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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From the Guest Editor’s Desk

The Emerging Impact of Flow Cytometry in Myelodysplastic Syndromes

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 diagnosis of MDS and other cytopenias.2,3

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.10 The key parameters within this score are: i) an increase in CD34+ progenitor cells within bone marrow nucleated cells (≥2%); ii) a decreased percentage of progenitor B cells within the CD34+ compartment (≤5%); iii) a decrease or increase of CD45 expression level on myeloid progenitor cells as compared to lymphocytes as a reference (≤4 or ≥7.5) and iv) a decrease in SSC of neutrophils as compared to lymphocytes (≤6).

The immature cell compartment is very heterogeneous. Therefore, beyond the classic CD45dim/SSClow/int profile, antibody combinations such as CD45/CD34/CD117/HLA-DR and CD45/CD34/CD123/HLA-DR are instrumental to identify myeloid progenitor cells (CD45dim and SSClow/int) among other populations that show overlapping CD45 and SSC features (e.g. B cell precursors, plasma cells, monoblasts, basophils, erythroblasts and plasma cell dendritic cell precursors).2 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 CD56.5,7,11,12,16-19

Evaluation of Dysplasia in the Immature Myeloid Progenitor Compartment

Maturing neutrophils are identified by their CD45sintSSCint-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 CD33bright, HLA-DR+ and CD11b+ 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).2

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).2,3
Evaluation of Dysplasia in the Monocytic Compartment

Morphological assessment of dysmaturity in the monocytic compartment 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 percentage 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. Thus, the only validated prognostic FC score is the FC scoring system by Wells et al. 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. 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. 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.\textsuperscript{27} 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.\textsuperscript{28} 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.\textsuperscript{2,3} 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.

**References**


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**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://mds-foundation.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/.

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**Tech it Out!**
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 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).

- 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 Symposium 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

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**

- 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

**Download our ASH Presentations online at [http://www.mds-foundation.org/ash-2012-presentations/](http://www.mds-foundation.org/ash-2012-presentations/)**

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

Health professionals learning more about MDS at the ASH conference

Crowd of 800+ hematologists participated in our sponsored satellite symposium
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 12th International Symposium on Myelodysplastic Syndromes

May 8-11, 2013 | Berlin, Germany

Advancing Research & Patient Care

www.kenes.com/mds

View the scientific programme and register today at a discounted rate!
## PRELIMINARY TIMETABLE

### WEDNESDAY, MAY 8, 2013

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<th>Time</th>
<th>Session</th>
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<tr>
<td>14:00-17:00</td>
<td><strong>Morphology in MDS</strong>&lt;br&gt;Basic Course&lt;br&gt;Teresa-vallespi, Spain&lt;br&gt;Ulrich Germing, Germany&lt;br&gt;Masao Tomonaga, Japan&lt;br&gt;Gina Zini, Italy&lt;br&gt;Richard Brunning, USA</td>
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<td>17:00</td>
<td><strong>Opening Ceremony</strong>&lt;br&gt;<strong>Chair:</strong> Arnold Ganser, Germany; Stephen Nimer, USA</td>
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<td>19:00</td>
<td>Welcome Reception</td>
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### THURSDAY, MAY 9, 2013

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<th>Time</th>
<th>Session</th>
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<td>8:30-10:00</td>
<td><strong>Plenary I: PathogenOMEs in MDS – new players and well known gamblers</strong>&lt;br&gt;Chair: Wolf-Karsten Hofmann, Germany</td>
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<td>10:00-10:30</td>
<td>Coffee Break</td>
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<td>11:30-12:30</td>
<td><strong>Interactive I: Challenging diagnostic cases – does molecular genetics lead the way?</strong>&lt;br&gt;Chair: John Bennett, USA</td>
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<td>12:30-13:30</td>
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<td>13:30-14:30</td>
<td><strong>Plenary III: What can MDS-specialists learn from ...</strong>&lt;br&gt;Chair: Mario Cazzola, Italy</td>
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<td>14:30-16:00</td>
<td><strong>Oral Session I – Pathogenesis</strong>&lt;br&gt;Chair: Brigette Schlegelberger, Germany</td>
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<td>16:00-16:30</td>
<td>Coffee Break</td>
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<td>16:30-18:00</td>
<td><strong>Poster Session</strong>&lt;br&gt;(+ guided poster discussion)</td>
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**The 12th International Symposium on Myelodysplastic Syndromes**

