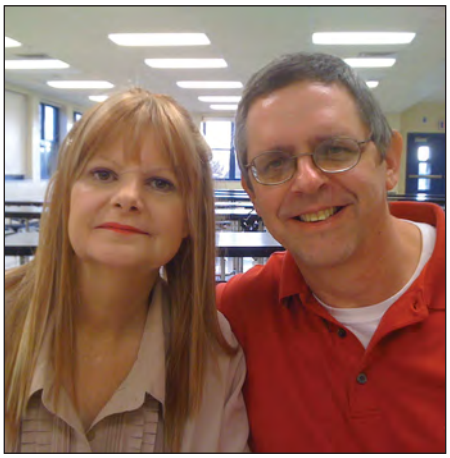
On an early summer day last year, Beth had to call off work because she was simply too tired to get out of bed. That wasn't like her at all. A veteran of the Iraq war, who got there just a month after the lead invasion in 2003, she was not a person to back down from any challenge.

For a little over a year, I'd been working days, and she had been working full-time nights. Our youngest daughter was in school, and this work schedule enabled us to avoid daycare expenses. Plus, we needed two incomes to make up for the eight months I had been unemployed during the recession.

But over the previous several months, Beth had been coming home more tired than usual, and complaining of headaches. On this Sunday morning, she came home and went right to bed. That afternoon, she had to call off work, something she never did. She couldn't get out of bed. She had a headache, body aches, swelling of the legs. Her supervisor said, "why don't you go to MedExpress and get yourself checked?" So we did.

The practitioner on duty that night examined her, came back in and said, "You need to have some tests tonight that I can't give you. I'm going to send you up to the emergency room".

They brought her in and took some more tests. Her hemoglobin level was 5.7,



Bethany Bugay with husband John Bugay, March 2012, at a school event.

dangerously low. (The normal range is 12–15). They gave her some blood transfusions and admitted her for more tests. One of the nurses told us that if she had cut herself and bled out to that level, she'd be unconscious. But because she dropped slowly to that level, her body gradually adapted to it.

Challenge 1: The Diagnosis Takes Time

At the hospital, there were a number of tests, one of which was a bone marrow biopsy. After all the tests that had been done and the bone marrow biopsy was headed for the lab, her hematology/oncology physician said he thought that it was most likely a viral infection causing her severe anemia.

A follow-up visit to our GP came back with the news: "you have a form of blood cancer". It was awkward for him and an incredible shock to us. He gave us a copy of the lab results, which said "Acute Myeloid Leukemia (AML) is indicated."

Her immediate thoughts turned to questions such as, "what's going to happen to me physically?" And the spiritual questions came up. "Am I prepared to die?" "Am I right with God?" As a family member, I was certainly concerned with her spiritual well-being. But in addition, we have six children, some of them young, and it was important to me to understand how to move forward through these challenges.

One of the hardest things about hearing the diagnosis "you have a blood cancer" is simply putting it into perspective. I spent some time Googling "AML", and found some excellent information, but it was certainly discouraging for us, because, as it turned out, I wasn't looking in the right ballpark.

But at that point, we didn't even have a good understanding of the diagnosis.

Challenge 2: Understanding MDS and Leukemia

A few days later, a brief talk with our hem/onc physician helped us to better understand where Beth's diagnosis fit within the world of leukemia. Science has greatly enhanced the medical field's understanding of the disease and its many different variations, especially from a genetic standpoint, but that doesn't make it any easier for the patient to understand what's going on.

Nevertheless, it was a conversation that enabled me to narrow the focus of my searches.

There are four types of "blood cancers": chronic and acute myeloid leukemia, and chronic and acute lymphoma. Of course, these are just terms that set the four types in contrast with each other, for the purpose of categorization; there are really a number of different subvariations in each of these categories, each with a broad range of things that can go wrong.

The particular group of leukemias that Beth had, AML, is a very nasty one. The preliminary diagnosis turned out to have been for a "pre-leukemia" version, one of the "myelodysplastic syndromes" (MDS).

We were scheduled to see yet another specialist, Dr. James Rossetti from West Penn Hospital in Pittsburgh.

He told us that the diagnosis was pretty clear about "what" it was but somewhat inconclusive on the severity continuum. There is a "risk factor" chart called the IPSS chart, and Beth was either at a "high" risk level (the highest of the four) for developing AML, or she actually had moved into AML. Dr. Rossetti did another bone marrow biopsy, and admitted her to the hospital for further testing.

What came back was something called CMML, or chronic myelomonocytic leukemia, a sort of hybrid kind of disease, between MDS and a "myeloproliferative" variation of the disease. More specifically, Beth was found to have "dysplastic CMML-2", which is not as bad as having the "myeloproliferative" version of CMML, but it is not a good thing.

Untreated, the prognosis for CMML was a lifespan of about 12–24 months. Dr. Rossetti was very clear that because of her age (50) and relative good health, she was a prime candidate for what they called a "bone marrow transplant" (BMT).

That in itself opened up a whole new world to have to understand. As it turned out, the hardest part was yet to come.

Challenge 3: The Treatment

After learning about the diagnosis, we finally got a complete overview of the treatment plan:

1. Two or three courses of Vidaza to try to slow or mitigate the effects of the disease. It was key to prevent the CMML from developing into AML.
2. A search for a donor.
3. Upon finding a donor, a period of "conditioning," intense chemo and full-body radiation, essentially to destroy her existing, damaged bone marrow.
4. The transplant itself, an infusion of adult stem cells from an anonymous donor.
5. Follow-up to check on the effects of the transplant.

The expectation was that the Vidaza would reduce her overall "risk level" (that her disease would progress into full-blown AML) and strengthen her body for "conditioning", which would kill most if not all of the cancer-causing function in her bone marrow.

The "transplant" would do two things. First, the new stem cells would take up residence in her bones and repopulate her now-destroyed bone marrow. Second, the differences in the DNA match would provide a "the graft-vs.-tumor effect" to suppress and kill any latent cancer function within her body.

Prior to the transplant, Beth's possible outcomes were:

- 30% cure;
- 20% immediate complications;
- 15% major longer-term complications;
- 35% chance of relapse.

