

# mdsnews

newsletter of the myelodysplastic syndromes foundation

## MDS News Highlights

### FROM THE GUEST EDITOR'S DESK

#### ■ *The Emerging Impact of Flow Cytometry in Myelodysplastic Syndromes*

Presented by Arjan A. van de Loosdrecht, MD, PhD  
and Theresia M. Westers, PhD



### FEATURING NEW IPHONE APP FOR IPSS-R: TECH IT OUT!



### 12TH INTERNATIONAL MDS SYMPOSIUM

May 8–11, 2013 • Berlin, Germany

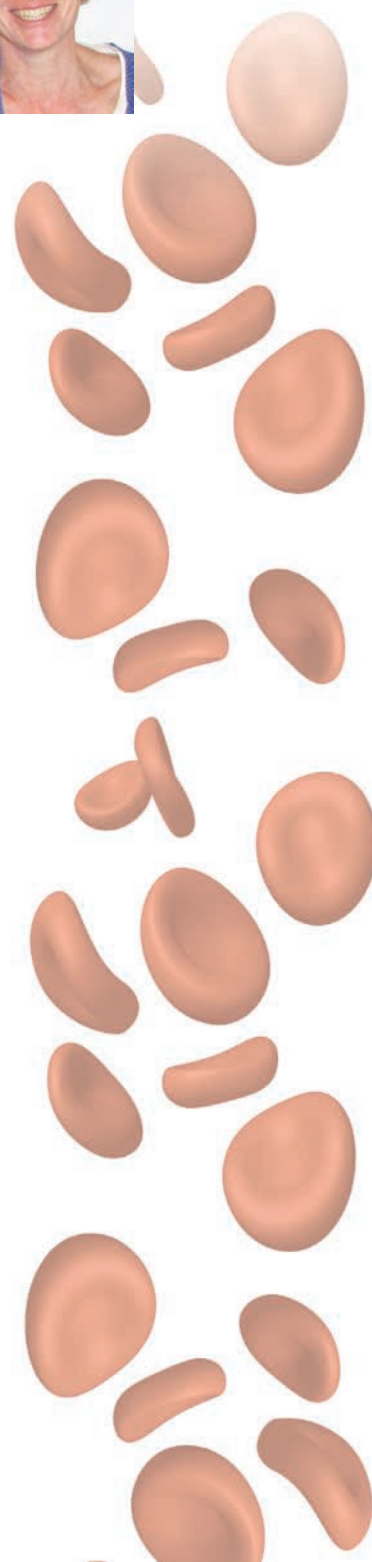
■ PLAN TO ATTEND!

### NEW FEATURE FOR MDS PATIENTS – CONNECT ON OUR PATIENT FORUM AND ZERO IN WITH AN MDS FOUNDATION EXPERT!

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[www.mds-foundation.org](http://www.mds-foundation.org)



## *The Emerging Impact of Flow Cytometry in Myelodysplastic Syndromes*



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Although cytomorphology is the mainstay in the diagnosis of myelodysplastic syndromes (MDS) it may be ambiguous, especially in cases with low blast counts and mild dysplastic features. In particular, in cytopenic patients with normal or inconclusive morphology and normal cytogenetics, additional diagnostic markers are necessary. Flow cytometry (FC) can play a key role. Flow cytometry has been introduced as an important co-criterion in the diagnosis of MDS. Moreover, it has been recommended recently as a tool in the diagnostic work-up of MDS if performed according to the guidelines as defined by the European LeukemiaNet (ELNet) Working Party on "Standardization of FC in MDS".<sup>1-4</sup> ELNet reports describe recommendations on implementation of FC (i.e. technical issues as sample preparation, instrument set-up and quality assessment, acquisition of data and gating strategy); the ELNet working group also proposes minimal criteria for the diagnosis and prognostic evaluation of MDS and other cytopenias.<sup>2,3</sup>

Analysis of bone marrow cells by FC can identify specific aberrations in both immature and maturing compartments among different hematopoietic lineages.

Since, MDS comprises a heterogeneous group of myeloid neoplasms, it is unlikely that a single specific marker can discriminate MDS from other cytopenias. Hence, the presence of multiple aberrancies has a higher predictive value for MDS than single aberrancies.<sup>5-8</sup> In line with this, current WHO2008 recommendations recognize the presence of three or more FC aberrancies as indicative of MDS.<sup>9</sup>

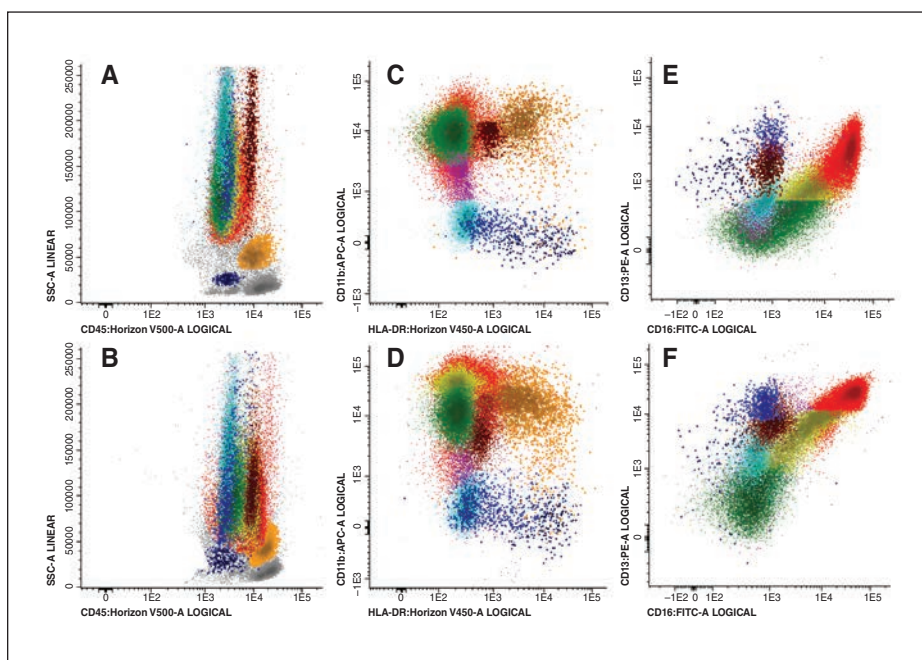
As demonstrated in a multicenter study on behalf of the ELNet, application of only four parameters enables to distinguish low-risk MDS without other specific markers (i.e. cytogenetics or ring sideroblasts) from non-clonal cytopenias.<sup>10</sup> The key parameters within this score are: i) an increase in CD34<sup>+</sup> progenitor cells within bone marrow nucleated cells ( $\geq 2\%$ ); ii) a decreased percentage of progenitor B cells within the CD34<sup>+</sup> compartment ( $\leq 5\%$ ); iii) a decrease or increase of CD45 expression level on myeloid progenitor cells as compared to lymphocytes as a reference ( $\leq 4$  or  $\geq 7.5$ ) and iv) a decrease in SSC of neutrophils as compared to lymphocytes ( $\leq 6$ ). The presence of two or more of these specific aberrancies identified 70% of low-risk MDS cases with a specificity of 93%.<sup>10</sup> Assessment of FC aberrancies of myeloid progenitor cells and the maturing myelomonocytic compartment can add valuable information.<sup>5-11</sup> Furthermore, FC analysis of erythroid dysplasia might provide supplementary information, particularly within low-risk MDS.<sup>12-14</sup> Few applications are available for FC analysis of the megakaryocytic lineage but no standardized approach is yet available.<sup>15</sup> The next paragraphs summarize current recommendations for FC analysis in MDS. Of note, evaluation of dysplasia by FC necessitates knowledge of expression levels in appropriate normal and pathological bone marrow controls.

## *Evaluation of Dysplasia in the Immature Myeloid Progenitor Compartment*

The immature cell compartment is very heterogeneous. Therefore, beyond the classic CD45<sup>dim</sup>/SSC<sup>low/int</sup> profile, antibody combinations such as CD45/CD34/CD117/HLA-DR and CD45/CD34/CD123/HLA-DR are instrumental to identify myeloid progenitor cells (CD45<sup>dim</sup> and SSC<sup>low/int</sup>) among other populations that show overlapping CD45 and SSC features (e.g. B cell precursors, plasma cells, monoblasts, basophils, erythroblasts and plasmacytoid dendritic cell precursors).<sup>2</sup> Observed aberrancies in the immature myeloid compartment in MDS are an abnormal intensity or lack of expression of CD45, CD34, CD117, HLA-DR, CD13, CD33, asynchronous presence of CD11b, and/or the expression of lineage infidelity markers such as CD5, CD7 or CD56.<sup>5,7,11,12,16-19</sup>

## *Evaluation of Dysplasia in the Neutrophil Compartment*

Maturing neutrophils are identified by their CD45<sup>int</sup>SSC<sup>int</sup>-bright profile. Other markers such as CD33, CD64, HLA-DR and CD11b are useful in distinguishing monocytes and hypogranular neutrophils. Neutrophils display diminished CD33 and CD64 expression, heterogeneous to bright CD11b and mostly lack HLA-DR as compared to CD33<sup>bright</sup>, HLA-DR<sup>+</sup> and CD11b<sup>+</sup> monocytes. One of the most frequently reported FC aberrancies in the maturing neutrophil compartment is an abnormally decreased SSC reflecting hypogranularity (example in **Figure 1**).<sup>2</sup> Next to decreased SSC, dysplastic neutrophils can display aberrant expression levels of certain antigens or an aberrant relationship among two or more antigens, e.g. aberrant relationships between CD13 and CD11b and/or CD13 and CD16 and between CD15 and CD10 (**Figure 1**).<sup>2,3</sup>



**Figure 1. Immunophenotypic patterns in the myelomonocytic compartment of an MDS bone marrow sample as compared to a normal control**

Multicolor density plots of a normal bone marrow sample and a case of MDS are illustrated in the upper row and lower row, respectively. Panel A and B depict CD45 (X-axis) vs. sideward light scatter (SSC; Y-axis) plots. Cell populations displayed are myeloid progenitor cells (CD45<sup>dim</sup>/SSC<sup>low</sup> to intermediate, dark blue), monocytes (CD45<sup>int</sup>/SSC<sup>int</sup>, orange) and neutrophils (CD45<sup>dim</sup>/SSC<sup>int</sup> to high in multiple colors). Granularity (presented as sideward light scatter: SSC) of MDS neutrophils in panel B is aberrantly decreased as compared to that of the neutrophils in a normal control (panel A), indicating hypogranularity; the latter also holds true for the eosinophils (in brown). In panel C and D maturation patterns of the myelomonocytic subpopulations are shown in HLA-DR (X-axis) vs. CD11b (Y-axis) plots. HLA-DR+CD11b<sup>-</sup> myeloid progenitor cells (dark blue) differentiate clockwise towards HLA-DR+CD11b<sup>+</sup> neutrophils; differentiation towards HLA-DR+CD11b<sup>+</sup> monocytes (in orange) occurs counterclockwise. The MDS case in panel D shows over expression of CD11b on more mature neutrophils (in red en pale green). In panel E and F maturation patterns of the selected neutrophil subpopulations are shown in CD16 (X-axis) vs. CD13 (Y-axis) plots. In panel E, the normal maturation from CD13+CD16<sup>-</sup> immature neutrophils (in blue), via a CD13<sup>dim</sup> interphase (in green) towards CD13+CD16<sup>+</sup> mature neutrophils (in red) is displayed; eosinophils are depicted in brown. The MDS case in panel F shows abnormal concave instead of convex maturation profile (panel E)

### Evaluation of Dysplasia in the Monocytic Compartment

Morphological assessment of dysmyelopoiesis in MDS is difficult unless there is marked monocytosis. By FC, monocytes can be defined based on their CD45 expression (intermediate-bright), SSC (intermediate) and additional markers such as HLA-DR, CD11b, CD64, CD36, CD33 and CD14. The use of CD14 alone may underestimate the per-

centage of monocytic cells particularly when immature forms are present. Aberrancies of interest in the monocytic lineage are an abnormal distribution of maturation stages, abnormal relationships of HLA-DR and CD11b, abnormal intensity of CD13 and overexpression of CD56. CD56 (and CD2) may even contribute to discriminate chronic myelomonocytic leukemia (CMML) from MDS/myeloproliferative neoplasms.<sup>20-21</sup>

### Evaluation of Dysplasia in the Erythroid Compartment

The erythroid population can be defined by its very dim to negative of CD45 expression and low FSC and SSC properties. Commonly applied markers are CD45, CD71, CD235a, CD36, CD117, and less frequently CD105. One of the most frequently observed aberrancies (80% of low-risk MDS) is an increased number of erythroid progenitors associated with a larger proportion of immature erythroid cells (CD117<sup>+</sup> or CD105<sup>+</sup>). Furthermore, in approximately 70% of the patients, abnormal relationship of CD71 vs. CD235a and/or decreased expression of CD36 is observed.<sup>7,12-14,22</sup>

### Flow Cytometry and Prognosis of MDS

Thus far, the only validated prognostic FC score is the FC scoring system by Wells et al.<sup>5,8,19,23</sup> This flow score weighs the percentage of myeloid progenitor cells and their aberrancies and the amount of aberrancies in the maturing myelomonocytic compartment. In clinical practice, WHO classification, International Prognostic Scoring System (IPSS and IPSS-revised) and WHO-based Prognostic Scoring System (WPSS) are all well validated and applied routinely.<sup>9,24-26</sup> Interestingly, within the subgroups or risk groups of the WHO, IPSS (-revised) and WPSS flow scores are rather heterogeneous. This implies that FC can identify patients with worse prognosis within validated risk categories.

### Application of Flow Cytometry in Predicting and Monitoring Treatment Response

Subgroups of in low and int-1 risk MDS with distinct clinical behaviour regarding transfusion dependency and progression can be identified by FC analysis of bone marrow cells.<sup>19</sup> Moreover, in a clinical decision model the absence of aberrant myeloid progenitors as assessed by FC in combination with low endogenous erythropoietin levels is predictive for



response to growth factor treatment.<sup>27</sup> In addition, aberrant marker expression on myeloid progenitors cells identifies patients who may not benefit from treatment with hypomethylating agents such as azacitidine in intermediate-2 and high risk MDS.<sup>28</sup> There are few data indicating that patients in complete remission for AML after high dose chemotherapy but with FC dysplasia might have worse clinical outcome suggesting persistence of (previously) undefined MDS. Finally, specific flow signatures are being recognized within specific cytogenetic subgroups such as in MDS with isolated del(5q). These flow signatures might have impact in monitoring MDS during treatment with lenalidomide.

### Concluding Remarks

Flow cytometric analysis is recognized and even recommended as a tool for diagnosis of MDS when performed according to the ELNet guidelines.<sup>2,3</sup> It is understood that currently these methods are not universally accepted outside of Europe because of the some technical issues raised. Thus, some institutions and guideline committees recommend further evaluation before acceptance of these flow cytometric methods for the diagnosis of MDS. Noteworthy, FC in MDS should only be applied as part of an integrated diagnostic approach. Results from FC analysis can add to better prognostification. Current investigations focus on the role of FC in monitoring the course of the disease in untreated (low risk) MDS patients and in the selection of patients who might benefit from emerging new drugs in low and high risk MDS.

### Acknowledgements

We would like to thank all participants of the ELNet and Dutch MDS FC working groups for providing input in the development of the ELNet guidelines for the assessments of FC in MDS.

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## INTERNATIONAL PROGNOSTIC SCORING

### Revised International Prognostic Scoring System for MDS



The manuscript describing the Revised IPSS (IPSS-R) for MDS is available now in the September 23, 2012 issue of *Blood* (vol.120, p2454). 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.

The IPSS-R calculator tool is accessible through the following URLs: <http://www.ipss-r.com> or <http://mdsfoundation.org/calculator/index.php>. An iPhone App for the IPSS-R calculator tool is also accessible through the Apple store (enter MDS IPSS-R).



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.mds-foundation.org/revisedprognostic-system-for-mds/>.

### Tech it Out!

Revised International Prognostic Scoring System (IPSS-R) for Myelodysplastic Syndromes

**Risk Assessment Calculator**

Tap screen to enter calculator

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#### Variables (units) [usual range]

##### Hemoglobin (g/dL) [4-20]

A Possible conversion for Hb values:  
10 g/dL=6.2 mmol/L, 8g/dL=5.0 mmol/L

##### Absolute Neutrophil Count (x10<sup>9</sup>/L) [0-15]

##### Platelets (x10<sup>9</sup>/L) [0-2000]

##### Bone Marrow Blasts (percent) [0-30]

##### Cytogenetic Category ?

Select Category ▼



# About the Foundation

## Who Are We?

The MDS Foundation, Inc. is an international organization established in 1994 by world renowned researchers dedicated to further scientific knowledge, patient support, and education in the myelodysplastic syndromes (MDS). The Foundation is based on the premise that international cooperation will accelerate the process leading to the control and cure of MDS.

## What is MDS?

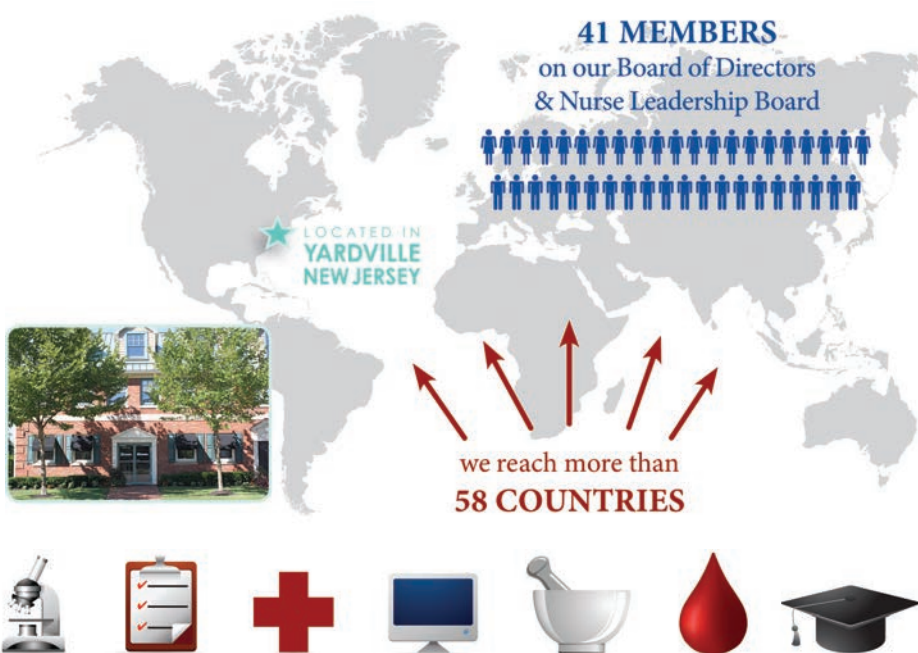
The myelodysplastic syndromes are a group of bone marrow disorders resulting in the ineffective production of normal mature blood cells. Many patients experience anemia from the lack of effective red blood cells, thereby requiring frequent blood transfusions. A shortage of white blood cells may cause malfunctioning of the immune system resulting in infections. Insufficient platelets can result in excessive bleeding. In about one-third of MDS patients, the disease transforms into acute myelogenous leukemia (also known as AML).

## What We Do

The MDS Foundation provides research grants for scientific investigators, sponsors international working groups of scientists and physicians to further diagnostic, prognostic and treatment techniques, and disseminates information on state-of-the-art research, clinical trials and treatments among the professional and patient communities. The Foundation also refers patients to its collection of "MDS Centers of Excellence," maintains an electronic forum on its website for interaction and support among patients, and provides educational programs for both health care professionals and patients and their families.

## Where We Are

The Foundation is located in Yardville, New Jersey and is active in more than 58 countries around the world. Our Board of



Directors consists, for the most part, of physicians and nurses actively engaged in searching for a cure of the disease. Our Nurse Leadership Board is comprised of specialized nurses sharing information and teaching others how to care for MDS patients. Together, the Board of Directors and the Nurse Leadership Board consist of 41 members representing 14 countries. Please see our website [www.mds-foundation.org](http://www.mds-foundation.org) for a complete list of our board members and other vital information about the disease and the Foundation.