**FRIDAY, MAY 10, 2013**

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<td>8:30-10:00</td>
<td>Plenary IV: Treatment of low risk MDS patients – the standard, the new</td>
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<td>Chair: Jacob Passweg, Switzerland</td>
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<td>Immunosuppressive therapy, Neal Young, USA</td>
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<td>The riddle of iron chelation in MDS, Valeria Santini, Italy</td>
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<td>ESAs/TSA – The higher the dose, the better the response? Sophie Park, France</td>
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<td>Lenalidomide as a standard treatment for low risk MDS with 5q abnormality? Alan List, USA</td>
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<td>This session is supported by an Unrestricted Educational Grant from Novartis Oncology.</td>
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<td>10:00-10:30</td>
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<td>10:30-11:30</td>
<td>Plenary V: Treatment of high risk MDS patients</td>
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<td>Chair: Pierre Feneux, France</td>
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<td>Molecular targets – treatment options, Stephen Nimer, USA</td>
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<td>Hypomethylating agents for treatment of high risk MDS, Norbert Gattermann, Germany</td>
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<td>Combination regimens in high risk MDS, Steven Gore, USA</td>
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<td>This session is supported by an Unrestricted Educational Grant from Celgene Corporation.</td>
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<td>Interactive II (allo SCT)</td>
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<td>Chair: Theo DeWitte, The Netherlands</td>
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<td>Patients selection, Corey Cutler, USA</td>
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<td>Pre treatment, Guillermo Sanz, Spain</td>
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<td>Management of graft versus host disease, Hans-Joachim Deeg, USA</td>
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<td>Lunch</td>
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<td>Meet the Experts</td>
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<td>Iron Chelation, Daniela Cilloni, Italy</td>
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<td>ESA, Martin Jädersten, Sweden</td>
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<td>Combination Treatment, Uwe Platzbecker, Germany</td>
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<td>13:30-14:30</td>
<td>Best abstracts (Bastianello-Awards)</td>
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<td>Chair: Arnold Ganzer, Germany, Stephen Nimer, USA</td>
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<td>14:30-16:00</td>
<td>Oral Session II – Treatment and trials</td>
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<td>Chair: Lionel Ades, France</td>
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<td>16:00-16:30</td>
<td>Coffee Break</td>
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<td>16:30-18:00</td>
<td>Poster Session (+ guided poster discussion)</td>
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**SATURDAY, MAY 11, 2013**

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

REGISTRATION
Discounted registration can be accessed online until April 29th. Please visit: www.kenes.com/mds

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<th>Regular fee From March 13th until April 29th</th>
<th>Onsite fee From April 29th</th>
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<tr>
<td>MDSF Member*</td>
<td>€ 540.00</td>
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<td>Non-Member</td>
<td>€ 600.00</td>
<td>€ 670.00</td>
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<td>Nurse**</td>
<td>€ 240.00</td>
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<td>Student***</td>
<td>€ 155.00</td>
<td>€ 190.00</td>
<td>€ 225.00</td>
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<tr>
<td>Pre-Symposium Course in Morphology</td>
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<td>Meet the expert lunch session</td>
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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

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. Aristotle 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 or contact 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

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.

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.

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 12th International Symposium on
MYELODYSPLASTIC SYNDROMES
May 8-11, 2013 | Berlin, Germany
Welcome to the 12th 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

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
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 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.

BRAND NEW & COMING SOON!

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.
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.
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.

For information about global activities, go to: www.rarediseaseday.org.