Challenge 4: The Transplant Itself

Beth actually ended up having six courses of Vidaza, which had the intended effect of controlling the spread of the disease and actually reducing the cellularity in her bone marrow (from 50% down to about 20%), partially doing the job of the "conditioning" step.

By November 9th a donor had been selected, and on December 14, 2011, the stem cells from our adult female donor were flown into Pittsburgh on an international flight. Beth received her transplant from approximately 9:45 pm until around 10:35.

This was "Day Zero" of her new life. And while the transplant itself may have been uneventful, as it turned out, there was a MRSA infection on her central line (used to input the stem cells). So the night of the transplant and for several days following, Beth experienced some of those "immediate complications": a fever as high as 103°F, violent chills and shakes.

At one point, she said, "It hurts Johnny".

"What?" I said.

"Everything," she said.

She was very frightened by the reaction. They treated her with a number of fever medications as well as ice packs. Meanwhile, I had taken off a great deal of time from work to spend time with her in the hospital. During that time, I had to run back and forth between home, to check on the kids, and hospital, to be with Beth.

Bethany with daughter Danielle (7), our youngest of six children, January 2012, at the height of complications.

In all, she spent the better part of three months in the hospital, and in the following weeks and months, Beth managed to get almost every type of complication you can get, including the ongoing MRSA infection, and a number of viral infections (treatments for which caused her body to swell uncomfortably with retained fluids), and she came very close to death.

Fortunately, that phase came to an end. Ongoing Chimerism tests have confirmed that her leukemia has not made a reappearance. As I write this, we are about 10 months out from the transplant. And the good news is, her body has healed over time. I told her shortly after the transplant, "you may feel terrible, but you don't have leukemia any more".

We are grateful to live at a time when medical science can offer such a promising, if complicated cure to what would surely have been a deadly disease.

Challenge 5: The Financial Complications

The various leukemia organizations offered plenty of helpful advice for dealing with insurance and other financial issues, but there are no easy solutions. My employer, Black Box Corporation in Pittsburgh, PA offered an excellent health insurance package. They also worked with me to obtain the necessary Family Medical Leave Act (FMLA) time off.

Through this whole process, Beth did not work because she was physically not strong enough, and I had to take a great deal of time off, to take her back and forth to doctor's appointments, and to spend time in the hospital. That meant we were going without of one of our two incomes for a long time, and both of our two incomes for at least several months.

Apart from the notion that my wife could die from this process, the financial challenges were the most frightening for me. And I have to say, frankly, that most of the financial advice that was offered was, while well-intentioned, not very helpful.

After the transplant, the Social Worker at the Hospital worked with us to file for Social Security disability payments. It didn't take long for this application to be processed (although you must wait five months after your last day of work before you can apply for it). This amounted to half of what she had been earning while working full time. Beth has also applied to the Veterans Administration for disability benefits; as I write, this application is still being processed some 10 months later.

But it was the people who knew us and who we interacted with on a regular basis who helped us the most.

Organizations such as the MDS Foundation... provide information that helps people to sort through all the ramifications of this unsettling diagnosis and give hope...

The vast majority of the financial help that we received came from private donations, after I had asked for it. My co-workers took up several collections. I had a personal blog, and I set up a Paypal account through which we could take private donations. Other bloggers as well helped us make our appeal for financial help.

Some teachers in the local elementary school our daughter attends chipped in with some fundraising activities. The school purchased Christmas gifts for our family, and a "Bowling for Bethany" event in April raised several thousand dollars for us.

Several churches made financial contributions to us. Our own home church was probably the biggest financial help throughout the process. In addition to helping us with rides to various appointments, they actually purchased a freezer for us, brought prepared, frozen meals on a regular basis, and made our mortgage payment for us for the better part of a year.

Concluding Considerations

"You have a blood tumor" is not the kind of thing anyone wants to hear. In just the last 10 years, advances in genetic science have greatly increased what is known about the various types of leukemias, and their various treatments. And MDS, formerly simply known as "pre-leukemia," itself now understood to be a complex of maladies with a bewildering array of possible causes, symptoms, and treatment options.

Organizations such as the MDS Foundation, the Leukemia and Lymphoma Society, and the National Marrow Donor Program (marrow.org) all provide information that helps people to sort through all the ramifications of this unsettling diagnosis and give hope to patients and their families.

The greatest amount of help still came from the doctors and nurses we dealt with on a daily basis, and the friends and churches in our various communities who took up our cause and spread the word, "Bethany Bugay, an Iraq war veteran, has a form of leukemia, and she needs your help."

Thanks to their help, we now have hope for the future.

My MDS Story

My name is Keith Hennig and on February 22, 1993 my father died of acute leukemia. He had refractory anemia that summer and my mother was a nurses' aid and her friend, the local doctor, told her that this was what his father had died from and to anticipate that this would be Dad's last Christmas. The refractory anemia would manifest into acute leukemia and he would die very soon after that. I received this information after Christmas and Dad got sick in early February. His direct involvement in our lives ended that February. However, as many people may have experienced, when you lose a parent you sort of re-evaluate your life and tell yourself that when you get the chance to do things for the groups that have helped or could have helped you make an effort to do so. My Dad's first wife died of breast cancer and he and my mom were always the neighborhood American Cancer Society drive leaders. You can sort of say that I have followed in their footsteps and have done the same thing now that I am married and have a family of my own.

I live in a small town in Wisconsin, pretty much like the one in Iowa I grew up in, and I love them both. This is the first place I have really called home since leaving my parents. I served on several city boards and made friends with other board members. One of those board members was Ron Carlsen. Ron and I served on the City Park Board for about 5 years together. I eventually moved out of the city limits but still live in the great community, and Ron and I go to the same church. One day he was on the prayer list, and when I found out it was MDS it was a real gut punch. I knew what comes next, you just die. So the next summer when Ron was putting together a benefit to sign up marrow donors, and was still alive and kicking, I went in and got on the list as a donor and asked him how it worked. I found out about the amazing network of MDS donors and the MDS Foundation. I have to say I was and still am impressed.

If my father had gotten sick in 2010 rather than 1993, I am much more confident he would be here today.

This is a picture of Dad and my brothers and I cutting wood with an antique gasoline engine with a buzz saw that he restored and loved.