## Our Fundraising Efforts

As a tax exempt non-profit, section 501(c)3 organization, donations to the MDS Foundation qualify for a U.S. tax deduction (it is essential to consult with your tax advisor to confirm your own tax situation).

The MDS Foundation actively seeks financial support for our mission and programs to continue providing services such as the following:

- International Working Group for Prognosis in MDS (IWG-PM)
- Young Investigator Research Grants

- Hot-line for patients and caregivers to speak with our Patient Liaison at 800-MDS-0839
- Numerous Face to Face Patient Forums in multiple cities with presentations by local physicians
- Online Patient Forum monitored by experts
- Designation of Centers of Excellence (COE) meeting the highest standards for diagnosis, treatment, and patient care
- Patient Referrals to COEs
- *Building Blocks of Hope*® handbook (in print or online) with complete written and video information on the care and treatment of MDS
- The MDS News Email Alerts
- Biennial International MDS Symposia for professionals & continuing medical and nursing education programs

Donations can be made on our website by credit card (through PayPal), or by check made payable and addressed to:  
The MDS Foundation, Inc.  
4573 South Broad St., Suite 150  
Yardville, New Jersey 08620



# Meeting Highlights and Announcements

THE AMERICAN SOCIETY OF HEMATOLOGY 53RD ANNUAL MEETING & EXPOSITION • DECEMBER 2012

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

## **Myelodysplastic Syndromes: Current Understanding & Management Approaches**

**Georgia World Congress Center  
Atlanta, Georgia**

The MDS Foundation held its 14th consecutive satellite symposium on Friday preceding the American Society of Hematology's annual meeting. The room was filled to capacity with an audience of more than 800 hematologists from around the world. We wish to thank our internationally renowned faculty – Drs. Neal S. Young, Timothy Graubert, Theo de Witte, Alan F. List and Mary M. Horowitz for presenting the most up-to-date information on effective management of MDS as well as current standard and recent novel therapeutic advances for MDS patients.

## **Highlights from 54th ASH Annual Meeting and Exposition**



*Members of our Nurse Leadership Board, Erin Demakos and Sandy Kurtin, always willing to lend a hand at the MDSF Exhibit Booth*



*Nurse Sandy Kurtin, Susan Hogan, Bergit Kuhle and Audrey Hassan (left to right)*

**Download our ASH Presentations online at  
<http://www.mds-foundation.org/ash-2012-presentations/>**

- Hematopoietic Stem Cell Transplantation (HCT) for MDS
- Impact of Co-Morbidities and Treatment on newly diagnosed lower risk MDS patients from the EU MDS Registry
- Somatic Mutations in MDS: Insight into their Prognostic and Biological Importance
- Biomarker Directed Treatment Approaches for MDS
- Current Management Approaches for Myelodysplastic Syndromes (MDS) Bone Marrow Failure in MDS: Role of Abnormal Telomere Dynamics



*Health professionals learning more about MDS at the ASH conference*



*Crowd of 800+ hematologists participated in our sponsored satellite symposium*



THE 12<sup>TH</sup> INTERNATIONAL SYMPOSIUM ON MYELODYSPLASTIC SYNDROMES

MDS 2013 will unite all professionals devoted to improving the quality of life of patients with Myelodysplastic Syndromes. Join the leading researchers, clinicians and educators in the field of haematology for a diverse scientific programme that ranges from basic workshops to the most cutting edge discoveries in MDS.

# The 12<sup>th</sup> International Symposium on **MYELODYSPLASTIC SYNDROMES**

May 8-11, 2013 | Berlin, Germany

**ADVANCING RESEARCH  
& PATIENT CARE**

[www.kenes.com/mds](http://www.kenes.com/mds)





## PRELIMINARY TIMETABLE

### WEDNESDAY, MAY 8, 2013

14:00-17:00	<b>Morphology in MDS</b> <b>Basic Course</b> Teresa Vallespi, <i>Spain</i> Ulrich Germing, <i>Germany</i> Masao Tomonaga, <i>Japan</i> Gina Zini, <i>Italy</i> Richard Brunning, <i>USA</i>	<b>Advanced course</b> Torsten Haferlach, <i>Germany</i> John Bennett, <i>USA</i> Marius MacKenzie, <i>The Netherlands</i> Jean Goasguen, <i>France</i>
17:00	<b>Opening Ceremony</b> <b>Chairs:</b> Arnold Ganser, <i>Germany</i> ; Stephen Nimer, <i>USA</i>	
19:00	<b>Welcome Reception</b>	

### THURSDAY, MAY 9, 2013

8:30-10:00	<b>Plenary I: PathogenOMEs in MDS – new players and well known gamblers</b> <b>Chair:</b> Wolf-Karsten Hofmann, <i>Germany</i> <b>The Genome.</b> Timothy Graubert, <i>USA</i> <b>The Spliceosome.</b> Seishi Ogawa, <i>Japan</i> <b>The Epigenome.</b> Joop Jansen, <i>The Netherlands</i> <b>Impact of alterations of OMEs for Classification: IWG-PM/Molecular.</b> Benjamin Ebert, <i>USA</i> <i>This session is supported by an Unrestricted Educational Grant from Celgene Corporation</i>	
10:00-10:30	Coffee Break	
10:30-11:30	<b>Plenary II: Diagnosis in 2013– state-of-the-art</b> <b>Chair:</b> Eva Hellström-Lindberg, <i>Sweden</i> <b>WHO 2013.</b> Ulrich Germing, <i>Germany</i> <b>Cytogenetic Advances.</b> Detlef Haase, <i>Germany</i> <b>IPSS-R(vised): Update.</b> Peter Greenberg, <i>USA</i>	
11:30-12:30	<b>Interactive I: Challenging diagnostic cases – does molecular genetics lead the way?</b> <b>Chair:</b> John Bennett, <i>USA</i> <b>RA/RCMD – RAEB-I – RAEB-II – AML.</b> Aristoteles Giagounidis, <i>Germany</i> <b>CMML: Clinical management.</b> David Bowen, <i>UK</i> <b>RARS-T: Molecular and clinical features of refractory anemia with ringed sideroblasts associated with marked thrombocytosis.</b> Luca Malcovati, <i>Italy</i>	
12:30-13:30	Lunch	<b>Meet the Experts</b> Molecular Diagnostics. Ghulam Mufti, <i>UK</i> Scoring. Mario Cazzola, <i>Italy</i> Overlap MDS/MPN. Nick Cross, <i>UK</i>
13:30-14:30	<b>Plenary III: What can MDS-specialists learn from ...</b> <b>Chair:</b> Mario Cazzola, <i>Italy</i> <b>Childhood MDS.</b> Charlotte Niemeyer, <i>Germany</i> <b>Novel genetic diseases associated with bone marrow failure.</b> Christoph Klein, <i>Germany</i> <b>Overlap of BMF and MDS.</b> Jaroslaw Maciejewski, <i>USA</i>	
14:30-16:00	<b>Oral Session I – Pathogenesis</b> <b>Chair:</b> Brigette Schlegelberger, <i>Germany</i>	
16:00-16:30	Coffee Break	
16:30-18:00	<b>Poster Session (+ guided poster discussion)</b>	

# The 12<sup>th</sup> International Symposium on MYELOYDYSPLASTIC SYNDROMES



## FRIDAY, MAY 10, 2013

8:30-10:00	<b>Plenary IV: Treatment of low risk MDS patients – the standard, the new</b> <b>Chair:</b> Jacob Passweg, <i>Switzerland</i> <b>Immunosuppressive therapy.</b> Neal Young, <i>USA</i> <b>The riddle of iron chelation in MDS.</b> Valeria Santini, <i>Italy</i> <b>ESAs/TSAs – The higher the dose, the better the response?</b> Sophie Park, <i>France</i> <b>Lenalidomide as a standard treatment for low risk MDS with 5q abnormality?</b> Alan List, <i>USA</i> <i>This session is supported by an Unrestricted Educational Grant from Novartis Oncology</i>
10:00-10:30	Coffee Break
10:30-11:30	<b>Plenary V: Treatment of high risk MDS patients</b> <b>Chair:</b> Pierre Fenaux, <i>France</i> <b>Molecular targets – treatment options.</b> Stephen Nimer, <i>USA</i> <b>Hypomethylating agents for treatment of high risk MDS.</b> Norbert Gattermann, <i>Germany</i> <b>Combination regimens in high risk MDS.</b> Steven Gore, <i>USA</i> <i>This session is supported by an Unrestricted Educational Grant from Celgene Corporation</i>
11:30-12:30	<b>Interactive II (allo SCT)</b> <b>Chair:</b> Theo DeWitte, <i>The Netherlands</i> <b>Patients selection.</b> Corey Cutler, <i>USA</i> <b>Pre treatment.</b> Guillermo Sanz, <i>Spain</i> <b>Management of graft versus host disease.</b> Hans-Joachim Deeg, <i>USA</i>
12:30-13:30	Lunch <b>Meet the Experts</b> <b>Iron Chelation.</b> Daniela Cilloni, <i>Italy</i> <b>ESA.</b> Martin Jädersten, <i>Sweden</i> <b>Combination Treatment.</b> Uwe Platzbecker, <i>Germany</i>
13:30-14:30	<b>Best abstracts (Bastianello-Awards)</b> <b>Chair:</b> Arnold Ganser, <i>Germany</i> ; Stephen Nimer, <i>USA</i>
14:30-16:00	<b>Oral Session II – Treatment and trials</b> <b>Chair:</b> Lionel Ades, <i>France</i>
16:00-16:30	Coffee Break
16:30-18:00	<b>Poster Session</b> (+ guided poster discussion)

## SATURDAY, MAY 11, 2013

8:30-10:00	<b>Oral Session III – Prognostication and QoL</b> <b>Chair:</b> Reinhard Stauder, <i>Austria</i> ; Sandy Kurtin, <i>USA</i>
10:00-10:30	Coffee break
10:30-12:00	<b>Plenary VI: Future perspectives and new drug development</b> <b>Chair:</b> Steven Gore, <i>USA</i> <b>Microenvironment.</b> Sten Jacobsen, <i>UK</i> <b>Next generation sequencing – diagnostic/prognostic key?</b> Alexander Kohlmann, <i>Germany</i> <b>Therapy related MDS.</b> Richard Larson, <i>USA</i> <b>Pipeline overview: Disease modifying drugs in MDS.</b> Guillermo Garcia-Manero, <i>USA</i>
12:00-12:30	<b>Closing Remarks</b>

Plenary Session

Interactive Session

Poster Session

Social Event

Oral Session

Best Abstracts



## THE 12<sup>TH</sup> INTERNATIONAL SYMPOSIUM ON MYELODYSPLASTIC SYNDROMES



### REGISTRATION

Discounted registration can be accessed online until April 29th. Please visit: [www.kenes.com/mds](http://www.kenes.com/mds)

	Early bird fee Until March 13th	Regular fee From March 13th until April 29th	Onsite fee From April 29th
MDSF Member*	€ 540.00	€ 600.00	€ 660.00
Non-Member	€ 600.00	€ 670.00	€ 720.00
Nurse**	€ 240.00	€ 290.00	€ 290.00
Student***	€ 155.00	€ 190.00	€ 225.00
Pre-Symposium Course in Morphology		€ 15.00	
Meet the expert lunch session		€ 10.00	

#### Fees for all Meeting Participants include:

- Participation in scientific sessions
- Entrance to the exhibition
- Opening ceremony and welcome reception
- The printed material of the Symposium
- A certificate of attendance
- Coffee and Lunch breaks - as indicated in the programme

### ACCOMMODATION

We have selected a variety of hotels across Berlin, being offered at a discounted rate to MDS participants. Detailed information about the official symposium hotel, room rates, cancellation policies and access to the online accommodation booking form, are available on the website: [www.kenes.com/mds](http://www.kenes.com/mds)

### PATIENT FORUM

Please join us on Saturday, May 11th in Berlin, Germany for our next MDS Patient & Family Forum. Guest speakers will include Prof. Dr. med. Aristoteles Giagounidis, Prof. Dr. med. Uwe Platzbecker and Angelika Bitter, RN. The forum will be offered in both English and German. For more information, visit: [www.LHRM.de](http://www.LHRM.de) or contact [buero@LHRM.de](mailto:buero@LHRM.de)

### CME ACCREDITATION

#### UEMS-EACCME

The 12th International Symposium on Myelodysplastic Syndromes (MDS 2013) has been accredited by the European Accreditation Council for Continuing Medical Education (EACCME) to provide the following CME activity for medical specialists.

The 12th International Symposium on Myelodysplastic Syndromes (MDS 2013) is designated for a maximum of, or up to, **18 (eighteen) European CME credits (ECMEC)**. Each medical specialist should claim only those hours of credit that he/she actually spent in the educational activity. The EACCME is an institution of the European Union of Medical Specialists (UEMS): [www.uems.net](http://www.uems.net)

#### American Medical Association (AMA)

Through an agreement between the European Union of Medical Specialists and the American Medical Association, physicians may convert EACCME credits to an equivalent number of AMA PRA Category 1 Credits™. Information on the process to convert EACCME credit to AMA credit can be found at [www.ama-assn.org/go/internationalcme](http://www.ama-assn.org/go/internationalcme).

#### Royal College of Physicians and Surgeons of Canada

Live educational activities, occurring outside of Canada, recognized by the UEMS-EACCME for ECMEC credits are deemed to be Accredited Group Learning Activities (Section 1) as defined by the Maintenance of Certification Program of The Royal College of Physicians and Surgeons of Canada. For more information, visit: [www.royalcollege.ca](http://www.royalcollege.ca).

#### Deutsche Ärztekammer Berlin

The 12th International Symposium on Myelodysplastic Syndromes (MDS 2013) is accredited by the Deutsche Ärztekammer Berlin. The following credits will be granted to participants: 3 CME points/ half a day.

## The 12<sup>th</sup> International Symposium on MYELODYSPLASTIC SYNDROMES

May 8-11, 2013 | Berlin, Germany



# Welcome to the 12<sup>th</sup> International Symposium on Myelodysplastic Syndromes

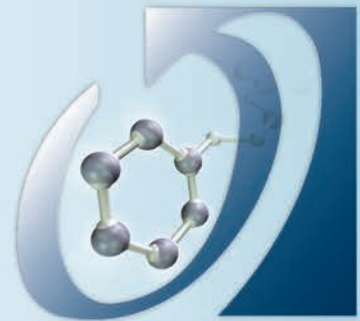
May 8 - 11, 2013 | Berlin, Germany

Our appreciation and gratitude to  
the MDS Foundation for raising  
awareness of the **ONTIME** Trial

**ONTIME** is a Phase III trial of rigosertib (ON 01910.Na)  
in MDS patients after DNA hypomethylating agents



Clinicaltrials.gov Identifier: NCT01241500  
[www.onconova.com](http://www.onconova.com)





## SAVE THE DATE AND PLAN TO ATTEND!

### MDS Symposium at 55th ASH Annual Meeting

The MDS Foundation invites you to New Orleans, LA, for its next Breakfast Symposium to be held at the 55th ASH Annual Meeting and Exposition.

**FRIDAY, DECEMBER 6, 2013**

**7 am to 11 am**

**Ernest N. Morial Convention Center**

**New Orleans, LA**



**VISIT THE MDS FOUNDATION BOOTH: #2813**

## BRAND NEW & COMING SOON!

**NEW!**

**Connect on our improved Patient Forum and zero in with an MDSF Expert.**

Look for this new feature on our free online discussion board of information exchanged between patients, caregivers, and family members. Where else can you have MDSF Experts at your fingertips addressing your unique concerns and personally have your questions answered?

***Will be available on mobile devices.***



## DO SOMETHING BIG IN 2013!

### *Be a Bone Marrow Donor*

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

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

BE  THE MATCH®

**NATIONAL  
DONOR  
MARROW  
PROGRAM®**



### *Be a Blood Donor*

We'd like to encourage everyone to give blood! Bone marrow failure disorders like MDS require patients to receive regular blood transfusions. Contact your local blood bank today.

***Give the Gift of Life!***

### The Myelodysplastic Syndromes (MDS) Foundation, Inc. Observes Rare Disease Day

February 28, 2013

The MDS Foundation, Inc. joined the National Organization for Rare Disorders (NORD) and others around the world in observance of *World Rare Disease Day* on February 28, 2013.

To raise MDS awareness at the state level and *Rare Disease Day* we went to the New Jersey State House with other patient groups on March 4, 2013. Our message was to ensure the needs of all rare disease patients are considered in future legislative policy and making sure "Every Patient Counts" is a NJ State imperative.

Senator Bucco's office created two Resolutions for us for *Rare Disease Day*. The first one honors all the Rare Disease Organizations in New Jersey. The 2nd Resolution states that the last day of February is acknowledged as *Rare Disease Day* in New Jersey.

MDS is a puzzling, life-threatening group of diseases of the bone marrow for which there are no easy cures or quick remedies. In MDS, the bone marrow is abnormal because of a variety of malignant changes. The result is ineffective production of normal mature blood cells, resulting in low blood counts (cytopenias). Various subtypes of the disease exist with variable prognoses, treatment options, and risk of developing leukemia.

A rare disease is one that affects fewer than 200,000 Americans. There are nearly 7,000 such diseases affecting nearly 30 million Americans.

On *Rare Disease Day*, people with rare diseases around the world promote awareness of the challenges of living with a rare disease. The global theme for 2013 is "Rare Disorders Without Borders."

World Rare Disease Day was launched in Europe four years ago and last year was observed in more than 60 nations. It is



always observed on the last day of February. On that day, patients and patient organizations will post stories, videos and blogs online and host events to raise awareness of these diseases, which are often called "orphans".

This year, the observance has special significance in the U.S. because 1983 is also the 30th anniversary of the Orphan Drug Act, which provides incentives to encourage companies to develop treatments for rare diseases, and of NORD, which was established by patient advocates in 1983.





## ONCOLOGY NURSING SOCIETY

**VISIT OUR BOOTH AT ONS!**

## Oncology Nursing Society 38th ONS Congress

**April 25 – 28, 2013**

**Walter E. Washington Convention Center  
Washington, DC**

The MDS Foundation is going to participate in the 38th ONS Congress which is a premier educational event for oncology nurses.

**CHECK OUT OUR BOOTH #244!**



THE SENATE AND GENERAL ASSEMBLY  
STATE HOUSE, TRENTON, N.J.

JOINT LEGISLATIVE RESOLUTION  
By Senator BUCCO and Assemblymen BUCCO and CARROLL

WHEREAS, The New Jersey Senate and General Assembly are pleased to acknowledge the last day of February 2013, as Rare Disease Day in the Garden State; and,

WHEREAS, Rare Disease Day, which will be an ongoing, annual observance, is an appropriate time for the citizens of this State to become informed about the nearly 7,000 of these maladies that affect approximately 30 million Americans, including thousands in this State, and they place a significant emotional and financial drain on caregivers, families, and employers; and,

WHEREAS, Half of the people affected by rare diseases in the United States are children, due to many of the conditions being genetic, and challenges facing individuals and families also include difficulty in obtaining timely, accurate diagnoses and physicians or treatment centers with needed expertise, limited treatment options that are more expensive, if available, and reimbursement issues related to private insurance, Medicare, and Medicaid; and,

WHEREAS, The National Organization for Rare Disorders and the numerous entities dedicated to rare diseases are commended for their selfless and tireless efforts in empowering families and individuals, encouraging and funding research into the cause of these maladies, and educating the public, medical professionals, and government agencies by disseminating information; and,

WHEREAS, It is both proper and fitting for the members of this Legislature to pause in their deliberations to acknowledge Rare Disease Day, and to salute the members and leaders of the National Organization for Rare Disorders and its myriad counterparts for their outstanding efforts in behalf of others; now, therefore,

Be It Resolved by the Senate and General Assembly of the State of New Jersey:

That this Legislature hereby notes the occurrence of Rare Disease Day, pays tribute to the meritorious record of service, commitment, and leadership of the many organizations uniting patients, families, and others, and urges all New Jerseyans to participate fittingly in Rare Disease Day on the last day of February 2013; and,

Be It Further Resolved, That a duly authenticated copy of this resolution be signed by the Senate President and the Assembly Speaker and attested by the Senate Secretary and the Assembly Clerk.