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 State of New Jersey Executive Department

Proclamation

WHEREAS, there are nearly 7,000 diseases and conditions considered rare (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 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 come 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.

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.

CHRISTIE
Governor
3. McQuilten ZK et al. Myelodysplastic syndromes.

2. Roeker LE et al. Risk of acute leukemia and sepsis were.

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, 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.


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.


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:


Patients with thrombopoietin levels ≥320 pg/mL tended to have low-risk MDS, responded to immunosuppressive therapy and had a better 5-year survival (approximately 94% as compared to <64% in those with lower thrombopoietin levels). The higher thrombopoietin levels may thus provide a favorable prognosis.


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).


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, multivariate 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.


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.


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:


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.

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.


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-RARα fusion Huët cells. The differential diagnosis of MDS features of dysplastic erythroblasts, resembling Faggot cells along with typical promyelocytes with bundles of Auer rods included the absence of PML-RARα fusion Huët cells. The differential diagnosis of MDS features of dysplastic erythroblasts, resembling Faggot cells along with typical promyelocytes with bundles of Auer rods included the absence of PML-RARα fusion Huët cells.


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

TREATMENT:

IMiDs:


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:


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.


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:


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.


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.
From The Foundation

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!

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.
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@mds-foundation.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!
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, 2013 – 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.

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

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 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 Tomczykoski at drtomczykoski@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

- Puget Sound MDS Support Group
  For more information call Janine Kowack at 206-992-0609 or email 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 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.

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 Patientstøttegruppen
  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.
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
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 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.

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.

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.

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 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
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

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MDS Patient Doug Nelson

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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.**
**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 Cylosporine (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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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.
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 then 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
cancer 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 Pherisis 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, Nupogen, that helped build his white cells. This was needed to prepare for the Pherisis 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 in 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 2½ 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 suffering, 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.
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!
International MDS Foundation Nurse Leadership Board

Erik Aerts, RN
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Internal Medicine-Oncology
Stem Cell Transplantation Ward and Polyclinic Hematology/Apherese/Stem Cell Transplantation
Zürich, Switzerland

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Clinical Nurse Specialist
Department of Haematology
St James’s Institute of Clinical Oncology
Leeds, United Kingdom

Angelika Bitter, RN
Universitätsklinikum Carl Gustav Carus
Dresden, Germany

Claudia Boglione, RN
Stem Cell Transplantation Nurse Mentor
University Hospital Careggi
Florence, Italy

Núria Borràs, RN
Hematopoietic Nurse
ICMHO Hospital Clinic
Barcelona, Spain

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Macmillan Lecturer/Practitioner in Cancer Nursing
Teaching Fellow
Edinburgh Napier University
Edinburgh, Scotland, United Kingdom

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Nursing Unit Manager
Haematology Day Unit
Calvary Mater Hospital
Newcastle, Australia

Nicole Crisp, MN, NP
Nurse Practitioner, Hematology
University of Alberta Hospital
Edmonton, Alberta, Canada

Erin Demakos, RN, CCRN
Administrative Director
Myelodysplastic Disease Center
Icahn School of Medicine at Mount Sinai
New York, New York, United States

Corien Eeltink, RN, MA ANP
Nurse Practitioner
Department of Haematology
VU University Medical Center
Amsterdam, The Netherlands

Lenn Fechter, RN
Nurse Coordinator,
Department of Hematology
Stanford Hospital and Clinics
Stanford, California, United States

Janet Hayden, RN, BSc(hons), MPH
Myeloid Clinical Nurse Specialist
Haematological Medicine
Kings College NHS Foundation Trust
London, United Kingdom

Emily A. Knight, RN, BSN, OCN
Hematology Registered Nurse Coordinator
Mayo Clinic
Scottsdale, Arizona, United States

Sandra E. Kurtin, RN, MS, AOCN, ANP-C
Hematology/Oncology Nurse Practitioner
The University of Arizona Cancer Center
Adjunct Clinical Assistant Professor of Nursing
Clinical Assistant Professor of Medicine
University of Arizona
Tucson, Arizona, United States