I like to volunteer. I am a Boy Scout and Venture Crew leader, a swim coach, and one of the youth leaders at St. John's Lutheran Church (sort of the un-churchy youth leader). This past summer while working on getting in better shape for my scouts' backpacking trip to Glacier National Park, my wife managed to get me signed up for a local version of "The Biggest Loser". I needed it. Not being one to not take advantage of a good opportunity, I got sponsors to help me pay for what is actually a fairly expensive little weight loss program. Once involved in this program, I wanted to see what I could do to raise some money for a good cause. The first one that came to mind was the MDS Foundation – the group that helped my friend Ron, and that could have quite likely saved my dad if they, and the technology, had been available then. I sent out emails to all the groups I help with and got several to pledge dollars for pounds of weight lost. With donations ranging from $.25 per pound to "Put me down and we'll see how you do" I was eventually raising money for MDS. I did not get involved with all this to lose weight, just to get in shape to make it over the mountains without keeling over. My idea of teaching boy scouts first aid is not having a heart attack 10 miles from the nearest road! However, I found that knowing that I was finally able to do something for Dad, even after he was dead, was pretty inspiring. I had lost about 9 lbs. before I got involved with the other "Fat Losers" (I thought it was a funny nickname but I am not sure all my compatriots were amused) and then lost another 51.4 lbs., 21.13% of my body weight during the competition. I managed to raise just over $1,000.00 for MDS. I have a couple of friends with the audacity to challenge me that they will double their pledge if I keep the weight off for the next 6 months! Well, I am down a couple more pounds and don't plan on stopping my fitness journey. I am signed up to do a 5K on Thanksgiving Day. I figure that way I can have mashed potatoes and gravy with my turkey! Dad liked taters and gravy and I think he would appreciate that.

Everybody dies but not everybody truly lives. My father died when he was 68 years old and I was 26. He had made it to 68 with an 8th grade education and left my mother a widow for the second time in her life. Since he died she has not wanted for anything. Finances have never been a worry for her. To put it into perspective, Dad heated our home with wood that he cut, and after his death it took almost 8 years before Mom burned through all he had cut, split and prepared. She spends her time enjoying the love and respect of her children, grandchildren, great grandchildren, and other friends and relatives. That is an impressive legacy and I have a responsibility to live up to it.

Thank you MDS Foundation for being there for all the parents and for their children who will get to have another Christmas with one another as a result of your work. On a slightly more personal note, thank you for helping me to eliminate some of the helplessness, both mine and that of the families of those stricken with MDS. I prefer a life sentence to a death sentence any day!

This is a "before" and "after" shot of me.

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Stem Cell Transplantation Ward and Polyclinic Hematology/Apherese/ Stem Cell Transplantation
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European Group for Blood and Marrow Transplantation
Nurse Researcher
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New Resources for Nurses

We are pleased to announce the launch of our Nursing Portal on the MDS Foundation website, a free resource developed to provide the nursing community with materials to help communicate with and support their patients with MDS. Access *http://www.mds-foundation.org/nursing-portal* to view our comprehensive set of resources. Here you can view the presentation slides and audio presentations of our educational symposium presented in New Orleans.

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

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
Scottsdale, Arizona
Ruben Mesa, MD/James Slack, MD/ Raoul Tibes, MD, PhD

The University of Arizona Cancer Center
Tucson, Arizona
Ravi Krishnadasan, MO, FACP

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

Moores Cancer Center at the University of California, San Diego
Rafael Bejar, MD, PhD
Peter Curtin, MD

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

UCLA Center for Health Sciences
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
James M. Foran, MD
Alvaro Moreno-Aspitia, MD

Sylvester Comprehensive Cancer Center
University of Miami Miller School of Medicine
Miami, Florida
Stephen D. Nimer, MD

University of Florida Shands Hospital
Gainesville, Florida
Christopher R. Cogle, MD

University of South Florida H. Lee Moffitt Cancer Center
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
Jamile Shammo, MD

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

INDIANA

Indiana University Simon Cancer Center
Indianapolis, Indiana
Larry Cripe, MD
Hamid Sayar, MD, MS

MARYLAND

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

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

MASSACHUSETTS

Children's Hospital Boston
Boston, Massachusetts
Inga Hofmann, MD

Dana-Farber Cancer Institute
Boston, Massachusetts
Richard M. Stone, MD/David P. Steensma, MD

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

MICHIGAN

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Detroit, Michigan
Charles A. Schiffer, MD

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

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Mark R. Litzow, MD

University of Minnesota Medical Center Fairview University of Minnesota Medical School
Minneapolis, Minnesota
Erica D. Warlick, MD

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St. Louis, Missouri
John F. DiPersio, MD, PhD

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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
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Hwei-Fang Tien, MD, PhD

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

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Oxford, United Kingdom
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Sally Killick, MD

St. James's University Hospital St. James's Institute of Oncology
Leeds, United Kingdom
David T. Bowen, MD

University Hospital of Wales
Cardiff, Wales
Jonathan Kell, MD

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.

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:
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.

Access is Key to Treatment

The MDS Foundation Will Provide Location Information for the Rigosertib (ESTYBON® ON 01910.Na) MDS Clinical Trial

ONTIME: Study Description (ON 01910.Na TRIAL IN MYELODYSPLASTIC SYNDROME)

A phase III study of rigosertib (Estybon®, ON 01910.Na) in myelodysplastic syndrome (MDS) patients after Vidaza® (azacitidine) or Dacogen® (decitabine) treatment. Rigosertib is a novel mitotic inhibitor of PLK and PI-3 kinase pathways.

The ONTIME MDS clinical trial is accessible at a wide variety of locations and key medical centers.

To find a trial site in your area where this study is being conducted, please visit http://mdsclinicaltrial.com/oncology-trials/ontime-study/site-locations/.

Consider the ONTIME Trial for the Treatment of MDS Patients after Azacitidine or Decitabine

– Accrual of patients is ongoing

If you are a physician or nurse and would like to refer a patient for enrollment into this clinical trial please contact the MDS Foundation at 800-MDS(637)-0839.

Learn more at
ASH 2012
Georgia World Congress Center
Atlanta Georgia
December 8–11th
Visit BOOTH 2307!