Attest:



Kenn M. Hinkle  
Secretary of the Senate



Dana M. Burley  
Clerk of the General Assembly

*Stephen M. Sweeney*  
President of the Senate

*Steven Y. Stein*  
Speaker of the General Assembly

In 1983, the Orphan Drug Act was passed by Congress to create financial incentives for companies to develop treatments for rare diseases. Since then, more than 400 orphan drugs and biologics have been approved by the Food and Drug Administration (FDA). It is estimated that approximately 15 million Americans benefit from these products, but that still leaves millions more with diseases for which there is no approved treatment.

For more information about *Rare Disease Day* activities in the US, go to: [www.rarediseaseday.us](http://www.rarediseaseday.us).

For information about global activities, go to: [www.rarediseaseday.org](http://www.rarediseaseday.org).



STATE OF NEW JERSEY  
EXECUTIVE DEPARTMENT

## Proclamation

WHEREAS, there are nearly 7,000 diseases and conditions considered rare (each affecting fewer than 200,000 Americans) in the United States; and

WHEREAS, while each of these diseases may affect small numbers of people, rare diseases as a group affect almost 30 million Americans; and

WHEREAS, many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected; and

WHEREAS, according to the Food and Drug Administration, nearly 340 orphan drugs and biologics approved for the treatment of rare diseases help between 11 and 14 million people, well over 15 million Americans with rare diseases have no treatment specific to their disease; and

WHEREAS, individuals and families affected by rare diseases often experience problems such as a sense of isolation, difficulty in obtaining an accurate and timely diagnosis, few treatment options and difficulties accessing or being reimbursed for treatment; and

WHEREAS, while some rare diseases, such as "Lou Gehrig's disease" and Huntington's disease, are relatively well known, many others that New Jersey families suffer with are not known at all by the public - so that patients and their families must bear a large share of the burden for raising funds for needed research; and

WHEREAS, the National Organization for Rare Disorders (NORD) is organizing a nationwide observance of Rare Disease Day on February 28, 2013, when patients, medical professionals, researchers, government officials and companies developing treatments for rare diseases will join together to focus attention on rare diseases as a public health issue;

NOW, THEREFORE, I, CHRIS CHRISTIE, Governor of the State of New Jersey, do hereby proclaim:

**FEBRUARY 28, 2013**

AS

**RARE DISEASE DAY**

in New Jersey.



*Kim Guadagno*  
L.T. GOVERNOR

GIVEN, under my hand and the Great Seal of the State of New Jersey, this fourteenth day of February in the year two thousand thirteen, the two hundred thirty-seventh year of the Independence of the United States.

*Chris Christie*  
GOVERNOR

## Highlights of Latest Literature in MDS

**Suneel D. Mundle, PhD**  
**Rhea Mundle**

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. Li X et al. Distinct clinical and experimental characteristics in the patients younger than 60 years old with myelodysplastic syndromes. *PLoS One*. 2013;8(2):e57392. *In contrast to Western countries, MDS in Asia is common in younger individuals <60 years. The study demonstrated that MDS in this <60 year patient population were more likely in females, mostly had low-risk category, longer survival expectancy, less AML transformation, with frequent trisomy 8, low p15 methylation, with low proliferation index and higher degree of apoptosis of marrow CD34+ cells. These cases had amplification of T cells and low degree of colony forming units (CFU) in vitro. The latter improved after elimination of activated T cells.*
2. Roeker LE et al. Risk of acute leukemia and myelodysplastic syndromes in patients with monoclonal gammopathy of undetermined significance (MGUS): a population-based study of 17315 patients. *Leukemia*. 2013; Feb 5 [Epub ahead of print]. *A total of 17315 individuals studied had 605 MGUS patients (~3.5%). The risk of developing MDS (HR=2.4) but not that of AML or ALL was significantly increased in MGUS patients than controls,*
3. McQuilten ZK et al. Myelodysplastic syndrome incidence, transfusion dependence, health care use, and complications: an Australian population-based study 1998 to 2008. *Transfusion*. 2013;Jan 10 [Epub ahead of print]. *This Australian retrospective study assessed 3149 MDS cases to show transfusion dependence (TD-MDS) in*

*56.3% males and 34.6% females. TD-MDS associated with new diagnoses of congestive heart failure (CHF), but not diabetes or liver disease. CHF was not the cause of death in these patients, however leukemia and sepsis were.*

### DIAGNOSIS/PROGNOSIS:

1. Seiki Y et al. Increased plasma thrombopoietin levels in patients with myelodysplastic syndrome: a reliable marker for benign subset of bone marrow failure. *Haematologica*. 2013; Feb 12 [Epub ahead of print]. *Patients with thrombopoietin levels  $\geq 320$  pg/mL tended to have low-risk MDS, responded to immunosuppressive therapy and had a better 5-year survival (approximately 94% as compared ~64% in those with lower thrombopoietin levels). The higher thrombopoietin levels may thus provide a favorable prognosis.*
2. Shih AH et al. Mutational analysis of therapy-related myelodysplastic syndromes and acute myelogenous leukemia. *Haematologica*. 2013;Jan 24 [Epub ahead of print]. *When genomic DNA from 38 t-MDS/AML patients was subjected to high throughput PCR/sequencing, TP53 mutations were most common (21%) and TET2 mutations were found in 10.5% patients. Mutations or loss of TP53 correlated with worse survival when compared to wild type TP53 (8.8 vs. 37.4 mo respectively,  $P=0.0035$ ).*
3. Kulasekararaj AG et al. TP53 mutations in myelodysplastic syndromes are strongly correlated with aberrations of chromosome 5, and correlate with adverse prognosis. *Br J Haematol*. 2013;160(5): 660–672. *TP53 mutation status was assessed in 318 MDS cases. With a 45 mo follow up, 9.4% patients were detected with TP53 mutations exclusively in patients with chromosome 5 abnormalities (19% in del5q and 72% with complex karyotype including -5/5q-). TP53 mutations could be linked to a high TP53 protein expression, int-2/high risk MDS category, high blast count and increased risk of*

*leukemic progression. Additionally, multi-variate analysis linked TP53 mutations with poorer survival as compared to patients with a wild-type TP53 (HR-3.8; OS-9 vs. 66 mo,  $P<0.001$ , mutated vs. wild type respectively). Once detected, TP53 mutation did not disappear in sequential testing, but when it did on azacytidine treatment the patient responded to therapy.*

4. Zhang Y et al. Expression of CXCR4 is an independent prognostic factor for overall survival and progression-free survival in patients with myelodysplastic syndrome. *Med Oncol*. 2013;30(1):341.

*Using flow cytometry, 81 MDS patients were studied for the expression of a receptor (CXCR4) for stromal cell-derived factor (SDF-1) in bone marrow cells. The elevated CXCR4 expression correlated with shorter overall- and relapse-free-survival as compared to its low expression.*

5. Bernasconi P et al. Validation of the new comprehensive cytogenetic scoring system (NCCSS) on 630 consecutive de novo MDS patients from a single institution. *Am J Hematol*. 2013;88(2):120–129.

*The study evaluated which cytogenetic grouping (NCCSS or IPSS) when combined with WHO classification would best predict clinical outcome of MDS. The best predictive model for OS was found to be that combining the number of cytopenias, WHO classification and NCCSS.*

### INTERESTING CASE REPORTS:

1. Shaharir SS et al. Disseminated tuberculosis masquerading primary myelodysplastic syndrome. *J Infect Dev Ctries*. 2013;7(3):286–288.

*The study reported a case of disseminated tuberculosis with right empyema and pancytopenia showing caseating granuloma with Langhan's cells in the marrow and acid-fast bacilli detectable in pleural fluid. The underlying primary MDS was revealed only after cytogenetics study showing trisomy 8. The study thus demonstrated importance of cytogenetics in differential diagnosis of MDS from hematologic manifestations of tuberculosis.*



2. Koh YR et al. A rare case of transformation of childhood myelodysplastic syndrome to acute lymphoblastic leukemia. *Ann Lab Med.* 2013;33(2):130–135.

*An 8 year old girl who presented with refractory cytopenia of childhood (RCC) had transformation to ALL only 3 months after diagnosis of MDS. The report also presents detailed cytogenetic and molecular microarray analyses.*

3. Ogura H et al. A case of myelodysplastic syndrome presenting with faggot-like cells. *Int J Hematol.* 2013;Mar 9 [Epub ahead of print].

*A 62 year old Japanese male presented with a marrow histology containing promyelocytes with bundles of Auer rods resembling Faggot cells along with typical MDS features of dysplastic erythroblasts, micromegakaryocytes and Pseudo-Pelger-Huët cells. The differential diagnosis of MDS vs. Acute promyelocytic leukemia included the absence of PML-RAR fusion on FISH testing. The clinical course was typical of MDS-RAEB2.*

4. Knight J and Czuchlewski DR. Acquired elliptocytosis of myelodysplastic syndrome. *Blood.* 2013;121(4)–572.

*MDS with del (20) (q11.2) case with progression of disease 5 years later showed development of elliptocytosis.*

## TREATMENT:

### IMiDs:

1. Kuendgen A et al. Lenalidomide does not increase AML progression risk in RBC transfusion-dependent patients with low- or intermediate-1 risk MDS with del(5q): a comparative analysis. *Leukemia.* 2012; Dec 21 [Epub ahead of print].  
*295 patients from two clinical trials (MDS-003 and MDS-004) were compared to 125 untreated RBC transfusion dependent del(5q)/ int-1 patients from a multicenter registry. At baseline, the lenalidomide treated patients had higher transfusion burden than controls (6 vs. 2 units/8 weeks). With a median follow up of 4.3 years from the first dose of lenalidomide, the treated group was found to have comparable risk of AML progression*

*(HR=0.969), but had significantly improved overall survival with treatment (HR=0.597, P=0.012).*

### Demethylating Agents:

1. Lee YG et al. Comparative analysis between azacitidine and decitabine for the treatment of myelodysplastic syndromes. *Br J Haematol.* 2013;Feb 21 [Epub ahead of print].  
*Among the total of 300 patients (203 treated with azacitidine and 97 with decitabine), propensity-score matching yielded 97 pairs in which, no significant difference was noted in ORR (44% vs. 52%), OS (26 vs. 22.9 mo), Event free survival (7.7 vs. 7 mo) or one-year rate of leukemic transformation (16% vs. 22%) with azacitidine or decitabine treatment respectively. However, the older patients (>65 yrs) had better survival with azacitidine.*
2. Merkel D et al. Predicting infections in high-risk patients with myelodysplastic syndrome/acute myeloid leukemia treated with azacitidine: A retrospective multicenter study. *Am J Hematol.* 2013;88(2): 130–134.  
*This retrospective study in 18 institutions in Israel evaluated 184 azacitidine treated patients (157 high risk MDS and 27 AML) that had 153 infection events in a total of 928 treatment cycles (16.5%) of which 75% events needed hospitalization and 20% were fatal. Multivariate analysis linked low Hb, low platelets and unfavorable cytogenetics with the risk of infections during azacitidine treatment.*

### PATHOBIOLOGY:

1. Damm F et al. SETBP1 mutations in 658 patients with myelodysplastic syndromes, chronic myelomonocytic leukemia and secondary acute myeloid leukemia. *Leukemia.* 2012;26:1137–1140.  
*The study showed approximately 15% prevalence of SF3B1 mutation in MDS and more than 50% of the patients with mutation had RARS.*
2. Velegraki M et al. Impaired clearance of apoptotic cells leads to HMGB1 release in the bone-marrow of MDS patients and induces TLR4-mediated cytokine production. *Haematologica.* 2013;Feb 12 [Epub ahead of print].

*The study showed that marrow monocytes in MDS patients (n=27) expressed higher levels of Toll-like receptor 4 (TLR-4) as compared to the healthy individuals (n=25). Moreover, patients' macrophages showed impaired engulfing of apoptotic cells and MDS marrow plasma revealed increased levels of a protein released from dying cells called high mobility group box-1 (HMGB-1) which is a ligand for TLR-4. Coincubation of patients' marrow monocytes with autologous marrow plasma resulted in overproduction of pro-inflammatory cytokines previously reported in MDS marrows.*

## 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. Tothova Z, Steensma DP and Ebert BL. New strategies in myelodysplastic syndromes: application of molecular diagnostics to clinical practice. *Clin Cancer Res.* 2013, Jan 17 [Epub ahead of print].
2. Khan H et al. Role of DNA methylation in the pathogenesis and treatment of myelodysplastic syndromes. *Semin Hematol.* 2013;50(1):16-37.
3. Otrrock ZK et al. The need for additional genetic markers for myelodysplastic syndrome stratification: what does the future hold for prognostication? *Expert Rev Hematol.* 2013;6(1):59–68.
4. Klimek VM. Recent advances in the management of therapy-related myelodysplastic syndromes and acute myeloid leukemia. *Curr Opin Hematol.* 2013;20(2): 137–143
5. Sekeres MA et al. Improving the diagnosis and treatment of patients with myelodysplastic syndromes through a performance improvement initiative. *Leuk Res.* 2013; 37(4):422–426.

***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.***

# IT HAS ARRIVED!

## Building Blocks of Hope™

A global MDS Foundation print and online patient advocacy initiative, providing a personalized educational program for the patient and caregiver to prepare, participate, and **LIVE** with MDS.

Access the website link <http://www.mds-foundation.org/bboh/> for more information. Here you can view and download an online PDF version of the complete handbook.

*Translations in Danish, French, German, and Spanish coming soon!*

## COMING SOON



The MDS Academy is a comprehensive global educational initiative designed to support health care providers involved in the clinical management and support of patients with myelodysplastic syndromes (MDS).

The MDS Academy incorporates a variety of clinical resources:

**Live Multidisciplinary Roundtable Workshops:** A series of regional four-hour case-based clinical workshops for oncology professionals involved in the diagnosis, treatment and clinical management of MDS. Attendees will meet with clinical experts in MDS, review the most recent clinical data, and discuss practical tools for management of the patient with MDS.

**Webinars:** A series of taped lectures covering key topics pertinent to the clinical management of patients with MDS.

**MDS Clinical Tool Box:** A variety of clinical tools that will be maintained on the MDS Foundation website including the IPSS-R calculator, summaries of the most recent published data, links to other online resources, and tools to assist patients/caregivers to take an active role in their MDS care.



Regional, Live, Interactive Case-Based discussions with clinical experts



Educational Webinars for Physicians, Nurse Practitioners, Physician Assistants, Nurses, and Pharmacists



Practical tools for clinical management of MDS



# Fundraising for MDS

## Karen A. Wenzel Annual Golf Tournament September 2012

The tournament this year was probably my favorite so far. We only had 50 golfers, but a lot of new faces came out. Every year seems to get better and better. It's a wonderful day for people to reminisce about my mom and just have a fun time!

We decided to have it in late September due to the schedules of my wife and I, and my father who is a big help. Unfortunately it was a bit cold and rainy, but we made the absolute best of it! We have raised \$4,300 for MDS...so far!

***For years to come we will  
continue to keep my mother's  
memory in our hearts  
and minds, and continue to  
support the MDS Foundation!***

**Paul Wenzel**

***Do you want to raise money  
for a cause that's important  
to you?***

***Do you have some  
fundraising ideas that you  
are willing to share?***

If your answer is yes, then the MDS Foundation would love to hear from you.

**Give us a call at 800-MDS(637)-0839 or email to [tiraca@mdsfoundation.org](mailto:tiraca@mdsfoundation.org). We'll be thrilled to speak to you!**

*A special thank you to Paul Wenzel who held his annual Golf Tournament in memory of his beloved mother, Karen A. Wenzel. He has found a way of keeping his loved one's memory alive by giving to the MDS Foundation and helping patients and families benefit from our educational and patient support programs.*

**Get Involved... We need your help!**



# Patient and Family Education Forums

## SPREADING THE WORD WORLDWIDE

### **FREE One-Day Conferences for MDS Patients and Their Families**

Ongoing meetings in the US and Europe addressing quality of life issues for MDS patients are planned for 2013. Learn the latest on the diagnosis and treatment of MDS from leading experts in the field. These conferences will occur in eleven cities around the world in 2013. A global patient forum will be held alongside the 12th International Symposium on MDS in Berlin, Germany.

#### **CALENDAR OF EVENTS**

February 23, 2013 – Gainesville, FL  
March 2, 2013 – San Diego, CA  
April 20, 2013 – Atlanta, GA  
May 11, 2013 – Berlin, Germany  
July 13, 2013 – Chicago, IL  
September 28, 2013 – Long Island, NY  
October 12, 2012 – Indianapolis, IN  
Philadelphia, PA (Date TBD)  
Buffalo, NY (Date TBD)  
Ann Arbor, MI (Date TBD)

Registration is required to attend. Contact Deborah Murray at 800-MDS(637)-0839 or email [dmurray@mds-foundation.org](mailto:dmurray@mds-foundation.org).

**For updates, check our website  
<http://www.mds-foundation.org/events>  
and facebook.**

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

### **Featured MDS Patient Support Group – New York, New York**

A new support group has begun meeting at Memorial Sloan-Kettering Cancer Center, 430 East 67th Street (Between York and 1st Ave) in New York City.

The group had their inaugural meeting on January 26, 2013 and their next meeting is scheduled for Saturday, April 13, 2013.

According to Lisa Tomcykoski, the daughter of an MDS patient, and Chair of this group, the support group got off to a strong start and the attendees were grateful and eager for future meetings to come.

Dr. Virginia Klimek spoke to the patients and welcomed them to the first support group meeting and Nurse Sandra Kurtin presented an audio/slide presentation to the patients and their families.

There were a lot of discussions throughout the meeting. The patients were very eager to give feedback to help see the group continue and progress.

All patients shared their stories with their condition and their day to day lives with MDS. There was a great deal of talk on the importance of finding the right doctor, finding a center of excellence, finding a doctor that takes the time to truly care. There was a couple seeking answers for their mother. They are seeing a local oncologist and came to the meeting in search of gathering information from other patients.

The group offered a great deal in terms of what they are looking for. Many of the patients attended a recent MDS Foundation Patient Forum in NYC. Dr. Virginia Klimek was the speaker. This forum held in NYC and

Dr. Klimek was very well received by the patients and families. Several patients asked if she could return to speak at future group support meetings.

The group loved the opportunity to sit around a large table and share their stories. They appreciated Sandra's presentation. The books were greatly appreciated. One gentleman said, "This is perhaps one of the best put together books I have seen."

Overall, I truly think the meeting was a huge success. The patients and families will benefit tremendously from future support groups. Dr. Klimek emailed me a lot of great information on getting started with support groups. I thank her for all of her assistance with the meeting and helping it start out in becoming a success. Also, the books Sandy provided are an excellent resource for the patients. The patients and caregivers loved the books.

A special thank you to Audrey Hassan, Dr. Klimek and Sandra Kurtin for making the first meeting such a great success.

*Dr. Lisa Florence Tomcykoski*

**UPDATE:** The MDS Foundation is saddened to report that Lisa's mother, Diane Lisa Tomcykoski, passed away in early March. We offer our sincere condolences to the Tomcykoski family and the many other people who cared about her. Dr. Tomcykoski will continue as the group leader for the NYC MDS Patient Support Group. We extend our deep appreciation to Dr. Tomcykoski for her dedication and support to MDS patients during this difficult time.



## Established MDS Patient Support Groups

### United States

#### ■ Chicago, Illinois MDS Support Group

Meets on the fourth Tuesday of the month from 1:30–3:00 pm at Northwest Community Hospital's Cancer Service department (lower level), 800 W. Central Road, Arlington Heights, Illinois.

Contact Kim Jensen at [kjensen@nch.org](mailto:kjensen@nch.org) or call: 847-618-6914.

#### ■ Lakeland, Florida Regional MDS Support Group

For more information call Vivian Paul at 863-698-5137 or Kathe Dempster at 863.816.8482.

#### ■ New York, New York MDS Support Group

Contact the group facilitator, Lisa Tomcykoski at [drtomcykoski@yahoo.com](mailto:drtomcykoski@yahoo.com) for further details.

#### ■ Philadelphia, Pennsylvania MDS Support Group

For more information call the MDS Foundation at 800-MDS(637)-0839 or email Audrey Hassan at: [ahassan@mds-foundation.org](mailto:ahassan@mds-foundation.org)

#### ■ Puget Sound MDS Support Group

For more information call Janine Kowack at 206-992-0609 or email [jkowack@comcast.net](mailto:jkowack@comcast.net).