Petra Lindroos Kolqvist, RN
Teamleader, Anemia Leukemia Team
Department of Hematology and Coagulation
Sahlgrenska University Hospital
Goteborg, Sweden

Arno Mank, RN
President EBMT Nurses Group
European Group for Blood and Marrow Transplantation
Nurse Researcher
Academic Medical Centre
Amsterdam, The Netherlands

Cindy Murray RN, MN, NP-adult
Malignant Hematology
Princess Margaret Hospital
Clinical Appointee
University of Toronto,
Lawrence S. Bloomberg Faculty of Nursing
Toronto, Ontario, Canada

Phyllis Paterson, RN, RSCN, Dip Onc
MDS Clinical Nurse Specialist
Cambridge University Hospitals
NHS Foundation Trust
Addenbrooke’s Hospital
Cambridge, United Kingdom

Jean A Ridgeway, MSN, APN, NP-C, AOCN
Leukemia/Stem Cell Transplant Nurse Practitioner
University of Chicago Medical Center
Department of Hematology Oncology
Chicago, Illinois, United States

Jayshree Shah, APN-C, AOCN, RN, MSN, BSN, BS, CCRP
Nurse Practitioner
John Theurer Cancer Center
Hackensack University Medical Center
Hackensack, New Jersey, United States

Natalie Singer, MSc, RN,BSc(Hons)
Macmillan Haemato/Oncology CNS
The Beatson West of Scotland Cancer Centre
Glasgow, Scotland, United Kingdom

Mary L. Thomas, RN, MS, AOCN
Hematology Clinical Nurse Specialist
VA Palo Alto Health Care System
Palo Alto, California, United States
Associate Clinical Professor
University of California, San Francisco
San Francisco, California, United States

Sara M. Tinsley, ARNP, AOCN
Malignant Hematology
Nurse Practitioner
H. Lee Moffitt Cancer Center
Tampa, Florida, United States
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
Raul Tilles, MD, PhD

The University of Arizona Cancer Center
Tucson, Arizona
Ravi Krishradsan, MD, FAAP

**CALIFORNIA**
Cedars-Sinai Medical Center
UCLA School of Medicine
Los Angeles, California
H. Phillip Koefler, 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 Curin, 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 California, San Francisco
San Francisco, California
Mark R. Litzow, 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 Shamma, MD

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

**INDIANA**
Indiana University Simon Cancer Center
Indianapolis, Indiana
Larry Crive, MD
Hamid Sayer, 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
Kelle 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
Johntmaal Jaiyesimi, DO

**MINNESOTA**
Mayo Clinic
Rochester, Minnesota
Mark R. Litzow, MD

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

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

**NEBRASKA**
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Cleveland, Ohio
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New Research Protocol Listing

NATIONAL CANCER INSTITUTE TRIALS

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

- Log on to www.cancer.gov
- Click on “Search for Clinical Trials”
- Click on “Type of Cancer” and type in ‘myelodysplastic syndromes’
- Hit search

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

To view listings of additional studies you can log onto www.clinicaltrials.gov. For telephone support, call the National Cancer Institute at 1-800-4-CANCER.

Announcing New Clinical Trials

NAME OF INSTITUTION:
Novartis Pharmaceuticals
TRIAL NUMBER: NCT00940602
Title of Trial or Description:
Myelodysplastic Syndromes (MDS) Event Free Survival With Iron Chelation Therapy Study (TELESTO)
A Multi-center, Randomized, Double-blind, Placebo-controlled Clinical Trial of Deferasirox in Patients With Myelodysplastic Syndromes (Low/Int-1 Risk) and Transfusional Iron Overload
Currently Recruiting Participants.
The primary purpose of this study is to prospectively assess the efficacy and safety of iron chelation therapy with deferasirox compared to placebo in patients with myelodysplastic syndromes (low/int-1 risk) and transfusional iron overload.
Contact the Novartis Clinical Trials Hotline at 800-340-6843 or go to www.clinicaltrials.gov for additional information and to view the active sites.