Learn More –
More information can be found at www.mdstrial.com or clinicaltrials.gov, the identifier is NCT01241500

Thank You!

Gifts to the Foundation

The MDS Foundation relies entirely on gifts and membership fees to further its work. We would like to acknowledge the generosity of the following individuals and organizations that have recently provided gifts to the Foundation:

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Mrs. Arlene Marie Lennox

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

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A memorial fund has been established in the name of

Mr. Barry Levin

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

Marilyn J. Litvin, *Framingham, MA*

A memorial fund has been established in the name of

Mr. Ronald Logan

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

Frank and Michele Cali
Dunmore, PA

Norma Pritchard and Family
Honesdale, PA

Glenair, Inc., *Glendale, CA*

Gordon, Maryann and Natalie Olsommer
Greentown, PA

Jim and Phyllis Cunningham
Clarks Summit, PA

Madeleine Reilly, *Macungie, PA*

RBLA of PA, Inc.
Stroudsburg, PA

Woodloch Pines Inc. and the Kiesendahl Family
Hawley, PA

Peter J. O'Brien
Mount Pocono, PA

Bob and Dru Scekeres
Mechanicsburg, PA

The Armillei Family
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Michael and Vincetta Nestor
Lake Ariel, PA

Kevin and Dr. Kristen Hollshwandner
East Stroudsburg, PA

A memorial fund has been established in the name of

Mr. Robert Long

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

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Michael & Sherry Roithmayr
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Mariko Chouinard, *Topanga, CA*

Susan Martin, *Herndon, VA*

David and Karen Viar
Centreville, VA

David Barbero
Centreville, VA

Richard Avidano
Levittown, NY

A memorial fund has been established in the name of

Ms. Ruth Glogow Lublin

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

Carol Ann Weiss, *Staten Island, NY*

A memorial fund has been established in the name of

Mr. Ralph Manheim

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

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Brooklyn, NY

Sheila Cavooris
St. James, NY

Jens Matthes
New York, NY

Richard and Marie Hamilton
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Jerry and Liddy Latter
Northport, NY

Heidi McGough
Commack, NY

Brice Fukumoto
Summit, NJ

Michael and Mary Martin
Port Jefferson, NY

Bill and Nancy Mallio
Winchester, MA

A memorial fund has been established in the name of

Mrs. Rosalie Marcus

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

Ben Hole
College Park, MD

A memorial fund has been established in the name of

Mrs. Patricia J. Marsh

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

Richard A. Fehrman
Sebring, FL

Donna Howerton
Sebring, FL

John Fehrman
Sebring, FL

A Tribute to Vi

Viva Lee Barnard McDaniels

1922–2012

Vi was born on October 6,1922 in Paris, Arkansas and came to Merced, CA with Mom, Dad, Brother and Sister in 1931. Vi attended Merced schools and graduated from Merced High School in 1941.

Vi married almost immediately after high school and worked in the retail sector during the war. From this marriage, Vi had a daughter and a son. She also was a volunteer airplane spotter for the then Merced Army Airfield.

Vi trained as a dental assistant and worked in that field during the 50's and 60's. That period was before x-ray education and the assistant would stay in the exam room while taking the x-rays. She often mentioned that while taking x-rays on small children, she would hold the film in the child's mouth while the x-rays were taken.

Vi and I were married in January, 1962, and although she was thirteen years older then I, everyone said and still says, that we were the perfect couple who adored each other. We must have been – as the marriage lasted over fifty years. What a joy she was.

Although we never had children of our own, there was often a baby or young child,

A memorial fund has been established in the name of

Mrs. Viva Lee Barnad McDaniels

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

Phil McDaniels, *Merced, CA*

M.J. Hollinger, *Willamina, OR*

who had been neglected in some fashion, in our home for periods of up to a year.

In my profession as a police investigator, we had the opportunity to live in several locations in California, and I retired in San Luis Obispo, CA. Shortly after, we moved back to Merced to be closer to Vi's family.

In late 2006, Vi was found to have a large aortic aneurysm and, after multiple CT scans and x-rays, and multiple refusals by cardiothoracic surgeons for surgery, she was accepted into a trial at Tucson Francisco Medical Center. That brought about more CT scans and x-rays, both before and after surgery on December 7, 2007, during which she had two Bates Graft Stents placed in the aorta. She often said it was a wonder she didn't glow in the dark.

In April, 2010, Vi was hospitalized with pneumonia and found to be anemic. She received two units of blood along with antibiotics for the pneumonia. In May, she was again found to be anemic and was referred to an oncology center with the results finding she had MDS. We often wondered if all the x-ray exposure she had contributed to having MDS. Vi had a round of chemo and her blood counts improved for several months before starting a downhill slide.

Vi passed away on June 10, 2012, peacefully and with family at her bedside, of sepsis brought on by a constant bladder infection and the transformation of the MDS into leukemia.

What else did this amazing woman do in her life time? She painted in oil, landscapes and animals mostly, with cows a big favorite. She worked in ceramics and was a gourmet cook.

She was a first class seamstress who made most of her own clothes and the clothes of whatever child was in the house at the time.

She was a hospital "Pink Lady" and a trout fisherman who could really catch them.

She was an antiques collector and a Notary Public who never charged for her services as "people need the money for their family."

And, in her last years, she knitted over 150 caps for the young cancer patients at Children's Hospital, Central California "because there was a need."

That's what she did.

I will close with a short piece by Edna St. Vincent Millay:

"Where you used to be, there is a hole in the world, which I find myself walking around in the daytime, and falling in at night. I miss you like hell."