#### ■ Southern California MDS Support Group

Meets on the third Saturday of the month at St. Mary Star of the Sea Church, 609 Pier View Way, Oceanside, CA 92054 at 2:30 PM.

Contact Susan Urban [susanurb@gmail.com](mailto:susanurb@gmail.com) or call: 760-438-5130.

#### ■ Stanford Cancer Center MDS Patient & Family Support Group

Meets the third Monday of the month from 6:30–8:00 pm at the Stanford Cancer Center, 875 Blake Wilbur Drive, Palo Alto, California, 2nd Floor Conference Room CC2105.

Contact Group Leader, Lenn Fechter, RN, BSN at: 650-725-0744.

#### ■ Folsom, California MDS Support Group

Will hold it's inaugural meeting on Tuesday, May 7, 2013.

For more information call Jalil Fardanesh at 916-984-6468 or email [jfardanesh@gmail.com](mailto:jfardanesh@gmail.com).

### International

#### Belgium:

- Belgische MDS Contactgroep  
<http://mds-foundation.org/psg/vlaamse>

#### Canada:

- Hamilton, Ontario MDS Support Group  
<http://mds-foundation.org/psg/cpsghhs>
- Toronto, Ontario MDS Support Group  
<http://mds-foundation.org/psg/cpsgt>

#### Czech Republic:

- Sdruzeni MDS  
<http://www.diagnoza-mds.cz>

#### Denmark:

- MDS DK Patientstøttegrupper  
<http://www.mds-and-you.info>

#### France:

- Association Connaître et Combattre les Myélodysplasies  
<http://asso.orpha.net/CCM>

#### Germany:

- MDS-Net Deutschland  
<http://www.mds-net-de.org>
- Interessengemeinschaft von und für MDS-Patienten  
<http://www.interessengemeinschaft-mds-patienten.de>

#### Japan:

- MDS Renrakukai  
<http://www.geocities.jp/mdsrenraku>

#### United Kingdom:

- UK MDS Patient Support Group  
<http://www.mdspatientsupport.org.uk>

## Global MDS Patient Support Groups

The overwhelming success of our Patient & Family Forums, which allowed patients to meet peers who live in their community, has led us to create permanent support groups worldwide. If you are interested in joining a few other people to help start a needed support group for MDS in your area, please contact us today.

# Patient Contributions

## PATIENT TESTIMONIALS

### ***Patients Speak Out...***

***“So happy to see @MDSFoundation has a twitter handle. You were all so good to my family when my father was newly diagnosed.”***

*Dee Ann @dee22ann*

***“Thank you so much. You guys are AWESOME.”***

I don't know how to quantify my gratitude to you and your staff. HOPE is powerful in recovery and that is what you and your staff provide with these tools; HOPE.

*Juan Amador*

***“I received my copy of “Building Blocks of Hope”. The work and effort you put into the Book shows in the finished product. My first word to Janet was “WOW.”***

Since my diagnosis in 2002, I have run across many physicians who have heard about MDS but don't know what it is or have never heard of MDS. Building Blocks of Hope fills that gap. For patients and caregivers it is a must either through hard copy or the Internet. Janet and I found it a pleasure and an honor to assist in your project.

*William Pearson*

***“Thanks for all the good information in the MDS News.”***

*Phyllis Simons*

***“I have been fortunate to work with the MDS Foundation in my role as Patient Advocate Liaison at Diplomat Specialty Pharmacy.”***

They have a wonderful caring staff and leadership that are increasingly finding ways to bring more education and information to the public about this rare disease.

*Brenda Hawkes*

***“Thank you for all you do!***

*Cathy Smith*

***“Thank you very much for inviting me to the patient forum.”***

It was a very good discussion provided by Dr. Bennett and Nurse Sara Tinsley. I very much enjoyed meeting everyone and learning about others experiences. I know I was the youngest MDS patient in the room, yet I was prepared for that in advance. I was happy that others could share their experiences, and give me hope for the future.

*Suzanne Bloom*

***“Everything you do to help is greatly appreciated. Thank you! You're a good organization.”***

*Leonard Yool*

***“It was nice to meet you at the forum.”***

I looked over the information packet that was given to all of us and it contained a lot of useful information. I just love Dr. Rossetti. To the folks that were there, maybe we will all keep in touch if they want to continue and talk about MDS.

*Vince Rusak*

***“The patient forum was simply wonderful. Thank you again to all involved!”***

*Michele Spring Fajeau*

***“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. Out of all the people there, only 5 people were from my area, Lakeland, and Winter Haven. We are planning on getting together once a month and now we know we are “No Longer Alone”, and we are just a phone call away when we need to talk with someone. The people whom I talked with all felt the same way.

*Richard Brackett*

***“It was so nice to meet you. You do such a nice job with the patients and the caregivers. I learned so much about MDS attending this seminar.”***

*Julie Bade*

***“I received your copy of Building Blocks of Hope. It was very informative.”***

There was a lot of information in it that I didn't even know about. Thank you so much for putting it together.

*Pat Thompson*

***“I just wanted to tell you how much Boris and I enjoyed the Patient Forum.”***

It was excellent and we came out with such good, pertinent information. Dr. Steensma is excellent and so patient with everyone's questions; he gives a wealth of facts with each question. Thanks for feeding us and organizing such a good program.

*Carol Ann Gould*

***“I just wanted to take a minute to let you know that my wife and I found your patient forum informative and useful.”***

Both of the speakers were standouts. And in our opinion, the meals were well done. Thank you and the MDS Foundation.

*John Cloutier*

***“I find your organization extremely helpful, and it is good to be able to attend the events which your Canadian representatives organize from time to time.”***

With a fairly rare disease, it was hard initially to get the right information, but when I found your organization online, it helped a great deal. Thank you for all you have done for me.

*Rosemary Pauer*



# Our Stories...

## BUILDING BLOCKS OF HOPE PRESENTATION

### Patient Presentation

November 1, 2012

Tampa, Florida

Robert Weinberg

My name is Bob Weinberg. I was diagnosed in 1998 at age 48 with MDS — RARS (refractory anemia with ringed sideroblasts). Here are my numbers: Since then I have received over 850 units of packed red blood cells. My white blood cells hover around 2.0, my absolute neutrophil count (ANC) between 500 and 700 and my platelets between 30,000 and 40,000. My blast count is under 5%. My current transfusion frequency is 7–8 days. I take 2,500 mg of Exjade daily. My ferritin level, checked monthly, ranges from 450 to 700. I have an MRI every year on my heart and liver, looking for embedded iron in those organs.

My MDS story began in the water. During my 30's and 40's, I was an avid swimmer. Every morning before going to work at a large high-pressure law firm in Philadelphia, I would sleepwalk my way to the local Y to swim my daily mile—thirty-six laps. I was only one of a group of groggy people who began their day with a swim. Side by side, we would glide through the water, and being competitive by nature, we each knew which swimmers would pass us and which swimmers we would pass. Until the winter and spring of 1997–98. That is when I found the morning swim's natural order of things out-of-whack. Those I usually passed started passing me. Those who would pass me once every four laps would pass me twice as often. So to build-up my stamina, I thought that I should jog as well. After running less than a city block, I had to stop, almost keeling over with a sharp pain in my chest, severe breathlessness, aching calves, a pounding heart and dizziness. Something was wrong, so I gave up jogging after one try and went back to the pool. Over a couple



MDS Patient Bob Weinberg

of months, my stamina and strength declined to where every one of my fellow swimmers passed me. I could not even swim six laps. I started to need a nap in the afternoon—at 48 years old. It was time to see the doctor and have my first ever physical.

That was on a Friday, and by Tuesday morning I learned the words “myelodysplasia” and “sideroblastic anemia.” I went right to Google. The first thing item that came up was an article on Carl Sagan. I knew I was in for a game-changer. My siblings were tested for a bone marrow match and both failed. My internist called to ask me if “my affairs were in order.” That is when the hematologist at the local hospital told me that he had patients like me with low hemoglobin, but manageable platelets and white cells, who lived on transfusions for 15 years. I then visited a specialist in MDS at a major university medical center for a second opinion. He said that I should not expect to live more than five years. I told him that I had a better offer from the hematologist at my local community hospital, and he said he could not match that. So, of course, I took the higher offer and my community hospital is where I have been treated for the last 14 and one-half years.

Not that I didn't visit the best of best in experts over the next 10 years—Stanford University, Memorial Sloan Kettering, Moffit Cancer Center, University of Rochester, Mt. Sinai. I remember my first visit with an international expert. I asked him what causes MDS. He quickly replied, “bad luck.” I took Revlimid on a clinical trial, but all it did was lower my blood counts, cause boils and make my hair itch. I took Vidaza, and it worked for 5 months, but within less than a year of starting it, I was back on a 14 day transfusion frequency.

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***I learned the words “myelodysplasia” and “sideroblastic anemia.” I went right to Google. The first thing item that came up was an article on Carl Sagan. I knew I was in for a game-changer.***

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So the family flew to Seattle in early 2006. We visited the Fred Hutchinson Cancer Center, which I was told was the place for MUD (matched unrelated donor) transplants. The doctor sat my wife, my 23 year old daughter, and me down at a small round table in a small windowless conference room and told us that I had only six months to live unless I submitted myself to a mismatched unrelated donor bone marrow transplant. Chances of surviving 5 years were 65%. So I gave notice at work and my wife and I leased an apartment in Seattle. But first, I took a 10 day motorcycle trip in Europe, where I conveniently broke my ankle when my Ducati spilled on gravel and landed on my foot. That set back the transplant schedule. Bones won't heal when your immune system is suppressed as it is in a BMT. By the time my ankle had healed, however, I decided against the unrelated mismatched procedure. That was 6 and half

years ago. I recently had the donor search re-run, and I learned that with the donors available and the billions of antibodies I have garnered from so many past transfusions, I should consider a BMT only if it is my very last option. So I am sticking with the transfusions.

By year 2009, transfusion frequency was down to 10 days, and I was faltering in meeting the pressures at work what with the interruptions for blood tests, feeling lousy and transfusions. So I cut my workload by 80%, became further involved in the MDS Foundation and spent much more time walking my dog. Meanwhile, antibodies seem to be destroying the transfused blood more quickly and preventing me from getting quite the same energy lift I used to get from a transfusion. But time marches on, and I have no sense that anything is coming to a close.

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***Recognizing that MDS comes in many shapes and sizes, I have lived by the following points.***

- 1. Don't worry about something that may happen in the future. I can worry about it when it happens.***
  - 2. Do everything I can to be informed so I can make intelligent choices.***
  - 3. Don't get caught up thinking that I am in a battle in which I have some control over whether I win or lose. We are in the realm of those things over which we don't have control.***
  - 4. If things don't work out, it is not because I did not fight enough, or I did not have faith enough, or others weren't praying for me enough.***
- 

## PATIENT STORY

### ***My MDS Journey***

**February 25, 2013**

**Doug Nelson**

Well, here I am almost 7 years after my syngeneic stem cell transplant for MDS. And, thanking my identical twin brother Denny every day for donating his stem cells for my transplant.

Thought I would share my journey after the transplant, beginning in July 2006.

After a small diversion post-transplant, fungal infection in my kidneys, I was released from Sloan-Kettering in July of 2006.

I spent the next year at home in Stamford, Connecticut. In July of 2007 I went back to work as a manager of William Raveis Real Estate. In June of 2008 my partner and I made the decision to retire to Durham, North Carolina.

Someone asked me what I was going to do during retirement. My comment was, "I'm going to do something; but I know what I will not do. And that is to obligate myself to be at the same place, the same time, 5 days a week."

I will say that I am now busier than ever, but on my own schedule. I sell real estate, I have designed and am marketing a fabric for the Green Roof Industry, I go to estate sales every weekend, and am on the HOA Board of

our townhome community. Now the newest member of our family is our labradoodle puppy, "Porter". In addition to all of the above, we are renovating a vintage 1928 home in Durham, close to Duke University.

The thing closest to my heart now is being an advocate for Vietnam Veterans, like me, who have been diagnosed with MDS because of exposure to Agent Orange while serving in Vietnam, and are not getting any compensation from the Veterans Administration.

MDS is not yet on the presumptive list of diseases caused by exposure to Agent Orange which automatically guarantees Vietnam Veterans VA compensation.

In short, I am back to normal activities; oh, did I forget to share with you that I swim a mile a couple of times a week.

My recipe for recovery is to get out and do things. Think positive and don't dwell on the "Why Me Syndrome".

I must say that along with a successful stem cell recovery, I look at life a little different. I know that there is no guarantee, so I do as much as I can and enjoy what I do. Hey, the little things don't bother me anymore. There is life after a transplant, but it's up to you to find it.

Most of all, I appreciate my partner, my family and friends more than ever.

*Regards, Doug Nelson*



*MDS Patient Doug Nelson*



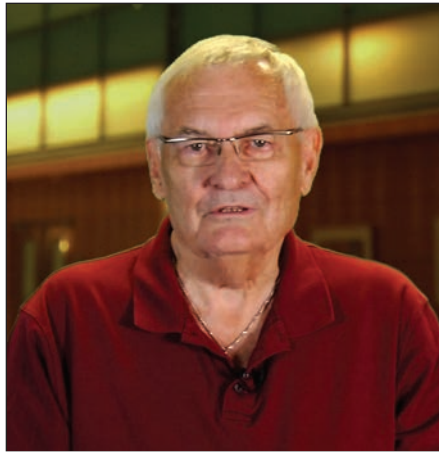
## My Story

### William Pearson

My name is William Pearson; I am 76 years old and live in Hamilton, Ontario, Canada. I was born and raised in Nelson, British Columbia. Following school, I played hockey for two years and after that worked in the steel manufacturing sector for 45 years. Following my retirement I started a consulting business. My consulting projects took me to different parts of Canada, Germany and Poland. When I was in Krakow, Poland, our office was within walking distance from our hotel and then from there I arranged transportation to different steel plants in that area. One week into the project I started to labour in my morning walk to the office. At this point I found it difficult and started to taxi back and forth. Walking about the steel plants became more difficult. Climbing stairways to operating decks became difficult. I found myself having to stop every 5 to 6 stairs before I could continue.

On my return to Canada my first visit was to my family doctor who ordered blood tests. She called me after receiving the results. My hemoglobin was 88 mg/dL (or 8.8 g/dL) – well below the normal range. She referred me to a hematologist. Thankfully, I wasn't going to a stranger, as I had seen the hematologist in the past with other problems. I find it more comfortable if you know the doctor you are about to see. The hematologist repeated the blood tests and at the next visit, I had a bone marrow biopsy and aspiration. (January 2003 hg.81[8.1])

In a follow-up appointment 6 weeks later, she indicated that the results didn't look good. She also needed to repeat the bone marrow to get more information to compare. I still kid her that she bent the needle during the second bone marrow aspiration on purpose, but she maintains it was my bone structure being so hard and nothing to do with her. At this point I started red blood cell transfusions to maintain my hemoglobin. (March 19, 2003)



*MDS Patient William Pearson*

On the next visit, she indicated the results of the two bone marrow procedures indicated a diagnosis of MDS. I don't remember any fear or concern other than what's next. We discussed the option of a stem cell transplant. If that was to proceed my sister would be the most suitable candidate. I called my sister to discuss this with her. My sister Jane lives on the west coast about 5 hours by plane. Her response was "How soon do you want me there?" Bone marrow transplants take time to plan and not all patients are able to have an allogeneic bone marrow transplant. My age at the time being 60+ was a factor, just outside the range recommended for this type of transplant. So the doctor suggested a pill, Danazol, which might help my bone marrow function better. She indicated that based on her experiences, it was working in about 5% of her patients.

After a period of time the drug stopped working and I was being transfused 2 units of blood at two week intervals (between April 2007 and January 2008). I had developed iron overload as a result of all of these transfusions. She referred me to a major cancer hospital in Toronto, about 60 kilometers away. The hospital (Princess Margaret Hospital) has the reputation of being one of the top cancer hospitals in the world. My 1st appointment was early in September 2007. I was referred to this

hospital in hopes of being fit into a clinical trial for new treatments for MDS. After another bone marrow procedure and several visits it was determined that I did not meet the criteria for any of the drug trials.

In December 2007, my doctor wanted to try a drug called Cyclosporine (auto immune suppressant). After reading all the literature on the drug I determined it was not for me. Big mistake on my part. My wife and I got to know the doctor very well seeing her every two weeks for 3 months. We developed an admiration and a dear respect for her. When she said it was the best treatment for me at that time and that we needed to consider it, our yes came very quickly. The results were very positive. At one of my appointments the doctor and Janet (wife) said phlebotomy in unison. I had a total of 3 which brought my iron overload out of the critical area.

Today I am still on cyclosporine and it is holding my hemoglobin in the range of 105 mg/dL (10.5g/dL). We can't increase the dosage because of it has affected my kidney function.

### *How is my Quality of Life?*

To sum it up, for the most part there has been little change. Some days are worse than others. An example—walking a kilometer one day without stopping and other days having to stop for a moment every 5 meters. Lifting is also a chore, housework exhausts me—sometimes my excuse works, but not too often as Janet knows it is a poor excuse to avoid it.

We still travel. In 2010, we went to Scotland for a holiday in conjunction with the MDS Foundation International Symposium. Janet and I spoke at an MDS forum for patients and their caregivers from all the European countries. We travel across Canada to the west coast yearly. I still play golf with the use of a power cart. The golf club puts a flag on my cart to allow me to take it to as close to my ball as possible excluding the greens.

### ***What are my fears?***

I am apprehensive about my life with MDS. I don't dwell on it and for the most part have little fear. The only time I get a bit edgy is after blood tests while I am waiting for results.

Early in my diagnosis I enrolled in the Leukemia Lymphoma Society first connection program until about a year ago. The LLS would contact me that X person would like to talk to someone with MDS. Being the only name in the databank I would be asked if I would contact a person regarding MDS – 95% of the folks were from the United States. I think that my sense of helping someone else took away my own anxieties.

I have seen a major change in the past 1 ½ years. MDS is no longer in the closet so to speak. A significant example is Robin Roberts, anchor for ABC Good Morning America. Robin went public on her show and many stories about MDS were in newspapers across the country. ABC continues with updates.

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***MDS is no longer in the closet so to speak. A significant example is Robin Roberts, anchor for ABC Good Morning America. Robin went public on her show and many stories about MDS were in newspapers across the country. ABC continues with updates...***

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### ***What are my hopes for the future?***

I'm not sure how a 76 year old man should feel. Quality of life and longevity of life are my biggest hopes and I would be satisfied with status quo. I do hope that in my lifetime I see research that would treat and maintain MDS of all types.

## **Stay Connected to the MDS Foundation...**

### ***Follow us on:***



### ***Support the MDSF!***

Please support the work of the Foundation in the battle against MDS and consider donating all year long. Kindly use the enclosed pre-addressed contribution envelope or go to [www.mds-foundation.org](http://www.mds-foundation.org) to make your donation.



**Every penny helps. All donations are tax-deductible.  
Thank you for your continued support!**



The MDS Foundation is very grateful for the heartfelt support of its donors. Our work as a non-profit organization depends on public funding, and we hope that you include us as one of the worthy charities that you support this year.

### ***Join the MDSF Development Committee!***

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](mailto:tiraca@mds-foundation.org) or call **800-MDS(637)-0839**.

## **A Special Thank You to**

**GABRIELLE'S  
ANGEL FOUNDATION  
FOR CANCER RESEARCH**



**We would like to especially thank**

***Gabrielle's Angel Foundation  
for Cancer Research***

**for their generous grant in the  
support of young investigators  
through the MDS Foundation.**

## **Thank You to Our Sponsors for Their Support**

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## Our Journey to Hope

### Tammy Karnes

Larry Karnes story begins in April of 2006. We were driving to a family reunion when Larry asked me to make him a doctor's appointment for that Monday. He had been feeling bad with night sweats, bloating, loss of appetite, and fatigue for the last several months and although his doctors had performed multiple tests, nothing definitive could explain how he was feeling. You can imagine my horror when he showed me a large knot on the side of his neck. It was as big as golf ball. I sat there in shock, and scared to death of what it might be. As usual though, Larry decided he would not dwell on what it might be. As a retired Maryland State Trooper it was ingrained in him to stay focused, remain calm, evaluate the situation, and respond appropriately. At this time it was just a lump and no more he said, and that's all we knew. The rest of the car ride was quiet, and I am not sure what we thought. But I believe we both knew that lump couldn't be good.