NAME OF INSTITUTION:
Celgene Corporation
TRIAL NUMBER: NCT01029262
Title of Trial or Description:
A Study of Lenalidomide Versus Placebo in Subjects With Transfusion Dependent Anemia in Low Risk Myelodysplastic Syndrome (MDS) Without Del 5Q (MDS-005)
Currently Recruiting Participants.
The primary purpose of this study is to compare the efficacy of Lenalidomide (Revlimid®) versus placebo in achieving red blood cell transfusion independence in the overall study population and in a pre-specified subgroup of patients with an erythroid differentiation gene expression signature predictive of Lenalidomide response.

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.

MDS FOUNDATION STORE

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
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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 Intermediate-1 Risk My**E**lodysplastic Syndrome (MDS)

**Key Inclusion Criteria**
- Age ≥18 years with low or intermediate-1 risk (IPSS) MDS
- WHO classification of RA, RARS, RCDM, 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 for your local Amgen Medical Information Contact.

ECOG PS = Eastern Cooperative Oncology Group Performance Score; EDATP = End of Active Treatment Period; EOTP = End of Treatment Period; IPSS = International Prognostic Scoring System; LTU = 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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Thank You!

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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 Cincinnati, OH
Don Kuse Cincinnati, OH

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 Forest Hill, MD
Mr. & Mrs. Edward Schroeder Bel Air, MD

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:
Euteneiri 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
Mr. James W. Frejd
Donations have been made in Mr. Frejd’s memory by:
Rich and Jill Myers Lemont, IL
Elaine Ahristain, Elmhurst, IL
Walter Joniec Schaumburg, IL
Mariano & Janice Geanconteri Streamwood, IL
The Valenzo Family Elk Grove Village, IL
The Daniels Family Elk Grove Village, IL
Bill and Jess Geanconteri Lake in the Hills, IL
Mariano & Janice Geanconteri Streamwood, IL
The Valenzo Family Elk Grove Village, IL
The Daniels Family Elk Grove Village, IL

A memorial fund has been established in the name of
Mrs. Joan Frejd
Donations have been made in Mrs. Frejd’s memory by:
Joslynn Anderson Markesan, WI
Elise Versimal Chicago, IL
Dick and Suzanne Potter Elk Grove, IL
Ken Spahr and Commercial South Team Yorkville, IL
John Fitzgerald Elk Grove, IL
Susanne Haush Elk Grove Village, IL
Mark and Janet Mason Libertyville, IL

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

A memorial fund has been established in the name of Ms. Elaine Frey
Donations have been made in Ms. Frey’s memory by:
James E. Frey
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
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
Dillon, Kimba and Hattie Vestal
Keller, TX
Ray Huhn
Pearland, TX
Andy and Karen Webster
Pearland, TX
Totos Solutions
Carrollton, TX
Keith and Joann Carlson
Ankeny, IA
Coppell Middle School West
Coppell, TX
Wed Night Poker Group
Arlington, TX
Harry and Margaret Shank
Arlington, TX

A memorial fund has been established in the name of John and Carol Kubala
Arlington, TX
Gary Hatch
Arlington, TX
Sarah Symscek
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
Evansville, WI
David and Simone Jean
Evansville, WI
Michael and Sandra Prochaska
Stevansville, MI
Jason and Daria O’Connor
Evansville, WI
James and Amy McNutt
Evansville, WI
Laura Balzer
Milwaukee, WI
Thomas and Lynn Olson
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
Novi, MI
Michael and Barbara Sbrocca
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
Columbus, GA
Christopher Boggs
Richmond, VA