Phil McDaniels, *Merced, CA*

A memorial fund has been established in the name of

Mr. Ronald H. Martenson

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

Jason Sanders
Chicago, IL

Jack and Mary Ridges
Naperville, IL

Carrie Galles, *Clive, IA*

Catherine Rooney
Chicago, IL

Charles W. Fultz
Lisle, IL

Mel and Rosemarie
Di Carlo-Cottone
West Chicago, IL

Carol Welch, *Elmhurst, IL*

Patti O'Brien
Geneva, IL

Phil and Colleen Vevang
Buffalo Grove, IL

Keith and Doris Nicodemus
Naperville, IL

Navistar Foundation,
Navistar, Inc.
Lisle, IL

Michael and Mary
Satterthwaite, *Worth, IL*

Thom and Linda Bond
Winfield, IL

A memorial fund has been established in the name of

Mr. Anthony Massone

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

Margaret Errico, *Stone Ridge, VA*

A memorial fund has been established in the name of

Mr. Floyd H. Mattern

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

Karen Mattern, *Spokane Valley, WA*

A memorial fund has been established in the name of

Mrs. Marlene Maunder

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

Robert Coffman
Woodbine, MD

Jon and Cheryl Bear
Burke, VA

A memorial fund has been established in the name of

Mr. Howard McCann

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

Bernard, Will, Tim, John M, Larry, Kevin, Tom, Todd and Chris
Annapolis, MD

A memorial fund has been established in the name of

Mr. Edward L. McCarthy

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

Michael and Kristen McCarthy
Elk Grove, CA

Leslie Hight
Pinehurst, NC

A memorial fund has been established in the name of

Mrs. Maria- Luise "Diane" McDonald

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

Deb Norman
Northfield, MN

Eugene and Christa Tunick
Rexford, MT

Dick Rank and Mary Kanak
St. Paul, MN

Eric and Sandra Horsman
Cottage Grove, MN

A memorial fund has been established in the name of

Mrs. Ruth Merfeld

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

Robert and Clare Kreuser
Shakopee, MN

Nancy A. Depaz, *Burnsville, MN*

Degia Piano Studio
Shakopee, MN

A memorial fund has been established in the name of

Mr. Charles R. Mertz

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

Richard and Claire Ashby
Lititz, PA

Arthur and Dottie Ponzio, *Galloway, NJ*

Andrew and Kay Myers
Lancaster, PA

A memorial fund has been established in the name of

Mrs. Minnie F. Merullo

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

Jeffrey and Elizabeth Bolton
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Plymouth Rock Assurance of NJ
Berkeley Heights, NJ

Associated Risk Managers
of New Jersey, *Latham, NY*

Brad and Alison Patkochis
Pittstown, NJ

Cumberland Insurance Group
Bridgeton, NJ

Linda D'Ambrosio
Oradell, NJ

Independent Insurance
Agents & Brokers of
New Jersey, Inc.
Trenton, NJ

A memorial fund has been established in the name of

Mr. George Milonas

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

Jeffrey and Kitty Philips
West Palm Beach, FL

Jeff and Jennifer Czyzewski
Ponte Vedra Beach, FL

Patricia, Judy, Valerie, Nyle,
Marriette, Christa, Zabrina,
Odetta, Melani, Karen, Vivian,
Reggie and Tim
Jacksonville, FL

Joyce Campbell, *Newton, NJ*

James and Patricia Coates
Apollo Beach, FL

Jack Harris, *Lafayette, NJ*

Pauline Seretis
Ledgewood, NJ

Steve Baldwin & Eileen Wyss
Hackettstown, NJ

A memorial fund has been established in the name of

Ms. Mary Miyawaki

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

Mary Miyawaki, *Honolulu, HI*

A memorial fund has been established in the name of

Mr. Don Moe

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

Truax Fire Department
Madison, WI

Phyllis L. Lee
Madison, WI

Dawn R. Way
Janesville, WI

A memorial fund has been established in the name of

Mr. A. Clay Mollman

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

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St. Louis, MO

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Carol Ross
Chesterfield, MO

Roy Pfautch, *St. Louis, MO*

Phil and Caroline Loughlin
Cambridge, MA

James and Mary Barnes
St. Louis, MO

Walter and Marilyn Sharko
Jacksonville, FL

Julie Linihan, *St. Louis, MO*

CB and Emily Gebhard
St. Louis, MO

Brock M. Lutz
Saint Louis, MO

Les and Wendy Borowsky
St. Louis, MO

David E. Stedelin
Centralia, IL

D. M. and Karen Shupp
Tomball, TX

C. W. Holmes, *St. Louis, MO*

David E. Stedelin
Centralia, IL

A memorial fund has been established in the name of

Mr. Richard B. "Dick" Moorman

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

James and Nancy Prussack
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Anthem, AZ

Thomas Jarrett, Jr.
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Rommel Miranda
Naperville, IL

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James & Kathleen Williams
Longview, WA

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Beaverton, OR

A memorial fund has been established in the name of

Mr. Garvin Morris

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

Art and Bonnie Hosie
Regina, SK, Canada

Ernie and Diane Avram
Regina, Sask, Canada

Alexander & Marjorie Moon
Calgary, AB, Canada

A memorial fund has been established in the name of

Mrs. Peggy Mozzone

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

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Atlanta, GA

Harry and Deanna Crews
Snellville, GA

Joseph Cohen
New York, NY

Crown Realty Professionals, Inc.
Conyers, GA

Charlie and Audrey Wolfe
Savannah, GA

Jimmy and Patsy Whitlock
Lilburn, GA

William M. Harris
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Stewart and Karen Hani,
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Wynnewood, PA

Robert Parker and
Nancy Gordon
Chevy Chase, MD

Dr. and Mrs. Sol and Trudy
Klioze, East Lyme, CT

A memorial fund has been established in the name of

Mr. Nathan

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

Albert and Tina Small, *Bethesda, MD*

A memorial fund has been established in the name of

Mr. Kenneth Nichols

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

Joan E. Nichols, *Millis, MA*

A memorial fund has been established in the name of

Ms. Barbara K. O'Connor

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Margaret O'Connor, *Lewisburg, PA*

A memorial fund has been established in the name of

Mrs. Arlene O'Donnell

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James J. O'Donnell, III, *Ocean City, NJ*

A memorial fund has been established in the name of

Mrs. Julie O'Hanlon

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Barbara Walz
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Patrick Keegan
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Dave Richards (and Brad)
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Englewood, CO