### The Diagnosis

It took several weeks before we got any answers to what the lump was. There were so many blood tests, biopsies, and scans that Larry had to endure over the weeks, that it was just a relief that we were finally getting an answer. On May 6, 2006 the doctor gave us the news that would change everything we ever knew. She said Larry had Stage II B Nodular-Hodgkin's Lymphoma. We knew that meant cancer. My brain was on override. Oh my God, she said cancer. My husband has cancer! My mind was racing, and heart was beating, and I was saying to myself don't cry, don't cry. Be strong and stay positive. I looked at Larry and he wasn't saying anything, just nodding. It wasn't until the car ride home that I realized he was in more shock than I was and he needed me to tell him what the doctor said. Larry was my rock and now I had to become his place to



lean on. He would need me to take in all the medical terminology so he could focus on healing. The doctor addressed treatment with him and felt that based on his tests he would need six months of chemotherapy/twice weekly, and that was his best option for the best outcome. We were ready to move forward so we could move forward with our future together.

### Opening up and Sharing with Friends, Strangers, and Learning to Live with Cancer

Larry has always been a very private person, and was not big on sharing his feelings. This was also in his upbringing, and was taught as part of police training from the academy. So calling the kids and telling them would be a job we did together. We called our oldest Lori first, and then her sister Kelly. We decided to wait and not call our youngest Crystal, since she was away in California at school. She would be home in several months and we would tell her then. The girls were clearly sad and worried about what might happen but we assured them as we had always done that their dad was a fighter and would beat this. Larry had me call his brother Sonny since he felt it might become too emotional. Our friends and family were also devastated by the news, and were super supportive in helping Larry with his recovery. Larry worked for the state of Maryland at the time as a bailiff for the District Court. His employers and co-workers were so very supportive and made it easy for him to work around his weekly treatments, and doctor's visits.

### Learning to Lose Control

At the time I was a licensed realtor which allowed me to make my own schedule and be able to be with Larry during all his treatments and tests. I was making a pretty good living and had saved, so financially we were in a good place and really didn't worry about being able to meet the bills or the extra expenses of cancer treatment. I felt I had pretty good control of the whole situation. We believed that Larry was going to beat this, and so did his doctors. We could afford for him not to work if he needed that. Over the next six months we made our weekly trips to oncologists, labs for blood work, diagnostic tests, and did not make many adjustments to our lives. We went on and tried to keep things as normal as possible. Larry's treatments didn't really affect his spirits much since he had very little nausea, and he didn't care a whole lot about the hair loss. In the beginning he gained weight due to bloating from medications and treatment. This however bothered him the most. He was now known as "Kojak" at work since he gave out lollipops to anybody who came into the court house with kids. Everyone thought that he was responding well since his blood work always was good. We even moved on to build our dream home during all of this. We decided that this diagnosis would not change our lives. That we would not let it control us. We believed that Larry would face this battle head on, and tackle it. Little did we know that cancer does not care what you decide, it has a plan of its own. It has all the control and how you react to it is up to you.

### A Second Diagnosis

#### An Aggressive Form of Hodgkin's Lymphoma

In March 2007 Larry completed his treatment with 48 rounds of chemotherapy. We both were exhausted, and relieved that his last scans did not show any new tumor growth. However if you looked at him you could clearly see his neck swelling, and

chest inflammation from new tumors spreading through his body. However we did not know what this was for sure. We had to wait for a new PET scan until mid-March/April because sometimes chemo can mask the outcome of these tests. By the time we did the PET scan it confirmed what we worried about. The tumors had spread through his body. The PET scan read “too numerous to count!” Our wonderful doctor, Dr. Mary DeShields, sent Larry’s case to Johns Hopkins Hospital in Baltimore, MD. By the end of May we were meeting with a team of doctors at Hopkins to talk about a bone marrow transplant. This would be his only hope for survival, and the odds were against him from the start.

His only brother was tested, and was disappointed that he was not a match. At the time, his daughters were unable to donate due to medical reasons. This left only one way for the transplant, he was going to have a Pheresis blood transplant—autologous bone marrow transplant. He would use his own bone marrow. The process was so long and in between he would undergo a second round of chemo. That had to be done in the hospital since it was super strong. So over the next month he would have 5 days of 24 hour rounds of chemotherapy called ICE. His odds of a remission were greater. If the tumors were to shrink, even a little bit, the odds would be better for his outcome of a cure. Larry had to undergo so many tests to prepare for the transplant, and I had to give him daily injections of a growth factor drug, Nuepogen, that helped build his white cells. This was needed to prepare for the Pheresis blood transplant. On the day set to remove and clean his blood with a machine called a pheresis, new problems arrived. Larry’s blood didn’t mobilize. This is where the white cells that have grown would not leave the marrow, and move into the blood stream so they could capture them. This meant they had to do the transplant the old fashioned way. They would now be drilling several small holes into his hips/backside to remove the bone marrow, clean it, and freeze it to use later.

## **Insurance**

We had insurance approvals to wait for that took several months, and then finally the date. The doctors called and said, October 10th. This was the day set for new beginnings. This was really weird and cool since this is also our wedding anniversary. Our stay at Hopkins would be a minimum of 60–90 days in hospital. To survive this he would have to be strong minded and follow strict rules. The smallest infection could kill him. He couldn’t leave his room for a week and then if he even went into the hall to walk, he had to wear a surgical mask everywhere. We were not allowed many visitors, and could not see our grandson at all during that time. We had to deal with a strange odor that smelled like a cotton candy/creamed corn combo. This was caused from the new marrow growing inside his body. The smell was nauseating for both of us. We believed the hard part was over, and now we could get back to some normal life. Boy we were naive. Little did we know that we were in for the rollercoaster ride of a lifetime, fully equipped with more emotions and decision making we ever could dream.

## **A Third Diagnosis**

In November 2007, we asked if we could go home for Thanksgiving and be with family. The doctors were hesitant but allowed us four days at home, and then back to Hopkins first thing Monday morning. Before going home they ran several tests, and would go over the results when we returned. The scan showed two enlarged lymph nodes in his right upper chest. The doctors at Hopkins felt that this was possibly the Hodgkin’s coming back and he would need to have radiation to ensure that it didn’t become aggressive. They could not do a biopsy since it was located in the lungs, and his platelets and other cell counts had not recovered completely yet from the transplant. So on January 7, 2008 we went in for his first round of radiation out of 17 planned treatments. His weight had dropped so fast, and his blood counts were almost to nothing when they decided that he could not

take on any additional radiation. He went from 195 lbs to 160 lbs in less than 3 weeks. We were sent back home again when Larry started having some breathing issues. He had to be readmitted to Hopkins for fungal pneumonia.

This was really serious since he did not have an immune system to help him fight off infection. He was also passing out and showed some signs of possible strokes or seizures and I requested a brain MRI. The test came back showing a small brain tumor and would need to be watched closely. He would be fighting the fight ever. Dealing with infections, no energy, and not really knowing what type of tumor was now growing inside his brain. The doctors did not know which way this would go. They believed that their jobs were done but would not give up on trying to help us or keeping us in the loop. This would be the beginning of the first of thousands of blood and platelet transfusions he is still receiving today. By May, Larry had decided that he no longer wanted to go to any hospital each week, and would go without any transfusions to see what would happen to his marrow. Larry wondered if it would grow on its own. Larry had been a survivor now for 3 years, and he wasn’t planning on going anywhere without a fight.

## **Finances**

At this point we had both been out of work for two years. Medical bills and travel to and from the hospitals, and just everyday living expenses had taken most of our life savings, and his monthly retirement could not meet our most basic needs. We had to make the decision to let our dream home go, and move to a rental. We both decided that being together was the most important thing. Larry was just getting back to being able to go back to work part-time, so long as I drove him. So this is when I decided to enroll in college as an education major, and left the high paced life of real estate. I first worked as an ESL (English as a Second Language) teacher for the state of Delaware and now I work for the Milford Boys & Girls Club as an art teacher. Larry eventually was



able to drive again, and life began to become a little normal for awhile. We made decisions that we would never put things off and that being together wherever that might be was our number one priority. Over the next 2 ½ years, we made work, vacations, family, school, and sometimes an occasional doctor became our normal life. The doctors had explained that Larry's bone marrow may not ever recover completely but he could learn to live with that, and it was a possibility that he may develop MDS (Myelodysplastic Syndrome). We decided that possibilities were too vague, and that was no way for us to live. Larry would not let us worry about something that may never happen.

### ***The Stroke and Terminal Diagnosis/MDS***

On August 21, 2011, our lives were thrown upside down and side-to-side once again. We had a birthday celebration for me with friends, and family. It was such a great day. Everyone was together, and Larry was running around playing squirt guns with our grandson, and cutting up and enjoying the day. He was feeling really good. The next morning Larry got up and was trying to tell me how tired he was but I really couldn't understand him. I asked if he was okay, and he replied that he was feeling tired but other than that he was fine. I told him to drink some water, and I would be out to get us some breakfast. As I entered the kitchen, I notice that he was having difficulty pouring juice, and asked him to sit down. He also had a hard time speaking, but his symptoms went away the longer he sat. However as he stood he got worse. We decided that we needed to go to the hospital immediately.

Once we arrived at our local hospital, he was diagnosed with having a stroke, and they wanted to start him on Heparin, a blood thinner to help stop him from stroking. I explained that he was not able to have this medication, and would not allow them to start treatment. We had been told at Hopkins to never let him receive blood thinners if his platelet counts were below 50,000, and his average was 21,000 or less. I also was

concerned that his other blood counts were extremely low, and wanted him moved to Hopkins. I contacted his transplant doctor at Johns Hopkins. She was very concerned and worked hard to have him moved from our local hospital to Johns Hopkins stroke unit, and then later, the cancer unit. Once we were there our worst thoughts were confirmed. Larry had developed a high grade of Myelodysplastic Syndrome as well as anti-phospholipid antibody syndrome which can cause a person to develop clots. He would require blood thinners to stop the strokes, but he also had platelet counts that would require him to have transfusions since they were lower than 20,000 on average. They began him on platelet transfusions prior to the Lovenox injections. This injection would become something he needs for the rest of his life. His treatment plan was going to be a tricky one. How would they keep him from stroking, and bleeding out? It would take endless monitoring, and multiple transfusions every week. He needed my full attention. He would also need occupational and speech therapy because the stroke left him unable to use his right arm and hand and his speech was not clear. This would mean work and school would have to be put on the back burner again. I was now a full-time caregiver, and Larry a full-time patient. He had his job and I had mine. The doctors would release us back to our home oncologist, and there Larry would begin his way back to a life that would never be the same.

### ***Bucket List***

The doctor's new diagnosis was six months to one year at best but could be more if God willing, and Larry being able to fight. We remained hopeful, and asked that everyone pray for him, and me that God give us both the strength to stay focused on living the best life possible. We decided to cash out life insurances policies to allow Larry some freedom to fulfill his bucket list. We made plans to travel to Disney World, vacation with our family to Nags Head, N.C., and a road trip to Mount Rushmore, South

Dakota. The staff and members at the club were great about it. I sent pictures each day so they could share in this experience with us. The staff took over the extra work, and the kids made things as easy for me as possible by keeping the art room clean, and making more cards for Larry. They prayed for healing, strength, and sent cards with well wishes. The Boys & Girls Club allowed me to work as I was able. Larry's job had always been there for us too. In the past they held his position open for his return but this time was different. Larry's stroke left him unable to return back to work. He was now disabled, and unable to hold a firearm or perform his duties as an officer of the court to the fullest extent. He was making progress with therapy, but would not recover fully to continue police work. This was the hardest part for him—not being able to work. He had spent most of his life working since he was 14 years old. He had spent six years in the Army National Guard, and then served the Maryland State Police as a Trooper for 27 years. He was a bailiff for the past eight years. He was a fighter, a father and a husband that always gave 120%. He was tough as nails.



### ***Boys & Girls Club: Keeping Our Spirits Lifted***

During this process Larry has encountered his share of trials and tribulations. He had to learn to let others

help him, and accept that being a man isn't about the outer strength, it's about the inner strength and what you can teach others. The members/kids at the BG Club have made great efforts in trying to raise awareness for cancer and especially MDS. This was the first experience for most of our kids in understanding what cancer can do to someone. They have great questions each week for Larry, and he was glad to answer them. This has helped a lot with his healing process because he gets to help the kids learn and they get to make him laugh. The kids have had great ideas to bring awareness to MDS, and try to help the best way they know how. They decided to make Larry's illness a front runner for our torch club fundraiser and community service events this year. They started by hosting a walkathon in October during breast cancer awareness month. They made bracelets, and sold them to help raise money for the cancer center Larry frequents each week. They have held a Hero Blood Drive and work hard to help get people to realize how important it is to donate blood. They used the holiday tree event that we decorate for our local Library each Christmas as a tribute to Larry, and others who have been battling MDS (Cancer). The ornaments were made by the kids by using the plastic caps from used vial bottles that contain medicine cancer patients. They also decided on multi

colors to represent all different types of cancer. The tree helped raise \$18.00 that went towards a local family dealing with cancer. Larry and I both believe that because of letting the kids be a big part of his experience, sharing his thoughts and fears, his laughter and sometimes tears with them, that it has allowed them to open up more about their own fears, and know that life is what you choose to make it.

### ***A True Test of Marriage***

We both have come to realize that through all of this we have grown stronger as human beings, and as a couple. This has been one heck of a journey for both of us. We have come to realize that we can endure most anything together, and that we are not alone in this journey of life. God chose us to endure this together. To share our experiences with others and help those who need it along the way. We both know that the true meaning of marriage is ENDURANCE. If you can endure, you can stand together strong, and know that your love will outlast even the cancer.

We also found out who our true friends are, and relied on them sooooo often. Friends that have been there for us every step of every day. They gave us comfort when we needed it most. A place to live, played games, shared food, laughter, and a few tears along the way. They have been our

salvation! There is no doubt that God has been with us all this time. If we ever had doubt in the past, this experience certainly is a testament to His greatness. Bringing people in and out of our lives just at the right times, walking beside us, lying down with us, and carrying us in His loving arms when we just could not do anymore. God has touched us with His infinite wisdom, teaching us patience and giving us strength and for that we are truly grateful.

When I think back to the first day and seeing that lump, I am so grateful for that lump. People say God sends you signs, and God sent us a lump. The cancer was there but we didn't know that until the lump presented itself. It was that lump that opened our eyes, and brought us to where we are today. Together sharing 20+ years of marriage! Larry and I still have a long road ahead of us, and he is still amazing all the doctors a year and half later after the stroke and MDS diagnosis. We had bumps in the road and had to move in with my parents for awhile but just recently purchased a home again. This too was a miracle! We have learned not to question but just thankful for it. I am back working three days week at the club and the BG Club is still a great support for us. I hope our story helps those who think that hope, faith, miracles are not possible. Larry is LIVING proof that anything is possible when you have HOPE!





# Nursing in MDS

## International MDS Foundation Nurse Leadership Board

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**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  
*Raoul Tibes, MD, PhD*

**The University of Arizona Cancer Center**  
Tucson, Arizona  
*Ravi Krishnadasan, MD, 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

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

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

### MINNESOTA

**Mayo Clinic**  
Rochester, Minnesota  
*Mark R. Litow, MD*

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

### MISSOURI

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

### NEBRASKA

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

### NEW JERSEY

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

### NEW YORK

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

**Columbia University Medical Center**  
New York, New York  
*Azra Raza, MD*

**Memorial Sloan-Kettering Cancer Center**  
New York, New York  
*Virginia M. Klimek, MD*

**Monter Cancer Center/  
NSLIJ Cancer Institute**  
Lake Success, New York  
*Steven L. Allen, MD*

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

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

**Roswell Park Cancer Center**  
Buffalo, New York  
*James E. Thompson, MD*

**University of Rochester Medical Center**  
Rochester, New York  
*Jane L. Liesveld, MD*

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

### NORTH CAROLINA

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

**Wake Forest University School of Medicine  
Comprehensive Cancer Center**  
Winston-Salem, North Carolina  
*Bayard L. Powell, MD*

### OHIO

**Cleveland Clinic Foundation  
Taussig Cancer Center**  
Cleveland, Ohio  
*Jaroslav Maciejewski, MD, PhD*



**The Ohio State Comprehensive Cancer Center, James Cancer Hospital and Solove Research Institute**

Columbus, Ohio  
Alison R. Walker, MD

**PENNSYLVANIA**

**The Western Pennsylvania Cancer Institute**

Pittsburgh, Pennsylvania  
James M. Rossetti, DO

**Thomas Jefferson University Kimmel Cancer Center**

Philadelphia, Pennsylvania  
Emmanuel C. Besa, MD

**University of Pennsylvania Cancer Center**

Philadelphia, Pennsylvania  
Selina Luger, MD

**TENNESSEE**

**Vanderbilt University Medical Center**

Nashville, Tennessee  
Madan Jagasia, MD  
Stephen Strickland, MD

**TEXAS**

**Cancer Care Centers of South Texas**

San Antonio, Texas  
Roger Lyons, MD

**Southwest Regional Cancer Center**

Austin, Texas  
Richard Helmer, III, MD

**University of Texas MD Anderson Cancer Center**

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

**WASHINGTON**

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

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

**WASHINGTON, DC**

**Georgetown University Hospital Lombardi Comprehensive Cancer Center**

Washington, D.C.  
Catherine Broome, MD

**WISCONSIN**

**Medical College of Wisconsin Bone Marrow Transplant Program**

Milwaukee, Wisconsin  
Parameswaran Hari, MD

**University of Wisconsin Madison Medical School**

Madison, Wisconsin  
Mark B. Juckett, MD

**OUTSIDE THE UNITED STATES**

**ARGENTINA**

**Sanatorio Sagrado del Corazón**

Buenos Aires, Argentina  
Marcelo Iastrebner, MD

**ARMENIA**

**Muratsan University Hospital**

Complex of Yerevan State Medical University  
Yerevan, Armenia  
Gevorg Tamamyan, MD

**AUSTRALIA**

**Peter MacCallum Cancer Institute**

University of Melbourne  
East Melbourne, Australia  
John F. Seymour, MD

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# 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](http://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](http://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](http://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](http://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](http://www.clinicaltrials.gov)**  
for additional information.

## MDS FOUNDATION STORE

### NEW MDS AWARENESS ITEMS AVAILABLE!

New MDS awareness items are now available through our online store and our popular Hope for MDS wristbands are still available. Have you told someone about the MDS Foundation recently? Help promote MDS awareness any way you can and purchase your items today!

For a donation of your choice, receive your custom item(s) as a "Thank You" for your generosity.