A memorial fund has been established in the name of Ms. Miriam Hyams’ Brother
Donations have been made in Mr. Hyams’ memory 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
Fort Lauderdale, FL
Steve Smith
Cooper City, 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 Ottie
Libby, MT
Joseph and Catherine Hirt
Tucson, AZ
Roberta Horton
Florence, AZ
Sanford and Joyce Vaughn
Florence, AZ
Robert and Cathryn Egger
Florence, AZ
Robert and Beverly Terranova
Florence, AZ
James F. Gifford
Marion City, IA
Joann Wilke
Florence, AZ
Lawrence and Virginia Hoc
Andy and Vivian Brumbaugh
Florence, AZ
Mary E. Rademacher
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:
Micheeleen 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. Kiey
Donations have been made in Mr. Kiey’s memory by:
Myra Kiey
Carroll 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 Clarksville, MD
- Earl and Virginia Stevenson Jr., Livonia, PA
- Rich Carlson, Berkle, MD
- Ed and Janet St. Jean Bowie, MD
- Donald and Cynthia Pulver Ocean City, MD
- Bill and Sandra Engels
- Margaret (Peggy) White Los Gatos, CA
- George Fousis, Louisa, VA
- Edward Krivak, Newark, DE

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 Delisle Pittsburgh, PA
- Syd and Christy Sprouse Richmond, VA

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 Naperville, IL
- Employees of Go West T-Shirt Com
  Fort Collins, CO
- Employees of Go West T-Shirt Company
  Loveland, CO

A memorial fund has been established in the name of Mrs. Barbara Pilch-Kueg Latchford
Donations have been made in Mrs. Latchford’s memory by:
- Josh and Elisabeth Stark Reston, VA

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 Birmingham, AL
- Russell Tucker Ashton, MD
- David Olivier Arlington, VA
- Wayne and Deborah Wilhelm Chattanooga, TN
- Ed and Mary Jo Baich Medford, OR

A memorial fund has been established in the name of 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 Grossman Atlanta, GA
- Grant A. Capelouto on behalf of The Capelouto Family Tallahassee, FL
- Susan Wilen New York, NY
- Michael and Karen Kaplon Memphis, TN
- Judy McDonald (Ladden) Birmingham, AL
- Mike and Jean 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 Gailshoff Atlanta, GA
- Joe and Jane Blawstein Birmingham, AL
- Stanley and Judy Sherman Atlanta, GA
- Laurie Max Birmingham, AL
- Judith D. Birnskey and Robert Metzger Birmingham, AL
- Dr. & Mrs. Marc Michelson Mountain Brook, 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 Mrs. Maria-Luise “Diane” McDonald
Donations have been made in Ms. McDonald’s memory by:
- Robert and Lori Huffman, Crystal, MN

A memorial fund has been established in the name of Mrs. 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. 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
- Mike and Louise Kenny Aspronchick, VA

A memorial fund has been established in the name of Mrs. Maria-Luise “Diane” McDonald
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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
- Mike and Louise Kenny Aspronchick, VA
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  Frank Friedman and the PCC Community
Charlotteville, VA  Charlottesville, VA
Andy & Danielle Lewandowski  Alvin “Val” Siedl
Palmyra, VA  Poughkeepsie, NY
Bob and Jane Dudgeon  Robert Van Buren
Granby, CT  Rutland, VT

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, Ashkum, IL  Betty J. Weber
Bill and Carol Christy  Nashville, TN
Watseka, IL  Ruth E. Savoie, Oregon, OR
Leslie A. Myers  Ronald & Marlene Zachgo
Watseka, IL  Ashkum, IL
Linda Scering  Harry F. Muller
Bradley, IL  Sheldon, IL
Oclye and Carol Bargmann  Judith A. Miller
Gilman, IL  Gilman, IL

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. Lilian 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 Kieze, East Lyme, CT

A memorial fund has been established in the name of Mrs. Paz Rodriguez Muniz
Donations have been made in Mrs. Muniz’s memory by:
Eric, Charlotte and Marc Aldaz, Garland
Linnea Muniz  Henderson and Laura
Hubert, NC  Fogelson, San Antonio, TX

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  Charlene Slider
Ocean City, NJ  Perkasie, PA

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  Steven Fujita
Kailua, HI  Honolulu, HI
Cain 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  Charlene Darro, Virginia Beach, VA
Gladstone, MI