Lisa Cohn, *Denver, CO*

Ed and Elizabeth Tomsic
Denver, CO

New West Physicians (Friends)
Golden, CO

A memorial fund has been established in the name of

Mr. Chris Okuhara

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

Francis and Jacquelyn Imada, *Kailua, HI*

A memorial fund has been established in the name of

Dr. Antonio K. Olmedo

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Sparks, MD

Credo Capital Management
Baltimore, MD

Orems Elementary School
Faculty & Staff, *Baltimore, MD*

John and Audrey Bagliani
Towson, MD

Moe Liu
The City College of New York
New York, NY

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Mrs. Cecilia A. Otterbein

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Jim and Debbie Madonna, *Oak Ridge, NJ*

A memorial fund has been established in the name of

Mr. Victor J. Palumbo

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Crawfordville, FL

Victor Andre Palumbo
Crawfordville, FL

Lauren and Thomas Baker
Altamonte Springs, FL

A memorial fund has been established in the name of

Mr. Donato Parisi

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A memorial fund has been established in the name of

Mr. Vincenzo "Vince" Pellerito

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Beverly Hills, MI

Toby and Kim Theodore
Plymouth, MI

Theresa Ziske
St. Clair Shores, MI

Gregory and Leah Lefler
Chesterfield, MI

Mary Hickey
Shelby Twp., MI

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Chesterfield, MI

Brian and Judith Meininger
Casco, MI

Frederick & Mary Ann Makinen
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Concetta Pellerito, *Richmond, MI*

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John and Barbara Martel
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Bill and Joanne Sisson
Rochester, MI

Nancy Mooneyham
Rochester Hills, MI

Larry and Marilyn Mills
Royal Oak, MI

Christine M. Pellerito
Frerndale, MI

A memorial fund has been established in the name of

Mr. Ronald D. Piacenti

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Paul Chow, *Plano, TX*

Robbie Marshall, *Dallas, TX*

Kevin and Carla Libby
Dallas, TX

Diane Menza, *Oak Park, IL*

Libby York, *Dallas, TX*

Caroline Withers
Fayetteville, NC

Alan and Ruth Greenthal
John Hardey, *Palatine, IL*

Rick and Cindy Beauregard
Lucas, TX

Brent and Leslie Hradek
Grapevine, TX

A memorial fund has been established in the name of

Mrs. Lovella Ann Hayes Ralstin

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

Robin Rolston
Irvine, CA

Royanne Holy, *Houston, TX*

Dr. Frost, Dr. Safdar and the
Pulmonary Hypertension Staff
Houston, TX

Mary Mills
Hendersonville, TN

Charley and Betty Hayes
Coffeyville, KS

Gloria Buchanan
Seabrook, TX

A memorial fund has been established in the name of

Mr. Elmer (Bill) Rawls, Jr.

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

Therese Kalbacher
Centerville, OH

Betty J. Soedler
Locust Grove, VA

Barbara Miller
Locust Grove, VA

Ralph and Maxine Marshall
Springfield, VA

Elizabeth Bolan
Purcellville, VA

A memorial fund has been established in the name of

Mr. Johnny Ramos

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

Everett and Lois Hornig
Wood-Ridge, NJ

Iris Muniz
Wood Ridge, NJ

A memorial fund has been established in the name of

Mr. Jon Arthur Reuscher

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

Colleagues of Mark Batarseh
Reston, VA

David and Cathy Chase
Falls Church, VA

Leanne Wells
Laurel, MD

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The Robison Family Fund
Gabriel and Lillian Batarseh
Florence, SC

John and Judy Harrison
Austin, TX

A memorial fund has been established in the name of

Mr. Jerome Richter

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

Geoffrey and Sandy Goldworm, *Cherry Hill, NJ*

A memorial fund has been established in the name of

Mr. Edward J. Ruhe

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

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Jerry and Kay Povazsay
Terre Haute, IN

J and Goldie Hicks, *Brazil, IN*

Thomas C. Martin
Rockville, TN

Shawn and Chris Becker
Ferdinand, IN

Doris Romas and Family
Brazil, IN

Dawn Maeder, *Brazil, IN*

Mr. & Mrs. Leroy Kerstiens
Ferdinand, IN

Ginny Hayes-Bennett
Indianapolis, IN

Leroy Kerstiens
Ferdinand, IN

A memorial fund has been established in the name of

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Ann Morgan, *Houston, TX*

Eddy J. Rogers, Jr.
Wimberley, TX

A memorial fund has been established in the name of

Mr. Abraham (Abe) Rosenthal

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

Martin and Deborah Segal, *Suga Land, TX*

A memorial fund has been established in the name of

Mr. Paul Rosinski

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

Ed and Carole Johnson, *Great Mills, MD*

A memorial fund has been established in the name of

Mrs. Sue Schieres

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

Robert Schieres, *Centerville, OH*

A memorial fund has been established in the name of

Mr. Fred E. Schmalz-Riedt

Donations have been made in Mr. Schmalz-Riedt's memory by:

Yvette Schmalz-Riedt, *Earlysville, VA*

A memorial fund has been established in the name of

Mr. Frank Samuels

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

Carol Kosberg, *Palm Beach, FL*

A memorial fund has been established in the name of

Mr. Philip J. Selch

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

Konnie Selch, *Centennial, CO*

A memorial fund has been established in the name of

Lt. Col. (ret) Robert G. Shain

Donations have been made in Lt. Col. Shain's memory by:

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Washington, DC

Larry Wisneski, U. S. Army Executive Flight Detachment
College Station, TX

Claude and Toni Bard
Pueblo West, CO

Rox Shain, *Parker, CO*

Art and Deb Pescatore
Hartsville, PA

Harry Charles Lymn
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Scott and Robin Paul
Doylestown, PA

Stanley C. Romberg
Ocala, FL

Charlotte J. Thielen
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Shirley Ann Cox, *Solon, IA*

Helen M. Romberg
Ocala, FL

Bradley & Kathleen McGowan
Kalona, IA

Jack and Marcia Bedell
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Don and Jean Kirshner
Bellevue, WA

Ronald and Henrietta Klein
Redmond, WA

Larry Jacobs, *Leawood, KS*
Andy and Carol Harris
Mercer Island, WA

Delores J. Urdang, Kathy Muleahy and Leonard and Marcia Molley
Shaker Heights, OH

Edward and Adele Bolson
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Norman & Barbara Walker
Freeland, WA

Len and Esther Morton
Tulsa, OK

A memorial fund has been established in the name of

Mr. Robert "Dewey" Smart

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Ron and Kim Thomason, *Franklin, TN*