### 3 WAYS TO ORDER:

1. **ONLINE** ► CLICK to SHOP ►  
<http://www.mds-foundation.org/merchandise/>
2. **BY PHONE** with credit card at  
800-MDS(637)-0839
3. **BY MAIL** with check enclosed to:  
The MDS Foundation, Inc.  
4573 South Broad Street  
Suite 150  
Yardville, NJ 08620

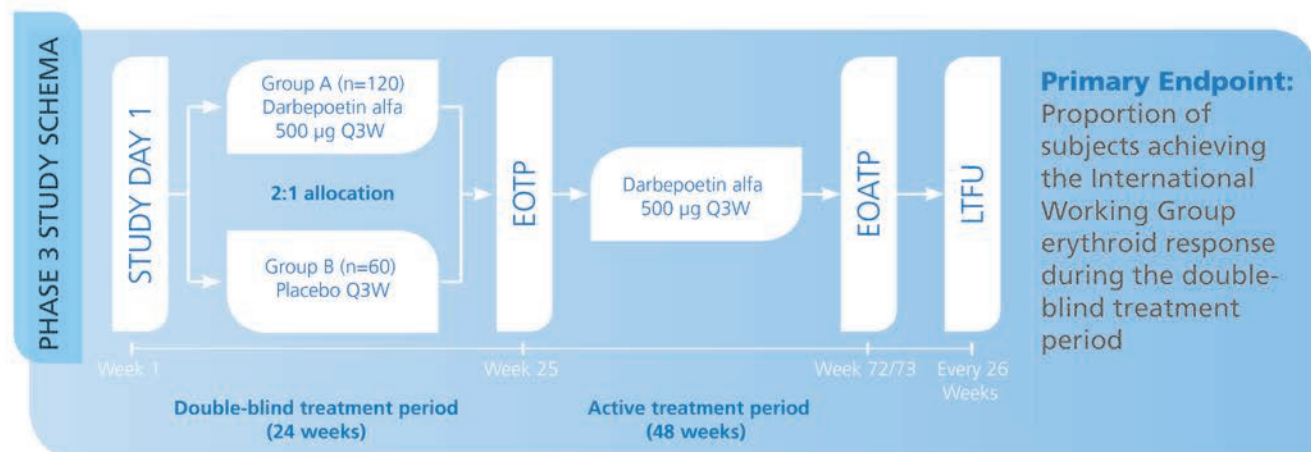
**Raising awareness is a year-round job!**

**Thank you for your support.**

# Recruiting Investigators



**A** Multicenter, **R**andomised, Double-blind, Placebo-**C**ontrolled Study of Darbepoetin **A**lfa for the Treatment of Anaemic Subjects With Low or Interme**D**iate-1 Risk My**E**lodysplastic Syndrome (MDS)



LTFU contacts occur every 26 weeks following EOATP for a minimum of 3 years from first dose of IP

## KEY INCLUSION CRITERIA

- ✓ Age ≥18 years with low or intermediate-1 risk (IPSS) MDS
- ✓ WHO classification of RA, RARS, RCMD, MDS-U, MDS with isolated del(5q), RAEB-1
- ✓ Hb ≤10 g/dL
- ✓ ECOG PS = 0 or 1

## KEY EXCLUSION CRITERIA

- ✗ Evidence of bone marrow collagen fibrosis
- ✗ High transfusion demand (≥4 units of RBC transfusion during either of 2 consecutive 8-week periods prior to randomisation)
- ✗ Previous or ongoing use of ESA therapy
- ✗ Previous or planned use of biologic response modifiers to treat MDS during double-blind treatment period

For information on study participation and recruitment, go to [www.amgenoncology.com](http://www.amgenoncology.com) for your local Amgen Medical Information Contact

ECOG PS – Eastern Cooperative Oncology Group Performance Score; EOATP – End of Active Treatment Period; EOTP – End of Treatment Period; IPSS – International Prognostic Scoring System; LTFU – Long-term Follow-up; Q3W – dosing every 3 weeks; WHO – World Health Organisation

Darbepoetin alfa is not approved for the use in patients with myelodysplastic syndromes (MDS) by the FDA, EMA and other local regulatory authorities. This information should not be construed as a recommendation for use of any product for unapproved uses.

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**A memorial fund has been established in the name of****Mrs. Love Pope Balkwill**

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Diane Petroni-Newhouse <i>San Jose, CA</i>	Tom and Christine Page <i>San Jose, CA</i>
Dr. and Mrs. William Belanger, <i>Monterey, CA</i>	

**A memorial fund has been established in the name of****Mrs. Barbara Ann Baldwin**

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

John and Cindy Baldwin <i>Atlanta, GA</i>	Larry Baldwin, <i>Plano, TX</i>
Robyn Roskydoll, <i>Keller, TX</i>	Citibank, BCQC Unit <i>San Antonio, TX</i>
Basilio, Maria, Basilio, Anthony & Lynne Kypuros, <i>Lakeway, TX</i>	Eugene Hawkins <i>Live Oak, TX</i>

**A memorial fund has been established in the name of****Mrs. Joan R. Barber**

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

John Jackson <i>Land O Lakes, FL</i>	Robert & Barbara Tallman <i>Altamont, NY</i>
Stanley and Norma Ordon <i>Schenectady, NY</i>	Helen J. Allen <i>Schenectady, NY</i>
Amy Lauterbach Pokomy <i>Berne, NY</i>	John and Donna Cullam <i>Altamont, NY</i>
Umberto and Mary Cavaliere <i>Schenectady, NY</i>	Robert & Sharon Kemmer <i>Delanson, NY</i>
Harry & Marion Worthington <i>Forestport, NY</i>	Howenstein & Carr Families <i>Schenectady, NY</i>
Ross and Marcia Moody <i>Schenectady, NY</i>	Kyle Piedmont <i>Schenectady, NY</i>

**A memorial fund has been established in the name of****Mr. John L. Barnhart, Jr.**

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

William Woodford and Staff, Charles & Woodford, LLC  
Attorneys At Law, *Baltimore, MD*  
Don Brooker, *Westerville, OH*

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

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

Curtis and Lauri Bussell <i>Lake Orion, MI</i>	Key Electronics, Inc. <i>Wixom, MI</i>
Bob and Bonnie Redmond <i>Troy, MI</i>	Janet Doty <i>Dearborn Heights, MI</i>
Robbie and Tabitha Crawford, <i>Willis, MI</i>	

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

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

Maurice Bartikofsky <i>Philadelphia, PA</i>	Janet Cherkasky <i>Rochester, NY</i>
Peggy Cherkasky & George Adler, <i>Pittsford, NY</i>	

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

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

David L. Bayer, *Bourbonnais, IL*

**A memorial fund has been established in the name of****Mr. Alfred Benavente**

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

Aaron Shoal, *San Diego, CA*     Albert Ju, *San Diego, CA*

**A memorial fund has been established in the name of****Mr. Wayne J. Bender**

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

Patricia Bender, *Venice, FL*

**A memorial fund has been established in the name of****Mr. Craig Linton Bexley**

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

Hamilton and Jodi Hunt <i>Tampa, FL</i>	Leon H. Cannon <i>Land O Lakes, FL</i>
Envirodev Properties, LLC <i>Lithia, FL</i>	Michael & Jean Shahnasarian <i>Tampa, FL</i>
Susan Lightbody, <i>Ocala, FL</i>	Rick and Julie Bannon <i>Saint Petersburg, FL</i>
Dan and Patricia Scupin <i>Miramar Beach, FL</i>	Steve, Pat and Ben Busch <i>Land O Lakes, FL</i>
A.G. Divers, <i>Tampa, FL</i>	Bryan L. Baldwin <i>Brandon, FL</i>
Rickey and Angela Rollison <i>Oxford, FL</i>	Mary Kate Bexley <i>Land O Lakes, FL</i>
The Bank of Tampa, <i>Tampa, FL</i>	The Roy Brooks Family <i>Lutz, FL</i>
Charles and Cecelia Lane <i>Tampa, FL</i>	Broyles, Rooks & Johnson, CPA's, P.A. <i>Tampa, FL</i>
Jackie Gardner and Jonathan Orebaugh <i>Tampa, FL</i>	Bryan L. Baldwin, Eric Hull, Meralex Farm <i>Brandon, FL</i>
E.R. and Jane Bourkard <i>Tampa, FL</i>	
Sebring, Sierra, <i>Tampa, FL</i>	

**A memorial fund has been established in the name of  
Mrs. Loydene Beaubien**

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

The Loretz Family <i>Los Altos, CA</i>	Ron and Linda Borgman <i>Monterey, CA</i>
Patrick Cairns Margaret Beaubien and Family <i>Alexandria, VA</i>	James A. Hanlon <i>Monterey, CA</i>
John and Carol Stornetta <i>Monterey, CA</i>	David Milligan <i>Lake Forest, IL</i>
Peter and Charlene Boulais <i>Pebble Beach, CA</i>	Ed and Barbara Battey <i>Palm City, FL</i>
Andrew Ghertner <i>Atlanta, GA</i>	Richard A. Ungaretti <i>Chicago, IL</i>
Carol Swartz <i>Monterey, CA</i>	Sandra C. Storm <i>Monterey, CA</i>
Jerry and Esta Holden <i>Carmel, CA</i>	John B. Coppedge III <i>Wadmalaw Island, SC</i>
Steve and Chris Goldner <i>Los Altos Hills, CA</i>	Dawn Satow <i>Livermore, CA</i>
Sid and Merv Dorr <i>Monterey, CA</i>	Paul and Pamela Boneham <i>Kenilworth, IL</i>
O.B. Upton III <i>La Quinta, CA</i>	Specifically Equine Veterinary Service <i>Buellton, CA</i>
Tom Usher <i>Portland, OR</i>	Kellie Weaver <i>Fresno, CA</i>
Bonnie Carson <i>Alexandria, VA</i>	Kenneth and Nancy Walker <i>Chicago, IL</i>
Dave Lawton	Bob and Mary Cushing <i>Carmel, CA</i>
Jim and Margo Tann <i>Salinas, CA</i>	South Bay Development <i>Campbell, CA</i>

**A memorial fund has been established in the name of  
Mr. Wayne Vincent Black**

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

Dona Sue Black Cool <i>Columbia, MO</i>	Richard and Beverly Dietz <i>Alexandria, VA</i>
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**A memorial fund has been established in the name of  
Mrs. Vivian Blackshear**

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

Suzanne Muterspaugh, *Sumter, SC*

**A memorial fund has been established in the name of  
Dr. Harry Blecker**

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

Herman and Elaine Blecker  
*Feasterville, PA*

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

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

Albert and Tina Small  
*Bethesda, MD*

**A memorial fund has been established in the name of  
Mr. William Bogaty**

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

Vanda High <i>New York, NY</i>	Robert High <i>New York, NY</i>
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**A memorial fund has been established in the name of  
Mrs. Sandra Lynn "Sandy" Bolar**

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

Creg Ostler and The Stoker Ostler Team <i>Scottsdale, AZ</i>	Hank and Nancy Trujillo <i>Colorado Springs, CO</i>
Ed and Judy Jones <i>Blue Springs, MO</i>	Robert and Norma James <i>Montgomery, TX</i>
Tim & Katie Jones & Family <i>Parker, CO</i>	Mark and Cathy Frame, Tim and David McMullen and Andy Prentice <i>Prairie Village, KS</i>
Todd Jones <i>Chicago, IL</i>	Margaret McCormick <i>Phoenix, AZ</i>
John and Carolyn Reece <i>Lees Summit, MO</i>	David and Sandra Roy <i>Flower Mound, TX</i>
Maryann Shores <i>Savannah, MO</i>	Young and Moon Kahn <i>Scottsdale, AZ</i>
Alan and Loretta Phares <i>Wichita, KS</i>	Ronald & Patricia Severson <i>Panama, NE</i>
Don and Marilyn Henry <i>Nacogdoches, TX</i>	Marvin Scholl and Angela K. Schmohr <i>Lincoln, NE</i>
L.W. and Marilyn Crites <i>Wichita, KS</i>	Larry Bolar <i>Vallejo, CA</i>
Ron and Marty Kixmiller <i>Rock Valley, IA</i>	Rosemary L. Thurston <i>Vallejo, CA</i>
Larry and Jenn Miller & Family <i>Sun Lakes, AZ</i>	
Dr. and Mrs. Ross and Sandra Padgham <i>Wichita, KS</i>	

**A memorial fund has been established in the name of  
Mrs. Ruth Borchardt**

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

John and Barbara Borchardt <i>Blair, NE</i>	John and Carol Rayer <i>Valley, NE</i>
Bode and Evelyn Labode <i>Omaha, NE</i>	L.D. and Helen Rasmussen <i>Omaha, NE</i>
Marcia Clark <i>Omaha, NE</i>	David & Pamela Schlotthauer <i>Omaha, NE</i>
Michael and Cynthia Troy <i>Eagan, MN</i>	Michael & Patricia Kojdecki <i>Valley, NE</i>
James and Linda Dunn <i>Bismarck, ND</i>	Children's of MN Professional Staff, <i>St. Paul, MN</i>

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

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

Linda Thomas, *Berea, OH*

**A memorial fund has been established in the name of  
Dr. Terry Bosworth**

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

Lynn Cavanaugh, *Canton, CT*

**A memorial fund has been established in the name of  
Mr. Joe Boyd**

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

Karen Boyd, *St. Louis, MO*

**A memorial fund has been established in the name of  
Mr. Edwin Ralph Braden**

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

Ray and Laura Kass, *Prescott, AZ*

**A memorial fund has been established in the name of  
Ms. Harriet Brenner**

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

Betty H. Hatchell <i>Columbia, SC</i>	Jay and Phyllis Horton <i>Salem, SC</i>
Kevin Haddigan <i>Mt. Pleasant, SC</i>	Mac & Barbara Christopher <i>Greenville, SC</i>
B-Tach, LLC <i>Eatontown, NJ</i>	Ruth Livadariu <i>Simpsonville, SC</i>
Bruce and Pam Stemerman <i>Potomac, MD</i>	The Muhler Company <i>North Charleston, SC</i>
Russ Pritchard <i>Charleston, SC</i>	Helen Burns <i>Mill Hill, London</i>
Birdie Donner <i>Greenville, SC</i>	Christopher Kearney <i>Charlotte, NC</i>
Ellen S. Kier <i>New York, NY</i>	Len and Eileen Kaufman <i>Boca Raton, FL</i>
Barbara Schwartz <i>Mason, OH</i>	Reynolds Investment Management Inc. <i>Greenville, SC</i>
Peter and Susan Braverman <i>New York, NY</i>	Ned and Ellen Dorman <i>Jericho, NY</i>
Nedene Greer <i>Greenville, SC</i>	Michael and Glenda Webb <i>Simpsonville, SC</i>
Russell and Betty Hitt <i>Falls Church, VA</i>	

**A memorial fund has been established in the name of  
Mr. Robert Jay Alan Brody**

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

The Dritz Family <i>Northbrook, IL</i>	Cathy Kominsky <i>Scottsdale, AZ</i>
Joanne Moffic Silver <i>Chicago, IL</i>	

**A memorial fund has been established in the name of  
Mr. Bill Burns**

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

C-SPAN Marketing & Friends  
*Washington, DC*

**A memorial fund has been established in the name of  
Mr. Edward Capaldo**

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

Emily Cartmell, *Pennsburg, PA*

**A memorial fund has been established in the name of  
Mr. Larry Cardonick**

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

Janet Wiener <i>Boynton Beach, FL</i>	Jerry and Renee Green <i>Boynton Beach, FL</i>
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**A memorial fund has been established in the name of  
Mr. Robert W. Carmichael**

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

Cheryl Carmichael

**A memorial fund has been established in the name of  
Mr. Roy C. Carter**

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

Abbie C. Carter  
*Philadelphia, PA*



**A memorial fund has been established in the name of  
Ms. Sarah T. Cecil**

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

Mrs. Robert Leake, *Fort Thomas, KY*

**A memorial fund has been established in the name of  
Mrs. Sharron Helen Chandler**

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

Arne Chandler, *Murrieta, CA*

**A memorial fund has been established in the name of  
Mr. Keming Chao**

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

Highland Park Library, *Dallas, TX*

**A memorial fund has been established in the name of  
Dr. Frederick Cook**

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

Page L. Wingfield, *Goldsboro, NC*

**A memorial fund has been established in the name of  
Ms. Tokiyo Ann Corcoran**

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

Barbara Trokan <i>Basking Ridge, NJ</i>	Daniel & Jeanne Sweeney <i>Arlington, VA</i>
Patricia C. Miller <i>Berlin, NJ</i>	Joseph Frommelt <i>Budd Lake, NJ</i>

**A memorial fund has been established in the name of  
Mr. Robert "Bob" D'Angelo**

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

Gerald and Marilynn Couse <i>Elizaville, NY</i>	Stu MacCatherine <i>North Haven, CT</i>
Gerald Brown, <i>Kingston, NY</i>	Dianne, Ken, Kristen & Andy Paulson, <i>Stone Ridge, NY</i>
John and Joann Deforest <i>Cottkill, NY</i>	Tisha Stoutenburg <i>Salem, NH</i>
Janet Kayarian <i>Clinton Corners, NY</i>	Gregory Worthen <i>Chelmsford, MA</i>
Robert Pietrobono <i>LaGrangeville, NY</i>	Mr. and Mrs. Paul Valanti <i>Thornwood, NY</i>
Mark and Eileen St James <i>Hebron, CT</i>	Richard & Diana Fodrowski <i>Stone Ridge, NY</i>
The National Association of Nurse Practitioners in Women's Health <i>Washington, DC</i>	Kevin and Annette Sullivan <i>Beacon, NY</i>
Chuck and Michele Mueller <i>Ridgefield, CT</i>	Winchester Financial Group Inc., <i>Stoneham, MA</i>
Donna Brady, <i>Kingston, NY</i>	Doreen, Ed, Eric and Allie Shulman, <i>Glen Allen, VA</i>
Debbie, Jimmy, Jeremy Smiseth <i>Stone Ridge, NY</i>	Dr. and Mrs. Al Gruner <i>Hurley, NY</i>

**A memorial fund has been established in the name of  
Ms. Margaret "Peg" Titus Dekker**

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

Melis Ertek, *Los Angeles, CA*

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

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

Ron and Thora duBois, *Stillwater, OK*

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

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

Marguerite DuFore, *San Mateo, CA*

**A memorial fund has been established in the name of  
Mr. Alessandro Degl'Innocenti**

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

Roberto Degl'Innocenti, *Miami, FL*

**A memorial fund has been established in the name of  
Mrs. Helen Denton**

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

The Denton Family, *Anchorage, AK*

**A memorial fund has been established in the name of  
Mr. William Robert DiScipio Sr.**

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

Jim and Judy Sellers <i>Lynnfield, MA</i>	Elsie Jamgochian <i>Arlington, MA</i>
George Dunn and Family <i>Lynn, MA</i>	Michael, Janis, Andrea DiScipio <i>Groton, MA</i>
Leda Barr, <i>Lynn, MA</i>	

**A memorial fund has been established in the name of  
Mr. Marion Dotson**

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

Doris Welsh, *Barnesville, OH*

**A memorial fund has been established in the name of  
Mr. Robert M. Drach, Sr.**

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

Elizabeth Drach, *Crown Point, IN*

**A memorial fund has been established in the name of  
Mr. Carl Duncan**

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

Steve and Donna Knight <i>Cincinnati, OH</i>	Sherman Chao <i>Indian Head Park, IL</i>
Don Kruse <i>Cincinnati, OH</i>	Benton and Lucille Dexter <i>Palm Desert, CA</i>

**A memorial fund has been established in the name of  
Mr. Genevieve "Dolly" Dyson**

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

The Pritchett Family <i>Forest Hill, MD</i>	Worley & Cynthia Umbarger <i>Churchville, MD</i>
Mr. & Mrs. Edward Schroeder <i>Bel Air, MD</i>	Phil and Janet Hauck <i>Forest Hill, MD</i>

**A memorial fund has been established in the name of  
Ms. Sharon Ehleringer**

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

Jeff Ehleringer, *Lino Lakes, MN*

**A memorial fund has been established in the name of  
Mr. Robert H. Eidd**

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

Texas Court Reporters Association, *Athens, TX*

**A memorial fund has been established in the name of  
Mr. Allen S. Eisner**

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

Barbara Townley, *Chicago, IL*

**A memorial fund has been established in the name of  
Mr. Andreas Fokas**

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

Ekaterini Fokas, *Astoria, NY*

**A memorial fund has been established in the name of  
Mrs. Evelyn Forney**

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

Forest Park Women's Club, *Cincinnati, OH*

**A memorial fund has been established in the name of  
Mrs. Donna Francis**

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

Dale and Vickie Trott, *Lenexa, KS*

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

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

Rich and Jill Myers <i>Lemont, IL</i>	Bill and Jess Geanconteri <i>Lake in the Hills, IL</i>
Elaine Atristain, <i>Elmhurst, IL</i>	Joslyn Anderson <i>Markesan, WI</i>
Walter Joniec <i>Schaumburg, IL</i>	Eliseo Villarreal <i>Chicago, IL</i>
Mariano & Janice Geanconteri <i>Streamwood, IL</i>	James and Arlene Goding <i>Sawyer, MI</i>
The Valenzo Family <i>Elk Grove Village, IL</i>	Dick and Suzanne Pottker <i>Elgin, IL</i>
The Daniels Family <i>Elk Grove Village, IL</i>	Ken Spaeth and Commercial South Team <i>Yorkville, IL</i>
Bill and Jess Geanconteri <i>Lake in the Hills, IL</i>	John Fitzgerald <i>Elk Grove, IL</i>
Mariano & Janice Geanconteri <i>Streamwood, IL</i>	Suzanne Hausch <i>Elk Grove Village, IL</i>
The Valenzo Family <i>Elk Grove Village, IL</i>	Mark and Janet Mason <i>Libertyville, IL</i>
The Daniels Family <i>Elk Grove Village, IL</i>	