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

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’s 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, Earlysville, VA

A memorial fund has been established in the name of Mr. Carl Douglas 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:
Weegryn 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:
Charles and Robin Lashbrook
Kansas City, MO  Kansas City, MO

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:
Vernon Squires
Winnetka, IL
Patrick and Sally Dix
Des Moines, IA
Pamela Bell
Chicago, IL
Susan Eaton
Fridonia, WI
Jack and Sally Daniels
Wilmette, IL
Michael Earl, Wilmette, IL
Tom and Lauren Evans
Naperville, IL
George & Michele Hinchcliff
Lake Forest, IL
Bill and Pat Mulligan
Arlington Hts., IL
Adelaide Meskill
York, ME
Anne Weisskopf
Palo Alto, CA
Dee Lafavour
Oak Park, IL
Dick Carey
River Forest, IL
League of Women Voters of Wilmette
Wilmette, IL
Erwin and Donna Feldman
Bloomfield Hills, MI
Mary E. O’Donnell
Lake Forest, IL
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
Centerenach, 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
Shoreview, MN
Howard and Carol Costello
Stillwater, MN
Dale and Marlene Johnson
Crookston, MN
Dr. & Mrs. Roger Orensteen
Edina, MN
Marvin and Diane
Magnuson and Family
Crookston, MN
Jeff Ehlertinger
Lino Lakes, MN
Lynn and Jean Schmidt
Bremidjy, MN
Diane P. Wells, Tulsa, OK
John M. Pope, Edina, MN

Trading Technologies International, Inc.
Chicago, IL
Carls and Silvia Borzutsky
Pittsburgh, PA
Peter and Nancy Lem
Wilmette, IL
Richard & Maryjeanne Burke
Chicago, IL
Adam and Jill Gantz
Farmington Hills, MI
Mark and Lauren Cohen
Northbrook, IL
Margaret Pearl
Seattle, WA

Jeffrey & Lynne Ehleringer
Lake, MN
Gerald and Carol Granley
Coopet, MN
Paul and Pamela Haugen
Mnoseapolis, MN
Ben and Gail Wong
Eden Prairie, MN
Peter & Deborah Jacobson
Maple Grove, MN
Roberto and Sonja Bar
Brooklyn Park, MN
John R. Schmidt
Cottage Grove, MN
Ramona C. Lackore
and Ren B. Adkins
Willmar, MN

Donations have been made in Mr. Schmidt’s memory by:
David and Peggy Engh
Shoreview, MN
Howard and Carol Costello
Stillwater, MN
Dale and Marlene Johnson
Crookston, MN
Dr. & Mrs. Roger Orensteen
Edina, MN
Marvin and Diane
Magnuson and Family
Crookston, MN
Jeff Ehlertinger
Lino Lakes, MN
Lynn and Jean Schmidt
Bremidjy, MN
Diane P. Wells, Tulsa, OK
John M. Pope, Edina, MN

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
Springfield, VA
National Association of Insurance and Financial Advisors
Falls Church, VA
Jenny Shaw and Children
Decatur, AL

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
Arlington, VA
James Mingiotta
Aurora, OH
Ronald and Nancy Nemes
Strongsville, OH
Thomas Maley
Berea, OH
Chuck and Mary McGowan
Aliquippa, PA
Tom Schlaflly
Naperville, IL
IMPACT Staff
Washington, DC
Walter Wise
Oakton, VA

A memorial fund has been established in the name of 
Mrs. 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 Merrill 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
West Palm Beach, FL
Lewis and Gail Koptowski
Palm Beach Gardens, FL
Barbara Frank
Jamaica, NY
Joy Palevsky
Briarwood, NY
Arthure and Jeanne Sloup
East Islip, NY

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 Stalikos
Donations have been made in Mr. Stalikos’s memory by:
Chris and Vasiliki Angelos
West Hartford, CT
Mary and Sue Low
Keypoint, NJ
Mr. and Mrs. Joseph Artelli
Holmdel, NJ
Mr. and Mrs. Joseph Liggio
and Family, Keypoint, NJ
Patti Malloy
Manasquan, NJ
Bill and Betty Hetherington
Keypoint, NJ