A memorial fund has been established in the name of

Mr. Kenneth Larry Smith

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

Barry Rynk, *Boca Raton, FL*

A memorial fund has been established in the name of

Mr. Bob Spear

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

Victor Arias, *Irving, TX*

A memorial fund has been established in the name of

Mrs. Virginia R. Stephenson

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

Howard Stephenson, *Lakeside, MT*

A memorial fund has been established in the name of

Mr. Billie Stierle

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

David Stierle, *Louisville, KY*

A memorial fund has been established in the name of

Mr. Paul Stutzman

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

Jerry, Gae and Kevin Monaghan, *Surprise, AZ*

Tricia Cowles
Westminster, CA

A memorial fund has been established in the name of

Mr. Robert Sudimack

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

Marjorie Sudimack, *Warren, OH*

A memorial fund has been established in the name of

Mr. Satoru "Sat" Sugiura

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

Kathy (Sakaguchi) Marquardt
Elk Grove, CA

Janet T. Tashima, *Turlock, CA*

Gaye Sakaguchi-Yee
Glendale, CA

Ed & Jodi Felt, *Turlock, CA*

A memorial fund has been established in the name of

Mr. H. Franklin Taylor, III

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

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Richmond, VA

Richard and Sallie Cross
Richmond, VA

Doug and Gloria Wetmore
Midlothian, VA

Deborah Mauzy, *Maidens, VA*

Lee and Patti Bourne
Montpelier, VA

Elliot and Tim Merial
Richmond, VA

Mr. and Mrs. Edward B. Evans
Mechanicsville, VA

Linda F. Young, *Glen Allen, VA*

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Richmond, VA

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Parker and Beverly Dillard
Richmond, VA

Spectrum of Richmond, Inc.
Richmond, VA

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Richmond, VA

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Rochester, MN

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A. E. Robertson, Jr.
Montgomery, AL

Mitch and Sue Forrester
Kilmarnock, VA

Steve and Martha Stokes
Glen Allen, VA

Anne N. M. Johnson
Midlothian, VA

Robert S. Brockmeier, Jr.
Henrico, VA

W. R. and Joan Branch
Ashland, VA

Base Crawlers, Full Force, Junton & Williams
Richmond, VA

A memorial fund has been established in the name of

Mr. Landon "Butch" Scott Temple, Jr.

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

VAACE, *Alberta, VA*

A memorial fund has been established in the name of

Mrs. Lucy Terranova

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

Art and Sue Smith
Norristown, PA

Paul and Betty Vagedes
Fairfield Bay, AR

Linda, Michelle, Laura, Erika, Emma, Nicole, Ted and Matt
Glenolden, PA

Warren and Linda Cohn
Norristown, PA

Russ and Joan Thayer
Troy, OH

Gerard and Patricia Giuffrida
Eagleville, PA

Benjamin and Lillian Risilia
Philadelphia, PA

Terry and Dolores Hertzberg
West Berlin, NJ

Marie Ridolfo
Philadelphia, PA

Dolores Boccuti, *Glendora, NJ*

Frank and Kathleen Boccuti
Clayton, NJ

Louise Amato, *West Berlin, NJ*

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West Chester, PA

Mr. and Mrs. Leonard Mac Adams, *Woodbury, NJ*

Mr. and Mrs. Carmen Visalli
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Lisa Severino
Cherry Hill, NJ

Roger, Kathleen and Angelina Boccuti
Philadelphia, PA

Maureen Musumeci and Family,*Philadelphia, PA*

Jesse and Cynthia Stoop
Farmingdale, NJ

Joseph & Kathleen Mancano
Haddon Township, NJ

A memorial fund has been established in the name of

Mrs. Doris Kjersgaard Thomas

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

Irene K. Roberts
Broomfield, CO

Lisa Severino
Cherry Hill, NJ

A memorial fund has been established in the name of

(Lt. Col. Ret.) USAF Timothy Louis Thomas

Donations have been made in Lt. Col. Thomas' memory by:

Ann M. Thomas, *Wichita Falls, TX*

A memorial fund has been established in the name of

Ms. Margaret D. (Peggy) Timmons

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

Dorothy D. Zeek
Sumter, SC

Tommie and Cindy Watts
Garden City Beach, SC

A memorial fund has been established in the name of

Mrs. Faith Darlene Togami

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

Nino M
Northbrook, IL

Dale R. Tanis
Geneseo, IL

Mike and Rhonda Whitney
Taylor Ridge, IL

A memorial fund has been established in the name of

Mrs. Jeanette Toth

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

Joseph Toth
Manalapan, NJ

Donna, Dave, Davy Bunton
Arlington, VA

A memorial fund has been established in the name of

Ms. Barbara Fayette Towne

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

Angelo and Lynn Pizzagalli
South Burlington, VT

Tom McCabe
South Burlington, VT

James and Judy Pizzagalli
Shelburne, VT

Alan Towne
Winthrop, MA

James J. Handy, CLU
Burlington, VT

John and Nancy Rivkin
Uniondale, NY

"Operations Department" of PC Construction Company
Essex Junction, VT

PC Construction Company
South Burlington, VT

A memorial fund has been established in the name of

Mrs. Anita Tremaroli

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

Frank and Terri Troic
East Meadow, NY

Steve and Marianne Tremaroli
Huntington, NY

Paula M. Danese
East Meadow, NY

Nick and Arlene Delmonaco
Edison, NJ

Charles and Marie Breussa
Wyckoff, NJ

A memorial fund has been established in the name of

Mr. Paul M. Vukelic

Donations have been made in Mr. Vukelic'S memory by:

Alan and Cynthia Stoeckel and Family, *Palatine, IL*

Jeannette Kiehl
Palatine, IL

A memorial fund has been established in the name of

Mr. Thomas Earl Walrath

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

Larry and Stephanie Seiple
Oakland, CA

A memorial fund has been established in the name of

Mr. Richard (Rick) Warner

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

Donald and Susan Kah
Hollywood, FL

Mike and Barbara Santomaso
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Allen and Glenna Long
Carmichael, CA