**A memorial fund has been established in the name of  
Mrs. Joan Frejd**

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

Joslyn Anderson <i>Markesan, WI</i>	Gene and Gaile Borchart John Fitzgerald <i>Elk Grove, IL</i>
Arlene Goding, <i>Sawyer, MI</i>	Suzanne Hausch <i>Elk Grove Village, IL</i>
Mr. and Mrs. Jack Dahlquist <i>Norridge, IL</i>	Ken Spaeth & Commercial South Team, <i>Yorkville, IL</i>
Chuck Brehm, <i>Morris, IL</i>	Susan Shallcross <i>Elk Grove, IL</i>
The Samborski Family <i>Hanover Park, IL</i>	John and Paula Ford <i>Elk Grove Village, IL</i>
Cindy Maechtle, <i>St. Charles, IL</i>	Barbara Ford <i>Elk Grove Village, IL</i>
George and Christine Baunach <i>Elk Grove Village, IL</i>	Mark and Janet Mason <i>Libertyville, IL</i>
Kristen Schlaff, <i>Chicago, IL</i>	
Bob & Jan Jacobs & Family <i>Muskegon, MI</i>	

**A memorial fund has been established in the name of  
Mr. Herbert G. Frey**

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

Elizabeth Frey                      John Frey  
*Freehold, NJ*                      *Allentown, PA*  
Robert, Sara, Jessica Frey, *Pittsburgh, PA*

**A memorial fund has been established in the name of  
Ms. Elaine Frye**

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

James E. Frye, *Palestine, TX*

**A memorial fund has been established in the name of  
Mr. Laurence F. Gard**

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

David Gard, *Lansing, MI*

**A memorial fund has been established in the name of  
Mr. Alfred A. Gianni**

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

Warren Robins, *Montclair, NJ*

**A memorial fund has been established in the name of  
Mr. Irving Glickman**

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

Geoffrey and Sandy Goldworm  
*Jupiter, FL*

**A memorial fund has been established in the name of  
Mr. Joseph Scott Green**

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

Bean O'Donnell, III, *St. Louis, MO*

**A memorial fund has been established in the name of  
Mrs. Craig Jackson Grover**

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

Southwest Research Institute  
*San Antonio, TX*

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

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

Bonnie Groves, *Hernando, FL*

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

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

Drew Cucuzza, *New Haven, CT*

**A memorial fund has been established in the name of  
Mr. Philip Dee Hayward**

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

Vestals, *Mansfield, TX*                      Keith and Joann Carlson  
Dillon, Kimba and Hattie Vestal                      *Ankeny, IA*  
*Keller, TX*                      Coppell Middle School West  
Ray Huhn, *Pearland, TX*                      *Coppell, TX*  
Andy and Karen Webster                      Wed Night Poker Group  
*Pearland, TX*                      *Arlington, TX*  
Totus Solutions                      Harry and Margaret Shank  
*Carrollton, TX*                      *Arlington, TX*

John and Carol Kubala  
*Arlington, TX*  
Gary Hatch, *Arlington, TX*

Sarah Symecko  
*Pearland, TX*

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

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

Amy Feinstein, *Roswell, GA*

**A memorial fund has been established in the name of  
Mr. Martin Heiss**

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

Robert and Ellen Busch, *East Meadow, NY*

**A memorial fund has been established in the name of  
Mr. Thomas Hennig**

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

Keith and Mary hennig                      Joseph and Jane Decker  
*Evansville, WI*                      *Evansville, WI*  
David and Simone Jeans                      Randall and Patricia Peters  
*Evansville, WI*                      *Evansville, WI*  
Michael and                      Arthur and Karla Camm  
Sandra Prochaska                      *Evansville, WI*  
*Stewartville, MN*                      Stephen & Kathleen Ver  
Jason and Daria O'Connor                      Kuilen  
*Evansville, WI*                      *Evansville, WI*  
James and Amy McNett                      Christopher & Denise Eager  
*Evansville, WI*                      *Evansville, WI*  
Laura Batzer                      Keith and Michelle Frey  
*Milwaukee, WI*                      *Evansville, WI*  
Thomas and Lynn Olson                      Carl V. Korfmacher  
*Evansville, WI*                      *Evansville, WI*

**A memorial fund has been established in the name of  
Mr. Louis Mario Hocker**

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

Kathleen Brinza                      Michael & Barbara Sbrocca  
*Novi, MI*                      *Birmingham, MI*

**A memorial fund has been established in the name of  
Mrs. Elma Lorraine Huggins**

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

The Flournoy Companies                      Christopher Boggs  
*Columbus, GA*                      *Richmond, VA*

**A memorial fund has been established in the name of  
Ms. Miriam Hyams' Brother**

Donations have been made by:

Howard and Diane Weinreich, *New York, NY*

**A memorial fund has been established in the name of  
Mr. Angelo Incorvia**

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

South Shore Counseling, *Wantagh, NY*

**A memorial fund has been established in the name of  
Ms. Hope (Esperanza) Irizar**

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

Cynthia Siska                      Keith Gurkin  
*Fort Lauderdale, FL*                      *Miami Beach, FL*  
Steve Smith                      Sergio and Tina Melicio  
*Cooper City, FL*                      *Hollywood, FL*

**A memorial fund has been established in the name of  
Jay "Jerry's Brother"**

Donations have been made by:

Geoffrey and Sandy Goldworm, *Jupiter, FL*

**A memorial fund has been established in the name of  
Mr. Doyle Jordan**

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

Linda Kay Fisher, *Bakersville, CA*

**A memorial fund has been established in the name of  
Mrs. Beverly Ann Kalfas**

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

Robert and Kay Otte                      Lawrence and  
*Libby, MT*                      Virginia Hochstatter  
Joseph and Catherine Hirte                      *Marshall, MN*  
*Tucson, AZ*                      Lowell and Doris  
Roberta Horton                      Trunkenbolz  
*Florence, AZ*                      *Florence, AZ*  
Sanford and Joyce Vaughn                      Jim Kalfas  
*Florence, AZ*                      *Florence, AZ*  
Robert and Cathryn Egger                      Todd and Jana Raasch  
*Florence, AZ*                      *Bellevue, WA*  
Robert and Beverly Terranova                      Donald Siplon  
*Florence, AZ*                      *Whitehall, MI*  
James F. Gifford                      Ron and Joanne Caya  
*Mason City, IA*                      and Family  
Joann Wilke                      *Naples, FL*  
*Florence, AZ*                      Gerald and  
Lawrence and Virginia Hoc                      Patricia Fraser  
Andy and Vivian Brumbaugh                      *Florence, AZ*  
*Florence, AZ*                      Dimitri L. Kalfas  
Mary E. Rademacher                      *Florence, AZ*  
*Peoria, AZ*

**A memorial fund has been established in the name of  
Mrs. Helen Kardon**

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

Leslie Furst, *Bethesda, MD*

**A memorial fund has been established in the name of  
Mr. Michael Alexander Karnacewicz**

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

Micheleen Karnacewicz, *Brooklyn, NY*

**A memorial fund has been established in the name of  
Mr. Joseph F. Kenney, Sr.**

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

James Paugh, *Palmer, MA*

**A memorial fund has been established in the name of  
Mr. Michael L. Kiely**

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

Myra Kiely, *Carol Stream, IL*

**A memorial fund has been established in the name of  
Mr. Joseph Kotelnicki, Sr.**

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

Tammy Gerber  
*Highlands Ranch, CO*

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

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

Michelle, Xuming and Lori Le <i>Clarksdale, MD</i>	Jody Low, <i>Rochester, NY</i>
Earl and Virginia Stevenson <i>Jr., Uniontown, PA</i>	Chuck and Natalie Fogarty <i>Laconia, NH</i>
Rich Carlson, <i>Berlin, MD</i>	Joseph and Sally Naret <i>Zellencople, PA</i>
Ed and Janet St. Jean <i>Bowie, MD</i>	Craig and Rebecca Landa <i>Freeland, MD</i>
Donald and Cynthia Pulver <i>Ocean City, MD</i>	Dave and Holly Morrison <i>Overland Park, KS</i>
Bill and Sandra Engels <i>Marco Island, FL</i>	Jerry and Ronnie Markey <i>Crofton, MD</i>
Gothard and Mary Lou Lane <i>Grand Lake, CO</i>	Len Paris and Family <i>Richmond, VA</i>
Margaret (Peggy) White <i>Los Gatos, CA</i>	David and Karen Schweizer <i>McMurray, PA</i>
George Foussekis, <i>Louisa, VA</i>	Patrick & Kristie Stevenson <i>Duryea, PA</i>
Edward Krivak, <i>Newark, DE</i>	

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

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

Jennifer Delsite <i>Pittsburgh, PA</i>	Ray and Kathy Stell <i>Blacksburg, VA</i>
Syd and Christy Sprouse <i>Richmond, VA</i>	Wade and Catherine Frye <i>Richmond, VA</i>

**A memorial fund has been established in the name of  
Mr. Dennis G. Lackie**

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

Ken Dvorak <i>Naperville, IL</i>	John and Catherine Roach <i>Libertyville, IL</i>
Employees of Go West T-Shirt Com <i>Fort Collins, CO</i>	Thomas and Janice Powell <i>Mundelein, IL</i>
Employees of Go West T-Shirt Company <i>Loveland, CO</i>	Theresa A. Buckman <i>Palatine, IL</i>
	Kathryn M. Lackie <i>Mundelein, IL</i>

**A memorial fund has been established in the name of  
Mrs. Barbara Pilch-Kuett Latchford**

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

Josh and Elisabeth Stark <i>Reston, VA</i>	James W. Freeman <i>Gaithersburg, MD</i>
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**A memorial fund has been established in the name of  
Mr. Eddie Leitman**

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

Deborah, Larry, Rachel and Eric Levine <i>Birmingham, AL</i>	Stanley and Beverly Erdreich <i>Birmingham, AL</i>
Russell Tucker <i>Ashton, MD</i>	Sunny Goldstein Franklin <i>Northridge, CA</i>
David Olivier <i>Arlington, VA</i>	Gary and Susan Goldstein <i>Birmingham, AL</i>
Wayne and Deborah Wilhelm <i>Chattanooga, TN</i>	Leslie Stone <i>Atlanta, GA</i>
Ed and Mary Jo Baich <i>Medford, OR</i>	Andre' Toffel <i>Birmingham, AL</i>

Alan and Paige Lichtenstein  
*Birmingham, AL*

L. Paul Kassouf & Co., P.C.  
*Birmingham, AL*

Lanny and Ricki Kline  
*Birmingham, AL*

Lynn Davis, *Weston, FL*

Bob and Dinah Grollman  
*Atlanta, GA*

Grant A. Capelouto on behalf  
of The Capelouto Family  
*Tallahassee, FL*

Susan Wilen  
*New York, NY*

Michael and Karen Koplon  
*Memphis, TN*

Judy McDonald (Ladden)  
*Birmingham, AL*

Mike and Joan Krawcheck  
*Birmingham, AL*

Charlotte Wilen *Atlanta, GA*

Carl Capelouto, *Atlanta, GA*

Steven and Patti Westbrook  
*Birmingham, AL*

William and Mary Pearson  
*Birmingham, AL*

Chris Hood  
*Birmingham, AL*

Stuart & Frances Galishoff  
*Atlanta, GA*

Joe and Jane Bluestein  
*Birmingham, AL*

Stanley and Judy Sherman  
*Atlanta, GA*

Laurie Max  
*Birmingham, AL*

Judith D. Borisky  
and Robert Metzger  
*Birmingham, AL*

Dr. & Mrs. Marc Michelson  
*Mountain Brk, AL*

Sam and Gina Shapiro  
*Atlanta, GA*

L.R. and Peggy M. Fortier  
*Birmingham, AL*

Kenny and Sandy Seton  
*Mountain Brook, AL*

Gayle, W. Leitman  
*Birmingham, AL*

**A memorial fund has been established in the name of  
Mr. Ronald Logan**

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

Marvin and Wendy Clymer, *Willow Grove, PA*

**A memorial fund has been established in the name of  
Mr. Rick Bo Low, Jr.**

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

Susan Graves, *San Diego, CA*

**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 Weiss, *Staten Island, NY*

**A memorial fund has been established in the name of  
Mrs. Doris M. Magiera**

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

Alan and Heidi Kozlowski  
*Olympic Valley, CA*

Thomas LeBlond  
*Cushing, ME*

Food Share Inc.  
*Palmer, MA*

Richard and Mary Jane Caron  
*North Brookfield, MA*

Mr. and Mrs. Edward J. Koss  
*Palmer, MA*

David and Carleen Coderre  
*Palmer, MA*

James Paugh  
*Palmer, MA*

Jeffrey J. Robinson  
and Kristine Sheehy  
*Chelmsford, MA*

FLEXcon Company, Inc.  
*Spencer, MA*

Mark Holmes  
*Berlin, CT*

St. Thomas the Apostle  
Bingo  
*Palmer, MA*

**A memorial fund has been established in the name of  
Mrs. Patricia J. Marsh**

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

John Fehrman, *Sebring, FL*

**A memorial fund has been established in the name of  
Ms. Jan Ross May**

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

Vero Beach High School Class of 1962, *Vero Beach, FL*

**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*

**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:

Robert and Lori Huffman, *Crystal, MN*

**A memorial fund has been established in the name of  
Ms. Marie B. McLaughlin**

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

Ann Bradshaw, *Providence Forge, VA*

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

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

Patricia Meling, *Arlington Heights, IL*

**A memorial fund has been established in the name of  
Mrs. Bonnie A. Merlet**

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

Mike Merlet, ASA Inc., *Madison, WI*

**A memorial fund has been established in the name of  
Mr. Charles R. Mertz**

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

Dorothy A. Mertz, *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:

Angelo Sansano  
and Jennifer Nicholas  
*Dover, NJ*

Bob Aitkens and Eric Mead  
*Little Silver, NJ*

Pat and Barbara D'Italia  
*Bedminster, NJ*

Daryl Hoffmann,  
Kurt and Krista Okeholm  
*Hampton, NJ*

Jeanne Toth  
*Bedminster, NJ*

Mike and Louise Kenny  
*Alexandria, VA*

**A memorial fund has been established in the name of  
Mr. Dennis Metts**

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

Marty and Sandy McGee  
*Vista, CA*

George and Midge Milam  
*Benton, KY*

Jerry and Kathy Sanderson  
*Benton, KY*

Carroll Evans  
Sunday School Class,  
First Baptist Church  
*Benton, KY*

Carolyn Burnett, *Paducah, KY*

Harold Metts  
*Memphis, TN*

Shane and  
E. Rhett Hobgood  
*Madison, MS*

Bill and Fredda Hobgood  
*Vicksburg, MS*

Mt. Zion  
(Sunday School Class)  
*West Paducah, KY*



**A memorial fund has been established in the name of  
Mr. Kenneth E. "Gene" Milburn**

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

Karen Bloomfield <i>Charlottesville, VA</i>	Frank Friedman and the PVCC Community <i>Charlottesville, VA</i>
Andy & Danielle Lewandowski <i>Palmyra, VA</i>	Alvin "Val" Sledd <i>Poquoson, VA</i>
Bob and Jane Dudgeon <i>Granby, CT</i>	
Rosemary, Doug, Michelle Caron, <i>Palmyra, VA</i>	

**A memorial fund has been established in the name of  
Mr. Edward L. Miller**

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

Pat Ward, <i>Ashkum, IL</i>	Betty J. Weber <i>Nashville, TN</i>
Bill and Carol Christy <i>Watseka, IL</i>	Ruth E. Savoie, <i>Onarga, IL</i>
Leslie A. Myers <i>Watseka, IL</i>	Ronald & Marlene Zachgo <i>Ashkum, IL</i>
Linda Scering <i>Bradley, IL</i>	Harry F. Muller <i>Sheldon, IL</i>
Clyde and Carol Bargmann <i>Gilman, IL</i>	Judith A. Miller <i>Gilman, IL</i>

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

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

John Pierce, *Jacksonville, FL*

**A memorial fund has been established in the name of  
Mrs. Lillian M. Morris**

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

Timothy P. Morris, *Naperville, IL*

**A memorial fund has been established in the name of  
Mr. Hersh Muchnick**

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

Sol and Trudy Kioze, *East Lyme, CT*

**A memorial fund has been established in the name of  
Mrs. Paz Rodriguez Muniz**

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

Eric, Charlotte and Linnea Muniz <i>Hubert, NC</i>	Marc Aldaz, Garland Henderson and Laura Fogelsong, <i>San Antonio, TX</i>
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**A memorial fund has been established in the name of  
Mr. Thomas Mabry Myall, Jr.**

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

The Poly Alumni Association, *Crowley, TX*

**A memorial fund has been established in the name of  
Ms. Paula Neidlinger**

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

Trudy Willauer, *Agoura Hills, CA*

**A memorial fund has been established in the name of  
Ms. Ruth Newman**

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

Rona Spiller, *Boynton Beach, FL*

**A memorial fund has been established in the name of  
Mrs. Arlene O'Donnell**

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

James J. O'Donnell, III <i>Ocean City, NJ</i>	Charlene Slider <i>Perkasie, PA</i>
--	--

**A memorial fund has been established in the name of  
Mr. Chris Okuhara**

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

Franco U. Imada <i>Kailua, HI</i>	Steven Fujita <i>Honolulu, HI</i>
--------------------------------------	--------------------------------------

Calin J. Kim, *Honolulu, HI*

**A memorial fund has been established in the name of  
Mrs. Claudia Ann Pappas**

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

John and Lucille Lynch <i>Gladstone, MI</i>	Charlene Darrow, <i>Virginia Beach, VA</i>
--	---

**A memorial fund has been established in the name of  
Dr. George S. Pascoe**

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

Cindy Shaw <i>Palm Harbor, FL</i>	Nick and Joan DeRosa <i>West Mifflin, PA</i>
Dorothy M. Ward <i>Pittsburgh, PA</i>	Robert and Joan Livingston <i>Jefferson Hills, PA</i>
David and Rayne Bird <i>South Park, PA</i>	John and Maureen Kelly <i>Bloomfield Hills, MI</i>
Harold and Kathryn Pascoe <i>Fort Myers, FL</i>	Ramon and Patricia Lozano <i>McKeesport, PA</i>
Ron and Mona Lee Everly <i>Fort Myers, FL</i>	Women's Bridge Club <i>West Mifflin, PA</i>
Gary and Michele Reed <i>Jefferson Hills, PA</i>	Duane and Nancy Richey <i>West Mifflin, PA</i>

**A memorial fund has been established in the name of  
Mr. Harvey Adam Pearlman**

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

Ken and Cynthia Eckstein, *Bridgewater, CT*

**A memorial fund has been established in the name of  
Mr. Alejandro Perez**

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

Ana Perez, *Glendale, AZ*

**A memorial fund has been established in the name of  
Mr. Louis F. Posillico**

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

Nicole Posillico  
*Havertown, PA*

**A memorial fund has been established in the name of  
Mr. Stephen M. Redpath**

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

Rosalyn Redpath, *Lyndhurst, 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, *Earlsville, VA*

**A memorial fund has been established in the name of  
Mr. Carl Douglass Riegel**

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

Springfield Missouri Convention & Visitors Bureau  
*Springfield, MO*

**A memorial fund has been established in the name of  
Mr. Milton Rogovin**

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

Wegrzyn Kahn, *Valrico, FL*

**A memorial fund has been established in the name of  
Mr. Abraham (Abe) Rosenthal**

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

Doctor Harold M. Rosenthal, *Houston, TX*

**A memorial fund has been established in the name of  
Mr. Charles W. Ruckh**

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

Jayne Butler <i>Warren, NJ</i>	Charles and Robin Lashbrook <i>Kansas City, MO</i>
Jennifer Cruickshank <i>Princeton, NJ</i>	Don and Elizabeth Goulding <i>Kansas City, MO</i>
Katarina Pfaff, <i>Parkville, MO</i>	