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
Springboro, OH
Hereford, GA
The Karasik Family
Naples, FL
Tom Capri
Palm Harbor, FL
Kenneth Wend
Plano, TX
ITT, Seneca Falls, NY
GAC Fitness and Family
Springboro, OH
Friends at Valpak
Largo, FL
Bob and Judy Perez
Bonita Springs, FL
Michael Doyle
Menasha, WI
Neil and Stephanie Liu
irvine, CA
Greg and Ann Courchane
Palm Harbor, FL
Doug and Peggy Frauling
Cross Point, IN
Joe and Judy Boisette
Carefree, AZ
David Baily
Palm Harbor, FL
Gus and Bren Pathenos
Manchester, MO
George Pathenos
Bridgeport, MO

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Strongsville, OH
Thomas Maley
Berea, OH
Chuck and Mary McGowan
Aliquippa, PA
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Naperville, IL
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Walter Wise
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Barbara Frank
Jamaica, NY
Joy Palevsky
Briarwood, NY
Arthure and Jeanne Sloup
East Islip, NY

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Marie Souder
Fort Lauderdale, FL

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West Hartford, CT
Mary and Sue Low
Keypoint, NJ
Mr. and Mrs. Joseph Artelli
Holmdel, NJ
Mr. and Mrs. Joseph Liggio
and Family, Keypoint, NJ
Patti Malloy
Manasquan, NJ
Bill and Betty Hetherington
Keypoint, NJ

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Hereford, GA
The Karasik Family
Naples, FL
Tom Capri
Palm Harbor, FL
Kenneth Wend
Plano, TX
ITT, Seneca Falls, NY
GAC Fitness and Family
Springboro, OH
Friends at Valpak
Largo, FL
Bob and Judy Perez
Bonita Springs, FL
Michael Doyle
Menasha, WI
Neil and Stephanie Liu
irvine, CA
Greg and Ann Courchane
Palm Harbor, FL
Doug and Peggy Frauling
Cross Point, IN
Joe and Judy Boisette
Carefree, AZ
David Baily
Palm Harbor, FL
Gus and Bren Pathenos
Manchester, MO
George Pathenos
Bridgeport, MO

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
West Palm Beach, FL
Lewis and Gail Koptowski
Palm Beach Gardens, FL
Barbara Frank
Jamaica, NY
Joy Palevsky
Briarwood, NY
Arthure and Jeanne Sloup
East Islip, NY

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 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:
Diana 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:
Leeann Young
Cherry Hill, NJ

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:
Mike Tersolo, Carlsbad, CA

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
Arlington, VA

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 Vinsapu
Donations have been made in Mrs. Vinsapu’s memory by:
Harriet E. Berteisen
Bedbrook, TX

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
Spenoorport, NY

A memorial fund has been established in the name of Mrs. June Marie Wakeley
Donations have been made in Mrs. Wakeley’s memory by:
Ann Wiegrycz
Orchard Park, NY

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
North Reading, MA

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

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Diana Swindell, Browns Summit, NC

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Cherry Hill, NJ

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Paul DeStefano
North Reading, MA

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
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**
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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:
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A Living Endowment donation has been made in honor of:
**Ron Eig**
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**Kevin Truong and Family**
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A Living Endowment donation has been made in honor of:
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A Living Endowment donation has been made in honor of:
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A Living Endowment donation has been made in honor of:
**Kevin Spawr**
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Adam Douglas Slawin, New Haven, CT

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**Tom and Dyann Panepinto**
This donation was submitted by:
Frank and Donna Gallo, Chicago, IL

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**Lynn and Beth McMillan**
This donation was submitted by:
Kevin & Sally Mahoney, Scottsdale, AZ

A Living Endowment donation has been made in honor of:
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This donation was submitted by:
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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
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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.