Arthur and Corinna Bilotti
Hollywood, FL

Billie E. Huggins
St. Simons Island, GA

A memorial fund has been established in the name of

Mr. Jim Warren

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

Carolyn Warren
St. Petersburg, FL

A memorial fund has been established in the name of

Ms. Selma Weiner

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

Bert and Marci Blicher
Delray Beach, FL

Luxury Partners LLC
Delray Beach, FL

Ronee Herz
Delray Beach, FL

Joanne Shaer
Boca Raton, FL

A memorial fund has been established in the name of

Ms. Alicia White

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

Lawrence and Melinda Zack
London, Ontario, Canada

A memorial fund has been established in the name of

Ms. Nellie White

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

Angelo and Rose Staikos, *Hazlet, NJ*

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.*

Roslyn Raney, *Menlo Park, CA*

Fay Wanetick, *Pittsburgh, PA*

A memorial fund has been established in the name of

Mr. N. Eugene "Whitey" White

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

Daryl E. Johnson
Cameron, IL

Mary H. Turner
Roseville, IL

James M. and Willa Deane Moore
Knoxville, IL

M. Elouise Swisher
Roseville, IL

Edward R. amd Diane C. Winkless
Tinley Park, IL

Gary and Linda Johnson
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Alexis, IL

Eldon R. and Virginia E. Aupperle
Toulon, IL

Penny L. Flesner
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Robert and Kim Strickler
Roseville, IL

Riley R. & Shirley J. Johnson
Monmouth, IL

Raymond C. Baldwin
Knoxville, IL

Barbara Hopkins
Knoxville, IL

James and Virginia Jean Norris
Tennessee, IL

Edwin and Lois Strickler
Roseville, IL

Harold G. and Mary K. Lain
Cameron, IL

Karen I. Ferguson
Roseville, IL

Harry E. Glesner
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Roseville, IL

Bradley and Jamie Becker
Macomb, IL

William and Shirley Wilson
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Janie Farquhar
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William and Marcia Brooks
Roseville, IL

Robert K. Sullivan
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Lyle H. Nelson
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Wayne and Marilyn Boydstun
St. Augustine, IL

Gary and Shirley Pringle
Galesburg, IL

Gary and Donna Hayes
Roseville, IL

Charlotte Downin
Galesburg, IL

Lyle and Norma Goedeke
Maquon, IL

Carl and LuAnn Johnson
Galesburg, IL

Robert J. and D.M. Hartzell
Gerlaw, IL

Bradley and Barbara Tillotson
Loveland, OH

A memorial fund has been established in the name of

Mr. Neal Eddins Wingfield

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

E. Joan Rollins
Oklahoma City, OK

Rev. and Mrs. Robert Shields
New Bern, NC

Carl and Marjorie Gore
Wilmington, NC

Page Wingfield
Goldsborog, NC

A memorial fund has been established in the name of

Mrs. Joan Zimetbaum

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

Nancy Strauss
Scarsdale, NY

Dr. and Mrs. Abraham Yurkofsky

A memorial fund has been established in the name of

Mr. Fred Zucker

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

Kenneth Richieri
New York, NY

Lee Riffaterre
New York, NY

A Living Endowment

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

A Living Endowment donation has been made in honor of:

Seth Cohen

This donation was submitted by:

Geoffrey & Sandy Goldworm, *Jupiter, FL*

A Living Endowment donation has been made in honor of:

Jonathan Cohn

This donation was submitted by:

Dr. Robert Cohn and Ruth Cohn Family Foundation

A Living Endowment donation has been made in honor of:

Robert W. Cook

This donation was submitted by:

Suzanne Demartini, *Plymouth, MA*

A Living Endowment donation has been made in honor of:

Gerald Duehr

This donation was submitted by:

Thomas Means, *New Berlin, WI*

Living Endowment donations have been made in honor of:

Benny F. Evatt

These donations were submitted by:

June M. Evatt, *Pendleton, SC*

Maureen Maughan, *Cranbury, NJ*

Peggy Cherkasky, *Pittsford, NY*

A Living Endowment donation has been made in honor of:

Irv Glickman

This donation was submitted by:

Geoffrey and Sandy Goldworm
Jupiter, FL

A Living Endowment donation has been made in honor of:

Joan Kane

This donation was submitted by:

Betty Jo Vail
Lititz, PA

A Living Endowment donation has been made in honor of:

Mahaveer Prabhakar

This donation was submitted by:

Rajeev B. and Elizabeth Prabhakar
Walnut Creek, CA

A Living Endowment donation has been made in honor of:

Arnold Schwartz

This donation was submitted by:

Gloria Schwartz
Woodland Hills, CA

Living Endowment donations have been made in honor of:

Elizabeth Schwartz

These donations were submitted by:

Candace D. Morgan
Portland, OR

Elizabeth Touchon
Portland, OR

Christine R. Schwartz
Madison, WI

A Living Endowment donation has been made in honor of:

Angelo Staikos

This donation was submitted by:

Angelo and Rose
Hazlet, NY

Living Endowment donations have been made in honor of:

Morey Storck

These donations were submitted by:

Newt & Lois Alterman, *Tarrytown, NY*

Herb & Gloria Portnoy
Briarcliff Manor, NY

Mel and Dr. Cynthia Chesner
Tarrytown, NY

Rita Wexler, *Tarrytown, NY*

Living Endowment donations have been made in honor of:

Diana Termine

These donations were submitted by:

Ronald and Linda Jaffe
Aurora, IL

George Zander, *Palos Hills, IL*

Patricia Adesso, *Bloomingdale, IL*

Carol Olivo, *Elmwood Park, IL*

Dave and Rhonda Meyer
Saint Charles, IL

Scott Termine, *Plainfield, IL*

Jean Laumann, *Naperville, IL*

A Living Endowment donation has been made in honor of:

Remo Tersolo

This donation was submitted by:

Susan Urban, *Oceanside, CA*

A Living Endowment donation has been made in honor of:

Ronald J. Vanskiver

This donation was submitted by:

Helen Vanskiver
Nottingham, MD

MDS Foundation Information

The Foundation's Board of Directors

mds foundation
the myelodysplastic syndromes foundation, inc.

Become a Member

The MDS Foundation would like to have you as a member. Membership is $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 $135.00 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.