**A memorial fund has been established in the name of  
Mrs. Mary A. "Mimi" Ryan**

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

Socrates C. Georgeades <i>Spring Hill, FL</i>	Vernon Squires <i>Winnetka, IL</i>
Illinois Tool Works Foundation <i>Glenview, IL</i>	Patrick and Sally Dix <i>Des Moines, IA</i>
Timothy D. O'Hara <i>Chicago, IL</i>	Pamela Bell <i>Chicago, IL</i>
Joe and Christina Perez <i>Chicago, IL</i>	Susan Eaton <i>Fredonia, WI</i>
Mr. & Mrs. Larry Faulhaber <i>Oak Park, IL</i>	Jack and Sally Daniels <i>Wilmette, IL</i>
Doctor and Mrs. Kevin McClone <i>Wilmette, IL</i>	Michael Earl, <i>Wilmette, IL</i>
John P. Ryan <i>Wilmette, IL</i>	Tom and Lauren Evans <i>Naperville, IL</i>
Richard and Joyce Morrison <i>Glenview, IL</i>	George & Michele Hinchcliff <i>Lake Forest, IL</i>
Margaret A. Malloy <i>Rocky River, OH</i>	Bill and Pat Mulligan <i>Arlington Hts., IL</i>
Barbara Sullivan <i>Nashville, TN</i>	Adelaide Meskill <i>York, ME</i>
John and Rosemary Butterfield <i>Park Ridge, IL</i>	Anne Weisskopf <i>Palo Alto, CA</i>
Mr. and Mrs. Alan Fox, <i>West Bloomfield, MI</i>	Dee LeFevour <i>Oak Park, IL</i>
Randi Marino <i>Potomac, MD</i>	Dick Carey <i>River Forest, IL</i>
Irwin List <i>Northbrook, IL</i>	League of Women Voters of Wilmette <i>Wilmette, IL</i>
John and Susan Kelty <i>River Forest, IL</i>	Erwin and Donna Feldman <i>Bloomfield Hills, MI</i>
	Mary E. O'Donnell <i>Lake Forest, IL</i>

Jim and Betty McCabe  
*Wilmette, IL*

Terra R. McClory  
*Glenview, IL*

Mike and Jean Cavanaugh  
*Wilmette, IL*

William and Carolyn Gifford  
*Evanston, IL*

Diane Tate, *Wilmette, IL*

Doris Oshana  
*Lincolnwood, IL*

Richard and Helen Myhre  
*Gainesville, VA*

Steven and Susan Leslie  
*Birmingham, MI*

Trading Technologies  
International, Inc.  
*Chicago, IL*

Carlos and Silvia Borutzky  
*Pittsburgh, PA*

Peter and Nancy Lems  
*Wilmette, IL*

Richard & Maryjeanne Burke  
*Chicago, IL*

Adam and Jill Gantz  
*Farmington Hills, MI*

Mark and Lauren Cohen  
*Northbrook, IL*

Margaret Pearl  
*Seattle, WA*

**A memorial fund has been established in the name of  
Ms. Bonnie L. Salter**

Donations have been made in Ms. Salter's memory by:  
Keith and Jacque Norris, *Glendale, CA*

**A memorial fund has been established in the name of  
Mr. Carlos M. Santiago**

Donations have been made in Mr. Santiago's memory by:  
Crowning Jewels  
*Centereach, NY*

**A memorial fund has been established in the name of  
Mrs. Sue Schieres**

Donations have been made in Mrs. Schieres's memory by:  
Robert Schieres, *Centerville, OH*

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

Donations have been made in Mr. Signorello's memory by:  
Sylvia Signorello, *Belvidere, NJ*

**A memorial fund has been established in the name of  
Mr. Donald Schimek**

Donations have been made in Mr. Schimek's memory by:  
Pat Schimek, *Easton, MN*

**A memorial fund has been established in the name of  
Mr. Keith D. Schmidt**

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

David and Peggy Engh <i>Shoreview, MN</i>	Jeffrey & Lynne Ehleringer <i>Lino Lakes, MN</i>
Howard and Carol Costello <i>Stillwater, MN</i>	Gerald and Carol Granley <i>Cloquet, MN</i>
Dale and Marlene Johnson <i>Crookston, MN</i>	Paul and Pamela Haugen <i>Minneapolis, MN</i>
Dr. & Mrs. Roger Orensteen <i>Edina, MN</i>	Ben and Gail Wong <i>Eden Prairie, MN</i>
Marvin and Diane Magnuson and Family <i>Crookston, MN</i>	Peter & Deborah Jacobson <i>Maple Grove, MN</i>
Jeff Ehleringer <i>Lino Lakes, MN</i>	Roberto and Sonja Bari <i>Brooklyn Park, MN</i>
Lynn and Jean Schmidt <i>Bemidji, MN</i>	John R. Schmidt <i>Cottage Grove, MN</i>
Diane P. Wells, <i>Tulsa, OK</i>	Ramona C. Lackore and Ron B. Adkins
John M. Pope, <i>Edina, MN</i>	<i>Willmar, MN</i>

**A memorial fund has been established in the name of  
Mr. Ronald W. Scott**

Donations have been made in Mr. Scott's memory by:  
David L. Scott, *Lombard, IL*

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

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

Arthur and Nora Steiger <i>Springfield, VA</i>	Robert H. Stotz <i>McLean, VA</i>
National Association of Insurance and Financial Advisors <i>Falls Church, VA</i>	John and Stephanie Adgate <i>Wake Forest, NC</i>
Jerry Shaw and Children <i>Decatur, AL</i>	Rhett Ferguson <i>Prattville, AL</i>

**A memorial fund has been established in the name of  
Mrs. Mary M. Sheppard**

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

TAUC, The Association of Union Contractors <i>Arlington, VA</i>	Chuck and Mary McGowan <i>Aliquippa, PA</i>
James Mirgliotta <i>Aurora, OH</i>	Tom Schlafly <i>Naperville, IL</i>
Ronald and Nancy Nemes <i>Strongsville, OH</i>	IMPACT Staff <i>Washington, DC</i>
Thomas Maley <i>Berea, OH</i>	Walter Wise <i>Oakton, VA</i>

**A memorial fund has been established in the name of  
Ms. Helene Sherk**

Donations have been made in Ms. Sherk's memory by:  
Mary Lou Iserson, *Tucson, AZ*

**A memorial fund has been established in the name of  
Mrs. Marilyn Simmons**

Donations have been made in Mrs. Simmons' memory by:  
Ceva Logistics, *Houston, TX*

**A memorial fund has been established in the name of  
Mrs. Katie Merritt Smart**

Donations have been made in Mrs. Smart's memory by:  
Roger Prehoda and Lori Smith  
*Holly, FL*

**A memorial fund has been established in the name of  
Mr. Robert E. Snyder**

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

Rita Ossias <i>West Palm Beach, FL</i>	Joy Palevsky <i>Briarwood, NY</i>
Lewis and Gail Koptowsky <i>Palm Beach Gardens, FL</i>	Arthur and Jeanne Sloup <i>East Islip, NY</i>
Barbara Frank <i>Jamaica, NY</i>	

**A memorial fund has been established in the name of  
Mr. Bruce R. Souder**

Donations have been made in Mr. Souder's memory by:  
Marie Souder  
*Fort Lauderdale, FL*

**A memorial fund has been established in the name of  
Mr. Angelo Staikos**

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

Chris and Vasiliki Angelos <i>West Hartford, CT</i>	John and Julie Mocci <i>Morganville, NJ</i>
Mary and Sue Lowe <i>Keyport, NJ</i>	Ellie Papacosma <i>Harpswell, ME</i>
Mr. and Mrs. Joseph Artelli <i>Holmdel, NJ</i>	George and Doris Cavuto <i>Bay Shore, NY</i>
Mr. and Mrs. Joseph Liggio and Family, <i>Keyport, NJ</i>	Joan Malloy, <i>Holmdel, NJ</i>
Patti Malloy <i>Manasquan, NJ</i>	William Kerchner <i>Keyport, NJ</i>
Bill and Betty Hetherington <i>Keyport, NJ</i>	John, Barbara, John, Dean and Christine DiGregorio <i>E. Patchogue, NY</i>

**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  
Mrs. Constance V. Stuckey**

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

Bob and Brenda Cody <i>Springboro, OH</i>	Bruce and Gail Runyan <i>Dacula, GA</i>
Tim and Cheryl Kelly <i>Buford, GA</i>	Bill and Sharon Tomko <i>Monticello, GA</i>
The Karakas Family <i>Naples, FL</i>	Paula Karides <i>Saint Louis, MO</i>
Tom Caprio <i>Palm Harbor, FL</i>	John and Paula Stuckey <i>Kettering, OH</i>
Kenneth Wenzl <i>Plano, TX</i>	Dave and Brenda Stuckey <i>Springboro, OH</i>
ITT, <i>Seneca Falls, NY</i>	Joann Holzshu, <i>Ocala, FL</i>
GAC Fitness and Family <i>Springboro, OH</i>	Craig and Kellie Coy <i>Springboro, OH</i>
Friends at Valpak <i>Largo, FL</i>	Roger, Betty, Brian Stuckey <i>Kettering, OH</i>
Bob and Judy Perez <i>Bonita Springs, FL</i>	Doris J. McKinney <i>Dayton, OH</i>
Michael Doyle <i>Mendham, NJ</i>	Carl and Jane Wilson <i>Marietta, GA</i>
Neil and Stephanie Liu <i>Irvine, CA</i>	Vicki Peters <i>Miamisburg, OH</i>
Greg and Ann Courchane <i>Palm Harbor, FL</i>	Trisha Emish, <i>Cincinnati, OH</i>
Doug and Peggy Fralinger <i>Crown Point, IN</i>	Robert and Eloise Mason <i>Hilton Head Island, SC</i>
Joe and Judy Boiseau <i>Carefree, AZ</i>	Jewel Downend <i>Springboro, OH</i>
David Baily, <i>Orefield, PA</i>	Mark and Julie Glockner <i>Villa Hills, KY</i>
Gus and Bren Pathenos <i>Manchester, MO</i>	W. Douglas Lewis <i>Atlanta, GA</i>
George Pathenos <i>Bridgeton, MO</i>	Rob and Alexis Wagnon <i>Saint Louis, MO</i>

**A memorial fund has been established in the name of  
Mr. Satoru "Sat" Sugiura**

Donations have been made in Mr. Sugiura's memory by:  
James and Kyoko Roseborough, *Piedmont, CA*

**A memorial fund has been established in the name of  
Mrs. Joann Suria**

Donations have been made in Mrs. Suria's memory by:  
Margaret Kennedy Schneider, *Daytona Beach Shores, FL*

**A memorial fund has been established in the name of  
Mr. Bob Swindell**

Donations have been made in Mr. Swindell's memory by:  
Ella and Les, Swindell, *Browns Summit, NC*

**A memorial fund has been established in the name of  
Mrs. Jennie Swiderski**

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

Emily Green, Rhea Krause <i>Southampton, NJ</i>	The Girls of 632 <i>Ardmore, PA</i>
Doctor and Mrs. Gerald Markowitz, Doctor and Mrs. Ernest Dellheim, Doctor and Mrs. David Block and Staff <i>Narberth, PA</i>	Ann Monahan <i>Pennsauken, NJ</i>
Suzanne Kadlic <i>Cherry Hill, NJ</i>	Stan, Ginny and Sue Swiderski <i>Cherry Hill, NJ</i>
Leeann Young <i>Collingswood, NJ</i>	Raymond & Sharon Cybulski <i>Elkton, MD</i>
	Karen M. Deacon <i>Cherry Hill, NJ</i>

**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:  
Ann C. Taylor, *Glen Allen, VA*

**A memorial fund has been established in the name of  
Mr. Remo Tersolo**

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

Don and Fran Albrecht <i>Huntington Beach, CA</i>	John Taylor, <i>Vista, CA</i>
Constantino & Eileen Albera <i>Banning, CA</i>	Carla Gauss <i>Bellflower, CA</i>
Margaret Tersolo <i>Carlsbad, CA</i>	Severino & Patricia Trapletti <i>Roseville, CA</i>
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Yasna Ouwkerk <i>Torrance, CA</i>	Leonard and Sylvi Jones <i>Plainfield, IL</i>
Debbie Carver <i>Oceanside, CA</i>	Maria Hickey <i>Arroyo Grande, CA</i>
Bernard and Lisa Gallizio <i>Nipomo, CA</i>	Susan M. Urban <i>Carlsbad, CA</i>
Robert and Helen Belcher <i>Banning, CA</i>	Campbell Tersolo & Assoc. <i>Solana Beach, CA</i>
	Mike Tersolo, <i>Carlsbad, CA</i>

**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 Thomas, *Wichita Falls, TX*

**A memorial fund has been established in the name of  
Mrs. Jeannette Toth**

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

Donna, Dave & Davy Bunton <i>Arlington, VA</i>	Joseph Toth <i>Englishtown, NJ</i>
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**A memorial fund has been established in the name of  
Ms. Julia Trebesiner**

Donations have been made in Ms. Trebesiner's memory by:  
Karlene Denby, *Houston, TX*

**A memorial fund has been established in the name of  
Mrs. Bettie Munden Tulloss**

Donations have been made in Mrs. Tulloss' memory by:  
Gus Tulloss, *Rocky Mount, NC*

**A memorial fund has been established in the name of  
Mrs. Connie Ann Visnapu**

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

Harriet E. Bertelsen <i>Benbrook, TX</i>	Beta Sigma Phi, Laureate Alpha Nu Chapter <i>McAllen, TX</i>
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**A memorial fund has been established in the name of  
Mr. Joseph H. Vogt**

Donations have been made in Mr. Vogt's memory by:  
Rogers and Kathy Dixon, *Atlanta, GA*

**A memorial fund has been established in the name of  
Mrs. Lynn C. Vokulich**

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

William and Judith Rose <i>Spencerport, NY</i>	RFBM-Estar Division at Eastman Kodak Company <i>Rochester, NY</i>
Joyce Miles <i>Rochester, NY</i>	Eileen S. Casey <i>Rochester, NY</i>
David & Barbara Leugemors <i>Henrietta, NY</i>	The Miesch Family

**A memorial fund has been established in the name of  
Mrs. June Marie Wakeley**

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

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Catherine Dixon <i>Niagara Falls, NY</i>	Olmstead School #156 Sunshine Club <i>Buffalo, NY</i>
Marianne Farallo <i>Lakeview, NY</i>	Kenneth & Elizabeth Wyras <i>North Tonawanda, NY</i>
Nancy L. Larson <i>Dunkirk, NY</i>	Frank Wakeley <i>North Tonawanda, NY</i>

**A memorial fund has been established in the name of  
Mr. Richard (Rick) Warner**

Donations have been made in Mr. Warner's memory by:  
Jean McCracken, *Hollywood, FL*

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

Donations have been made in Mr. Warren's memory by:  
Carolyn J. Warren  
*St. Petersburg, FL*

**A memorial fund has been established in the name of  
Mrs. Karen A. Wenzel**

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

Paul DeStefano <i>North Reading, MA</i>	Paul Wenzel <i>Weymouth, MA</i>
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**A memorial fund has been established in the name of  
Mrs. Patricia Irene White**

Donations have been made in Ms. White's memory by:  
Amy Chiu, *Lincolnwood, IL*

**A memorial fund has been established in the name of  
Mr. Perry Whitley, Jr.**

Donations have been made in Mr. Whitley's memory by:  
Ross Jackson, *Carmi, IL*

**A memorial fund has been established in the name of  
Mr. Neal Eddins Wingfield**

Donations have been made in Mr. Wingfield's memory by:  
Page L. Wingfield, *Goldsboro, NC*

**A memorial fund has been established in the name of  
Mrs. Gladys W. Winkle**

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

Dan and Carol Seely <i>Haymarket, VA</i>	Lena L. Crabtree <i>Gainesville, FL</i>
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**A memorial fund has been established in the name of  
Mr. Walter S. Wolodkin**

Donations have been made in Mr. Wolodkin's memory by:  
Thomas Ross, *Palatine, IL*

**A memorial fund has been established in the name of  
Ms. Hilde Yates**

Donations have been made in Ms. Yates' memory by:  
Bob and Candy Burroughs, *Tucson, AZ*

**A memorial fund has been established in the name of  
Mrs. Joan Zimetbaum**

Donations have been made in Mrs. Zimetbaum's memory by:  
Dr. Jane Wachs, *Ardsey, NY*

**A memorial fund has been established in the name of  
Doctor Marcel Zimetbaum**

Donations have been made in Dr. Zimetbaum's memory by:  
Dr. Jane Wachs, *Ardsey, NY*

## **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*.

**Diane Dempster, Tucker, GA**  
**Roslyn Raney, Menlo Park, CA**  
**Fay Wanetick, Pittsburgh, PA**



## 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:**

***Ethel Muskat***

This donation was submitted by:

**Geoff and Sandy Goldworm, Jupiter, FL**

**A Living Endowment donation  
has been made in honor of:**

***Mindy Rose***

This donation was submitted by:

**Geoff and Sandy Goldworm, Jupiter, FL**

**A Living Endowment donation  
has been made in honor of:**

***Mr. and Mrs. Edwin Ladov***

This donation was submitted by:

**Geoff and Sandy Goldworm, Jupiter, FL**

**A Living Endowment donation  
has been made in honor of:**

***Frank and Donna Gallo***

This donation was submitted by:

**Tom & Dyann Panepinto, Pittsburgh, PA**

**A Living Endowment donation  
has been made in honor of:**

***Robin Roberts***

This donation was submitted by:

**William Boyd, Kingsport, TN**

**A Living Endowment donation  
has been made in honor of:**

***Arnold Schwartz***

This donation was submitted by:

**Gloria Schwartz, Woodland Hills, CA**

**A Living Endowment donation  
has been made in honor of:**

***Flora Greenwald***

This donation was submitted by:

**Carol Pomeroy, Mount Marion, NY**

**A Living Endowment donation  
has been made in honor of:**

***Ron Eig***

This donation was submitted by:

**Sharon Leonard, Edison, NJ**

**A Living Endowment donation  
has been made in honor of:**

***Kevin Truong and Family***

This donation was submitted by:

**Raymond P. Lutomski, Cortlandt Manor, NY**

**A Living Endowment donation  
has been made in honor of:**

***German Wong***

This donation was submitted by:

**Tania Amador, Jamaica, NY**

**A Living Endowment donation  
has been made in honor of:**

***Paige McKelvy***

This donation was submitted by:

**Shawn McKelvy, Radford, VA**

**A Living Endowment donation  
has been made in honor of:**

***Kevin Spawr***

This donation was submitted by:

**Adam Douglas Slawin, New Haven, CT**

**A Living Endowment donation  
has been made in honor of:**

***Tom and Dyann Panepinto***

This donation was submitted by:

**Frank and Donna Gallo, Chicago, IL**

**A Living Endowment donation  
has been made in honor of:**

***Lynn and Beth McMillan***

This donation was submitted by:

**Kevin & Sally Mahoney, Scottsdale, AZ**

**A Living Endowment donation  
has been made in honor of:**

***Janet Law***

This donation was submitted by:

**Joyce Law, New York, NY**

**A Living Endowment donation  
has been made in honor of:**

***Chet and Dorinda Adamick***

This donation was submitted by:

**Paul and Chris Jolie, Rutland, MA**

**A Living Endowment donation  
has been made in honor of:**

***Joanne Tersch***

This donation was submitted by:

**Paul and Chris Jolie, Rutland, MA**

**A Living Endowment donation  
has been made in honor of:**

***Raechel Ruch and  
Stephanie Ruch***

This donation was submitted by:

**Annabelle Schwartz  
Southampton, PA**

**A Living Endowment donation  
has been made in honor of:**

***Mahaveer Prabhakar***

This donation was submitted by:

**Rajeev B. and Elizabeth Prabhakar  
San Francisco, CA**

**Living Endowment donations  
have been made in honor of:**

***Bob and Barbara Wolfe***

This donation was submitted by:

**Donald and Susan Lauffer  
Bartlesville, OK**

**Bill and Betty Wolfe  
Princeton, NJ**

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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 a special subscription rate of \$135.00 for *Leukemia Research* (a substantial discount from the current institutional subscription rate of \$2,373), reduced professional registration fees at International Symposia, and issues of *The MDS News*.

**Please visit us at:**  
**[www.mds-foundation.org](http://www.mds-foundation.org)**